

Children as caregivers

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Abstract

Caregiving is usually associated with adults' responsibilities. Official statistics and research have demonstrated, however, that many children and young people in the global North and South have substantial, regular caring responsibilities for family members with chronic illnesses, impairments or other care needs. This chapter conceptualises children's roles as 'caregivers' and the care work they do. It then analyses the available evidence on outcomes of children's caregiving and the factors and processes influencing their involvement. While research reveals that caregiving may have positive as well as negative outcomes for children's well-being, formal and informal safety nets are needed, especially in resource-limited settings, to alleviate children's care work. Children's and families' experiences suggest that social protection measures and support for those being cared for as well as those providing care would help to ensure that caregiving does not have long-term negative impacts on children's personal development, education, health, family relations, peer interactions, social participation, employment opportunities and socially expected transitions to adulthood.

Introduction

This chapter¹ focuses on children's roles as caregivers within families with impairments, chronic illness or other care needs and draws parallels between research findings in the global North and South. Although much of the literature on children's caregiving roles has been dominated by research conducted in the UK, Australia and the US to date, a growing body of research explores the lives of caregiving children in resource-limited contexts in the global South. The rapid increase in research on children's caring responsibilities in Africa, in particular, has been largely instigated by a wider research and policy concern about the social impacts of orphanhood and AIDS in Sub-Saharan Africa. This has resulted in a geographical focus on children's care work in the regions most affected by the epidemic in Eastern and Southern Africa. Many of the insights gained through mainly qualitative and participatory research with children caring in

households affected by HIV are however relevant to theorising young caregiving in families experiencing other impairments, illnesses or other care needs and in other geographical locations.

Drawing on this literature, this chapter analyses the implications of caregiving for children's *well-being*, in terms of their lives in the present, in addition to children's *well-becoming*, in terms of their personal development, future lives and transitions to adulthood. First, I discuss children's caring responsibilities in relation to global and local concepts of childhood and propose ways to conceptualise children's care work in differing contexts. I then discuss outcomes of children's care work and analyse the factors that influence their caring roles and outcomes. I suggest some possible future directions for research with caregiving children and by way of conclusion, I synthesise the key findings about the implications of caregiving for child wellbeing.

Global childhoods and children's caring responsibilities

In Western constructions of childhood, children are not expected (or encouraged) to take on substantial or regular caregiving responsibilities. 'Childhood' is viewed as a 'special' or 'protected' phase, with adults, state agencies and social welfare professionals in the global North charged with safeguarding and protecting children and young people until they make the transition into 'adulthood' (Dearden and Becker, 2000; Frank, Tatum and Tucker, 1999). Such and Walker (2005, p.43) argue, for example, that family policy in the UK is underpinned by idealised notions of childhood as a 'temporal oasis' of innocence, when children are free of 'pressures and cares', while responsibility is constructed as an 'attribute of adulthood'.

However, official statistics and research have demonstrated that many children and young people in the global North and South² have significant caring responsibilities for family members with chronic illnesses and impairments (Becker, Aldridge and Dearden, 1998; Robson, 2004; Becker, 2007). Furthermore, evidence from many countries suggests that children are regularly involved in household and domestic chores and that responsibilities form an everyday part of children's lives and social relationships with family members (Such and Walker, 2004; Miller, 2005; Ridge, 2006; Solberg, 1997; Katz, 1993; 2004; Punch, 2001). In many countries in the global North, boys and girls have a low average level of involvement in housework (Miller, 2005), but a minority make a substantial contribution to sustaining family life through their responsibilities for domestic chores, financial support, childcare, emotional care and self-care (Morrow, 1996; Ridge, 2006; Solberg, 1997). In her review of time-use studies, Miller (2005) argues that in all societies, girls spend significantly more time doing household work than boys. While girls often have substantial household responsibilities in the global South, this may be balanced to some extent by boys' greater involvement in income-generating work (ibid). In many different contexts, globally, children are actively engaged in negotiating and renegotiating their duties with parents and others within the household (Solberg, 1997; Punch, 2002; Ridge, 2006). Furthermore, children's roles and responsibilities are often differentiated according to norms of gender, age, intergenerational relations, household composition and sibling birth order (Punch, 2001; Solberg, 1997; Such and Walker, 2004).

Idealised Western constructions of childhood have become globalised through discourses of international development and human rights and national social welfare institutions and policies, resulting in the emergence of a 'good childhood' (Boyden, 1997). However,

this notion of childhood, in which children's time is spent predominantly within the family home, in full-time education or recreation as part of their socialisation and preparation for a productive adult life, bears little resemblance to the lived realities of childhood for children and youth in the global South. Despite decreases in the overall proportion of children who are engaged in productive work globally, almost a third of children (32.8%) aged 5-17 in Sub-Saharan Africa were estimated to be 'in employment'³ in 2008, while a quarter (25.3%) are involved in 'child labour', a far greater proportion than in any other continent (worldwide average of 19.3 per cent in employment and 13.6 per cent in child labour) (ILO, 2010). Despite the significant contributions that children make to their families, the ILO definition of 'children in employment' excludes work undertaken in the child's own household, rendering children's, especially girls', unpaid work contributions within the family invisible. Girls' greater workload of domestic responsibilities may reduce their spatial mobility and mean that they have less time available for schooling, private study and outdoor play compared to boys, which can disrupt their school attendance, result in poor educational outcomes and reduce potential opportunities for informal learning, peer socialisation and participation in the community (Katz, 1993; Koda, 2000). International child welfare concerns, however, are focused on the exploitation of children's labour in more visible forms of productive work and the gendered- and age-related impacts of children's social reproductive work within the family are rarely considered within development policy and planning.

Conceptualising children's care work

Despite socio-cultural constructions of care, Becker (2007, p.24) comments, 'unpaid caregiving is labour', and, 'recognising these activities as care work is to politicize and to make public the activities, roles, value and outcomes that characterise unpaid and family-hidden caregiving, and to identify these issues as concerns for social and public policy and for social development'. In both the global North and South, Becker (2007) suggests that the work that 'young carers'⁴ do is distinct from the usual household work that young people engage in because of the wider range of household and caring tasks undertaken by 'young carers', particularly children's involvement in the personal or 'intimate' care of their parent/relative, as well as the frequency, time spent and outcomes of these tasks. Becker (2007) suggests that children's informal caring in the global North and South can be conceptualised as a continuum, ranging from 'caring about' to 'caring for'⁵ a family member, along which all children's caregiving activity can be located (see Figure 1, adapted from Becker's original continuum). Young carers would be placed at the 'high' end of the continuum, that is, 'caring for' a family member, which involves substantial, regular and significant caregiving activities, usually for a co-resident relative 'in relations of very intimate proximity' (Barnett and Land, 2007, p.1066), with evidence of significant negative outcomes. The continuum distinguishes young people's unpaid caring roles and responsibilities within the family from the responsibilities of most children by suggesting that care work at the 'high' end goes beyond cultural expectations of children's contributions to their household, with respect to norms of age, gender and generational relations among others.

INSERT FIGURE 1 HERE

The continuum highlights the fact that the majority of children are involved in low levels of caring, while a small proportion are involved in much higher levels of caring, with differential

outcomes partly dependent on the extent and nature of the caregiving as well as being related to structural and other factors, as I discuss later. Evans and Becker's (2009) research revealed that children's caring roles shift and change over time and place. In the context of families affected by HIV, children's positioning on the continuum needs to be understood as fluid rather than static, as children's caring responsibilities change over time and space, depending on fluctuations in a parent's health as well as a parent's requirement for assistance and their changing access to informal and formal safety nets that may alleviate children's care work. While the continuum of young caregiving in Figure 1 is helpful in highlighting the different levels of caregiving that children may be involved in and the way caregiving may shift over time and place, it should also be noted that this model does not include the response of the person receiving care. Other conceptual approaches such as an ethic of care (Tronto, 1993) may be more helpful in interpreting caring relations and the reciprocity that may develop between caregivers and care-receivers, particularly between caregiving children and parents/relatives.

In Table 1, I categorise the socio-spatial and embodied dimensions of young people's everyday care work, based on the available research evidence about children's caring responsibilities from the global North and South, especially African contexts. Evans and Becker's (2009) comparative study of children caring for parents with HIV in Tanzania and the UK found that despite differences in the intensity and time taken to do particular tasks, overall, the range of support that young people provided for their parent/relative with HIV was broadly similar in both the global North and South. It is important to note, however, that the particular activities outlined in Table 1 vary across time and space and some, such as income-generation activities, are more likely to be specific to Southern contexts, as discussed below.

Most dimensions of children's everyday care work (seven of the nine categories of caring activities listed in Table 1) are focused predominantly in and around the social space of the household, with the exception of income generation and community engagement activities that are usually reliant on young people's interactions and mobility beyond the immediate household. However, several aspects of children's household chores and healthcare support for their relative may involve social reproductive work and mobility outside the household which may provide opportunities to socialise with their peers and siblings, such as fetching water, collecting wood, subsistence agriculture, going to the market or collecting medicine and/or providing food/ care within a hospital/clinic setting, in addition to young people's income generation and community engagement activities.

Table 1: Dimensions of children's and young people's care work globally (adapted from Evans and Becker, 2009; Evans, 2010).

Caring activity	Examples
Household chores	Cooking, washing dishes, sweeping, cleaning and tidying, fetching water and firewood, laundry, heating water for baths, shopping, cultivating food for consumption, tending livestock, cutting wood, running errands

Health care	Reminding parent/sibling/ relative to take medication, giving and collecting medication, accompanying them to hospital and providing care while in hospital, assisting with mobility, preparing special nutritional food, cleaning, treating and dressing sores, infections and wounds, massaging the body
Personal care	Washing/bathing parent/relative, assisting to eat, dress and use the toilet
Child care	Getting siblings ready for school, bathing siblings, supervision, resolving arguments and conflict between siblings, help with school work
Emotional support	Talking and comforting parent/sibling/ relative, giving advice and guidance, 'being there' for them
Self care	Personal care of self, taking medication, getting ready for school, private study, personal development, training, developing life skills and livelihood strategies etc.
Income-generation activities	Cultivating crops and produce for sale, rearing livestock, casual agricultural and construction work, fishing, working in a factory, shop or bar, selling produce, cooked food, charcoal and other goods, domestic work, running errands for neighbours, begging
Household management	Allocating tasks, paying school contributions, organising school/vocational training, reminding parent/sibling/relative about appointments, paying bills and resolving financial problems, budgeting, future planning and decision-making
Community engagement	Maintaining social networks, seeking support from and cooperating with relatives, neighbours, friends, NGOs, members of faith community, participating in neighbourhood, school, faith community, youth and NGO meetings, activities, celebrations and events.

Although most children in both the global North and South regularly undertake some domestic tasks, research suggests that children with caring responsibilities carry out a wider range of household chores according to a daily routine and these are more time consuming than for children living in households without a chronically ill or disabled relative. Young people with caring responsibilities in Zimbabwe, Lesotho, Tanzania and Kenya reported significant and regular responsibilities for many household chores (Robson *et al.*, 2006; Bauman *et al.*, 2006; Evans and Becker, 2009; Skovdal *et al.*, 2009). Domestic chores are more time-consuming, labour intensive and often require physical strength and fitness in the global South due to disparities in living standards and limited access to basic services such as clean water and energy saving equipment. When an adult household member, particularly mothers, are unable to undertake their usual domestic responsibilities due to chronic illness or disability, children's household chores are likely to increase, especially in rural areas. Furthermore, research in Tanzania suggests that young people's household chores did not differ significantly according to gender, despite conventional gendered expectations within households; although a slightly higher proportion of girls and boys were involved in activities focused around the household or outdoors respectively, both genders were equally involved in some activities traditionally

perceived as ‘women’s work’, such as washing dishes, making tea and fetching water (Evans and Becker, 2009).

Research has highlighted the significance of children’s roles in providing healthcare for parents/relatives with HIV within the home as well as responding to emergencies and nursing parents/relatives during periods of serious ill health (Evans and Becker, 2009; Robson, 2000; Skovdal *et al.*, 2009). Many young people in the UK and Tanzania helped their parent/relative to adhere to anti-retroviral drug regimes and, owing to the fluctuating nature of HIV-related illness, young people’s regular responsibilities for household chores were often interspersed with periods of more intensive care for their parent/relative during episodes of parental ill health or hospitalisation. For example, Emily⁷ (aged 17), who lived with her father and sister in the UK, used to wake up at 5 am to help wake her father and prepare something for him to eat before he took his medicine:

He has to wake up really early to take his medication, so I would wake up at that time, and I wake him up and encourage him to go, help him maybe go to the bathroom. He’d wash up, and I’d have to prepare something for him to eat, because he would have to eat before taking the medication, or he would just, you know, would take his medication and if he wants to go back to bed, I’d help him back into bed, and then I would kind of just be there to check up on him and ask him if he was alright. (Evans and Becker, 2009, p.137)

Furthermore, in the absence of adequate home-based care, nursing and palliative care programmes in Africa, many young people may provide intensive nursing and personal care for parents/relatives with HIV and other life-limiting illnesses at the end of their lives. The high level of healthcare support that children provide clearly distinguishes their roles and responsibilities from those of children living in households unaffected by chronic illness or impairment. The narrative of Good Luck⁷ (aged 18), who cared for his mother in the final stages of AIDS-related illness illustrates the intimate, highly embodied nature of young people’s caring roles in this context:

Her health started deteriorating slowly. She would be poorly one day and would be better the next day and would resume doing her usual chores at home. She also ran a small business. Later she became very poorly and couldn’t get out of bed. So that is when I started caring for her full time. [...] I used to bathe her, she didn’t mind that I was a boy. When it was time to go to hospital I would take her there. When she was very poorly and couldn’t walk, I used to carry her. Sometimes she wasn’t able to eat on her own, so I would feed her. When she vomited, I used to wash the soiled clothing. Later when she disclosed her status to me, the doctors gave me gloves for washing soiled clothing and some for using when bathing her and tending her sores. So, that is how I cared for her until she died (Evans and Becker, 2009, p.138).

Children’s assistance with the personal care of parents/relatives is a further aspect of their care work that clearly distinguishes their responsibilities from those of other children (Becker, 2007;

Robson *et al.*, 2006). Gender matching between caregiver and care-recipient is culturally preferred, especially when providing intimate personal care, due to cultural taboos about sexuality and bodily intimacy (Robson, 2004; Evans, 2011b). In the UK, parents avoided asking their child to provide personal care if they did not share the same gender. However, almost as many boys (aged under 18) interviewed in Tanzania provided care for their mothers/ female relatives as the number of girls (Evans and Becker, 2009). Furthermore, girls and boys sometimes provided personal care for a parent/relative of a different gender, despite the fact that this subverted cultural boundaries of bodily intimacy across genders and generations (see example of Good Luck above). While boys' and young men's involvement in care may destabilise conventional gendered constructions of care and the meanings associated with masculinity, this was at an individual rather than societal level (*ibid*). Furthermore, boys and young men may be subjected to stigmatisation, bullying and harassment because their caring roles transgress gender as well as age norms, as research in the UK has also revealed (Becker and Becker, 2008).

Research with young carers in the UK acknowledges that 'childcare' is often one of the caring tasks that children perform to assist disabled parents (Becker *et al*, 1998; Dearden and Becker, 2004). In Tanzania and the UK, young people regularly assisted their parent with HIV in providing childcare for younger children in the household (usually their siblings and sometimes cousins), some of whom were also living with HIV (Evans and Becker, 2009). Girls appeared to be more likely to provide childcare and often spent longer looking after younger siblings than boys in these families. Sibling caregiving responsibilities could be significant, as Sarah's daily routine below reveals. Sarah (aged 16) lived in the UK with her mother with HIV and younger sisters, the youngest of whom had challenging behaviour. She described her caring responsibilities on the days when she did not attend college:

My little sister's awake most of the night.[...] So sometimes like I have to wake up and make her sleep with me or sometimes I go and make her something to drink or eat and then I have to stay up. I'll wake up again early in the morning and make sure that all my sisters are going to school and then they will go and make themselves some breakfast and I'll look after my little sister so she doesn't disturb my mum. And then my mum will wake up to take her medication at 8 o'clock and then I'll give my little sister some breakfast and then I would get her dressed and make sure she's ready for [nursery] school, help my mum help her get ready for school [...].

Then my mum would take her to school and then I would wash up the dishes, clean the house. My mum would come back, [I would] give my mum the bills, make sure she's paid her bills on time, check if she's got any appointments. Sometimes I help her fill up her medication box and then help her with the shopping in the afternoon, do some work, then I would help my mum cook before my sisters come back from school. And then when they're back from school usually she allows me to do my work and she'll look after my little sister because she's a bit of trouble [...] she's like very violent. And then I help my mum get my little sister ready to have a bath and when my mum is done with that I just rest until she goes to sleep (Evans and Becker, 2009, p.144)

For young people heading households without a co-resident adult, childcare of younger siblings represents a key focus of their care work. Older siblings' significant roles in caring for younger siblings and in socialisation and providing informal training have been widely documented in many societies in the global South (Cicirelli, 1994; LeVine *et al.*, 1996; Weisner, 1982). Sibling caregiving is usually performed on a temporary basis to free up time for mothers, rather than being an a full-time caregiving role that young people adopt following parental death. In the context of the HIV epidemic, however, research with child- and youth-headed households in Tanzania, Uganda (Evans, 2011a; 2012) and Zambia (Bell and Payne, 2009) has revealed that young people provided moral guidance and informal teaching to their siblings, resolved arguments and tried to meet their siblings' emotional and material needs, as they attempted to fulfil the parental role their mother or father would have performed if they were still alive. Older siblings in Tanzania and Uganda sought to maintain intra-generational hierarchies of age and sibling birth order in order to manage younger siblings' behaviour and maintain a position of respect as the eldest sibling heading the household (Evans, 2011a).

Research with children caring for parents with a range of impairments in the UK has identified emotional support as a significant aspect of their caring roles (Aldridge and Becker, 2003; Dearden and Becker, 2004). Similarly, in Tanzania (Evans and Becker, 2009), Namibia (Thomas, 2006; Evans and Thomas, 2009) and Zimbabwe (Bauman *et al.*, 2006), many young people provide emotional support to parents/relatives with HIV, including talking and comforting them, giving hope and reassurance, offering advice, being a confidante, keeping them company and 'being there' for them. Evans and Becker's (2009) research found that young people were more likely to provide emotional support to their parent/relative when they were aware of their parent/relative's HIV status. Furthermore, young people often engage in considerable 'emotion work' to manage their presentation of self and protect the person they are caring for from the emotional demands of their care work (Evans and Thomas, 2009; Evans, 2011a).

The term 'self care'⁸ is useful in categorising a range of individual, embodied activities for which children are usually expected to take increasing responsibility as they grow older, but which in the absence of adult caregivers, they may perform without adult support or guidance. This may include hygiene and personal care, taking medication (which may be particularly important for children living with HIV and needing to adhere to a strict anti-retroviral drug regime), getting ready for school, taking time out for oneself, developing life skills and engaging in other personal development activities with little adult supervision or involvement. My research suggests this concept is particularly relevant for orphaned young people who live independently in sibling-headed households (Evans, 2012). Although the research was based on a very small sample, young people caring for siblings in child- and youth-headed households in Tanzania and Uganda reported spending an average of 24 hours per week in self-care activities, in addition to time spent on their other caring tasks. The concept is also likely to be relevant when parents/adult relatives may not be able to fulfil their usual parenting roles due to mental health problems and/or drug or alcohol use problems (although little research to date has investigated children's care work in these contexts in the global South⁹).

Income generation activities emerged as an important difference between children's caring responsibilities in the global North and South (Evans and Becker, 2009). The income-generation activities listed in Table 1 are specific to young caregiving in the global South, although research suggests that young caregivers in the global North may also engage in part-time paid work to help the family pay the bills, alongside their unpaid care work (ibid). While many young people living in poor households are likely to engage in income generation activities in the global South, casual labour and work in the informal sector represents a key element of children's care work in households affected by disability, as children seek to replace household income lost through a parent's/ adult relative's illness, impairment or death. Younger children in Tanzania combined their income-generation activities with schooling, where possible. John (aged 11) for example, usually returned home from school at 2 pm and then worked until 6 pm, doing casual jobs for neighbours to earn money to buy vegetables for the family: "*I wash people's clothes, dishes and I clean their houses. I earn about 1,500 TZS [equivalent to 70p] per day*" (Evans and Becker, 2009).

Income earning activities are often a crucial dimension of the caring responsibilities of orphaned young people living in sibling-headed and grandparent-headed households. My research with sibling-headed households revealed that many young people, especially young men, often perceived their caring role predominantly in terms of providing financial support for themselves and their younger siblings (Evans, 2012). Boys and young men heading households in Uganda and Tanzania reported that they spent on average 34 hours per week working to support the family, while girls and young women heading households in contrast spent much less time (average of 11 hours a week) engaging in income-generation activities, due to gendered constructions of care and inequalities in access to employment opportunities (Evans, 2012).

The breadwinning role of young people who head households is often closely linked to their role in managing the household and making decisions. As Bell and Payne (2009) note, historically notions of household headship have been based on income-generation. In Payne's study of child-headed households in Zambia, income earning represented an 'especially "powerful" responsibility', as this gave young people 'control and authority in terms of decision-making around household finances and more generally' (Bell and Payne, 2009, p.1032). However, the level of young people's economic contributions to the household did not always determine which sibling was regarded as the 'overall leader and decision-maker' (ibid). As research with children caring for parents with HIV has also found, young people's individual attributes, competences and aptitudes for particular caring tasks (in this instance, leadership, decision-making, organisational and budgeting skills) were also significant in influencing children's responsibilities within the family, in addition to hierarchies of age, sibling birth order and gender (Evans and Becker, 2009). For children caring for parents/adult relatives, household management tasks are likely to be a less significant aspect of their care work, since disabled parents/ adult relatives usually retain their position of power within the household, in accordance with wider generational norms and age hierarchies. Thus, parents/relatives maintain overall authority and responsibility for decision-making about household resources and other matters, in spite of their illness or impairment (Robson *et al.*, 2006; Evans and Becker, 2009) and provide guidance to children to enact these decisions.

Research from Eastern and Southern Africa has highlighted the ways that young people's care work is embedded in social relations and reciprocal responsibilities beyond the immediate household (Thurman *et al.*, 2008; Germann, 2005; Skovdal *et al.*, 2009; Evans and Becker, 2009; Evans, 2011a). Since the 1990s, gender and development commentators have called for recognition not just of women's social reproductive and productive roles, but also of their 'community managing' roles in maintaining social networks and engaging in community events and development processes (Moser, 1989; Momsen, 1991). Given the importance of young people's social networks and access to informal and formal resources in sustaining households affected by chronic illness and disability, it seems appropriate to include the category of 'community engagement' as a key dimension of young people's everyday care work. Young people caring for siblings in Uganda and Tanzania confirmed the relevance of this element of their care work (Evans, 2012) and this category also appears to have wider relevance for children caring in other situations. The category of community engagement may also be significant in analysing outcomes for children, in terms of spatial mobility, opportunities for play, peer interactions and social participation in the community.

Outcomes for children's 'well-being' and 'well-becoming'

Much of the research on young carers in the UK, US, Australia and other countries in the global North has drawn attention to negative outcomes of care for children's well-being and well-becoming, in terms of education, health, social lives and transitions to adulthood (Becker *et al.* 1998; Dearden and Becker, 2004; Frank *et al.* 1999; Aldridge and Becker, 2003; Thomas *et al.* 2003; Becker and Becker, 2008). In common with this literature, the emerging body of research on children's care work in the global South, particularly in the context of the HIV epidemic in Eastern and Southern Africa, has tended to focus on the impacts of care on children's lives. This research has identified a range of negative outcomes that are broadly comparable to or are considered more severe than those experienced by young carers in the global North (Evans and Becker, 2009; Robson *et al.*, 2006; Bauman *et al.*, 2006; Bray, 2009). This is due to the fact that children's care work in Africa is often located at the high end of the continuum of young caregiving (see Figure 1), within a broader context of widespread poverty and lack of formal support systems in many African countries.

Studies in Tanzania, Zimbabwe, South Africa and Rwanda have identified negative impacts of care for children's emotional wellbeing, in terms of anxiety about a parent/relative's illness, anticipatory and unresolved grief (Evans and Becker, 2009; Donald and Clacherty, 2005), depression (Bauman *et al.*, 2006; Boris *et al.*, 2008), poor self worth and poor internal locus of control (Donald and Clacherty, 2005). Despite close relationships within the family in Tanzania, some young people caring for parents with HIV and some siblings heading households found their responsibilities overwhelming and felt unable to share their emotions with others (Evans and Becker; Evans, 2011a). In Tanzania and South Africa, research has suggested negative outcomes of care for children's physical health and welfare, such as hunger and undernourishment (Bray, 2009), tiredness, fatigue and reduced access to healthcare (Evans and Becker, 2009). Studies in Tanzania, Uganda and South Africa have also identified the small risk of children becoming infected with HIV through direct nursing of family members with HIV, accidents in the home, combined with children's often limited knowledge of modes of HIV

transmission and lack of medical supplies (such as gloves) to protect carers (*ibid*; Bray, 2009; Akintola, 2004).

Within the domain of the family, negative impacts identified in Tanzania and Namibia included tensions in adapting to changed roles and responsibilities and discriminatory and antagonistic relationships with parents, siblings and relatives (Evans and Becker, 2009; Evans and Thomas, 2009). In Uganda, Tanzania, Zimbabwe and Namibia, some young people had direct experiences of isolation, ostracism and stigmatisation within the extended family, including loss of property, that were related to their caring relations and proximity to their relative with HIV (Evans and Becker, 2009; Evans and Thomas, 2009; Evans, 2011a). Furthermore, young people participating in these and other studies (Robson *et al.*, 2006; Evans, 2005) reported experiences of stigmatisation, bullying and harassment by their peers and other community members linked to their caring roles and the stigma of poverty, orphanhood and AIDS.

In terms of educational impacts, research from Zimbabwe (Bauman *et al.*, 2006), Namibia (Thomas, 2006), Tanzania (Robson *et al.*, 2006; Evans and Becker, 2009), Uganda (ILO and Government of Uganda, 2004 cited in Bray, 2009; Evans, 2012) and Kenya (Skovdal *et al.*, 2009) found that the school attendance of many young people was regularly disrupted by their care work, with children having to miss sometimes considerable periods of schooling due to their parent/ relative's need for care. Children's academic performance and long term educational outcomes may be affected, as they found it difficult to concentrate because of tiredness or anxiety about their parent/relative, missed exams and lacked adequate time for private study (Evans and Becker, 2009; Skovdal and Ogotu, 2009). Many young people in Tanzania found negotiating time and space for private study difficult when they were caring for sick parents/relatives within often overcrowded home environments, having to study late at night or early in the morning (Evans and Becker, 2009). For example, Maureen⁷ (aged 19) explained:

I used to leave [school] at 2.30pm to come home. When I got home, I would prepare something for them [mother and step-father] for them to eat, wash mum's fungus, wash the soiled clothing because she used to relieve herself in bed. So I couldn't do any homework with all that going on. Then I had to prepare the evening meal, bathe dad while he criticised me. I tried to study at night, but my dad would complain that the lamp was disturbing him so he couldn't sleep. So I had to put out the light and go to bed (ibid, p.180).

Maureen felt that the conflict between her school work and caring responsibilities had led to her failure in the school leaving examinations (*ibid*). Studies in Tanzania (Evans and Becker, 2009; Robson *et al.*, 2006), Uganda (Evans, 2012) and South Africa (Akintola, 2004) also suggest that young people with caring responsibilities experiencing extreme poverty may be less likely to complete primary or secondary education than their peers, although as Bray (2009) notes, there is a lack of quantitative evidence to support these mainly qualitative findings.

Research from the UK suggests that young carers' spatial mobility in the wider community, engagements with their peers and opportunities to take part in leisure and other opportunities may be restricted due to their caring responsibilities within the home (Dearden and Becker,

2004; Thomas *et al.*, 2003; Evans, 2011b). In Evans and Becker's (2009) research, almost two thirds of the young people interviewed in the UK felt that their caring responsibilities in some way restricted their social lives and engagement in leisure and other activities, whereas just over a third of the young people in Tanzania reported this. Several young people in the UK felt that the negative aspects of their caregiving related to not having enough time and space to themselves, because their caring responsibilities conflicted with their own interests and activities. This appeared to be linked to age; as young people became teenagers they increasingly wanted to socialise with friends and engage in extracurricular activities independently from their family, but found their time to do so was limited because of their caring responsibilities. Although few young people, parents or service providers in Tanzania mentioned reduced spatial mobility or restrictions on the time they could spend with friends due to caring responsibilities, some children expressed a preference to stay at home, close to their parent/relative, so that they could respond to their parent/relative's requests for assistance when needed, rather than spending time with their peers away from the household (*ibid*). Furthermore, some young people reported experiences of stigmatisation and ostracism by their peers and neighbours due to their close proximity to a parent/relative with HIV.

Care work may also have negative impacts on young people's transitions to adulthood, since it may result in poor employment prospects, long term emotional impacts, risks of early pregnancy, sexual abuse and exploitation, crime and alcohol/drug use problems (Evans and Becker, 2009; Evans, 2012). Dearden and Becker (2000, p.43) identify three key ways that caring affects young people's transitions to 'adulthood' in the UK. First, 'Caring can be stressful, particularly for young people living with parents who experience pain, mental distress, or who have a terminal or life threatening illness. In a few cases stress and depression were severe enough to lead to physical and psychological ill health'. Second, even where young adult carers had left home they often continue to worry about the 'cared for' person. Some resumed their caring responsibilities when they returned home or made arrangements to visit the family home on a daily basis in order to provide care. Finally, young adult carers may gain skills and competencies through young caring but these were often gained at a cost of them missing school and not getting qualifications. In addition, research with young adult carers in the UK has shown that young people may associate caregiving with many positive aspects (Becker and Becker 2008), although the transition to adulthood, and from children's to adult social and welfare services in the UK context, is problematic for many young people, who may need additional support and services to assist them.

Despite high aspirations for their long-term future, Evans and Becker's (2009) research found that some young people caring for parents with HIV in Tanzania expressed a sense of uncertainty about their more immediate future. 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 also expressed their worries and concerns about how their parent would manage on their own when they moved away from home to study at university. For young people caring for siblings in Tanzania and Uganda, socially expected transitions to independent adulthood, such as completing education, migrating for work opportunities or achieving the financial means to marry and support their own families were sometimes delayed because of young people's caring responsibilities (Evans, 2012).

Evans and Becker (2009) note that it is difficult to distinguish the negative impacts of caring from wider processes of poverty, social exclusion and marginalisation that many children living in households where family members have impairments, chronic illness or other care needs are likely to experience. Researchers have increasingly called for children's care work to be theorised from a resilience perspective (Newman, 2002a; Evans, 2005; Becker, 2007), since this may help to explain individual differences among children in 'getting by' (Backett-Milburn *et al.*, 2008) and managing their caring responsibilities. Rather than focusing on risk, the concept of resilience emphasises people's strengths in coping with adversity and their agency in engaging with protective factors that may help to reduce their vulnerability (Rutter, 1990; Howard *et al.*, 1999; Newman, 2002b). Protective factors may be associated with *individual attributes*, such as problem-solving skills, high aspirations, faith and religious beliefs, positive peer relationships; *family characteristics*, such as caring and supportive family relationships, a secure base and sense of belonging; or *aspects of the wider community*, such as the availability of external support or resources, a positive school environment, opportunities for participation (Schoon, 2006; Evans and Pinnock, 2007; Newman, 2002b; Schoon and Bynner, 2003). However, these factors are likely to be context-specific and may vary cross-culturally (Evans, 2005; Howard *et al.* 1999; Schoon and Parsons, 2002).

Research in the global North has identified a number of positive outcomes of caregiving for children. Dearden and Becker (2000) found that caring developed children's knowledge, understanding, sense of responsibility, maturity and a range of life, social and care-related skills. Caring also helped to bring many children closer to their parents in terms of a loving, caring, relationship. Similarly, Aldridge and Becker's (2003) research with 40 families where a child was caring for a parent with severe mental illness found that children's caregiving helped to allay some of the fears, concerns and anxieties that they had about their parent's condition because it gave children control and direct involvement in the provision and management of care work. The authors suggested that in some instances caring helped to enhance parent-child relationships and helped children to feel included when often, outside the domain of the family, they were ignored and not recognised by health, social care and other professionals.

Research in African contexts has also identified a number of positive outcomes. These include: developing children's knowledge and understanding about their parent's/relative's illness or disability; a sense of responsibility, maturity, self-esteem and pride in taking on a socially valued caring role; fostering closer family relationships; and a range of life, social and care-related skills and personal qualities, such as empathy, listening and responsiveness (Evans and Becker, 2009; Skovdal *et al.*, 2009; Bauman *et al.*, 2006; Donald and Clacherty, 2005). Robson *et al.*'s (2006) research in Zimbabwe identified a number of educational, personal and emotional benefits for young carers, such as learning new skills, gaining experience and taking on responsibilities, developing stronger emotional bonds between the 'carer' and 'care recipient', and developing emotional maturity and pride in caring. The authors suggest, however, that these positive benefits that young people identified as part of their caregiving could represent survival strategies for dealing with distressing experiences of caring for a sick and dying relative.

Skovdal *et al.* (2009, p.592) suggest that young people in Kenya ‘constructed positive carer identities’ based on local cultural understandings of ‘childhood as a period of duty and service’. Furthermore, in Kenya and Tanzania, caring did not appear to have any significant effects on some young people’s school attendance or academic performance (Skovdal *et al.*, 2009; Evans and Becker, 2009). Young people usually managed to combine schooling with their caring responsibilities. For the majority of young people interviewed in Tanzania and the UK, doing well at school and continuing their education was their main priority for the future, as education was seen by children and parents as key to improving their employment prospects and life chances. Indeed, several parents/relatives emphasised their commitment to ensuring that their children did not miss school because of their illness and caring responsibilities. As one woman with HIV being cared for by her grandson in Tanzania said: *‘I don’t like children skipping classes because I only have Standard Four [four years of primary school] education. So I don’t want them to be illiterate, I make sure they go to school even when I am seriously ill.’* (Evans and Becker, 2009, p.182). Most children and parents in Tanzania and the UK did not want teachers to know about their parent’s illness or children’s caring responsibilities because of fear of stigmatisation, confirming previous UK research with families affected by HIV (Lewis, 2001; Cree *et al.*, 2006). Educational resilience in such instances appeared to be related more to informal support from parents, peers and individual teachers, young people’s high aspirations and level of interest and motivation, rather than supportive institutional environments or awareness of young caregiving among teachers (Evans and Becker, 2009).

In several studies, the quality of the relationship between the child and person they care for and the strength of children’s social ties and access to peer and social support in the community are identified as key factors that may help to protect children from the negative impacts of caregiving (Robson *et al.*, 2006; Evans and Becker, 2009; Evans, 2011a; Skovdal *et al.*, 2009; Thurman *et al.*, 2008; Bray, 2009). Evans and Becker’s (2009) research found that parents with HIV continue to maintain their important parenting role, in terms of providing love, emotional support, guidance and discipline to their children, even when they are very sick and rely on their children to care for them. In contrast, as noted earlier, young people caring for siblings without a co-resident adult often lacked a close loving relationship with a parent/adult relative who could provide emotional support and guidance (Evans, 2012; Francis-Chizororo, 2008), and thus young people heading households in such contexts appear to be particularly vulnerable to negative outcomes.

While research has helpfully started to document the positive as well as negative outcomes of care for young people, it remains unclear how and to what extent positive experiences may protect children in the longer term (Bray, 2009). Furthermore, while children who take on a caring role may develop resilience that helps to protect them psychologically and socially, Bray (2009, p.30) suggests that younger siblings of children with caring responsibilities could be ‘highly vulnerable’, since they witness the ‘chronic and debilitating illness’ of parents/relatives, but do not benefit from developing closer emotional ties through a caring role or gain from a sense of responsibility, pride and emotional maturity.

Factors influencing children’s caring roles and outcomes

Having discussed the nature of children's care work and the outcomes for children's wellbeing, this section analyses the factors and processes that influence why individual children take on caring roles within families in particular places. Becker *et al.*'s (1998) analytic framework of the factors which 'push' or 'pull' some children into unpaid caring roles in a household include the nature of the illness/disability, family structure, gender and co-residence, status and power, the availability and nature of external support. Robson's (2000; 2004) qualitative research with young people (aged 15-17) caring for ill family members in Zimbabwe suggested that these 'push and pull' factors for young caring were relevant in the context of Sub-Saharan Africa. Factors influencing whether children become young carers in Zimbabwe included: 'the degree of illness, availability of support services, poverty, family structure, co-residence, status/power, gender, age, educational level and income-earning ability' (Robson, 2000, p.67).

Robson (2000; 2004) and Evans and Becker (2009) link children's everyday experiences of caring in Sub-Saharan Africa at the micro-level to broader processes of global economic restructuring, the HIV epidemic and policies that 'download responsibility for care' onto women, children, families and communities (Ogden *et al.*, 2006, p.333). Figure 2, adapted from Evans and Becker (2009), highlights the range of individual, relational and structural processes that may influence children's caring roles for family members with a range of impairments and care needs in both the global North and South. Global forces such as economic liberalisation and transnational migration, the prevalence of impairment, health inequalities and epidemics such as HIV, international development goals and priorities for donor aid, global and national welfare regimes, legislative frameworks and interventions to support children and families, caregivers and disabled people and facilitate their participation in decision-making processes, as well as socio-cultural beliefs and values such as gender norms, constructions of care and childhood, structure the macro environment in which young caregiving takes place. At the community level, the availability of formal and informal safety nets significantly influences whether young people take on caring roles and can potentially alleviate or increase the extent of their care work. Micro-level factors such as the parent/relative's health, disclosure of their health status/ impairment, poverty and changes in household structure, as well as individual differences among young people, such as gender, age and sibling birth order, the quality of their relationship with the parent/relative they care for, personal attributes and co-residence are likely to have significant influences on whether children take on caring roles, the extent of their care work and outcomes for children's wellbeing.

These risk and protective factors and processes do not represent a list of universal or 'global composites' (Rutter, 1990, p.182). Rather, the figure illustrates how different processes shape children's caring trajectories in specific socio-spatial contexts; some processes will have more or less relevance or influence in particular places. Young people negotiate their caring trajectories within both the constraints and the possibilities of these complex processes and factors and may embrace, resist or contest the identity of 'carer/ caregiver' and the responsibilities and expectations placed on them. This highlights the importance of investigating children's agency, while taking account of the broader macro-scale, structural inequalities that influence caregiving children's well-being.

INSERT FIGURE 2 HERE

Future research directions

As noted earlier, the majority of research on children's caring roles in the global South has focused on caregiving in families affected by HIV in Eastern and Southern Africa. While this has helped to highlight the nature of children's care work in resource-limited settings, some aspects of the research findings, such as the impact of stigma and the nature of children's care work for relatives with a fluctuating life-limiting illness may be particular to HIV. Future research in Africa and elsewhere in the global South focused more broadly on children's caring roles in relation to disability and ageing could help to unravel the commonalities and differences between children's caring roles and outcomes for family members affected by HIV and for parents/relatives with other impairments and needs for care. There is a need both to quantify the extent, nature and outcomes of children's care work in the global South, as well as to further qualitative understandings of caring practices, relations and outcomes in order to make visible children's caring roles and to inform policy and development interventions to support this group of marginalised young people and their families (Becker, 2007).

The quality of the relationship between children and those they care for, especially the close bonds that develop between children caring for parents/adult relatives, has been highlighted as a crucial factor that may protect children from negative outcomes of care and enhance their well-being (Evans and Becker, 2009; Bray, 2009). This raises questions about the resilience and vulnerability of young people with caring responsibilities who lack or have irregular/unpredictable access to a significant adult relative who is able to provide love, emotional support and guidance, as well as about the resilience of younger siblings who do not take on caring roles within the family. Research has only recently started to explore the caring experiences of young people heading households without a co-resident adult and little research to date has investigated relations, practices and outcomes for children caring for parents/relatives with mental health problems or for those with drug or alcohol use problems. Research with child- and youth-headed households has tended to engage with anthropological literature on 'sibling caretaking' to date (see for example, Dahlblom, 2008) and there is scope for greater engagement with the young caregiving literature and care research more broadly, as I have sought to do (Evans, 2011a; 2012).

In recognition of the importance of relationality in understanding children's lives, future research on children's caring roles in the global South could explore how young people negotiate caring practices and inter- and intra-generational power relations with those they care for and others in the community. In particular, research to date suggests that there may be significant differences between children's situation depending on the generational caring relations and interdependencies that develop within particular household forms in particular places. The socio-spatial practices, relations and outcomes of care for children caring for a parent with a chronic illness or impairment are likely to differ significantly from those of orphaned children caring for an elderly grandparent or from those of children caring for their siblings independently without a co-resident adult relative. Patterns of mobility, the fluid nature of household structures combined with the devastating impacts of the AIDS epidemic in Eastern and Southern Africa mean that young people may find themselves taking on caring roles in all of these situations, as their caring pathways change over time. There is much scope for further research in the global South to

explore the influence of inter- and intra-generational power dynamics and diverse caring relations on the socio-spatiality of children's caring roles, outcomes and changing trajectories over time.

This relational and intergenerational approach to theorising children's caring roles also responds to recent calls for a lifecourse perspective informed by a time-space framework (Bowlby *et al.*, 2010) in order to examine the diverse, often contradictory nature of young people's pathways and transitions between the generational boundaries of 'childhood', 'youth' and 'adulthood' (Hopkins and Pain, 2007; Evans, 2008). I have found the concept of 'caringscapes' (McKie *et al.*, 2002) particularly useful in theorising young people's everyday practices and caring pathways through time and space (Evans, 2012). The concept draws attention to the organisation and social patterning of practical activities of caring, as well as the feelings and subjective positions of different actors involved in caring pathways across different temporal and spatial contexts. Young people's lifecourse transitions are shaped by caring pathways which shift over time and space, within a broader landscape of care. 'Successful' socially expected transitions to adulthood, such as completing education, migrating for work opportunities or achieving the financial means to marry and support their own families may be delayed or restricted because of young people's caring responsibilities. Thus, by taking on 'adult' caring roles and responsibilities that do not conform to Western or African constructions of childhood, young people blur the boundaries of 'childhood', 'youth' and 'adulthood', subverting conventional notions of children's dependence on adults and demonstrating their agency (Evans, 2011a).

Drawing on Tronto's (1993) ethic of care perspective, Evans and Becker's (2009) research highlighted the interdependent nature of caring relations, acknowledging that there is no fixed division of roles between 'care-givers' and 'care-receivers'. The reciprocal nature of care and high level of responsiveness, particularly in terms of mutual emotional support, has been most clearly demonstrated to date in caring relations between children and parents (Evans and Thomas, 2009; Aldridge and Becker, 2003). While caring practices, emotions and social interactions between caregivers and care-receivers were often characterised by Tronto's (1993) four ethical values of attentiveness, responsibility, competence and responsiveness, research with families affected by HIV revealed that carers' competence to provide good care in Africa was undermined by poverty, insufficient material resources and the need to sustain livelihood activities, which sometimes resulted in conflicts and tensions within caring relationships (Evans and Thomas, 2009). Further research on the interdependencies, emotional interactions, meanings and quality of relationships within families experiencing disability and a need for care could make significant contributions to broader fields of research on care, disability and emotions. Additionally, research in the global South suggests that caring responsibilities and activities are often shared and negotiated between different family members (including siblings, parents, grandparents, aunts, uncles and so on) in a range of household forms (Evans and Becker, 2009; Punch, 2002). Greater understanding of the ways that family members of all ages and generations negotiate household chores, caring responsibilities and decision-making processes within and beyond the social space of the household would provide further insights into the home and family relations in the global South.

Finally, while children's caring roles may remain the key focus of research, a more relational approach to age (Vanderbeck, 2007) and an ethic of care perspective (Tronto, 1993) foreground the importance of seeking to understand the perspectives of those being cared for, as well as those providing care, which will necessarily have implications for research methodologies and approaches. Research, policy and development interventions therefore need to recognise the ways that care is embedded in social relations, cultural norms and structural inequalities operating in different configurations in particular places.

Summary

This chapter has sought to conceptualise children's caring roles, provide an overview of research findings about outcomes of caregiving and analyse the complex range of factors and processes that influence their involvement in care work at different spatial scales. The available evidence suggests that young caregiving globally may result in both positive and negative outcomes for children's well-being and well-becoming, in terms of their personal development, health, education, family relationships, peer interactions, social participation, employment prospects and socially expected transitions to adulthood. Children's care work can be located on a continuum, ranging from low levels of caring responsibilities for a few hours each week, which is regarded as culturally appropriate, according to norms of age, gender and generational relations, to high levels of 'full-time' substantial and regular caregiving each week, which is regarded as culturally inappropriate and where there is evidence of significant negative outcomes for children's well-being. While caregiving may be associated with some positive outcomes, such as closer family relationships, that may help to protect children, research suggests that formal and informal safety nets are needed, especially in resource-limited settings, to alleviate children's care work and ensure that it does not have long-term negative impacts. Analysis of outcomes, risk and protective factors and processes influencing children's involvement in caregiving indicates that a holistic approach is needed that seeks to understand the different domains of children's lives and wider structural inequalities, social norms and global processes that influence why a proportion of children in different societies are likely to have significant, regular caregiving responsibilities that may be detrimental to their wellbeing. While the bulk of research on young caregiving has been conducted in the global North to date, the growing literature on caregiving children in Eastern and Southern Africa has revealed the relevance of cross-cultural analyses. Future research could usefully draw on these insights and further explore differences in children's and families' experiences in order to enhance protective processes and strengthen social support for caregiving children, families and communities in diverse socio-spatial and temporal contexts.

Notes

1. This chapter is a revised, extended version of Evans' (2010) article in *Geography Compass* and draws on more extensive discussions in Evans and Becker's (2009) book *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*.
2. The terms 'global North' and 'global South' are used with an awareness of their problematic nature, as they are geographically imprecise and establish a simplistic binary opposition between rich and poor countries that does not adequately account for diversity within each region.

3. The ILO definition of 'children in employment' encompasses the economic activities undertaken by children, whether for the market or not, work in both the formal and informal economy, inside and outside family settings, for a few hours or full time. However, it excludes domestic work undertaken in the child's own household and schooling. Children in 'child labour' are a subset of 'children in employment' and include children in the worst forms of child labour and children in employment below the minimum wage, excluding children engaged in 'permissible light work' (ILO, 2010, p.6)
4. Becker (2000, p.378) defines young carers as: "Children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision".
5. A distinction is often made in the literature between 'caring about' and 'caring for' (Noddings, 1984; Ungerson, 1983). 'Caring for' others implies that care is performed directly through everyday practices of care 'in relations of very intimate proximity', whereas 'caring about' others implies that care is less direct and may be performed at a distance (Barnett and Land, 2007, p.1066).
6. Several researchers draw a distinction between young people's involvement in 'instrumental activities of daily living' (such as shopping, cleaning, household chores) and the more care-related 'activities of daily living' (such as personal care and assisting with mobility) (Morrow, 2005; Becker, 2007). Becker (2007, p.32) comments, "The evidence from developed and developing countries indicates that many young carers have to perform more tasks (and spend longer on them) that are Instrumental Activities of Daily Living (such as shopping and housework) *in addition* to the more care-related Activities of Daily Living (such as intimate and personal care)".
7. Young people's accounts have been anonymised with pseudonyms to protect their identity.
8. The concept of 'self care' has been used to date predominantly in research in the global North within the medical/ nursing literature in terms of the management of particular chronic illnesses or medical conditions (eg. Gaut and Keickhefer, 1988) and within child development literature, in terms of so-called 'latch-key children' and parental decisions to leave children unsupervised in out-of-school settings (eg. Cain and Hofferth, 1989; Casper and Kristin, 2004).
9. Payne's (2009) research with child-headed households in Zambia included children living with a parent with alcohol use problems.

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