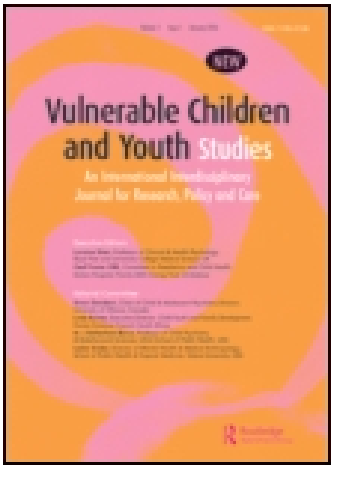

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Young carers in South Africa: tasks undertaken by children in households affected by HIV infection and other illness

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'Young carers' are children who take on adult responsibility in response to familial illness. South Africa's high disease burden, limited health care capacity and cultural notions of children's familial duty suggest a large population of 'young carers' in this country. This study aims to explore the nature of responsibility among children affected by illness in deprived South African communities. A total of 349 children and adolescents aged 10–18 years in illness-affected households in the Western Cape province were recruited via community- and school-based convenience sampling. Data about their daily life, responsibilities and the impact of familial illness were collected via semi-structured interviews. Caring tasks involving intimate contact and medical treatments were relatively common among children in the sample, and nearly all children were engaged in some type of responsibility, from caring tasks to housework, childcare and earning money. Children frequently indicated their responsibilities constituted a substantial burden. Responses suggested a tension between duty to care and appropriateness of intimate contact between parents and children required for some caring responsibilities. Children often linked their tasks burden to familial illness, though further quantitative research is needed to identify the drivers of child responsibility.

Keywords: young carers; child caregivers; parentification; orphaned and vulnerable children; Africa

Introduction

The South African context suggests large numbers of 'young carers': high disease prevalence not limited to human immunodeficiency virus (HIV) infection (Bradshaw et al., 2003; Bradshaw, Norman, & Schneider, 2007; Norman, Bradshaw, Schneider, Pieterese, & Groenewald, 2006); limited public-sector capacity to provide necessary palliative and hospice care (Case & Paxson, 2011; Shisana et al., 2003); policy encouraging home-based and community-based care (DOH, 2001); and cultural values that stress children's familial duty (Organization of African Unity, 1990; Robson, 2000, 2004).

Young carers are defined as 'children and young persons under 18 who provide or intend to provide care, assistance, or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult' in response to familial health problems (Becker, 2000, p. 378). While the majority of black South African children perform in household chores (83.9%) (Statistics South Africa, 2011), it is unclear what distinguishes 'usual' from 'unusual' responsibilities. Given the scale of illness burden, studies of children's responsibilities in general are likely to include high

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proportions of tasks resulting from familial illness. For instance, Bray (2003) found that among black youths in South Africa, 9% of boys and girls aged 15–17 provided care for adults, 8% of boys and 10% of girls in the same age group shopped for groceries and household goods, and 2% and 9% provided care for other children. While the former task would only be performed in response to adult illness or disability, children could perform the latter tasks in the absence of familial illness; however, their burden could be exacerbated by the needs of those who are unwell (Bray, 2003; Skovdal & Ogutu, 2009; Warren, 2007).

In contrast to developed nations with lower disease burdens and greater health care capacity, research on this topic is limited in sub-Saharan Africa (Becker, 2007; Skovdal, 2009). Existing studies are dedicated to identifying 'young carers' as a phenomenon in sub-Saharan Africa, understanding resilience within affected children, evaluating role changes between ill parents and caring children and evaluating the impact of caring responsibility on children's psychological well-being (Bauman et al., 2006; Evans & Becker, 2009; Gwandure, 2007; Robson, 2000, 2004; Robson, Ansell, Huber, Gould, & Van Blerk, 2006; Skovdal, 2009).

The aim of this article was to explore the nature and range of responsibilities that children in deprived South African communities perform and how they relate to familial illness. A secondary aim was to inform quantitative research on the types of responsibilities on which to compare children who are affected and unaffected by familial illness. Existing measures of young carer responsibility (Joseph, Becker, Becker, & Regel, 2009; Mika, Bergner, & Baum, 1987; Sessions & Jurkovic, 1986) have all been developed in and for Western settings and may not be relevant to the South African context.

Evans and Becker (2009) note that children in their Tanzanian cohort reported tasks not found among their English sample, including fetching water, tending livestock and farming. In addition to different ranges of tasks, young carers in sub-Saharan Africa appear to have greater responsibility time and intensity burdens when engaging in housework (Andreouli, Skovdal, & Campbell, 2013; Evans & Becker, 2009; Robson & Ansell, 2000) or providing care (Bauman et al., 2006). Much of the difference is likely due to poverty and lower levels of development, which introduces greater or unique needs. For instance, indoor plumbing is ubiquitous in the UK, though rare among traditional and informal homes that make up a large proportion of households in South Africa (Budlender, Chobokoane, & Mpetsheni, 2001). Thus, it is important for research to identify not just what, but how much children in deprived South African settings do as a result of familial illness.

Methods

The study contained a qualitative and quantitative component. The qualitative component allowed children to elaborate on the nature of responsibilities they take on as a result of another person's illness, while the quantitative component recorded instances of responsibility.

Sampling strategy

Recruitment relied on community- and school-based convenience sampling in urban and rural townships areas that had been designated 'most deprived' within the Western Cape in the Provincial Indices of Multiple Deprivation (Noble et al., 2006). Study sites included townships in the urban Cape Flats region outside Cape Town and rural areas including

Beaufort West and Oudtshoorn on the eastern end of the province. In communities and schools, research assistants described the purpose of the study to children as seeking to understand the experiences of children living with an ill person. Children were asked to identify themselves if they wished to participate. Written informed consent was sought from both child and primary caregiver.

Data collection

All data were collected between September and December 2008 during face-to-face interviews with children. Interview schedules were based on an open-ended 'journal' questionnaire used in Evans and Becker (2009), which was adapted from Healthlink Worldwide (2006). Three isiXhosa-speaking research assistants conducted all interviews, which lasted about an hour, and recorded children's responses on the hardcopy interview schedule. The primary assessments of children's responsibilities included two sets of open-ended questions: (1) a section where children were asked what they did to help when someone in their home was ill and (2) a section where children were asked to describe their every activity in a typical 24-hour period. The two-pronged approach was designed to elicit data on responsibilities that children did and did not associate with the burdens of familial illness.

Children were asked how the person's illness had changed their daily life in terms of schooling, relationships, health, feelings and any other way. Another section asked about the types of support that children received and would like to receive. Children were asked to identify everyone with whom they lived, who was ill and with what and their relationship to them. To account for children who either did not want to disclose or were unaware of ill person's HIV status, children were asked about a range of acquired immune deficiency syndrome (AIDS)-related symptoms from a verbal autopsy in Lopman et al. (2006). Categorisation of AIDS illness via the verbal autopsy utilised a conservative approach of three or more AIDS-related symptoms (e.g. weight loss, shingles).

This study received ethical approvals from the University of Oxford, the University of Cape Town and the Western Cape Department of Education.

Analysis

Qualitative responses were thematically analysed to identify, code and categorise children's responsibilities and how they relate to familial illness using four elements of the 'good code' approach described in Boyatzis (1998, pp. x–xi). First, we developed labels for caregiving phenomena identified in the data, by which individual tasks, categories (personal care; domestic responsibilities) and subcategories (intimate care, medical care, housework, childcare, income-generating activities) were named. These labels were primarily derived from existing research on 'young carers' in sub-Saharan Africa (Evans & Becker, 2009; Robson, 2000; Robson et al., 2006). Second, we developed definitions of what each theme represented. Responsibilities were any task performed for the benefit of another person or group of people. Positive instances for each main label were subcategorised based on the type of need addressed: 'personal care' addressed the need of an ill person, while those subcategorised as 'intimate care' specifically addressed a normal bodily need (e.g. toileting, bathing) and 'medical care' addressed medical treatment needs (e.g. administering medicine or accompanying an ill person to a health care provider). Activities categorised as 'domestic responsibilities' addressed a household

need and included those directed towards household maintenance (housework), caring for other children (childcare) and earning money (income-generating activities). Third, we developed a process for knowing when to ascribe a label to qualitative data. Activities were coded as responsibilities when children explicitly stated that they performed a task for the benefit of another person. Last, we described any qualifications or exclusions to identifying themes. Tasks must have been performed for the benefit of another person or group of people and would not be considered such if performed solely for self-benefit. 'Income-generating activities' were automatically considered a responsibility due to implications of poverty and child labour.

Following coding of responses, quantitative components describing frequencies of responsibilities and breakdowns by age and gender were analysed in IBM Corp. (2013).

Results

Participant characteristics

Participants included 349 children aged 10–18 years who indicated they were living with at least one ill adult. Average age of participants was 13.4 ± 2.3 years at the time of interview, with the majority aged between 10 and 13 years (55.9%; n = 195). A majority of participants were female (60.7%; n = 212) and from an urban area (61.0%; n = 213). Two-thirds (68.1%; n = 237) were attending school regularly, 29.6% (n = 103) were missing some school, and 2.3% (n = 8) had dropped out entirely (one child refused to answer).

All children were living with at least one ill family member, and one-quarter (24.4%; n = 85) were living with two or more. Children were identified with 440 coresident ill individuals (Figure 1). Illness type and prevalence are presented in Figure 2.

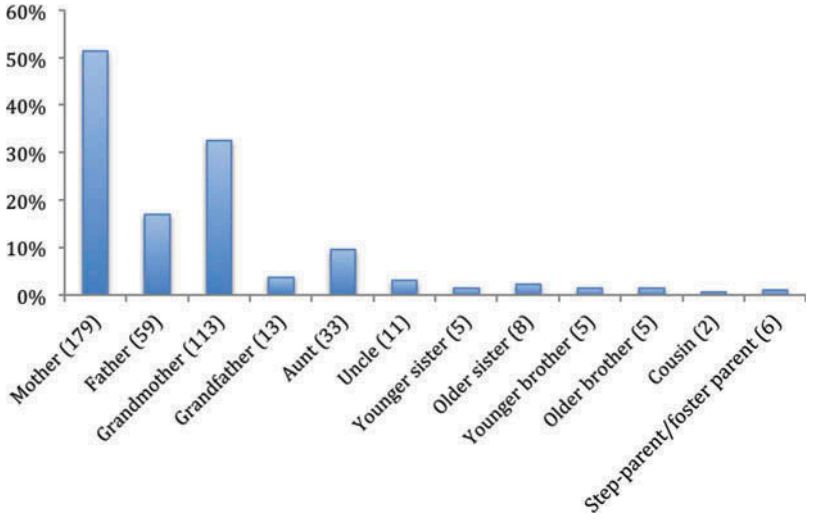

Figure 1. Proportion of coresident ill family members present in each child's household.
Note: Percentages total more than 100% as one-quarter of children participating in this study (26.9%; n = 94) were living with two or more ill adults/other family members.

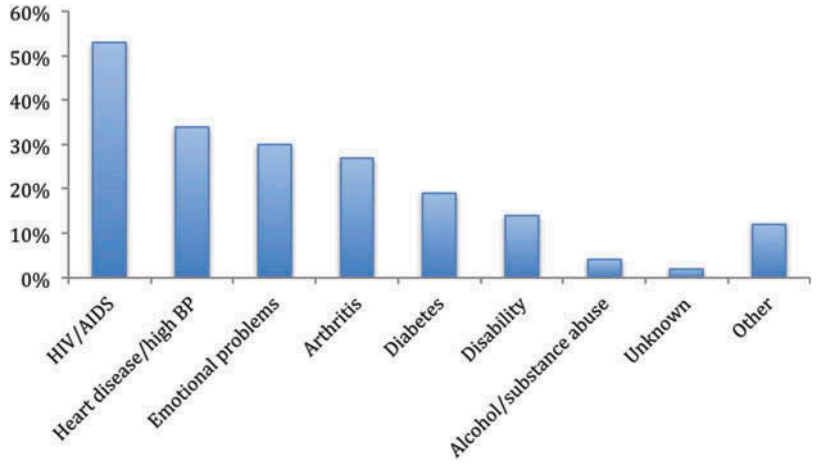

Figure 2. Type and prevalence of illness among family members.
Note: Percentages total more than 100% due to comorbidity in two-thirds (68.4%; n = 301) of family members who were categorised as ill.

Range and nature of children's responsibilities

Children's responsibilities are presented by category and prevalence/frequency and broken down by gender-dichotomised age categorisations (10–13 and 14–18 years) in Table 1. However, as the children were recruited using convenience sampling, the categorical distributions and differences should not be considered representative and have not been assessed statistical significance.

Two-thirds of the sample were providing personal care (64.5%; n = 225), and almost all were performing some type of domestic responsibility (98.6%; n = 344). Half the interviewed children were providing intimate care (47.9%; n = 167). A high proportion helped an ill person to eat (42.7%; n = 149), while comparatively few bathed (4.0%; n = 14), dressed (1.1%; n = 4) or cleaned up after someone had vomited or had diarrhoea (0.3%; n = 1). One-third (n = 116) were responsible for administering medication, usually described as 'tablets'. One child reported giving injections to treat her grandmother's diabetes. One in 15 children reported accompanying an ill person to the hospital (6.3%; n = 22); daily schedule entries and qualitative responses indicated that this task entailed substantial time commitments (Table 2). When asked what type of support she would like to receive, one 13-year-old girl who reported spending up to nine hours waiting with her mother who was ill with AIDS at the clinic said, 'I wish I could have someone to look after her whenever she goes [to the clinic]'. Such long wait is not that far outside the range of 4 to 6 hours normally experienced in sub-Saharan Africa (Hardon et al., 2007).

More than one-quarter of the children sampled were caring for other children in the home (28.1%; n = 98). One 18-year-old girl whose mother was ill with AIDS told interviewers, 'When my mom gets sick I have to come home and look after the children while she is at the hospital'. When asked what type of support she would like to receive, she responded, 'It would be nice to have someone who looks after us while my mother is in the hospital'.

A small number of participants were engaging in income-generating activities, all within the informal economy (3.2%; n = 11). Most of these children were aged 14–18 years (81.8%; n = 9). The most common job description was vending items such as plastic bins,

Table 1. Proportion of sampled children engaging in responsibilities by gender and age.

	Total, % (*n*)	Boy, % (*n*)	Girl, % (*n*)	Aged 10–13 years, % (*n*)	Aged 14–18 years, % (*n*)
Personal care	64.5 (225)	65.7 (90)	63.7 (135)	64.1 (125)	64.9 (100)
Intimate care	47.9 (167)	51.8 (71)	45.3 (96)	48.2 (94)	47.4 (73)
Bathe the unwell person	4.0 (14)	0.7 (1)	6.1 (13)	2.1 (4)	6.5 (10)
Care/watch/check/keep company with the unwell person	13.5 (47)	12.4 (17)	14.2 (30)	12.3 (24)	14.9 (23)
Clean up vomit or diarrhoea	0.3 (1)	0.0 (0)	0.5 (1)	0.0 (0)	0.6 (1)
Dress/change clothes	1.1 (4)	0.7 (1)	1.4 (3)	0.5 (1)	1.9 (3)
Help to eat/feeding	42.7 (149)	47.4 (65)	39.6 (84)	44.6 (87)	40.3 (62)
Lift/move unwell person	2.9 (10)	2.2 (3)	3.3 (7)	4.1 (8)	1.3 (2)
Massaging unwell person	2.9 (10)	2.2 (3)	3.3 (7)	4.1 (8)	1.3 (2)
Toilet	0.3 (1)	0.0 (0)	0.5 (1)	0.0 (0)	0.6 (1)
Wash feet	0.6 (2)	0.0 (0)	0.9 (2)	0.5 (1)	0.6 (1)
Medical care	37.2 (130)	34.3 (47)	39.2 (83)	36.4 (71)	38.3 (59)
Accompany to hospital/clinic	6.3 (22)	5.8 (8)	6.6 (14)	5.1 (10)	7.8 (12)
Buy/collect medications	1.1 (4)	1.4 (3)	0.7 (1)	0.0 (0)	2.6 (4)
Give treatment/medication	33.2 (116)	29.2 (40)	35.8 (76)	33.3 (65)	33.1 (51)
Remind to take treatment/ medication	2.6 (9)	2.9 (4)	2.4 (5)	1.0 (2)	4.5 (7)
Domestic responsibilities	98.6 (344)	98.5 (135)	98.6 (209)	97.9 (191)	99.4 (153)
Housework	98.3 (343)	97.8 (134)	98.6 (209)	97.4 (190)	99.4 (153)
Clean house/yard	95.7 (334)	94.9 (130)	96.2 (204)	95.4 (186)	96.1 (148)
Clean/make others' beds	6.0 (21)	3.6 (5)	7.5 (16)	7.2 (14)	4.5 (7)
Cook	77.1 (271)	65.7 (90)	85.4 (181)	71.8 (140)	85.1 (131)
Fetch water	5.4 (19)	7.3 (10)	4.2 (9)	6.7 (13)	3.9 (6)
Garden/plough	0.3 (1)	0.0 (0)	0.5 (1)	0.0 (0)	0.6 (1)
Grocery shopping	67.0 (234)	67.9 (93)	66.5 (141)	66.7 (130)	67.5 (104)
Heat water	14.3 (50)	10.9 (15)	16.5 (35)	9.7 (19)	20.1 (31)
Laundry	83.7 (292)	78.8 (108)	86.8 (184)	84.1 (164)	83.1 (128)
Serve food	6.0 (21)	3.6 (5)	7.5 (16)	6.7 (13)	5.2 (8)
Take out rubbish	1.7 (6)	2.9 (4)	0.9 (2)	2.1 (4)	1.3 (2)
Wake family	44.1 (154)	46.7 (64)	42.5 (90)	42.6 (83)	46.1 (71)
Wash dishes	39.3 (137)	33.6 (46)	42.9 (91)	43.1 (84)	34.4 (53)
Childcare	28.1 (98)	24.8 (34)	30.2 (64)	28.2 (55)	27.9 (43)
Feed children	2.6 (9)	2.2 (3)	2.8 (6)	3.1 (6)	1.9 (3)
Look after children	20.9 (73)	20.4 (28)	21.2 (45)	23.1 (45)	18.2 (28)
Take children to school	4.3 (15)	4.4 (6)	4.2 (9)	3.6 (7)	5.2 (8)
Wash children	9.5 (33)	5.8 (8)	11.8 (25)	7.7 (15)	11.7 (18)
Income-generating activities	3.2 (11)	2.9 (4)	3.3 (7)	1.0 (2)	5.8 (9)
Farmwork	0.3 (1)	0.0 (0)	0.5 (1)	0.0 (0)	0.6 (1)
Sell produce/goods/work in a shop	2.9 (10)	2.9 (4)	2.8 (6)	1.0 (2)	5.2 (8)
Total engaged in at least one type of responsibility	99.7 (348)	100 (137)	99.5 (211)	99.5 (194)	100 (154)

Note: These values are based on convenience sampling methodology and should not be taken as representative.

chips or sweets, while others worked in shops. A small number of children were observed cleaning sheep heads ('smiley') and shin for sale in order to raise money for school fees, while one brother and sister pair were interviewed as they sold alcohol from the back of their home, covering for their parents while they were out. One 18-year-old girl delivered medicines and treatments throughout the community.

Table 2. Example of adolescent participant's responses to the daily schedule section of interview schedule (urban girl, 16).

Time	What do you do?	How do you feel?
6am–8am	I clean my mother's bed (20 mins). I fetch and boil water for her to drink for her treatment (30 mins). I wake up my siblings (20 mins). I cook breakfast for everyone (20 mins). I get ready for school (30 mins).	I feel good to help my family. Sometimes I feel sad.
8am–8.30am	I take my siblings to crèche (30 mins) and then I go to school. Sometimes I miss school if I have to take her to the clinic.	I can't concentrate at school. I am worried.
2pm	I get back from school. I sweep the floor (20 mins). I go to the shop to buy food (25 mins). I wash clothes for everyone and pack the dry clothes from yesterday in the wardrobe (1 hour).	I am proud of myself for helping them.
5pm	I cook supper for the family (60 mins but I can do my homework while it is cooking).	[Nothing written]
8pm	I give the sick people their treatment (30 mins). I wash up from dinner (20 mins) and then I go to bed.	I am worried about them.

Familial illness and child responsibility

Some children linked increases in their responsibilities directly to familial illness. One 14-year-old girl described the impact of her grandmother's poor health due to high blood pressure and arthritis as such:

> Since my grandmother became sick I now have to take on more responsibilities and I am always worried and sometimes lose my mind. If she's sick I'm not even going to play. I just want to stay at home and look after her. This really affects me and I'm not always happy about this.

Her responsibilities and grandmother's struggles with illness made it difficult for this girl to concentrate at school. In addition to washing, feeding and giving medications to her grandmother, she helped relatives cook and clean the house. Her sisters, however, appeared to offer little help, tending to disappear on weekends since their grandmother became ill.

Several children noted they only provided care when necessary and that times of need varied. One 12-year-old girl said, 'If my mother can't eat by herself I feed her'. Another 16-year-old girl described how her responsibilities were dependent on the availability of people willing and able to help: 'If there is a shortage of people in my home, for example my mother is at work, I must help. Even if my mother is there I must help her if she is busy'. Conversely, an 11-year-old boy described how his household faced need, although allocation of responsibility had left him out: 'My sister is the one who works very hard but also my mother is helping'.

Some children discussed the indirect link between familial illness and domestic responsibility. One 18-year-old girl explained: 'Since my mom got sick [HIV/AIDS] I've had to take on more responsibilities and be a mother to my sister and brothers'. This participant elaborated with a description of how responsibility affected her own life, 'I have to do housework and homework for them and I don't get time for myself. I miss class sometimes. I don't get enough sleep at night because my younger brother cries at

night'. One 12-year-old boy was economically supporting his family and mother who was living with HIV/AIDS, having dropped out of school to sell chips and sweets.

Many children described their increased responsibility in a negative light. One 18-year-old girl who left university to care for her mother who was living with HIV/AIDS said, 'It is not nice to live with someone who is sick because you have to do everything. You can't do stuff you want to do'. Another 16-years-old girl described her experience living with her aunt who has diabetes following her own mother's AIDS-related death, saying, 'I am forced to help. [My aunt] can do it sometimes but a lot of times we work very hard even if it is not for her being sick'.

A few children expressed sentiments echoing the 'generational bargain' as described in Collard (2001). Speaking on the expectation to care for grandmother, who was ill with arthritis and heart disease, one 16-year-old girl said, 'I'm supposed to help her because there is no one to help except me, because when my grandmother is sick it is compulsory to help her'. Another child, a 14-year-old boy, was explicit about the role of reciprocity, saying:

> To have a parent is not something to play about. It is something you must care for. A parent must be cared for by those they gave birth to. A parent also does not give birth just for the sake of it but for us to care for them when something happens to them.

Children expressed ambivalence regarding their duty to provide care for ill family members. For instance, one 15-year-old boy hinted at the social pressures to care for his aged grandparents and how it might reflect on his character, saying 'I am afraid not to look after them as if I don't take care of them'. In contrast, one 14-year-old boy described the inappropriateness of a child of his age to provide care for an adult; regarding his grandmother, who was unable to walk, speak or feed herself, he said, 'I don't come near her. I don't help her because only older people come to help her. It is not that I don't like to come but just that it is a big task for children'. These quotes contrast with children's sense of obligation to care for the ill with perceived appropriateness of some tasks.

Discussion

The aim of this article was to identify a range of responsibilities found among children affected by familial illness in deprived South African communities, with the secondary aim of informing construct measurement for future research to explore how parental illness and socio-economic factors affect children's caring and responsibility burden.

Children in illness-affected households engage in a wide range of responsibilities as the result of familial illness, most notably in providing care for the ill. In some cases, children indicated that familial illness was a source of noncaring responsibilities, such as the 18-year-old girl who in effect became surrogate parent to her siblings when her own mother was too ill.

Children's notion of duty was especially interesting when explored within the context of the 'generational bargain', which posits that parents provide care for children with the understanding that the child, when she/he is an adult and their parent older or elderly, will reciprocate this care (Collard, 2001). While some children appeared to tacitly endorse the 'generational bargain' in their statements on responsibility, others indicated that it was inappropriate for them to care for an adult at their young age. The tension between familial duty and age appropriateness of providing care has been noted in other papers (Martin, 2006; Skovdal, 2009; Withell, 2009), which reported children being stigmatised

for providing care to their parents. Akintola (2006) describes home community-based carers sending children away when giving demonstrations of proper care techniques, despite children often being the ones to provide care. Adult carers argue that children are incapable of providing proper care (Kang'ethe, 2010), a notion echoed by some children in this study. Other research points to the humiliation adults experience in being cared for by children (Martin, 2006). Children in this study also expressed displeasure with having to take on adult roles, such as the girl who wanted someone to care for her and her siblings when her mother was ill, and the children who unhappily missed classes or left university to care for ill family members. One of the major difficulties of the generational bargain in this context is that HIV/AIDS, which primarily affects adults of parenting and working age (Kahn, Garenne, Collinson, & Tollman, 2007; Oramasionwu, Daniels, Labreche, & Frei, 2011), obliges children to take on caring roles before they are adults. Families may not see this as appropriate, but acknowledge its necessary for household survival (Skovdal, 2009).

Comparisons with existing research indicate contextual differences within sub-Saharan Africa, at least in terms of children's responsibilities. For instance, very few children in this study were involved in any type of farmwork despite being recruited in farming communities. Farming was a task that distinguished young carers in sub-Saharan Africa from those in Western settings (e.g. UK, Australia, the USA) (Evans & Becker, 2009). Another contrast between this study and studies from other parts of sub-Saharan Africa was the complete absence of tasks like collecting firewood and making fires for warmth and cooking (Abebe, 2007; Evans & Becker, 2009; Robson, 2000; Robson & Ansell, 2000; Ruiz-Casares, 2009; Skovdal, 2010; Skovdal & Andreouli, 2011; Skovdal & Ogutu, 2009; Skovdal, Ogutu, Aoro, & Campbell, 2009). This was likely related to the relatively high level of development in the Western Cape province. While the Western Cape has a large agricultural sector, it has the second lowest proportion of agricultural households of the nine South African provinces at 2.9% (Statistics South Africa, 2013). Further, during data collection, most households were observed using paraffin gas for heat, precluding the need for wood fires. However, it is possible that they are common in other, less developed parts of South Africa.

A number of children linked their noncaring responsibilities to familial illness, including childcare and domestic tasks. However, it is as yet unclear how much of this is due to the burden of familial illness and how much is part of the range of responsibilities normally experienced among children in deprived South African communities. Existing qualitative research describes how familial illness can result in children taking on or increasing their noncaring responsibility (e.g. Evans & Becker, 2009; Robson, 2000, 2004), and this study provides the example of the 12-year-old boy who dropped out of school to earn money in response to his mother's AIDS illness. However, only quantitative research using representative samples can accurately assess the responsibility burden children face as a result of familial illness.

Study limitations and strengths

The study relied on convenience sampling methods, likely producing a biased sample. As such, quantitative findings including responsibility frequencies should be interpreted with extreme caution. However, use of both community- and school-based sampling allowed for the inclusion of children both attending and missing school, a broader range of participants than a services-based or school-based recruitment strategy would have

produced. The section where children described their activities in a typical 24-hour period did not distinguish between weekdays and weekends, which could have enhanced the range of responsibilities captured. Previous research has found substantially larger responsibility time burdens during the weekend among African children due to the competing demands of the school day (Skovdal, 2009).

There was a substantial risk of interviewer bias given the inherent vulnerability of young carers in South Africa and the Western origin of the study and 'young carers' concept. Both factors had the potential to result in contextually inappropriate and biased interview questions that would gloss over the unique aspects of this phenomenon in South Africa. This was partially mitigated by the collection of all data through local isiXhosa-speaking interviewers.

A limitation – and strength – was the reliance on children's reports. In terms of strength, this allowed for responses from the group of interest, in this case children in illness-affected households. Some of their responses, however, raise questions about their reliability. For instance, children from the same households provided inconsistent information on the number and symptoms of coresident ill family members and even disagreed on seemingly objective data such as the number of people living in their home.

A major strength of this study was the large sample size and geographic variation of participants. The large sample increased the likelihood that rarely occurring, but nevertheless important responsibilities (e.g. toileting an ill adult) were captured. Evidence from existing literature suggests that children's demographics strongly influence their range of responsibilities; the large sample and wide range of children increased the likelihood that this study captured rare and demographically constrained responsibilities.

Conclusion

Through the use of children's responses, this study illustrates a large, though not comprehensive, range of responsibilities among children living with ill parents, grandparents and other relatives. Findings should be interpreted within the context of other research on the impact of familial illness on children's responsibilities in sub-Saharan Africa. Quantitative research is necessary to establish links between child responsibility and familial illness in order to understand the impact on their health and well-being in regions with a high prevalence of acute and chronic disease.

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