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Publication date:
2012

Document version
Early version, also known as pre-print

Citation for published version (APA):
AFRICAN JOURNAL OF AIDS RESEARCH
ISSN 1608-5906 VOLUME 11(3) OCTOBER 2012

Special Issue: Resilience and coping strategies of HIV-affected children in sub-Saharan Africa*

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The authors and guest editors gratefully acknowledge the generosity of UiB Global at the University of Bergen, Norway for funding this special issue.
Introduction to the Special Issue

Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa

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Many children and youths living in low-resource and high-HIV-prevalence communities in sub-Saharan Africa are presented with daily hardships that few of us can even imagine. It is therefore no surprise that most research reporting on the experiences of HIV-affected children in resource-poor settings focuses on their poor health and development outcomes, casting them as victims. However, there is a growing trend to draw on more strengths-based conceptualisations in the study and support of HIV-affected children and youths. In this introduction to a special issue of The African Journal of AIDS Research, we cement this trend by providing a theoretical exposition and critique of the 'coping' and 'resilience' concepts and draw on the 11 empirical studies that make up this special issue to develop a framework that appropriates the concepts for a particular context and area of study: HIV-affected children in sub-Saharan Africa. The articles included here show, albeit in different ways and to different degrees, that the resilience of HIV-affected children in the region is an outcome of their agency and interactions with their social environment. Policy actors and practitioners working to support HIV-affected children in Africa should take heed of the proposed framework and draw on the research presented here to build coping-enabling social environments — presenting children and youths in Africa with greater opportunity to actively deal with hardship and work towards a more promising future.

Keywords: family, HIV/AIDS, households, orphans and vulnerable children, psychosocial aspects, qualitative research, resource-poor settings, social capital, social networks, youths

Background

There is growing interest in the study of lives lived well despite conditions of hardship (see Ungar, 2005, and Ungar, 2012a, for handbooks of some of this work). However, with poverty and disease framing much research in sub-Saharan Africa, there has been little progress in exploring how social environments in Africa not only leave children vulnerable and at-risk but can also provide them with opportunities to actively cope with daily struggles, enabling resilience. Against this background, and in our interest to highlight resilience as an outcome of children’s active participation with a supportive social environment, this special issue, drawing on studies that report on the perspectives of children in low-resource and high-HIV-prevalence regions of sub-Saharan Africa, maps out the characteristics of a coping-enabling social environment — offering service providers with a framework to facilitate children’s resilience.

Millions of children throughout sub-Saharan Africa wake up every day having to face the devastating impact of disease and poverty, so why focus on children affected by HIV and AIDS? As explained by Kofi Annan, former Secretary General of the United Nations (UN) in his opening speech of the 2006 UN General Assembly’s High-Level Meeting on AIDS, HIV has spread more rapidly, further and with more long-term effects than any other disease. The disease continues to spread and is causing distress and hardship for millions of children throughout the region. Although it is difficult to predict how many children are affected by HIV, primarily because of variances in local perceptions of vulnerability and definitions of orphanhood (Bennel, 2005; Meintjes & Giese, 2006; Skinner, Tsheko, Mtero-Munyati, Segwabe, Chibatamoto, Mfecane et al., 2006), UNAIDS (2010) estimates that between 2001 and 2009 the number of orphaned children due to AIDS in sub-Saharan Africa increased from 8.9 million to 14.8 million.

HIV and AIDS are exceptionally complex, and formal responses, in addition to strengthening health services, must consider how social relations, dynamics and inequalities moderate and mediate the epidemic. HIV does not merely impact individuals, but through widespread stigma, reduced productivity and long-term illness, affects entire households and communities above and beyond any other illness. Children are often at the forefront, witnessing the devastating impacts of HIV and AIDS. Although much attention has been given to orphaned children, children’s experiences of HIV-related hardship start long before they become orphaned. As parents fall ill, children typically take on a caring and nursing role as well as increased...
responsibility in sustaining their own households (Robson, Ansell, Huber, Gould & Van Blerk, 2006; Evans & Becker, 2009; Skovdal, Ogutu, Aoro & Campbell, 2009). Children are likely to be stigmatised by peers, family and community members through their association with HIV and AIDS (Campbell, Skovdal, Mupambreiyi & Gregson, 2010; Campbell, Skovdal, Mupambreiyi, Madanhire, Robertson, Nyamukapa & Gregson, 2012) and they are likely to begin the grieving process the moment they realise their parents are at risk of dying. With HIV often debilitating household members of working age, such households are frequently short of resources, leaving children vulnerable to more extreme poverty and neglect. Children affected by the HIV epidemic are repeatedly reported to be at increased risk of malnutrition (Madhavan & Townsend, 2007; Kimani-Murage, Holding, Fotsu, Ezeh, Madise, Kahurani & Zulu, 2011; Bachman DeSilva, Skalicky, Beard, Cakwe, Zhuwau, Quinlan & Simon, 2012), more likely to be withdrawn from school or perform poorly (Case, Paxson & Abeidinger, 2004; Robson & Kanyanta, 2007; Cluver, Operario, Lane & Kganakga, 2012; Guo, Li & Sherr, 2012), more likely to fall ill and to have fewer opportunities to access medical care (Kidman, Hanley, Subramanian, Foster & Heymann, 2010; Bachman DeSilva et al., 2012).

While such observations accurately reflect children’s lack of social power, experience of poverty, and the breakdown of family and community networks — and are crucial for the mobilisation of resources and responses (Seckinelgin, 2007) — they do little to highlight nuances and contextual factors that moderate or mediate the negative impact of HIV on children. Although there are exceptions and good examples of research that highlights the contradictions and complexity (e.g. Nyamukapa & Gregson, 2005; Pagnier, Kurzinger, Kahn, Kone, Hampshire & Dye, 2008), a growing number of commentators agree that there is a tendency to focus on the negative effects of HIV and orphanhood (Andrews, Skinner & Zuma, 2006; Ennew, 2005; Meintjes & Giese, 2006; Skovdal, 2012) and call for greater attention to the resilience of children and youths living in resource-poor and HIV-affected communities (Betancourt, Meyers-Ohki, Charrow & Hansen, 2012; Skovdal, 2012).

Nonetheless, the focus on children’s victimisation is at the core of much child-centred policy and research in Africa (Edwards, 1996; Boydten, 1997) and reflects the innocence and vulnerability with which children have become associated (Fassin, 2008). Western ideologies continue to frame much research in Africa within generalised categories, such as childhood and mental health, with little room to consider meanings in the local setting (Edwards, 1996; Boydten, 1997; Nsameneang, 2012). For example, if one starts from the assumption that a ‘normal’ childhood should be characterised by innocence and play, it is only a short step towards representing children living in rural African communities affected by HIV, whose life circumstances reduce their opportunities for innocence and play, as being ‘abnormal’ and potentially ‘troubled,’ vulnerable to psychosocial distress and in need of adult care, support and psychological intervention. The construction of African children as vulnerable has sparked debate over some of the unintended consequences of such victimising representations (Meintjes & Giese, 2006; Cheney, 2010; Kessi, 2011; Skovdal, 2012). These authors raise the concern that children, in order to be supported, need to act and think in ways that reflect the international aid industry. Cheney (2010, p. 8) argues that casting HIV-affected children as vulnerable “creates an untenable demand for OVC services and potentially reifies vulnerability as an ironically privileged and empowered identity.” Not only does such a preoccupation with the vulnerabilities of children in difficult circumstances overshadow more culturally relevant and strengths-based conceptualisations of self and wellbeing, it fosters a culture of relief addressing pathology and immediate needs at the expense of programmes that ensure the appropriate protective mechanisms are in place to enhance resilience.

In response to this trend we convened a symposium at the 1st International HIV Social Science and Humanities Conference, in Durban, South Africa, June 2011, with the title: ‘When orphaned children make the best of difficult circumstances: Implications for theory, policy and practice.’ The aim of the symposium was to present research highlighting the coping strategies of children living in communities affected by HIV and to discuss, in a multidisciplinary forum, how the social sciences — using concepts such as coping and resilience — can help advance and appropriate interventions looking to address the hardships of children. Children’s participation with their social environment as a strategy to cope with hardship was a common theme across the research presented. Participation was conceptualised around the idea that societies have their own understandings of childhood, and the studies presented here highlight a variety of perspectives pertaining to children’s agentic capabilities and vulnerabilities. We used the term coping to refer to people’s ability to deal successfully with or handle a difficult situation. This special issue of the African Journal of AIDS Research is organised around this topic and presents some of the conference papers and other solicited articles on this topic.

To conceptually locate the work presented in this issue within a wider social-science context, we first examine how different understandings of childhood underpin the framing of research. We then discuss current debates about the use of the terms resilience and coping. Finally, we present an overview of the articles, followed by some concluding comments on resilience as an outcome of children’s participation with their social environment.

**HIV-affected children: passive victims, active agents and resilience**

The conceptual point of departure of much child-centred research framed by the HIV epidemic is constructed around two perspectives. The most dominant perspective follows the developmental psychology paradigm and reflects the influence of Jean Piaget’s theory of developmental stages (see Piaget & Mays, 1972). Although Piaget (1929) recognised children as constructivists and acknowledged the role of the social environment in shaping their language skills and understandings of the world, his theory that children, through a series of age-specific stages, are able to engage in specific types of thinking and competencies has been used to develop a cognitive map of how individuals...
Kjørholt (2009) that dichotomising children as passive and vulnerable beings, in need of adult guidance and support until they have reached adulthood or adult rationality (James, Jenks & Prout, 1998). Ansell (2005) argues that the ideal of stage-wise cognitive competencies is an inherently Western construction — one that is being used by child-welfare agencies and the medical profession to test and see whether children can be characterised as ‘normal.’

The ‘new social studies of childhood’ perspective argues that the notion of childhood is a social construct and that studies on childhood must consider social variables (e.g. culture, ethnicity and gender) (Prout & James, 1997). This perspective sees children as social actors who are able to shape their own realities and it accepts the possibility that children, across developmental stages, are active and competent beings who can actively appropriate their social world as opposed to passively grow into it (Matthews, Limb & Taylor, 1998; Holloway & Valentine, 2000; Christensen, 2004).

Crudely said, these two perspectives on child development and children’s competencies epitomise the analytical lenses that tend to guide research questions and shape research outputs. They are manifested in disciplinary traditions and contribute to a conceptual gap between the more anthropological literature that views African children as social and active participants who offer benefits to their households, and the more biomiedically aligned HIV-related literature that represents orphaned and HIV-affected children as victims. This gap, as we highlight in this section, has contributed to representations of children as either passive victims or active agents. We concur with Abebe & Kjerholt (2009) that dichotomising children as either active agents or passive victims is problematic and undermines the possibility for what Kesby, Gwanzura-Ottemoller & Chizororo (2006) call ‘other’ childhoods within a given context. So, while we locate ourselves with the anthropological literature and fully recognise the social competencies of children, we also acknowledge that children’s opportunities to exercise agency and achieve good health and wellbeing are limited or enabled by the social context in which they are located (cf. Hutchby & Moran-Ellis, 1998; Skovdal & Andreouli, 2011).

The literature on HIV continues to be largely unmindful of children’s agency and the fact children in many parts of rural sub-Saharan Africa are trained from an early age in a variety of life skills to prepare them for life’s struggles. Boys living in households affected by HIV in western Kenya, for example, are reportedly taught how to cook (traditionally a female role) in preparation of the possible premature death of their parents (present) and spouse (future) (Skovdal et al., 2009). Although there are many examples of children’s interdependence rather than mere dependency on adults for care and support, the notion that children are passive victims in need of adult care and support, predominates in studies looking at the care arrangements of HIV-affected children. An expanding number of studies are reporting on the struggles faced by caregivers of children affected by HIV in meeting their needs. Nyambu, Wandibba & Aagaard-Hansen (2003) argue that grandparents caring for orphaned children are burdened by costs related to schooling, healthcare and food, which in effect results in what they call a ‘lost retirement.’ Building on such observations, many studies have sought to examine the psycho-social impact of such struggles on orphan caregivers. Ssengonzi (2007 and 2009) in a qualitative study in Uganda found elderly caregivers to report anxiety about their future health and wellbeing. Their anxiety was related to their inability to pay for school-related expenses, fulltime caregiving of younger orphans (below the age of 6 years) and care for children living with HIV (Ssengonzi, 2007 and 2009). Elsewhere in Uganda, Kagotho & Ssewamala (2012) report on a quantitative baseline survey of 297 caregivers which found most caregivers of HIV-affected children to be female and to suffer from depression, particularly if they perceived themselves to be short on social support. Using standardised measures in neighbouring Kenya, Oburu and Palmerus compared levels of stress between 115 biological mothers and 134 adoptive grandmothers (Oburu, 2005) and between 128 adoptive and 113 grandmothers with a part-time partial parenting role (Oburu & Palmerus, 2005). Both studies found adoptive grandmothers to suffer from elevated levels of stress, primarily because of limited instrumental support and uncertainty of the children’s adjustment. In a similar context, Ice, Yogo, Heh & Juma (2010) and Ice, Sadruddin, Vagedes, Yogo & Juma (2012) examined the impact of orphan caregiving using perceived (‘perceived stress scale’ with Luo participants) and physiological (blood pressure; salivary cortisol) measures with 640 elders. Comparing caregivers with non-caregivers, they found orphans’ caregiving to contribute to a deterioration of perceived mental health, but found no or only a minimal relationship between caregiving and poor physical health or their physiological stress levels (Ice et al., 2010 and 2012).

These studies, framed by the HIV-related discourse, implicitly cast orphaned and HIV-affected children as a burden to their suffering caregivers. They assume children are passive recipients of support and are unmindful of the fact that African children have traditionally spent large parts of their childhood away from their parents in an effort to strengthen family kin ties and spreading the costs and benefits of children (Caldwell & Caldwell, 1987; Lloyd & Desai, 1992; Serra, 2009). Not only is it an important part of children’s socialisation (Raum, 1940; Katz, 1986), facilitating an early sense of responsibility, belonging and collective responsibility (Katz, 1996; Sharp, 1996), it is a testimony of the benefits children bring to the elderly and sick in a region of the world where old-age pensions and social security are a rarity (Serra, 2009).

Only a few researchers writing within the context of HIV and AIDS have bridged the conceptual differences and documented the benefits of children’s contribution to their households. Ansell (2005) and Skovdal (2010) have usefully linked the needs and circumstances of fostering households and the capacities of children, highlighting children as social agents and the reciprocity of care and support that co-exist within HIV-affected households. Abebe (2008) and Abebe & Aase (2007), through case studies of working children
in Ethiopia, examine the reciprocal relationships evident in HIV-affected households, emphasising the role children play in their fostering household. There is a need to examine children's perspectives of their care arrangements. Not only is this likely to highlight the reciprocity of care and support evident within the household, it will demonstrate children's agentic capabilities and give us insight to the decisions and choices children make in order to cope with hardship.

Unsurprisingly, reports of HIV-affected children as vulnerable, deprived and 'at risk' have also stimulated a large and rapidly expanding body of research looking at the psychological distress of HIV-affected children (e.g. Cluver, Fincham & Seedat, 2009; Nyamukapa, Gregson, Wambe, Mushore, Lopez, Mupambireyi et al., 2010). A recent review of this literature identified 31 peer-reviewed resources on the mental health of HIV-affected children in Africa (Skovdal, 2012). The majority of these articles, 23 in total, focus on the psychological distress experienced by HIV-affected children (e.g. Makame, Ani & Grantham-McGregor, 2002; Bauman, Foster, Silver, Berman, Gamble & Muchaneta, 2006; Cluver, Gardner & Operario, 2007; Ruiz-Casares, Thombs & Rousseau, 2009; Kaggwa & Hindin, 2010), while only 9 set out to explore social psychological pathways towards improved mental health (e.g. Evans, Daniel, Apila, Bjorg & Lie, 2007; Skovdal et al., 2009; Skovdal & Andreouli, 2011). The review uses this preoccupation with psychological distress as a platform to argue that not only is much of this research driven by global and decontextualised understandings of childhood and mental health, it is guided by a biomedical paradigm that uses standardised scales and measures (often developed in the 'global North' to measure deviance) at the expense of qualitative and resilience-focused research that brings forward the perspectives of children and can be used to appropriate psychosocial responses (Skovdal, 2012). Stressing the importance of gathering children's perspectives, a few recent studies that interviewed HIV-affected children about their perceptions of mental health identified a mismatch between local and global understandings of mental health (Harms, Kizza, Sebunya & Jack, 2009; Betancourt, Rubin-Smith, Beardslee, Suluc, Fayida & Safren, 2011).

While there is no doubt that many HIV-affected children experience feelings of anxiety and depression, and that a pathological focus serves the important purpose of highlighting the hardship experienced by millions of children in Africa, it is crucial that such a focus does not overshadow the plurality of experiences of HIV-affected children and the ability of some to deal with hardship (Skovdal, 2012).

Resilience is widely regarded as a useful counterpart to a focus on vulnerability. The term resilience is often used to refer to a person's capacity to adapt, recover from or remain strong in times of hardship (Masten, Best & Garmezy, 1990; Luthar, Cicchetti & Becker, 2000). An advantage of resilience research is that by definition the term acknowledges both the presence of risk and adversity as well as local strengths and pathways to wellness. Evans & Becker (2009), looking at children caring for parents with HIV, argue that researchers need to move away from a focus on the 'vulnerability' of this group of children to one concerned with 'resilience.' This, however, should be done with recognition that resilience research can be just as normative and divorced from children's everyday reality as research that focuses on risk factors and their vulnerability (Boyden & Mann, 2005). Evans & Becker (2009) involved 15 caregiving children in Tanzania and 9 caregiving children in the United Kingdom in a study seeking to comparatively map out the living and care arrangements of children caring for HIV-infected parents. In addition to identifying problems of stigma, poverty, poor physical and emotional health, social isolation and poor academic performance, Evans & Becker (2009) also identified the importance of supportive school environments, young people's friendships and supportive social networks.

While it is important to highlight the protective factors, social resources and ecologies that enhance the resilience of children, as also done by contributors of two resilience-focused handbooks (see Ungar, 2005 and 2012a), we now need to identify how children in different contexts actively negotiate access to these social resources — unpacking pathways that lead to wellbeing and ultimately resilience. To move this agenda forward, the articles included in this special issue all examine, albeit in different ways and contexts, how children make use of, or negotiate access to, the care and support arrangements available to them.

**Resilience through participation and coping**

The concept of resilience is heavily contested and debated. Although there are many different definitions of resilience, they are broadly similar and refer to the positive adaptation of people in difficult situations. Reflecting on their work with children in resource-poor settings, Boyden & Mann (2005, p. 20) argue that "resilience provides a useful metaphor for the empirical observation that some children, possibly the majority, are surprisingly able to adjust to or overcome situations of serious adversity." As much as resilience usefully encourages us to look beyond pathology and the vulnerabilities of children, its metaphorical understanding makes it difficult to identify and operationalise social pathways towards resilience.

Academics and practitioners who have sought to describe the pathways that lead to resilience can be broadly divided into two camps. On one hand you have those who see the locus of change, or unit of analysis, at the individual level. They see resilience as something intrapersonal, as a trait of the individual. This camp has given rise to prominent theorists like Bandura (1977), who developed the concept of self-efficacy, and Antonovsky (1987), who developed the concept of sense of coherence. These concepts have developed over time to reflect a more recent and popular view of resilience as an outcome of positive interaction between the individual and their social environment (Rutter, 1987; Ungar, 2005 and 2012b). Ungar (2010 and 2011) has been instrumental in moving this agenda forward and has highlighted the need to view resilience in relation to the opportunities that are available for personal growth. While we fully support Ungar’s (2012a, p. 14) drive to shift common understandings of resilience away from individual capacities to the possibilities within social ecologies and agree that an “interactional, environmental, and culturally pluralistic perspective” is necessary, we feel greater attention must be brought to the interface between the
individual (and groups of individuals) and the social environment. Although Ungar (2008) has touched on this interface, arguing that resilience is both the capacity of individuals to navigate their way to social support and a condition of the individual’s social environment, his important works fall short of providing solid and contextual empirical insight about this interface.

Reflecting on current trends in resilience research in relation to children facing hardship, Boyden & Mann (2005) highlight four additional limitations. First, they argue that the theory is confusing and riddled with imprecision. The popularity of the term has meant its use has grown exponentially, but in the process lost its analytical significance to conflicting conceptualisations and definitions of the term. Second, resilience refers to the ability of some children facing hardship to cope better than expected. However, who defines hardship and better-than-expected outcomes is problematic. They argue that hardship and resilience “is as much a matter of perception as of situational fact” and they give examples of how some cultures actively encourage ‘steeling’ (Boyden & Mann, 2005, p. 10). Risk and resilience are therefore culturally and normatively loaded terms that are socially constructed (Ungar, 2004). Third, much of the existing literature has been conducted in the global North, creating a context from which the benchmark of a ‘normal’ childhood is examined. Fourth, and related, much of the existing literature draws on the views and perspectives of adults to understand the risk and resilience of children, resulting in adult interpretation. Boyden & Mann (2005, p. 11) argue that such a trend has meant that “resilience is conceived of more as the absence of pathology rather than the presence of personal agency in children.”

What these limitations ultimately call for is greater attention to children’s perspectives on how they actively deal with hardship in particular contexts. We need to look at how children’s social environments enable or limit their capacity to cope successfully (using their agency) with hardship through interaction with their surroundings.

Coping and resilience both have a strong history in and connotations to Western psychological sciences, rooted in a focus on individual capabilities, traits and strategies. However, arguably because of its metaphorical understanding, social studies have embraced the concept of resilience and transformed it into a concept that is increasingly used to investigate the dynamic and social processes that help individuals deal with hardship. Coping on the other hand continues to be conceptualised as the cognitive and behavioural response of individuals to deal with hardship (Lazarus, 1993). Although coping is seen as a process that can change over time and is the result of a dynamic interplay between a person and his or her environment (Lazarus & Folkman, 1984), the unit of analysis, and the locus of change of much coping research remains at the level of the individual. This is illustrated by the scholarly work included in the Oxford Handbook of Stress, Health and Coping (Folkman, 2011). The handbook presents the work of leading scholars in the field of coping and stress, covering an array of models and theories, developmental perspectives, accounts of the social aspects of coping, coping processes and interventions. One of the more socially oriented theories described in the handbook pertain to Taylor’s (2011) tend-and-befriend theory. Taylor’s theory is that during times of hardship people benefit from affiliations with other people. She argues that while social support networks or affiliations are important for the coping of individuals, social transactions are less so (Taylor, 2011). She thus suggests that people facing hardship cope through a perception of others’ availability to provide support in times of hardship, and not necessarily through the actual support. Another chapter with a social spin is by Revenson & DeLongis (2011) who draw on dyadic and relationship-focused coping theories to describe how couples deal with the chronic and physical illness of one of the partners. They highlight the cognitive and behavioural efforts that couples draw upon to manage and sustain their social relationship.

A consequence of this individualistic focus is the notion that coping skills can be taught (such as positive thinking and appraisal) (e.g. Moskowitz, Hult, Bussolari & Acree, 2009; Moskowitz, 2011) and that individuals have the ability to change. While this is important and probably helpful to many people, social studies often take it as a starting point that it is not the individual who needs to be taught, or change, but the social environment and the wider political economy for its contribution to poverty and social marginalisation. Furthermore, coping has become associated with the process of overcoming psychological distress and not the more mundane daily struggles of getting food on the table and taking care of loved ones. So without undermining the importance of cognitive coping styles of individuals, we want to promote a more social psychological understanding of coping within social studies, one that refers to the ability of people to successfully engage in actions or processes that help them overcome a problem or difficulty.

While coping and resilience are interconnected and both pertain to the active process of adapting successfully to hardship, Rutter (2012, p. 34) clarifies that “the two are not synonymous because coping is essentially an individual feature, and moreover one that implies some overt action…. In particular, it ignores the social context and social influences, both of which can be very influential.” Rutter (2012) summarises a key weakness and strength of current theorisations of coping, the weakness being its preoccupation with the individual as the unit of analysis and the strength being its association with an action through participation.

Put slightly differently, Helmreich (1996, p. 276), looking at the resilience and ‘ordinary magic’ (cf. Masten, 2001) of holocaust survivors, argues: “It (coping) is not a story of remarkable people. It is a story of just how remarkable people can be.” Lemay (2005, p. 13) sees this as a key difference between resilience and coping and paraphrases Helmreich (1996): “Coping is the science of remarkable people whereas resilience is the story of how remarkable people can be.” These differentiations reiterate some of the shortcomings of the theories of coping (being too individualistic) and resilience (being a metaphor and rather vague). Although resilience researchers look to identify the conditions that enable resilience, primarily through the interface between risk and protective factors, processes and social ecologies, we lack a ‘science’ of how the social
environment enables people to be remarkable, or, more specifically, how resilience is an outcome of people's engagement with a coping-enabling social environment. While some progress has been made for such a 'science' in the disaster-response literature (e.g. Coles & Buckle, 2004; Pfefferbaum, Reissman, Pfefferbaum, Klomp & Gurwitch, 2007), we hope, through our discussion of the articles in this special issue, to broaden the scope of resilience research in social studies of HIV and AIDS, and to encourage researchers to look at how social environments, including the political economy, enable or prohibit children to actively engage with local resources to cope with hardships. We need to recognize the importance of agency and chart out the characteristics of a coping-enabling social environment.

**Discussion of the articles in this special issue**

**Resilience through coping-enabling social environments**

Drawing on the perspectives of HIV-affected children from diverse contexts and experiences in sub-Saharan Africa, the articles in this special issue take this agenda forward. They all point to the importance of identifying and learning from children's interaction with their social environment as a pathway to resilience.

To demonstrate children's different abilities to navigate for support from their social environment, we have superficially clustered the articles in relation to their social ecological focus. Here we consider three levels, or circles of support around the child, and the interactions between them: the household, the community and wider society. The inner circle, the household, consists not only of family members (who may or may not provide support) but also of household assets, such as housing and agricultural land. The next circle is the community, which in this issue refers to the transformative social spaces and relations that schools and psychosocial interventions offer children to interact positively with community members. The outer circle refers to the political economy and the opportunities that government provision of health and welfare services, such as antiretroviral therapy (ART) and cash transfers, offer children to cope with hardship. At each level, children are found to access both material and relational resources. We recognize that clustering the articles in this way is an oversimplification and we acknowledge that all the studies, albeit in very different ways, demonstrate children's interaction with all the circles of support available to them.

The article by Lee (this issue) crystallizes the importance of considering children's and youths' agency as a way to cope with hardship. She provides a useful framework for understanding how children and youths strategically and tactically navigate through their social environment, drawing on available social, emotional and material resources, as a way to cope with hardship. Working with 25 children and youths, ages 9 to 24 years, heading households in very constrained social settings in Rwanda, Lee contends that they are not passive in their situation, but their ability to act is moderated by their social environment. She notes youths' remarkable ability to mobilize resources that will not only help them but also the children under their care. However, the expected social support networks, namely extended families, neighbours and community leaders, are sometimes unwilling or unable to help, and they may even undermine the efforts of youths to cope and add to their social suffering. Even the role of NGOs is not straightforward and they may cause harm while intending to help. Youths exhibit agency as they navigate the available social networks, picking and choosing those that are helpful rather than harmful. It is often small acts of social support that give orphaned youths a 'breathing space' to build a locus of control and begin to make longer-term plans for living rather than just surviving day to day. Lee argues that recognizing social relationships that are supportive to children and youths is critical, as these can be further cultivated, thus enabling young people's ability to cope with hardship.

Three articles look explicitly at the care and support arrangements of HIV-affected children and youths and highlight the ways they deal with hardship at the household level. Using the sustainable livelihoods framework, Evans (this issue) identifies inherited land and property as key assets for child- and youth-headed households to successfully cope with hardship and examines local community responses to safeguarding the inheritance of orphaned children and youths. In doing so she points to some of the strategies that children and youths heading their own households adopt to participate in this process and enhance resilience. Evans draws on data from 15 orphaned young people heading households, 18 of their siblings, and 39 NGO workers and community members, from both rural and urban areas in Tanzania and Uganda. She identifies human and social capital as significant social enablers in protecting property rights and enhancing the skills and capabilities of young people to make active use of their land/property. NGO support can take the form of legal advocacy, material and emotional support and agricultural inputs and life-skills training to compensate for the loss of intergenerational transfer of knowledge. Evans notes the importance of listening to young people's perspectives on what they need and recognizing their agency; for example, the young people prioritized the provision of basic needs ahead of employment or emotional support. Evans also demonstrates the role that youth-led collective mobilization and peer support can play in enhancing resilience and tackling stigma and property-grabbing in the community.

The article by Daniel and Mathias (this issue) contrasts the experiences and coping strategies of 12 orphaned children (ages 14 to 18 years) in Tanzania without adequate adult care who either remain in rural areas in child-headed households or who are trafficked to serve adults in Dar es Salaam. The three child-headed households all had access to agricultural land and two were able to negotiate support from extended family networks. Echoing Evans (this issue), land proved crucial to the household's ability to cope. The nine trafficked girls were deceived, isolated, abused and entirely dependent on their employers but all managed to take control and escape, sometimes with the help of a neighbour or church member.

Andersen (this issue), rather than looking at assets at the household level, focuses on children's relationships with family members, friends, neighbours and church members.
Her informants included 20 caregiving children (ages 6 to 16 years) in Kenya. She discusses some of the strategies children use to cope as primary caregivers of parents living with HIV and on antiretroviral therapy, including their ability to navigate available social and economic support structures. She draws attention to two components influencing the consequences of children’s caring activities as well as their ability to cope: 1) the dynamics of their parent’s health condition while on antiretroviral therapy, and 2) the context in which children navigate for social and economic resources.

Two articles focus on psychosocial interventions. The article by Thamuku and Daniel (this issue) concerns an intervention that provides children in Botswana with a space for reflection and transformation. In the context of the dominant child-rights framework for psychosocial support for orphaned children, they examine an alternative approach which uses rites of passage and rites of affirmation as part of a broader programme to strengthen the psychosocial wellbeing of orphaned children. Ten children, ages 13 to 15 years, attending a retreat were involved in the research; in addition, numerous documents from the NGO that designed the approach were analysed. Rites of passage were purposefully used to create a kinship-like group for the orphaned children attending a retreat, to promote solidarity so that the members are mutually supportive on return to their village. Rites of affirmation were used to help each participating child, witnessed by the group, commit to the strengthening and transformation they experienced on the retreat.

Wood, Theron and Mayaba (this issue) present a potentially ground-breaking tool for caregivers, service providers and educators to inexpensively boost the resilience of children orphaned by AIDS. Their research explored whether reading culturally relevant stories to children orphaned by AIDS could promote resilience. The authors requested a panel of psychologists to select stories that contained resilience-enhancing content from folktales that had been collected from community members. The panel identified 22 stories that were embedded with examples of positive role models, moral lessons and metaphors of positive adjustment which could promote new and positive ways of thinking. One story per week was read to 20 orphaned children in an orphanage in South Africa without any further adult input. An innovative pre-and post-intervention evaluation of drawings, written stories and conversations with the children, indicated that post-intervention they seemed to choose to see themselves more positively and as having a more secure relationship base with caregivers. It was also observed that the children, through their own initiative, would act out the stories later on in the day, which could imply that the telling of the stories also enabled them to participate in developing their own resilience through this imaginary play activity, as they identified with the ‘heroes’ of the stories. The intervention thus seemed to provide the children with a space to develop more positive and empowering thoughts which bolstered their resilience and encouraged their awareness and use of the social drivers of resilience found in their immediate social ecologies (such as with school and friends).

Two articles discuss the opportunities available within the school environment to help children cope with hardship. First, Skovdal and Ogotu (this issue) use a social-capital framework to explore how 48 HIV-affected and caregiving children (ages 12 to 17 years) in Kenya cope with hardship by forming supportive friendship groups. They note the importance of both children’s agency (to strategically establish a mix of friendship structures) and the contextual factors such as the school environment in providing a space for the development of ‘peer social capital.’ The authors highlight how a context characterised by social solidarity and an ethics of care and assistance can encourage children to set up peer support groups to come to other’s aid in times of need.

Second, employing ‘appreciative inquiry’ to frame the discussion of adolescents coping strategies, Kahanare (this issue) examines the possibilities of the school environment to be supportive of adolescents affected by HIV. A total of 20 Grade-11 pupils from two schools in South Africa participated the study. Using a participatory visual method (PhotoVoice) for data collection, Kahanare enabled the adolescents to reflect on both coping-enabling and coping-inhibiting factors within the school environment. Her findings point to some of the ways adolescents affected by HIV navigate through the school environment to access resources. Like Skovdal and Ogotu, Kahanare found collaboration and mutual support among friends and peers to be an important pathway to resilience. Recognition by teachers as well as their ability to listen sympathetically and help in emergencies was also valued by the adolescents. Other school-based activities, such as peer education programmes, and NGO and church support as well as the use of social media as a source of information were also mentioned as providing opportunities for adolescents to actively cope with hardship.

Finally, three articles highlight the enabling role of a favourable political economy, understood as the provision of health and social-welfare services. Midtbø, Shirima, Skovdal and Daniel (this issue) explore how disclosure and the provision of ART help HIV-positive adolescents cope with stigma and challenges in seeking treatment. Using data from a total of 28 HIV-positive adolescents (ages 12 to 19 years) in Tanzania and Botswana, the authors identify several pathways between disclosure and ART on the one hand and adolescent coping and wellbeing on the other hand. Once they knew their HIV status, the adolescents were able to make sense of and actively participate in their treatment. They made strategic decisions about disclosing their HIV status to others and about whom to approach for support. Disclosure enabled the adolescents to actively engage with supportive social environments at several levels, from that of society (ART provided by the government or an NGO), to reciprocal peer-support in groups and support from key family members. Active participation in their treatment and support boosted the adolescents’ sense of confidence and control of their lives.

Two articles highlight, among other things, the opportunities and challenges that children and youths face in navigating access to cash transfers. Van der Brug (this issue) provides unique insight into some of the long-term implications of orphanhood and HIV. She presents a
longitudinal study of 14 orphaned or vulnerable children from Namibia and examines changes in their perspectives of challenges and coping strategies. Children aged 9 to 12 years participated in the research in 2003. And, in 2010–12, the same 14, now adolescents, commented on the changes in their lives and what had facilitated improvements. Most of the adolescents described their situation as better than in 2003 and perhaps the most obvious change was that nine of the 14 had been enrolled in a cash-transfer programme (state-provided child grant) for at least some of the time. They also described their agency in getting away from abusive home situations by telling other relatives about their mistreatment or by running away. They asked for financial support from family members and expressed the intention to reciprocate support to the family once they started earning their own income. The adolescents demonstrated an ability to positively reflect on changes in their living and care arrangements, noting that their own actions and decisions had contributed to the improvements in their lives.

A number of the contributions to this special issue highlight the importance of social relations in helping HIV-affected children cope with hardship. Van Dijk and Van Driel (this issue) present a more critical stance and assess the ‘use-value’ of the extended family network and community members. In doing so they importantly highlight some of the limitations of social relations as enablers of children’s coping with hardship. The authors draw on research with 20 child or youth-headed households in South Africa. They found that social support in the context of Port Elizabeth, South Africa, was not only limited, but often unpredictable or unreliable, or given only in exchange for errands and chores. A lack of social accountability and solidarity made it difficult for the children and youths to navigate for social support. Furthermore, the authors exemplify how children and youths without an adult guardian, coupled with a misrecognition of their agentic capabilities (they still had a social status as children), are unable to apply and seek support from a social cash-transfer programme. Van Dijk and Van Driel find that although child-headed households in this context only have limited room to manoeuvre for social support, once someone committed to show them love and respect, they were more positive about the quality of support no matter how minimal it was. Van Dijk and Van Driel question the contribution of the extended family and community (i.e. the actors normally expected to support orphaned children and child-headed households) to children’s coping capability and they provide a useful counterargument to some of the contributions here, reminding us of the difficult realities facing many HIV-affected children and the need to build coping-enabling social environments.

As evidenced by the contributions to this issue, the agency of HIV-affected children, moderated by a variety of social enablers (e.g. social norms and social recognition of children as social actors), play a significant role in shaping their experiences and capacities to access resources that help them cope with hardship. The articles featured here further this theoretical insight by tackling the critical interface between children's agency, social enablers and the social protection resources available for children in the context of HIV in sub-Saharan Africa. Table 1 summarises the pathways to resilience — understood as the mediation between children’s interaction with local resources and social enablers — as identified by the articles in this issue. As a result of these observations, we conceptualise a coping-enabling social environment for HIV-affected children and youths as a context that provides children and youths with opportunities to actively deal with hardship and work towards a more promising future. This framework suggests that children's coping with HIV is an outcome of the resources/assets, social enablers, and opportunities for participation which a given context avails to vulnerable children.

**Concluding comments**

A great deal of attention has been given to the needs of HIV-affected children and the risks associated with living in a household affected by HIV. This has led to a focus that overshadows the fact that many children and youths, as exemplified by all the articles in this special issue, are not passive victims who sit and wait for help, but are competent social actors who actively cope with difficult social circumstances through skill and ingenuity. However, recent academic debate and policy interest in the concept of resilience is catching on to the HIV-related literature, encouraging a shift in focus. Despite this interest and debate, the metaphorical ambiguity of the concept of resilience has meant that little has been done to contextually theorise pathways to resilience and move beyond a simplistic view of resilience as an outcome of children’s access to protective factors. This special issue contributes to the existing literature on resilience and coping by providing a theoretical exposition and critique of the two concepts, and appropriates them for a particular context and area of study: HIV-affected children in sub-Saharan Africa. As such, we hope that this special issue lays a foundation for dialogue on the topic of resilience and social science among researchers working in the field of HIV and AIDS in Africa.

All the articles highlight the hardship experienced by many HIV-affected children in sub-Saharan Africa and the fact that many struggle to cope. Many children come from families severely affected by HIV, giving rise to new forms of household arrangements and compositions. ‘Normal’ support structures (e.g. extended family and community support) are often under increased pressure, leaving many children to fend for themselves or look for alternative support. Nonetheless, despite these difficulties, all the studies testify to children’s creativity and demonstrate their active role in negotiating access to support and strategically navigating through the social support networks available to them. Children’s agency and navigation through social support structures is a key pathway to resilience. However, as illustrated by the articles here, children’s pathways to resilience cannot be conceived independently from the enabling or inhibiting role of the political economy, community-based networks and the household environment, since all of these circles of support, or sites of marginalisation, are interconnected and shape the social environment that predicts children’s wellbeing and capacity to negotiate support. Furthermore, children’s ability to cope with one challenge does not necessarily equate to resilience. Our examination of the studies included in this special issue
Table 1: Pathways to resilience: children’s agency, social enablers, and local resources

<table>
<thead>
<tr>
<th>Social ecologies</th>
<th>Resources that help children cope</th>
<th>Social enablers that avail resources and opportunities for coping</th>
<th>Avens for intervention by external agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home environment and the extended family</td>
<td>Protection from abuse and security of property and land assets</td>
<td>Children’s agency and social participation</td>
<td>Train and support youth paralegals to protect children from property- and land-grabbing; legal advocacy; strengthening of child-protection services.</td>
</tr>
<tr>
<td></td>
<td>Agricultural inputs and skills training</td>
<td></td>
<td>Livehood-sustaining activities and training.</td>
</tr>
<tr>
<td></td>
<td>Family bonds</td>
<td></td>
<td>Parenting skills training.</td>
</tr>
<tr>
<td>Community-level factors (indigenous community networks)</td>
<td>Peer social capital</td>
<td></td>
<td>Enable and empower community networks to respond to the poverty-related needs of HIV-affected children.</td>
</tr>
<tr>
<td></td>
<td>Livelihood support from community members</td>
<td>* The social recognition of children’s agency</td>
<td>Advocacy for children’s right to participate.</td>
</tr>
<tr>
<td></td>
<td>Public acknowledgement of children as social actors</td>
<td>* Ethics of care and assistance</td>
<td>Facilitate life-skills seminars to all community members (using existing community networks, digital media, and afterschool clubs).</td>
</tr>
<tr>
<td>Community-level factors (externally facilitated support)</td>
<td>Knowledge and skills training</td>
<td>* Social solidarity</td>
<td>Facilitate psychosocial support interventions.</td>
</tr>
<tr>
<td></td>
<td>Space for reflection and transformation</td>
<td>* Social networks</td>
<td>Implement home-based-care services; sensilise HIV-related services to the needs of children living in households affected by HIV; set up mentoring schemes for support of child-headed households.</td>
</tr>
<tr>
<td></td>
<td>Home visits and support from community-health and adherence-support workers</td>
<td>* Social norms and cultural expectations</td>
<td>Scale up state-level cash-transfer programmes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>* Religion and faith.</td>
<td>Improve HIV-related services to increase access and adherence as well as consider the unique needs of children, both as caregivers and survivors living with HIV.</td>
</tr>
<tr>
<td>Political economy</td>
<td>Cash transfers</td>
<td></td>
<td>Facilitate child-friendly and orphan-competent schools.</td>
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<tr>
<td></td>
<td>Antiretroviral therapy access</td>
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<tr>
<td></td>
<td>Education</td>
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</table>

demonstrates that the extent to which HIV-affected children are able to engage in multiple coping strategies and demonstrate resilience depends on: 1) the quality of the social environment (availability of social enablers) and its ability to share meaningful resources; 2) children’s individual competencies and ability to negotiate support from the social environment (agency); and, 3) the ongoing and long-term interaction between children and their communities, allowing them to participate in community life and draw on local representations and knowledge structures to give them meaning and reflect on life’s challenges.

Methodologically, the research presented here confirms the importance of child and adolescent participation in research. It is increasingly recognised that effective social protection strategies need to consult and consider the perspectives of children and youths (Myers & Bourdillon, 2012). As illustrated by the contributions to this special issue, incorporating the perspectives of children and youths into this debate not only highlights their priorities, as opposed to those of adults and donor agencies, but contributes to new theoretical thinking about resilience and coping. Conceptually, this has allowed us to build on earlier observations by Ungar (2005), Boyden & Mann (2005) and Panter-Brick (2002), and contextually examine the importance of viewing resilience as an outcome of children’s agency and interaction with their social environment. Theoretically we have highlighted the need to see coping — in a social psychological sense — as an instrumental pathway to resilience, enacted through participation and facilitated by the social environment, both through the availability of meaningful resources and social enablers. There is an urgent need to take heed of these findings and facilitate the development, and in some cases strengthening, of coping-enabling social environments through holistic and structural interventions that involve community members and children alike, and in the participatory process solidify the important social enablers that support children to cope and demonstrate resilience.

Acknowledgements — We thank all the reviewers of the papers submitted for publication in this special issue, as well as our colleagues for their constructive feedback as we conceived the issue. Special thanks to Jo Boyden for her invaluable feedback on earlier drafts of this introduction. We are grateful to Kevin Kelly for giving us the opportunity to guest edit this issue of the African Journal of AIDS Research, as well as to Sue Cooling for helping us through the process. This special issue would not have been possible without financial contributions from the Norwegian Research Council and UiB Global at the University of Bergen.
References


Youths navigating social networks and social support systems in settings of chronic crisis: the case of youth-headed households in Rwanda

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Youth-headed households in Rwanda live in a context of chronic crisis, where poverty, disease and uncertainty are not exceptional but characterise people’s daily lived reality. Struggling under the pressures of economic deprivation, social isolation, abuse and exploitation, these youths experience social suffering and feel the impact of social forces on their everyday lives. Yet, amid constraints in the environment, youths demonstrate resilience by actively navigating their social networks and working to create opportunities for the future. The article describes qualitative research carried out in three communities in Rwanda, between 2006 and 2010, examining the support systems of Rwandan youths affected by the HIV epidemic and socio-political conflict and exploring how youth heads of households navigate social networks in order to buffer the suffering in their lives. It is argued that social support is vital for these youths as they struggle to survive, seek to gain a degree of control over their lives, and strive to have a hopeful future. Examples show the remarkable ability of such youths to confront adversity by mobilising resources and exhibiting agency, although they may continue to experience suffering when support is lacking. The article concludes that to improve wellbeing and reduce suffering for youth-headed households, it is critical to recognise the social relations that may limit or enhance these youths’ ability to navigate their social environment. Youths’ agency needs to be recognised as a means to reduce the detrimental impacts of their actions and instead build on positive strategies, enabling them as they navigate their life course towards future possibilities. Finally, the dual role of youth heads of households — as individuals in adult roles and as youths — should be recognised, with initiatives to build them up designed around economic strengthening and mentorship.

Keywords: adversity, Africa, agency, HIV/AIDS, psychosocial aspects, resilience, settings of conflict, youth-headed households

Introduction

For youths living in settings of chronic crisis, the impacts of poverty, disease and uncertainty are not exceptional, but characterise their daily lives (Vigh, 2006). One Rwandan youth commented:

‘I became an orphan when I was 10 years old. It was 14 years ago that I became an orphan. It’s been 14 years that I have been living alone, arranging myself to live. I work, but sometimes I miss the jobs and I pass days without eating. I find this difficult and it is a disordered life like this. For 14 years I have been living like this’ (24-year-old male head of household, Rwanda, May 2006).

Youths in such an environment experience social suffering in part as a result of the impacts of larger socioeconomic forces in the environment (Kleinman, Das & Lock, 1997). Constraints in the immediate environment may threaten youths’ ability to survive and work towards future aspirations. In Rwanda, children and young people who head households face economic impoverishment and social marginalisation. Yet these youths are not passive in their struggles. In the midst of adversity they may show resilience, as when they strive to care for siblings and creatively seek solutions to difficult problems (Ward & Eyber, 2009). Youths often employ a range of social and economic tactics in order to survive, and they construct strategies to open up opportunities for their lives (De Boeck & Honwana, 2005a; Christiansen, Utas & Vigh, 2006a).

This study examines the everyday lives of youths in three communities in Rwanda in order to explore how youths in settings of hardship navigate their social terrain, how they manoeuvre through social power relations and networks, and how they mobilise social support amid constraints in their environment. A brief discussion on the socio-cultural context is given, highlighting the shifting social structures and systems of care in Rwanda. In order to understand the ways that these youths navigate their social environment, I use key theoretical concepts concerning youths’ agency and social navigation. The article presents emergent findings from ethnographic research with young household heads in Rwanda through a case study, with the main themes having arisen from participatory sessions with Rwandan youths. Finally, I draw conclusions and discuss the implications for programmes and policies affecting youths.

Over the past few decades, children and youths have been increasingly recognised as social actors embedded in social contexts and who are able to make decisions.
that impact their own lives as well as those around them (Christiansen, Daniel & Yamba, 2005). Their resilience has also been acknowledged — a view that challenges conceptions that children and youths are mere victims of the hardships they face. The next section examines theoretical ideas about youths’ agency — meaning the possibility of young people to act within their context (Vigh, 2008). I discuss the socio-cultural context of youths in Rwanda while recognising that social and cultural contexts influence how young people exhibit resilience, develop (Boyden, 2003), and move along their life course.

Youths and shifting social structures in Rwanda

In sub-Saharan Africa, the dual impact of violent conflict and an era of HIV and AIDS (see Jones, 2005) has led to dramatic changes in family units and a need to re-evaluate shifting social networks and systems of care (Barnett, 2005; Christiansen, 2005). Unaccompanied youth-headed households, wherein the head of the household is not the parent of the children in the household, increasingly occur throughout the region (Daniel, 2005; Donald & Clacherty, 2005; Thurman, Snider, Boris, Kalisa, Nkunda Mugarira, Ntaganira & Brown, 2006; Francis-Chizororo, 2008; Ruiz-Casares, 2009; Evans, 2010). Though sibling caregiving has been the norm in many societies (Mead, 1928; Weisner, 1982; Mann, 2004), youth-headed households as a care system lack the supervisory presence of adults and therefore have been described as an aberration of traditional care structures and as a sign of the social safety net breaking down (Roalkvam, 2005).

Historically, Rwandan lineages were made up of inzu, a house of three generations which included grandparents, married sons and grandchildren (Thomson, 2009). Older generations played a large role in the lives of youths, who received counsel from parents and grandparents when they were married (De Lame, 2005). Today, the capacity of Rwandan communities to care for and support children and youths has been diminished as a result of what MacLellan (2005, p. 4) calls the “double attack of conflict and AIDS,” both through the loss of potential caregivers for young people and through tearing apart the social ties that may have existed before. Of 690,000 orphans present in Rwanda in 2009, UNICEF (2009) estimated that 130,000 had been orphaned by AIDS. Furthermore, the frequent abusive relationships of extended kin toward youths (Rose, 2005; Thurman et al., 2006) is symbolic of the social shifts that have occurred in Rwanda.

The 1994 genocide, which killed over 800,000 people, as well as surrounding violent events throughout the 1990s, caused radical shifts in the composition of households amid a high number of parental deaths (Des Forges, 1999). In 1996, 13% of all households nationwide were believed to be headed by children (Agency for Cooperation in Research and Development, 2001). By 2006, the office of the Minister of Family and Gender Promotion (2006) stated that 21% of Rwandan children had lost one or both parents and identified ‘children living in households headed by children’ as a group of orphans and vulnerable children that required particular forms of support. Through extended fieldwork in Rwanda, I learned that many orphaned youths move from home to home, often working as domestics, and are at times exploited by kin or non-kin. Oftentimes these youths eventually settle with siblings and other unrelated children in a home left to them by a parent.1

Youth-headed households struggle day to day under pressures of severe economic deprivation, livelihoods exploitation, and property-rights abuses (MacLellan, 2005; Rose, 2005; Evans, 2010; Ruiz-Casares, 2010). Their social relationships are often detrimental, characterised by sexual and physical abuse and economic exploitation (Roalkvam, 2005; Yamba, 2005; Thurman et al., 2006; Ward & Eyber, 2009). Youth-headed households in Rwanda commonly experience isolation and rejection in their communities (Ward & Eyber, 2009), often fearing that neighbours and even relatives would rather hurt them than protect them (Thurman et al., 2006).2 Nonetheless, as Reynolds (1997, p. 149) remarked of youths in sub-Saharan Africa, these young people have “created structures of support that warrant close attention.” In a study of youths in Namibia, Ruiz-Casares (2010) argues that understanding local systems of care and support for youth-headed households is critical to planning comprehensive models of support, and yet few studies have focused specifically on the topic of social networks in this age group. In Rwanda, social support has been recognised as critical to the wellbeing of youth-headed households (Thurman et al., 2006; Ward & Eyber, 2009), particularly as there has been a weakening in the caregiving system.

Youths’ social navigation along the life course

The position that life stages are defined purely by physiological and biological conceptions of development has been challenged by claims that young people are socially embedded and that ‘youth’ is a constructed category which varies according to context (De Boeck & Honwana, 2005a; Hart, 2008). The transition between life stages has been recognised for its dynamic nature, wherein the life course of an individual is not seen as a linear path where right and wrong choices are made (Boyden, 2008) but viewed as fluid movement between social categories, with the possibility of straddling multiple categories at once (Christiansen et al., 2006a; Langevang, 2008). Langevang (2008) argues that some strands of life (such as marrying) may move ahead, while others (for example, building a house or securing a stable job), may lag behind. Christiansen et al. (2006a) denote two main perceptions of youths: as ‘being’ (recognising youths as a group with distinct social characteristics) and ‘becoming’ (referring to youths’ movement towards ‘adult’ status). In situations where a constraining environment inhibits youths from achieving the societal ideals of adulthood, they may experience frustration in relation to unfulfilled expectations (Vigh, 2006; Hart, 2008).

Christiansen et al. (2006a, p. 12) argue that youths’ movement along the life course is not only between life phases, such as between the socially constructed categories of ‘child’ and ‘adult,’ but also “between positions of power, authority and social worth.” With their lives structured by social relationships, youths will seek ways to gain a degree of control over their lives, often beginning from a position of relative powerlessness. The recognition that everyday social interactions occur in a “field of relational power” (Das
& Kleinman, 1997, p. 1) is important for the study of youths’ social navigation amid extreme constraints and suffering, as it demonstrates how those in positions of relatively little power are nonetheless able to exhibit resilience and act within these social systems. As Das & Kleinman (1997) argue, people embody the social, political and economic forces in their milieu, but they also act, in turn, on the world around them.

Social-suffering theory, as Pedersen (2002) highlights, stresses the importance of understanding how the social forces in one’s environment work at societal, community, and family levels to shape an individual’s experience of suffering, as well as experience of its opposite, such as health and wellbeing. According to Kleinman, Das & Locke (1997, p. ix), “Social suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems.” According to this approach, then, marginalised youths who are in relatively powerless positions due to their age as well as their social status may be more likely than others in society to experience suffering and to face harsh adversity in their daily lives.

Vigh (2008) proposes the analytic concept of ‘settings of chronic crisis’ to reflect the normalisation and ‘routinisation’ of crises endured by particular populations who deal on a daily basis with the impacts of harmful social forces like poverty, conflict and disease. He applies the concept to ‘youth’ and uses the term ‘social navigation’ to describe the way youths in contexts of chronic crisis steer their lives through a complex environment (Christiansen, Utas & Vigh, 2006b). Social navigation requires assessment of both “immediate dangers and possibilities as well as an ability to envision the unfolding of the social terrain and to plot and actualize one’s movement from the present into the imagined future” (Vigh, 2006, p. 52). Thus, the concept of social navigation is useful for an analysis of youths whose lives are shaped by the HIV epidemic and conflict, as they envision future opportunities and strive towards them even while facing large constraints in everyday life.

De Certeau (1984), in a description of tactics and strategies, adds an important distinction that can be applied to youths’ social navigation. He defines a ‘strategy’ as a calculation of power relationships, based on what Honwana (2005, p. 49) describes as a “locus of power.” The social ‘actor’ is able to think about the possible outcomes of their potential actions (De Certeau, 1984). A ‘tactic,’ however, is used when the actor lacks this locus of power and “operates in isolated actions, blow by blow” (De Certeau, 1984, p. 37) on the terrain of another’s power. This distinction has recently been applied to studies of youths in settings where crisis is the norm rather than the exception (e.g. Horwana, 2005 and 2006; Utas, 2005a and 2005b; Baines, 2009). Horwana (2005) takes this differentiation and develops the theoretical concepts of ‘tactical agency’ and ‘strategic agency,’ applying it to the case of child soldiers. Horwana (2005) argues that children are unable to plan for the long term, but by acting in an interstitial space, they apply tactical agency, seizing opportunities in the moment in order to improve their chances of survival and a better life in the short term. Baines (2009) builds on this argument by applying it to a young man in the chronic crisis setting of northern Uganda; he was abducted to be a child soldier but then employed the tactic of excelling as a perpetrator of violence in an attempt to gain a sense of control over his life. In the context of the civil war in Liberia, Utas (2005a and 2005b) introduced the concept of ‘victimcy’ of young women as a type of tactical agency that is hidden in passive victimhood and often rewarded by pity (Utas, 2005a).

In contrast, Schepers-Hughes (2008) describes ‘tactics of resilience’ among youths in other settings of chronic crisis (i.e. shanty-town dwellers in Brazil, and among members of the liberation struggle in South Africa) who display hardness and toughness in order to deal with the adversities of everyday life.

These examples demonstrate the variety of ways that youths employ tactics — “the art of the weak” (De Certeau, 1984, p. 37) — to navigate through daily life, particularly when the planning of long-term prospects is not a possibility. These actions may be beneficial or harmful to the youths in the long term, yet help them survive in the moment.

Considering the relational nature of youths’ social terrain, an exploration of the ways in which youths navigate social networks and access social support will shed light on the dynamics of the web of interactions — both positive and negative — in which youths are embedded (cf. Borgatti, Mehra, Brass & Labianca, 2009). According to Kirmayer, Sehdev, Whitley, Dandeneau & Isaac (2009, p. 73), “Social networks are the very stuff of community” and represent practical, emotional and instrumental ties that link individuals and groups. Social support refers to the ‘content’ of the social ties: that is, the emotional, material or instrumental support that might be received through relationships in the course of daily life (Van Aken, Coleman & Cotterell, 1994). Although social networks may facilitate supportive exchanges, they may also represent relationship ties that are detrimental (Van Aken et al., 1994; Lincoln, 2000) — for example, the exploitive relationship between a Rwandan orphan and a member of the extended kin who steals his or her property (see Rose, 2005). In such a web of interactions, youths may exhibit resilience by strategically drawing on sources of social support through networks that are helpful, while seeking to avoid those relations that may harm them and their households. However, even participation in supportive relationships may cause distress, as in the case of youths who experience excess pressure as they care for younger children in the household (Mann, 2008; Kirmayer et al., 2009; Evans, 2010).

Methods

As argued by Christiansen et al. (2006a) and Utas (2005b), an exploration of youths’ everyday lives can reveal the ways that youths actively pursue opportunities and seek meaning in daily life activities amid the constraints imposed by their environment. This study used a qualitative and ethnographic approach to generate a deeper understanding of the situations of youths through participant observation and engagement with both the youths and their communities. The ethnographic engagement sheds light on the various ways that Rwandan youths navigate their life trajectory and social networks over time. The data are from research...
carried out between 2006 and 2010, with youths and their communities, in conjunction with a faith-based organisation (FBO), in two rural and one peri-urban area of Rwanda. Initial research carried out in 2006 focused on the psycho-social wellbeing of child-headed households. This involved participatory group activities, focus group discussions and semi-structured interviews.

A purposive selection strategy was used to recruit youths who were heads of a household. They were recruited through local FBO leaders and associated HIV-related support groups. The young participants heading households (17 females; 8 males) ranged from age 9 to 24 years, as previous findings had determined that the local definition of child household head was not limited to those under the legal age of 18. Ethical approval was obtained from Queen Margaret University (Edinburgh, UK) and the local FBO. The research was clearly explained to all the participants, and freely given, verbal informed consent was sought.

In 2007, following the initial research recommendations, a community-based pilot initiative to strengthen community resiliency and the capacity to care for young people (hereafter referred to as the 'pilot project') was designed and implemented in three areas, among a total of 188 households, through the local FBO in partnership with a Canadian FBO. The research was carried on with these communities during subsequent visits between 2007 and 2010 (approximately twice per year). Fifteen formal participatory sessions and 16 semi-structured interviews were conducted with youths during this time; and 15 focus group discussions were done with mentor volunteers. These activities were planned concurrently with the pilot project’s coordinator who carried out quarterly meetings with youths and mentors in each area. Informal conversations and participant observation during the research activities and day-to-day interactions were also critical to providing insight into the youths’ social environment.

**Personal engagement**

As a foreign researcher and practitioner who had been a part of the youths’ lives, I acknowledge that my engagement with them altered their life course. Sharing in the youths’ lives, prior to the intervention as well as during the pilot project, provides a unique opportunity for a researcher of social networks. The intersection of various levels of the social environment — individual, family, community and global — is representative of the world in which they live. Though many marginalised youths have little access to the benefits of globalisation, such as technology, innovation and employment (Comaroff & Comaroff, 2005; Langevang, 2008), interaction with international non-governmental organisations is often a part of daily life. Acknowledging the presence of the partner institutions and myself as actors in their social worlds, my interaction and observation allowed for an exploration of the youths’ experiences and perspectives as they navigated the social relations of their everyday lives.

**Data analysis**

Transcripts of interviews and group sessions, and notes and visual outputs from the participatory activities, collected between 2006 and 2010, were examined for the purposes of this article. The transcribed data was analysed by recognising patterns in the everyday lives of the participants and searching for the meaning they attributed to social support and their movement along their life course. The patterns and units of meaning that emerged from the data were synthesised into larger emerging themes which provided insight into the ways that youths navigate social networks and support systems over time.

Three main themes emerged: 1) youths navigate constraints in their environment in order to survive, employing tactical agency; 2) youths garner social support in order to gain control over their lives; and, 3) by employing strategic agency, youths navigate social networks towards achieving a hopeful future. The data were grouped into these themes to provide a framework for the analysis and subsequent discussion of the findings.

The article presents the emergent findings in two ways: through articulation of an illustrative case study and through discussion of the themes that emerged in participatory sessions with youths. The following case study (‘Emmanuel’s story’) maps and illustrates the key themes, which are explored in greater detail in the findings and discussion section, with the analysis done in relation to other participants in the study. As a qualitative and exploratory study, the findings and discussion do not aim to generalise nor claim to be representative of all youth heads of households in Rwanda. Instead, the article provides an in-depth illustration of the perceived issues facing these youths in adverse circumstances.

**Case study: Emmanuel’s story**

In June 2010, in a small mud-brick church building in rural Rwanda, Emmanuel led a meeting with me, some Rwandan colleagues based in Kigali, and members of the local youth association of which he was president. He proudly described the recent accomplishments of the association, which he had started three years before when he mobilised 48 other youths who led households and who each initially contributed 300 Rwandan francs (~US$0.50). Emmanuel highlighted the group’s achievements, including being hired by the local government office to do small jobs such as carrying water from the river and preparing food for a vocational training school. Just as Emmanuel began to tell us about the group’s aspirations, his phone rang. The confident and youthful look on his face quickly became one of concern. Hurriedly, he explained that his sister was sick and then mounted his friend’s bicycle and left.

Emmanuel was 22 years old when we first met. He had been caring for a younger brother and two sisters since his mother died of AIDS six years earlier. He explained:

> ’Before, it was fine when we lived with both parents. From, my father died… I was preparing to go to high school. When he died, our family did not have the means to keep me in school, so I started to go to vocational school. When my mother died in 2000, it became hopeless.’ (November 2006)

Unable to pay school fees or leave his sisters alone, he dropped out. Emmanuel and his siblings lived on less than one-eighth of a hectare of land in the house their
parents left them. Without skills, he farmed their meagre plot and worked on other people’s farms to provide for his household. He complained that he was often not paid as promised for the work he did for others. This deepened his sense of powerlessness and diminished his trust in people in the community.

Giving up on his own chances to study, he struggled to pay the secondary school fees for his younger brother who had succeeded in the state exam. Emmanuel explained: ‘We had a goat; I sold the goat, but still did not have enough money to send him to school. I then sold my bicycle and he was able to go’ (November 2006). He explained that after his brother left for school, his feelings of dejection returned. The same month, he questioned himself: ‘I was able to send him this year, but what else could I sell next year? What will I do in the coming years?’ The struggle to pay for school fees, a uniform and materials meant that his brother missed several terms over the following years.

Emmanuel struggled daily to work and find food for the family. He had difficulty juggling the responsibilities of caring for his sisters, who were not yet of school age, in addition to running the home. He told me that he often went without food so that the younger ones could eat.” He had no time for friends and felt that he had no one to talk about his problems. When the siblings were first orphaned, they had received some visits from relatives and neighbours, but the visits had stopped.

Emmanuel was also asked to fulfill his community obligation as a night guard, whereby each household is expected to provide one adult on a rotating schedule to spend the night walking through the village to ensure security. This request upset Emmanuel who felt that his community was neglecting his family’s situation. With his younger brother away at secondary school, he worried about leaving his sisters alone, fearing for their vulnerability to sexual abuse: ‘I have tried to explain that I have to be at home with my family, but unfortunately no one listens’ (November 2006). He defined this period as his time of greatest despair.

Emmanuel revealed that although his household’s lack of food and proper shelter and his inability to adequately care for his siblings were grave concerns, a challenge of equal importance was his inability to adequately care for his brothers. He defined this period as his time of greatest despair.

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Emmanuel revealed that although his household’s lack of food and proper shelter and his inability to adequately care for his siblings were grave concerns, a challenge of equal proportion was a lack of opportunity to succeed in life:

’If we want to farm, there is not enough land. If we want to keep animals at home, there is nowhere to put them. If we want to start a business, we lack skills and have no capital’ (November 2006).

And so, without clear means towards a future with possibilities, Emmanuel moved through life day by day, struggling to respond to everyday challenges.

Emmanuel recalled how his mother went to a local church when she was alive; in desperation, one Sunday morning, he also went. People there from the HIV-support group remembered his mother and decided to help him raise funds for his brother’s education. He shared with me that even though the people were poor themselves, they would sustain fundraising on his behalf for two years: ‘If not for the support I got from church I would have died of stress and problems’ (September 2007).

Our first visit as researchers in 2006 also altered the course of Emmanuel’s life. By calling together youths who headed households to participate in the research project, many youths discovered they were not alone in their struggles. Emmanuel felt that he could relate with other people in the community who lived with similar burdens. When I saw him again half a year later (May 2007), life’s daily challenges remained, but now he dreamt of being a mechanic and having a business and supporting his family.

With his new-found solidarity with peers who lived in similar circumstances, and with the support of the church members, Emmanuel mobilised the youths and formed an association. He went to the local government office with the rest of the youth committee to register their youth association. During my next visit (September 2007), he enthusiastically showed me the papers that confirmed their registration. He had also acquired a mentor through the pilot project, who visited him regularly. Though he knew that material support would be unlikely, by April 2008 he felt he could trust his peers, his mentor, and members of the church community to help in times of desperation.

In June 2010 Emmanuel proudly showed me his mechanic’s uniform, having finished his training. He told me that his brother continued to do well in school and his sisters were now in primary school and so he encouraged them to study and do well. However, Emmanuel expressed a feeling of being left behind in life — like he had been robbed of the opportunity to go to secondary school or start a family, unlike his non-orphaned peers. And yet his commitment remained with his siblings.

Findings and discussion

Emmanuel’s story illustrates how youths navigate the social terrain around them, employing tactics that ensure survival. It also reveals how power relations may constrain youths as they steer through their life course. Facing a field of relational power, Emmanuel employed tactical agency, actively navigating social networks from his relatively subordinate position in society — such as working on other people’s farms or selling assets in order for his family to survive. He had sought out social support from the local church, which helped him regain a degree of control over his life. Bolstered by people in the community through both informal (neighbours) and formal (organisations) relationships, Emmanuel was able to plan and work towards his future, learning and employing his skills as a mechanic while providing for his younger siblings. And yet, as he strove to move along his life’s course, he faced the reality of straddling two life stages: living as a youth who enjoys being with peers and who desires to eventually marry and set up his own household, and acting as a parent responsible for supporting three younger siblings.

As Emmanuel’s story illustrates, mobilising social support through networking is critical for youths for three main purposes. First, youths manoeuvre through social networks in order to seek short-term solutions that will ensure the survival of themselves and their households. Second, social support works to provide ‘breathing’ space (sometimes economic, other times social or emotional), which allows youths to gain a sense of control over their lives. Third, youths are able to work towards future possibilities as they
come across support from their social networks. However, youths do not necessarily enter into these processes in a linear fashion. Additionally, as circumstances and relationships change, youths may return to social spaces where a hopeful future appears difficult or impossible to achieve, and once again they must operate through temporary solutions to ensure survival on a daily basis.

The next section elucidates the three themes concerning youths’ mobilisation of social support, through an analysis of the case study and a presentation of findings from the participatory sessions with other Rwandan youth heads of households.

**Youths navigate social networks in order to survive**

Emmanuel was not alone in his struggles:

> ‘For the future, we try to work, but we will ask God that we can be happy with what we have and that we will not desire in life things that we cannot obtain and that we will never have’ (Jean d’Amour, 17-year-old head of household, May 2006).

Many youths strive to survive day to day, with little social support and limited opportunity to work towards future opportunities. Jean d’Amour lost both his parents in 1994, and after his aunt died several years later he was left completely alone. Having dropped out of primary school, he tried each day to find work. With a short-term outlook on life and little social support, Jean d’Amour tried to lower his expectations of ever having enough resources and power to attain the future he desired. It is in such a context that youths exhibit tactical agency, working to create short-term solutions just to survive.

Emmanuel came to feel hopeless and disappointed with his neighbours and relatives: ‘At first [when my parents died], people would come to visit us, but they stopped, and now we are alone’ (May 2007). However, he exhibited tactical agency as he sought out resources, exploring other social networks and finally accessing assistance from the local church. As a tactic not only for his own survival, but to invest in his brother’s future, Emmanuel had dropped out of school permanently and sold his main assets — a goat and a bicycle. At the time, this was all he could do. Though he gave up the chance to sell goat milk or have a bicycle taxi service, selling these assets was a calculated decision for the short term and one that was sacrificial. This exemplifies the critical situation and life-changing decisions that many youth heads of households find themselves in — having to drop out of school and giving up meals for siblings (Donald & Clacherty, 2005; Thurman et al., 2006).

Carrying out supportive actions that may not benefit themselves in the long term (e.g. sacrificing either their own schooling or an asset for the welfare of their siblings), works to motivate youths to continue in their daily struggle. Though youths like Emmanuel may receive limited social support outside their household, by providing social and material support to younger children under their care, they remain tied to socially supportive relations — relationships where they provide support to others. The term ‘tactic of resilience,’ though used quite differently from Scheper-Hughes (2008), seems appropriate, as youths’ acts of selflessness and care for others, in turn, gives them a sense of responsibility, which enables them to continue the daily struggle to find the means for their household to survive.

**Short-term perspectives in a constrained environment**

In a problem-solving activity, the youths were asked to choose a problem they were facing and come up with every possible solution to the problem — whether a good or bad choice. After doing this assignment in a group, each group presented their problems and solutions followed by a discussion.

A problem-solving presentation by one group of young household heads showed their degree of suffering and sense of desperation, as they frequently prayed for God to intervene and provide for them, and as they hoped to be supported by well-wishers (see Box 1). The presentation also revealed their feelings of disappointment and relative powerlessness because of extended family members’ lack of support. The title given to their problem, ‘Missing employment because we are young,’ shows that they made a connection between the treatment they received and their social position as a ‘youth.’ Yet their discussion revealed their resourcefulness — through getting small jobs, stealing or sex work in order to survive, if employment were not available. One youth said:

> ‘The days to come, we do not think about. But we pray to God because we don’t even know if we will still be alive. It is only God who maybe can know. The future, we ourselves do not think about, because we don’t even think that we will be alive’ (Justice, 15-year-old male head of household, May 2006).

Justice dropped out of school when his mother left the home in 2000; every day he would go out to look for small jobs to support his two sisters in school. His case shows that despite uncertainty about the future, youths make decisions (like dropping out of school to find work) that help them survive in the moment, whether harmful or beneficial in the long term.

**Tactics employed in a field of relational power**

As youths make daily decisions to ensure their survival, they do not act in isolation, but navigate through complex social terrain. In Emmanuel’s case, his plot was too small for farming so he worked in other people’s fields. Although he was desperate to find the means for daily sustenance and to send his brother to school, his exploitation by community members who failed to pay him for his work served to deepen his suffering. When he tried to appeal his case about night-time guarding, he was ignored and his worries were reinforced as he had to leave his sisters alone and vulnerable at night while he performed his night-time guard duty. The detrimental nature of these social relations was significant. His sense of rejection by people in positions of power led Emmanuel to feel as though the local leadership and policies were not only failing to protect his family, but actually making their situation more unbearable.

This example of how local administration structures may disregard the suffering of youths and their situations of vulnerability is not an isolated one. Scheper-Hughes (2008) and Vigh (2008) highlight how crises related to political and
Box 1: Presentation of a problem-solving activity by youth heads of households, aged 15–24, at a peri-urban site in Rwanda, May 2006; the participants were asked to choose a problem they were facing and come up with every possible solution — whether a good or bad choice

<table>
<thead>
<tr>
<th>Boy A</th>
<th>The problem is ‘Missing employment because we are young.’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boy B [interjects]:</td>
<td>Or when you get a small job they don’t give your salary as it was promised.</td>
</tr>
<tr>
<td>Boy A</td>
<td>We try to do many things. It can make you steal because you miss the money.</td>
</tr>
<tr>
<td>Girl A</td>
<td>To beg.</td>
</tr>
<tr>
<td>Girl B</td>
<td>In such situations, sometimes people choose to pray to God to provide for them things to eat.</td>
</tr>
<tr>
<td>Girl A</td>
<td>Some could choose to be prostitutes in order to get money for surviving.</td>
</tr>
<tr>
<td>Boy C</td>
<td>Or we waste much time waiting for the extended family to share their food with us, but they don’t do anything for us.</td>
</tr>
<tr>
<td>Girl B</td>
<td>If they find a generous family who can take them in, this is another option.</td>
</tr>
</tbody>
</table>

Social processes are intimately related to personal crises among youths. A grave issue exposed through a drama acted out by youths in Emmanuel’s imidugudu (village or community housing area) further documents this and demonstrates the subjugated position of youth-headed households in relation to those in power. The youths prepared the drama in anticipation of a visit from the pilot-project coordinator. In the drama, the youths represented how they feared their houses would be destroyed by local authorities if they were not up to standard according to Vision 2020, the national government’s policy for development.8 In the drama, young people were warned that since their home did not have a tin roof it would be demolished. After begging for help from neighbours and pleading with the community leaders to not tear down the house, it was eventually demolished. The youths powerfully depicted the ways that various social and political forces can affect the core of physical and social security — by depicting the loss of a home because of a regulation. In the drama as in real life, the youths lacked a locus of control — the power and possibility to act in a situation in order to lead to the outcome they hoped for.

**Social support enables youths to gain control over their lives**

It emerged from the research that one key function of social support — whether emotional, practical or instrumental — is that it could enable youths to gain a degree of control over their lives. For Emmanuel, camaraderie with peers and the support of church members provided him respite or breathing space, thereby building up his locus of control and allowing him to think about future possibilities. This was not necessarily accommodated through connectedness to the social networks themselves, but through supportive relationships within these networks. Emmanuel found individuals at the church who provided both social and material support. And even though the material support could not be indefinitely maintained, knowing that someone cared served to relieve his burden enough to give him a sense of control, even if limited, over his life.

The experience of a young woman living in a rural area also reveals how social support contributes to youths obtaining a sense of control over their lives. I met Adeline in 2006, when she was 15 years old. In a session with other young women who headed families, she described the link between her social isolation and economic vulnerability: ‘The only visitors I have want sexual favours’ (June 2006).

Claudine (age 19) further explained the situation of young women heads of households:

> ‘If you go for two days without food and the young ones are all crying, could you say — No — to a man who gives you 200 Rwandan francs? I am not proud of it; I hate it, but what else can I do?’ (November 2006)

This comment shows the gravity of the situation, whereby some relationships were merely exploitive, representing detrimental social ties that would cause emotional and physical harm to the youths involved. It also demonstrates the tactical agency exhibited by young women within an extremely constrained environment and amid abusive relationships. Though the actions implied had potentially harmful long-term effects, such emotional distress, pregnancy or contracting HIV, these are examples of young women acting to ensure not only their own survival, but also the survival of others under their care.

When I met Adeline three years later, she had participated in the pilot project, had a mentor who visited her weekly, had learned to sew and was part of a sewing cooperative with other youths. A drama presented during a participatory session revealed the social transformation that had taken place in her life. The youths were instructed to create a drama about how they might handle the challenges they face. In the drama, Adeline (now age 18) was at home, thinking aloud about her plans to save money and purchase her own sewing machine. A ‘sugar daddy’ entered her house and began to pressure her to have sex; she stood up and rebuked him, saying ‘I don’t need you anymore. I can provide for myself. But look at your old shirt. I don’t need you, but I can sew you a shirt!’ (May 2009) The drama revealed her newly gained sense of control over her life, which allowed her to make decisions about the potentially negative and positive impacts of her actions.

**Youths navigate towards future possibilities: the road to ‘respectable’**

Finally, the data reveal that given a degree of control over the direction that their lives could take, youths will employ strategic agency — planning their course through complex social terrain, and garnering social support that will help them attain their envisioned future. Emmanuel, at last with the space to make a long-term plan, had mobilised his peers to form an association that would provide the members with social and material support; and he dreamt
of having his own business to support his family. Like the Ghanaian youth in Langevæng's (2008, p. 2044) study, Emmanuel had a sincere “concern to become a somebody” — someone recognised in society as ‘respectable.’ Although daily challenges remained, camaraderie with peers and the support of mentors served to buffer social suffering in their lives enough to allow them to work towards a hopeful future, meanwhile seeking economic opportunities as a group and helping each other through difficult times. The youths who belonged to the group were emotionally strengthened by their meetings, as well as materially supported as required, for example through repairs to their dwellings or through the support of mentors served to buffer social suffering in their daily challenges remained, camaraderie with peers and the group. Thus, they may take on an adult role such as creatively looking for employment and garnering social support to gain the resources needed for surviving as well as reaching their goals. Youths — from urban and rural areas, educated and uneducated — should be recognised as leaders and meaningfully involved in planning and decision-making of policies and initiatives that affect them. At the community level, inter-peer collaborations (e.g., the formation of youth groups) should be promoted as well as social linkages between youths and others in the community, such as through mentorship programmes and youths’ involvement in community and cultural activities. Finally, youths should be encouraged to acquire skills that will help their employability, and likewise encouraged to start or scale up income-generating projects.

Importantly, policymakers and programmers should be aware of the dual role that youth household heads play: as adults, often acting as breadwinners and parents to siblings, and as youths. Considering the social and economic problems facing youths who head households in settings of chronic hardship, it is critical to support these youths in their desire to gain a degree of control over their lives so that they can begin to strategise their movement along the life course and avoid making decisions that may cause them harm. If youth heads of households are able to gain a sense of control over their situation, they are better placed to develop a vision for their future and develop plans they can work towards. Thus, policies and programmes designed for youths should recognise the positive strategies employed by such youths, such as creatively looking for employment and garnering social support to gain the resources needed for surviving as well as reaching their goals. Youths — from urban and rural areas, educated and uneducated — should be recognised as leaders and meaningfully involved in planning and decision-making of policies and initiatives that affect them. At the community level, inter-peer collaborations (e.g., the formation of youth groups) should be promoted as well as social linkages between youths and others in the community, such as through mentorship programmes and youths’ involvement in community and cultural activities. Finally, youths should be encouraged to acquire skills that will help their employability, and likewise encouraged to start or scale up income-generating projects.

Conclusions and recommendations

Considering the social and economic problems facing youths who head households in settings of chronic hardship, it is critical to support these youths in their desire to gain a degree of control over their lives so that they can begin to strategise their movement along the life course and avoid making decisions that may cause them harm. If youth heads of households are able to gain a sense of control over their situation, they are better placed to develop a vision for their future and develop plans they can work towards. Thus, policies and programmes designed for youths should recognise the positive strategies employed by such youths, such as creatively looking for employment and garnering social support to gain the resources needed for surviving as well as reaching their goals. Youths — from urban and rural areas, educated and uneducated — should be recognised as leaders and meaningfully involved in planning and decision-making of policies and initiatives that affect them. At the community level, inter-peer collaborations (e.g., the formation of youth groups) should be promoted as well as social linkages between youths and others in the community, such as through mentorship programmes and youths’ involvement in community and cultural activities. Finally, youths should be encouraged to acquire skills that will help their employability, and likewise encouraged to start or scale up income-generating projects.

Importantly, policymakers and programmers should be aware of the dual role that youth household heads play: as adults, often acting as breadwinners and parents to siblings, and as youths. Consideration should be given to the emotional and economic constraints that this group of youths have due to heightened family responsibilities. Interventions for youth heads of households should be designed to increase their positive social ties in the community; as recommended by Rwanda’s Ministry of Local Government (2003), activities could include a mentorship component and socioeconomic support. The example of Rwanda is exemplary as its policies recognise children who live in child-headed households as a vulnerable group. However, it is recommended that the relevant policies also be applied to young household heads who are over age 18 years.

This study has shown that social actors at the community and societal levels can have positive or negative impacts on the lives of youth heads of households. Kirmayer et al. (2009) argue that insufficient attention has been paid to deficiences at the structural level — such as policies or institutions that may in fact contribute to the suffering of individuals. This leads to missed opportunities for effective
interventions that could build individuals’ resiliency and ability to buffer suffering due to difficult circumstances (Kirmayer et al., 2009). Exploring the impact of socio-structural influences on youths’ wellbeing and their ability to exhibit strategic agency is a critical area for further research, with the potential for findings that could guide policies and interventions for vulnerable youths.

In order to reduce the suffering of youths facing adversity, interventions need to acknowledge the aspect of social relationships in the environments of youths; this would include both supportive relationships as well as relations that may maintain or exacerbate youths’ suffering. Moreover, youths’ agency should be recognised and the strategies of youths ought to be built upon so as to reduce their detrimental actions, while their resiliency is strengthened, enabling them to navigate along their life course towards a future with opportunities.

Notes

1 This was revealed through the research in Rwanda. Yamba (2005) also supports this, telling the story of a young household head in Zambia who goes from home to home before settling in a house left by the parents.

2 Thurman et al. (2006) state that among the 692 youth heads of households interviewed in their study in Rwanda, 86% reported that they felt rejected by the community and 57% said they felt the community would rather hurt them than help them.

3 The participatory activities included problem identification and problem-solving, the construction of timelines and schedules, problem matrices, daily activity profiles, and dramas.

4 In some cases, the individual was considered a ‘child’ until the time they married. In other cases, at the time the parents had passed away, the oldest child in the household was under 18 years. For these reasons and because of the serious need for many of the older children to access psychosocial and other services, MacLeLan (2005, p. 6) argues that “it may be disadvantageous to identify a child-headed household solely on the legal age of the head”; hence, the inclusion of older youths as child-headed household is reasonable.

5 Original research was done through the Institute for International Health and Development at Queen Margaret University (Edinburgh, UK), as part of the graduate studies programme in international health.

6 A more detailed description of the research method is recorded in Ward & Eyber (2009).

7 A programme-development survey with 188 households in 2006, of which Emmanuel was a part, revealed that 73% of the youth household heads said they ate just one meal a day and 50% reported they had gone without food in the past week in order to spare food for younger household members.

8 This document was released in Rwanda by the Ministry of Finance and Economic Planning in 2000 and was last revised in 2009. It outlines a ‘pro-poor’ strategy to “fundamentally transform Rwanda into a middle-income country by the year 2020” (Ministry of Finance and Economic Planning, 2009, p. 8). While there is no significant mention of youths in this document, Rwanda has a Ministry of Youth and a National Youth Council, revealing the government’s interest in youth issues.

9 A recently published and highly relevant book by Sommers (2012) highlights the situation faced by young men and women in Rwanda who find themselves ‘stuck,’ unable to build homes or to become stable enough to marry, and thus not able to move forward on a path to a socially respectable adulthood.

10 Sommers (2012, p. 238–239), in his research with youths and officials in rural and urban areas of Rwanda, articulates the importance of involving youths in reframing policies that impact youths, such as policies that will affect housing and economic opportunities in formal and informal sectors.

Acknowledgements — The author would like to acknowledge her colleagues in Rwanda who have tirelessly dedicated their time and energy to strengthening communities in their country and the courageous and tenacious youths who shared their experiences and perspectives and who opened their doors to us. Appreciation is also extended to Canadian colleagues of the faith-based NGO, Queen Margaret University, The University of British Columbia and to the Vanier Canada Graduate Scholarships (Government of Canada) for supporting this research through scholarly guidance and financial support.

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References


Safeguarding inheritance and enhancing the resilience of orphaned young people living in child- and youth-headed households in Tanzania and Uganda

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This article explores the resilience of orphaned young people in safeguarding physical assets (land and property) inherited from their parents and sustaining their households without a co-resident adult relative. Drawing on the concept of resilience and the sustainable livelihoods framework, the article analyses the findings of an exploratory study conducted in 2008–2009 in Tanzania and Uganda with 15 orphaned young people heading households, 18 of their siblings, and 39 NGO workers and community members. The findings suggest that inherited land and property were key determining factors in the formation and viability of the child- and youth-headed households in both rural and urban areas. Despite experiences of stigma and marginalisation in the community, social networks were crucial in enabling the young people to protect themselves and their property, providing access to material and emotional resources, and enhancing their skills and capabilities to develop sustainable livelihoods. Support for child- and youth-headed households needs to recognise young people’s agency and should adopt a holistic approach to their lives by analysing the physical assets, material resources, and human and social capital available to the household, as well as giving consideration to individual young people’s wellbeing, outlook and aspirations. Alongside cash transfers and material support, youth-led collective mobilisation that is sustained over time may also help build resilience and foster supportive social environments in order to challenge property-grabbing and the stigmatisation of child- and youth-headed households.

Keywords: asset inheritance, HIV/AIDS, human capital, orphans and vulnerable children, participatory research, policy development, poverty, social capital, sub-Saharan Africa, sustainable livelihoods

Introduction

Three decades of the HIV epidemic have led to changing patterns of care and inheritance in East and southern Africa (Drimie, 2003; Oleke, Blystad & Rekdal, 2005). For example, an estimated 1.3 million children (aged 0–17 years) in Tanzania in 2009 lost one or both parents to AIDS; in Uganda, the figure was 1.2 million children (UNAIDS, 2010). This represents 6% of children under age 18 in Tanzania and 7% in Uganda (UNICEF, 2009). Although the majority of orphaned children in the region are cared for within the extended family, the loss of the parental ‘middle generation’ has led to the emergence of new household forms, such as child- and youth-headed households where siblings live together independently without a co-resident adult relative (Foster, Makufa, Drew & Kralovec, 1997).

Studies in Rwanda (Thurman, Snider, Boris, Kalisa, Nyirazinyo & Brown, 2008), Tanzania and Uganda (Luzze & Ssedyabule, 2004; Evans, 2011), Zimbabwe (Germann, 2005; Francis-Chizororo, 2008) and Namibia (Ruiz-Casares, 2009) reveal the poverty, stigma and marginalisation that child- and youth-headed households may face. Research with orphaned children suggests that their inheritance rights may be denied (Van Blerk, Ansell, Robson, Hadju & Chipeta, 2008), although few studies have explicitly focused on these issues. The stigma surrounding HIV and AIDS and children’s weak socioeconomic position in the community are identified as factors contributing to the difficulties of orphans in safeguarding their deceased parents’ land and property (Drimie, 2003; Evans, 2005; Rose, 2007).

Research with child- and youth-headed households also recognises young people’s resilience and agency in adopting coping strategies. Researchers have increasingly called for children’s and families’ experiences to be conceptualised from a resilience perspective in order to help understand individual differences in dealing with adversity, managing caring responsibilities, and exiting from or avoiding chronic poverty (e.g. Evans, 2005; Becker, 2007; Boyd & Cooper, 2007). Resilience is defined as “an individual’s capacity to recover from, adapt to, and/or remain strong in the face of adversity” (Boyden & Cooper, 2007, p. 1). The concept of resilience emphasises people’s strengths in coping with adversity and their agency in engaging with protective factors that reduce their vulnerability (Rutter, 1990).

Conceptual framework

The sustainable livelihoods framework developed by Chambers & Conway (1992) has informed approaches to
poverty alleviation in the ‘global South’ since the 1990s. This framework adopts a holistic approach to people’s livelihoods by viewing these as encompassing the capabilities, assets and activities required to make a living (Chambers & Conway, 1992). Thus, a key component of the sustainable livelihoods framework is the identification of people’s access to, and use of, a range of assets. Assets can be conceptualised in terms of different forms of capital, such as:

- **natural capital**: land and environmental resources, property rights;
- **physical capital**: property and goods, machines and tools, transportation, livestock, food, energy, communications, infrastructure;
- **human capital**: labour resources in a household and the community, including people of different genders, ages and generations, health status and ability, education, qualifications and skills;
- **social capital**: networks, membership of groups, support mechanisms, trust and reciprocity, diasporic networks, shared cultural and religious values, language and other markers of cultural identity; and,
- **financial capital**: income, savings, jewellery, access to credit, remittances, pensions (see Carney, 1998).

Previous research informed by the sustainable livelihoods framework also suggests that non-material aspects, such as human capabilities and social capital, as well as physical assets and material resources, play an important role in building resilience to shocks and stresses (such as sickness, death and environmental shocks) (Ellis & Mdoe, 2003).

The actor-orientated local focus of the sustainable livelihoods framework has been critiqued however for its tendency to downplay structural constraints, such as politics and power, and for its failure to engage with processes of economic globalisation, the challenges of environmental sustainability, and transformatory shifts in rural economies (De Haan, 2007; Scoones, 2009). Furthermore, many studies use the household as the main unit of analysis and give limited consideration to factors that may influence capabilities at the level of the individual, such as a sense of wellbeing and gendered or generational power relations within the household. Despite the prominence of the sustainable livelihoods framework in development policy and research, few studies to date have used this framework to analyse young people’s livelihoods or access to assets (Van Blerk et al., 2008). De Haan (2007) calls for a new generation of livelihood studies that consistently includes in the analysis a consideration of power relations at the individual, meso and macro levels.

Following this approach, recent literature has investigated the relationship between intra-household use of, and control of, assets and the intergenerational transmission of poverty (Soto Bermant, 2008). A key defining feature of ‘chronic poverty’ is its extended duration and the notion that people who experience “significant deprivations for a period of five years or more” are more likely to remain poor for much of their life course and pass on their poverty to subsequent generations (“intergenerational transmission of poverty”) (Hulme & Shepherd, 2003, p. 405). Access to assets is regarded as crucial to ensuring the financial, physical and emotional security of household members in the present and in the future (Soto Bermant, 2008). In much of sub-Saharan Africa, longstanding customary laws underpin social relations at the levels of the clan, community and household, and explicitly privilege men and exclude women from asset ownership and inheritance (Bird & Espey, 2010). Traditional inheritance practices mean that land and property are usually divided among male heirs following the death of a male household head. However, male heirs are also regarded as responsible for the maintenance of widows and children belonging to the family (Armstrong, Chuulu, Himonga, Letuka, Mokobi, Ncube et al., 1995). Gender discriminatory inheritance practices following widowhood or divorce can have major impacts on the socioeconomic position and security of women and children. While a growing body of literature has revealed gender inequalities in asset inheritance, few studies have explicitly addressed children’s inheritance rights and the difficulties they may face in safeguarding their inherited assets.

This article responds to these limitations in the literature by exploring how orphaned young people in Tanzania and Uganda safeguard inherited physical assets and sustain their own households. Although many of the young people interviewed experienced chronic poverty and some only had precarious access to the land and other assets and resources needed to sustain their households (discussed in Evans, 2011 and 2012), this article focuses on young people’s resilience in managing their own households as well as analysing the practices of nongovernmental organisations (NGOs) that support them. Following an overview of the research methods, I discuss the findings of qualitative participatory research with orphaned young people, NGO staff and community members. Drawing on the sustainable livelihoods framework, I identify key protective factors at the levels of the individual, household and community, and analyse NGO practices that helped to build the young people’s resilience. In conclusion, I highlight the implications for policy development and practice.

**Methods**

Due to the hidden nature of young people’s care work, a small purposive sample of young people (under age 25) who cared for their siblings without a co-resident adult relative were identified through NGOs working in rural and urban areas in Tanzania (Kagera region, Dar es Salaam, and Mbeya) and Uganda (Kampala, Mpigi, Mukono, Wakiso and Luwero districts). The regions were selected due to very high levels of orphanhood, differences in NGO approaches, and their contrasting rural/urban locations.

In Tanzania, Mbeya region had the highest level of orphanhood, where 17% of children were estimated to be orphans; the figures were 13% in Dar es Salaam and 11% in the Kagera region (Tanzania Commission for AIDS [TACAIDS], National Bureau of Statistics & ORC Macro, 2005). In Uganda, the highest percentage of orphaned children in 2005 lived in the Central region (18% of children had lost one or both parents) and 15% of children were estimated to be orphans in Kampala (Uganda Bureau of Statistics, 2006). In the study areas in both Tanzania and
Uganda, most ethnic groups follow patrilineal inheritance systems in which male children usually inherit land and other assets when they come of age, and women usually gain ‘usufruct rights’ to land and property through their father, husband, sons or other male relative.

The main characteristics of the NGOs that participated in the research are summarised in Table 1. These organisations were selected to provide insight into a diverse range of approaches to supporting young people and to facilitate recruitment. Since the original focus of the study was on caring roles in child- and youth-headed households, each NGO was asked to identify 2–5 orphaned young people aged under 25 years who cared for their younger siblings without a co-resident adult relative. The means of recruitment via NGOs may have resulted in an atypical sample of particularly vulnerable young people who were currently accessing or had recently accessed services and external support. However, the difficulties in gaining access to young people performing a caring role — a group that tends to be highly marginalised — made this approach necessary. In practice, some of the young people received very little or no support from the organisations that identified them for the study. Thus, the sample reflects a diverse range of experiences in accessing NGO support.

In the first phase of the research, 12 semi-structured interviews were conducted with orphaned young people from eight child-headed households, three youth-headed households, and one ‘skipped-generation’ household (comprised of a grandmother and orphaned children, which later became a child-headed household when the grandmother died) (see Tables 2 and 3). In 10 of the 12 interviews, the eldest co-resident sibling who considered that they had the greatest caring responsibilities was interviewed. In one instance, the youngest of three brothers was interviewed, since his older brothers were working at the time. For one group interview, the three eldest siblings in the household considered that they jointly shared responsibility and therefore were interviewed together. Two individual and four group interviews were conducted with a total of 15 project workers from the five NGOs. In Tanzania, three focus groups were conducted: in Mbeya, with six young people with caring responsibilities and with three younger siblings; in Nshamba, Kagera region, with five young women who led or participated in a self-defence group and with five community leaders and NGO staff members (Table 2).

Thematic analysis identified commonalities in the young people’s experiences of living in a child- or youth-headed household, as well as differences in their experiences according to gender, age, sibling birth order, rural/urban location and country of residence. A short report was written and translated into Kiswahili and Luganda in order to feed back the findings to participants.

In the second phase of the research, participatory workshops were held in the three main research locations of Kampala, Nshamba and Mbeya, with a total of 33 orphaned young people (15 young people heading households and 18 of their siblings) and with 39 NGO workers and community members (see Table 2). Young people living in a child- or youth-headed household who had participated in the first phase were invited to participate in a one-day workshop alongside one or more of their siblings, and transport was arranged through NGO workers and their travel expenses were reimbursed. At the workshop, I presented an overview of the preliminary findings, based on thematic analysis of the interview data and used participatory methods (such as ranking of the young people’s priorities), in order to further discuss the findings. I sought to involve the young people in identifying key messages from the research and priorities for action through the co-production of creative research outputs (such as art posters and video-recorded drama and song performances). The findings and the young people’s ranking of priorities, their posters and the video-recorded performances produced in their locality were presented to NGO staff and community members at a workshop the following day in order to stimulate discussion on how to improve opportunities and support for young people living in child- and youth-headed households.

In Tanzania, I conducted the interviews, focus groups and workshops in Kiswahili, and the data were transcribed and translated into English with research assistance. In Uganda, the interviews were conducted in English, with interpretation to or from Luganda provided by NGO workers, although

**Table 1:** Characteristics of the nongovernmental organisations (NGOs) participating in the research

<table>
<thead>
<tr>
<th>Primary focus and location of the NGO</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV-related support (Mbeya region, Tanzania)</td>
<td>Support for orphans and vulnerable children, voluntary HIV counselling and testing and home-based care for people with HIV. Project partner of the national Jali Watoto programme for ‘Most-Vulnerable Children’ at the time of the research, funded by the Global Fund for Malaria, TB and HIV/AIDS.</td>
</tr>
<tr>
<td>Community-based rehabilitation for disabled people (Dar es Salaam, Tanzania)</td>
<td>Support for disabled people and their families, orphans and vulnerable children, and HIV-affected families with a disabled family member. Project partner of the national Jali Watoto programme for ‘Most Vulnerable Children’ at the time of the research, funded by the Global Fund for Malaria, TB and HIV/AIDS.</td>
</tr>
<tr>
<td>Psychosocial support for orphans and vulnerable children (Kagera region, Tanzania)</td>
<td>Well-established programme of psychosocial support and youth-led community action for orphans and vulnerable children in the region. Supported by a range of funders and a partner organisation of REPSSI, a psychosocial support organisation based in South Africa.</td>
</tr>
<tr>
<td>Rights organisation of women living with HIV (Uganda)</td>
<td>Well-established organisation of women living with HIV, which works at the local, regional and national levels with families affected by HIV. Received funding from USAID, among other sources.</td>
</tr>
<tr>
<td>Community-based HIV-support organisation (central Uganda)</td>
<td>Recently established, small-scale community organisation offering emotional support to HIV-affected families. Largely sustained by community volunteers at the time of the research.</td>
</tr>
</tbody>
</table>
some of the young people spoke English. The audio-recordings were later transcribed. Workshops were conducted in English and Luganda with research assistance. Informed consent, confidentiality and the safety and security of the participants and researcher in the collection and storage of the data and dissemination of the findings were of paramount importance throughout the studies. All participants’ accounts are anonymised throughout this article to protect their identities.

This article draws in part on analysis conducted for a larger project on asset inheritance and the intergenerational transmission of poverty (see Evans & Day, 2011). The interview transcripts with young people were reviewed and thematically analysed using a template broadly informed by the sustainable livelihoods framework. This provided a holistic summary of each interviewee’s access to material and non-material assets and household resources, in addition to their perceptions and experiences of significant events and changes in their lives over time. Key characteristics of the young people interviewed are summarised in Table 3. The visual and audio-visual data gathered in the workshops and interviews and focus groups with NGO workers and community members were also thematically analysed. While this small qualitative sample cannot be seen as representative of child- and youth-headed households in Tanzania and Uganda, it provides insight into a diverse range of experiences of orphaned young people caring for their siblings without a co-resident adult relative and the resources and assets they draw on to manage their lives in communities severely affected by HIV in East Africa.

Results and discussion

Safeguarding inherited physical assets

Almost all the young people interviewed had inherited agricultural land, property and/or other assets from their parents (see Table 3). According to conventional inheritance practices in patrilineal societies, paternal relatives would usually keep children’s land and other inherited property in trust until they reached the age of majority (Rose, 2007). However, the death of both parents due to AIDS, children’s negative experiences of foster care, a fear of losing access to their late parents’ assets, and the availability of NGO support resulted in some young people (especially older children) securing control of their land at a younger age than usual. Young people’s ownership of land, property and other assets before they are considered to have made a ‘successful’ transition to adulthood, however, challenges the conventional norms of inheritance, household formation, and generational relations. This was sometimes sanctioned by property-grabbing, stigmatisation, exploitation and accusations of wrong-doing in the community (Evans, 2011).

The young people’s experiences suggest that these inherited physical assets were crucial to the formation and viability of the child- and youth-headed households. Such households appeared to be more common in rural areas due to a lower cost of living, the wider availability of land, and the livelihood opportunities that access to agricultural land offered in terms of food security and providing a source of income. This corresponds to previous findings in Uganda (Luzze & Ssedyabule, 2004) and Namibia (Ruiz-Casares, 2009). When they inherited property in urban areas, particularly where housing was sufficient both for siblings and for tenants, young people were able to continue living together and earned an income in the informal sector alongside performing their household care work.

Several young people in Tanzania articulated their transition to becoming the head of the household as a shared decision that enabled the siblings to stay together and safeguard their inherited land. The young people’s decisions were motivated by a fear that relatives and/or neighbours would appropriate their land if they moved away to live with relatives, as well as by concerns about fitting into new routines and being mistreated within foster households. For instance, Hamisa (age 19) feared that she would lose access to her inherited property if she moved away to live with a relative. She requested that a young cousin come to

Table 2: Research methods used with the sample of participants in Tanzania and Uganda

<table>
<thead>
<tr>
<th>Category of participants</th>
<th>Methods</th>
<th>Young men heading households</th>
<th>Young women heading households</th>
<th>Younger siblings in child- or youth-headed households</th>
<th>NGO staff members</th>
<th>Community leaders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1: 2008</td>
<td>12 interviews with young people aged 12–23 (11 individual and one group interview)</td>
<td>5</td>
<td>9</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Two individual interviews and four group interviews, each with 2–5 NGO staff members</td>
<td></td>
<td></td>
<td></td>
<td>15</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Three focus groups</td>
<td>3</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Phase 2: 2009 (two workshops in each location: Kampala, Nshamba and Mbeya)</td>
<td>Six participatory diagramming activities</td>
<td>6</td>
<td>8</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Six arts activities to co-produce outputs</td>
<td>6</td>
<td>8</td>
<td>18</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Six focus group discussions</td>
<td></td>
<td></td>
<td></td>
<td>25</td>
<td>14</td>
</tr>
</tbody>
</table>
## Table 3: Key characteristics of the orphaned young people interviewed in Tanzania and Uganda

<table>
<thead>
<tr>
<th>Young person interviewed (pseudonym)</th>
<th>Age</th>
<th>Other household members</th>
<th>Locality</th>
<th>Asset ownership</th>
<th>Education</th>
<th>Sources of income/access to material resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sophia (female) 21</td>
<td></td>
<td>Three younger siblings (ages 15–19), one with physical impairments; own child age 5</td>
<td>Dar es Salaam, Tanzania</td>
<td>Inherited mother’s house</td>
<td>Studying in Form 4 of secondary school</td>
<td>One sister sells water in neighbourhood; receives NGO support.</td>
</tr>
<tr>
<td>Hamisa (female) 19</td>
<td></td>
<td>Cousin (age 9); older sister at boarding school, and older brothers living in town</td>
<td>Muleba district, Kagera, Tanzania</td>
<td>Inherited parents’ house and farm</td>
<td>Studying in Form 3 of secondary school</td>
<td>Cultivates food crops; receives NGO support.</td>
</tr>
<tr>
<td>Kadogo (female) 14</td>
<td></td>
<td>Three younger siblings (ages 7–12)</td>
<td>Muleba district, Kagera, Tanzania</td>
<td>Inherited parents’ house and farm</td>
<td>Studying in Standard 5 of primary school</td>
<td>Cultivates food crops, sells vegetables at market, and rears small livestock; receives NGO support.</td>
</tr>
<tr>
<td>Rickson (male) 19</td>
<td></td>
<td>Two younger siblings (ages 9 and 13)</td>
<td>Kagera, Tanzania</td>
<td>Inherited parents’ house and farm</td>
<td>Studying in Form 3 of secondary school</td>
<td>Cultivates food crops and coffee, which they sell; receives monthly allowance for volunteer work in community as well as NGO support.</td>
</tr>
<tr>
<td>Johannes (male), Anita and Benita (females) 17, 16</td>
<td></td>
<td>Two younger siblings (ages 7 and 10)</td>
<td>Kagera, Tanzania</td>
<td>Inherited parents’ house and farm</td>
<td>Eldest not in school due to HIV-related chronic illness; sisters in Standard 6 of primary school</td>
<td>Cultivates food crops; receives monthly allowance for volunteer work in community as well as NGO support.</td>
</tr>
<tr>
<td>Diana (female) 15</td>
<td></td>
<td>Grandmother and five younger siblings (ages 8–14), but three do not stay in household permanently</td>
<td>Mpigi, Uganda</td>
<td>Own home; insecure access to agricultural land</td>
<td>Left secondary school after year 4</td>
<td>Cultivates food crops; sells milk produced by cow.</td>
</tr>
<tr>
<td>Jamiru (male) 16</td>
<td></td>
<td>Five younger siblings (ages 4–10); older brother (age 18) migrated to Kampala</td>
<td>Mpigi, Uganda</td>
<td>Inherited father’s property</td>
<td>Left primary school after year 5</td>
<td>Has difficulties securing rental income from relatives; sells drinks for a small company; sells cooked food in the neighbourhood; cultivates food crops for consumption and for sale on land that he hires; older brother provides small financial contributions when possible.</td>
</tr>
<tr>
<td>Harriet (female) 17</td>
<td></td>
<td>Four younger siblings (ages 2–14); own baby age 5 months</td>
<td>Mukono, Uganda</td>
<td>Inherited parents’ house and land</td>
<td>Completed all seven years of primary school</td>
<td>Cultivates food crops; rears hens; sometimes sells mukene (small fish) when aunt sends supplies; receives educational support for siblings from a teacher.</td>
</tr>
<tr>
<td>Amina (female) 16</td>
<td></td>
<td>Three younger siblings who are living with HIV (ages 6, 7 and 10); brother (age 15) at boarding school</td>
<td>Kampala, Uganda</td>
<td>Inherited mother’s house and rental property</td>
<td>Completed all seven years of primary school</td>
<td>Income from three rented rooms, but often faces difficulties securing rent from tenants and/or step-father; receives NGO support.</td>
</tr>
<tr>
<td>Isack (male) 12</td>
<td></td>
<td>Step-brother (age 19) and brother (age 16); another brother (age 16) lives with an aunt, and a sister (age 9) lives with a grandmother</td>
<td>Wakiso, Uganda</td>
<td>Inherited parents’ house and farm and land some distance away</td>
<td>Studying in year 1 of secondary school</td>
<td>Eldest brother does casual construction work, other siblings in school; all household members cultivate food crops; receives NGO support.</td>
</tr>
<tr>
<td>Godfrey (male) 17</td>
<td></td>
<td>Three younger brothers (ages 8, 12 and 14)</td>
<td>Luwero, Uganda</td>
<td>Rents a room</td>
<td>Left secondary school after year 2</td>
<td>Uncle took over land where they once cultivated food; does casual agricultural labour; cultivates some food crops on very small patch of land.</td>
</tr>
<tr>
<td>Celia (female) 16</td>
<td></td>
<td>Lives alone; younger brother and sister living with relatives following a period together as a child-headed household</td>
<td>Luwero, Uganda</td>
<td>Inherited house and agricultural land</td>
<td>Studying in year 2 of secondary school</td>
<td>Cultivates food crops; receives NGO support.</td>
</tr>
</tbody>
</table>

Number of child-headed households 8
Number of youth-headed households 3
Number of skipped-generation households 1
Total number of households (Tanzania and Uganda) 12
live with her to reduce her loneliness: ‘I thought, I am grown up; if I go to live with them and I am a student, they will grab my properties. How will I start again? I decided to stay here, but I will ask if there is someone who can help me and come to stay here.’

Another sibling-headed household had formed following the young people’s negative experiences of harassment and mistreatment. Johanes (age 17) and his four younger siblings lived with their aunt and uncle following their parents’ death, but found that they were treated differently from their aunt’s biological children. The cash transfers they received from an NGO were also misappropriated by their aunt. The siblings decided it was better to move back into their deceased parents’ house:

Anita: When our parents first died we lived with our aunt and her children. But then she started to harass us. So it was best for us to move out and live on our own.

Johanes: We had to become self-sufficient.

The siblings sought support from NGO workers and their peers to rebuild their inherited home and cultivate their farm. Orphaned young people in the research locations were regarded as particularly vulnerable to property-grabbing following their parents’ death. The young people identified the need to address property-grabbing and the harassment they experienced as key messages for community members, policymakers and practitioners; they made video-recorded dramas to show the problems they may experience when relatives or neighbours try to appropriate their inherited home and land. In Kampala, the drama commenced with the children saying together: ‘We are children whose parents have died. We don’t have anything to eat and there are people who intimidate us. They want to grab our property. We are in a bad situation; we are in a very bad situation!’ The young people in Mbeya ended their drama with this message:

‘We’d like to ask all organisations, we pray to God, for all organisations around the world who safeguard the rights of children to be aware of this problem, to look after children, to be very close to children who have been orphaned, children who have relatives who say that they have come to help us, but in fact, they have come to harass us, throw us out of the house and take our property that was left to us by our parents.’

The majority of NGO staff interviewed thought it was better to support orphaned children to continue living together in their inherited parental property rather than for siblings to move in with foster relatives. They thought that this helped to strengthen the siblings’ emotional bonds and enabled them to safeguard their inherited assets from unscrupulous relatives who might otherwise sell the children’s property. Supporting children to grow up in their inherited parental home was also thought to increase the social inclusion of orphaned children, since they could maintain supportive relations with their deceased parents’ friends, neighbours and kin in their original home communities.

Material resources and external support

Half of the child- and youth-headed households who had inherited physical assets were able to draw on a range of material and emotional resources, household labour, social networks and external support that enabled them to sustain the household. The young people’s narratives revealed how physical assets and material resources could combine with other factors to build their resilience. Sophia (age 21) lived in Dar es Salaam with her three younger siblings (ages 15–19) and her own daughter (age 5) in the property they inherited from their mother. Sophia regarded the house they inherited as crucial to the viability of their sibling household; without a house to live in, she thought that many orphaned siblings would separate and engage in risky activities on the street. Since their mother’s death in 2004, the orphaned siblings had received educational support from a HIV support NGO as well as food aid and emotional support from an NGO supporting disabled people. Access to these material resources enabled Sophia to return to secondary school to study for her Form 4 leaving qualification. This support also enabled the next oldest sister, who had physical impairments and used a wheelchair, to complete Form 4 of secondary school, enabled the third sister to complete primary school (she sold water in the neighbourhood to earn money to support the household) and also enabled their younger brother to continue his studies.

Wellbeing, outlook and aspirations

High aspirations and a positive outlook have been identified as important protective factors for children experiencing adversity (Newman, 2002). The findings suggest that young people’s wellbeing, including their feelings about their caring responsibilities, their outlook and their aspirations for the future, may have a significant influence on their resilience and capabilities. Sophia saw her caring responsibilities as ‘normal’ once she had adjusted to her changed position within the household following her mother’s death:

‘I have many responsibilities because my siblings need to eat [and have] clothes and different things for their life. So I am the one to think of what to do that will benefit me and my siblings…. At the beginning, I saw it as a burden, but now I am used to it and I see it as normal.’

Sophia had high aspirations (she wanted to become a doctor) and was committed to caring for her siblings until they had completed their schooling, emphasising the importance of studying hard, completing secondary school and obtaining a good job to support herself and her siblings in the future. Sophia’s sense of wellbeing and positive outlook for the future was, however, linked to accessing continued material support for herself and her siblings:

‘It is mainly those services that will enable us to reach our life goals, where we will be able to live independently…. My future life will be very good, and I will be able to support others just like I have been supported.’

In contrast, the young people who had very little access to material support had often experienced stigmatisation in the community, had lost access to assets such as land, and consequently had not been able to continue their schooling,
had low aspirations and expressed a sense of hopelessness about the future. For example, Godfrey (age 17) cared for his three younger brothers and struggled to pay for the rented room where they lived in a village in Luwero district, Uganda, by doing casual agricultural labour. Conflict with their uncle meant that the brothers could no longer cultivate food crops on the parcel of land that they used to access. Godfrey did not identify any positive aspects about caring for his brothers, did not feel he could talk to anyone about their problems, and although he wanted to train to become a welder or a builder, he tried not to think about this, as he lacked any such opportunities. He felt overwhelmed by his responsibilities in providing for his brothers; the interpreter explained: ‘He feels painful [pain], because he’s not the mother, he’s not the father, but he has to take the responsibility, especially on clothing, mmm, looking for eats [food], as if he’s a parent.’ When asked how he saw his life in the future, the response was: ‘He’s not feeling well, there is no future.’ Such experiences of chronic poverty, stigma and exclusion can compromise young people’s wellbeing and restrict their ability to support their siblings and exit poverty traps in the future.

Human capital
In addition to physical and financial assets, material resources, and individuals’ wellbeing, outlook and aspirations, the human capital available within child- and youth-headed households helped to build siblings’ resilience. In the case of Sophia and her siblings, elements of human capital that appeared to strengthen their capabilities included the fact that Sophia was 17 years old when she started caring for her siblings, and her siblings were all aged 10 years or more when their mother died, which meant that they already engaged in many self-care activities; and Sophia’s previous caring responsibilities (caring for her mother during her illness, for her disabled sister, and for her own baby), which are likely to have helped to prepare her for sibling caregiving and household headship. Further elements that strengthened the siblings’ human capital include the fact that they shared the domestic responsibilities, had close loving relationships, and were committed to stay together in their inherited home; and the availability of labour resources, since they had a sibling who had completed school and who did paid work to support the household while the other siblings continued their education.

It should be noted, however, that such aspects of human capital could be simultaneously regarded as factors leading to the household’s vulnerability. These include, for example, Sophia’s curtailed secondary education and limited labour resources due to catching up on studies that she had been unable to complete due to her pregnancy; the young age and care needs of Sophia’s own daughter; the care needs of her sister who used a wheelchair and required assistance with mobility; and the stigma that the siblings experienced within the extended family and community due to their status as an orphan-headed household and Sophia’s position as a young, unmarried mother. Sophia found it difficult to find time for private study and sometimes had to miss school due to her caring responsibilities. The household’s dependence on her younger sister’s insecure, low income in the informal sector and on finite NGO support could eventually force Sophia to abandon her studies, increasing the likelihood that she would experience chronic poverty over her life course. Furthermore, the fact that the household was headed by a young woman, who would not usually be expected to inherit property due to patrilocal marriage practices, meant that the household was vulnerable to property-grabbing if their relatives attempted to appropriate the home the siblings had inherited from their mother. Similar vulnerability and protective factors related to human capital can be identified for the other child- and youth-headed households (see Table 3).

Social capital
In addition to physical assets, wellbeing, material resources and human capital, the social capital that the young people developed represented a crucial factor in building resilience. Previous research by Germann (2005) in Zimbabwe and others showed that many young people developed close interdependent relationships with their siblings and strong informal and formal support networks in rural and urban areas. Despite negative experiences of stigmatisation and harassment, orphaned young people often relied on their peers, extended family members, neighbours, community and faith leaders, and NGOs for material and emotional support and protection.

The young people emphasised the importance of friendships and support from their siblings and peers in assisting each other in agricultural or income-earning strategies. As Rickson (age 19, Tanzania) commented: ‘We are friends, we stay together, we collaborate on what to do, we ask each other — How is your life? We share experiences…. We work together…. For example, if I have to do weeding in our farm, he comes and helps me, and once we have finished my farm I go to his home and help him as well. For example, during the school holidays, we help each other with different things, like looking for fertilizers.’

Several young people said that they sought advice from neighbours and community leaders in resolving conflicts with their younger siblings, as well as seeking protection when they were harassed and threatened with physical and/ or sexual violence at night. Developing supportive relations with adult community leaders and support workers could represent an important strategy for young people to protect their property and safeguard their inheritance. The Kampala workshop drama showed the young people seeking legal help from the local council chairperson, who considered the case and upheld the young people’s inheritance rights. Land rights depend on people’s social relations within an ethnic group, family/clan relations, marital relations, friendship, patron/client relations, relations with authorities at various levels of society (Odggaard, 2002). Children’s claims to land under customary tenure therefore depend on their status and on the social capital they are able to draw on within the community. Indeed, the research found that community leaders and support workers sometimes played important roles in advocating for orphaned young people’s inheritance rights.
Protective factors in safeguarding assets and building resilience

The analysis (as summarised in Table 4) indicates that a number of protective factors may significantly reduce the vulnerabilities that child- and youth-headed households face. While none of the households could access all of these resources, the young people’s life stories suggested that it is the combination of some physical and financial assets, material resources, individual factors (such as age and capabilities when the eldest sibling started caring; household members’ health and wellbeing, motivations, values and beliefs, outlook and aspirations), relational factors (such as the support of older siblings/relatives who can share unpaid and paid work responsibilities, or strong social ties) and structural factors (e.g. access to education, skills development, healthcare, employment opportunities) that help to safeguard inheritance and build the resilience of child- and youth-headed households.

NGO practices that help to build the resilience of child- and youth-headed households

As noted earlier, material and emotional support from NGOs played a significant role in sustaining the child- and youth-headed households participating in the study, particularly in Tanzania. Analysis of the perspectives of service providers, support workers, and young people reveals a number of practices that enhanced young people’s capacity to support themselves, such as: legal support and advocacy; development of life skills and livelihood strategies; material, practical, emotional and peer support; and, community mobilisation and education.

The NGO workers and young people identified legal support, advocacy, and education as key means for assisting orphaned young people to safeguard their deceased parents’ assets and challenge cases of property-grabbing. Service providers in Tanzania explained how they advocated on behalf of orphaned children who had experienced property-grabbing, by liaising with neighbours, community leaders at the village and ward levels, and, if necessary, with social welfare authorities and lawyers. Education about children’s rights, particularly regarding inheritance rights, child abuse and the legal system, was regarded as vital in ensuring that young people were aware of their rights and how they could avoid mistreatment. Young women leading peer self-defence clubs in Kagera region commented on how useful they had found training on children’s rights to protection from sexual abuse and early marriage. They emphasised the need for more education about their rights: ‘They were lawyers, they really taught us a lot about how to take the law about child abuse.... Because we want to know

Table 4: Protective factors in safeguarding inherited assets and building resilience in child- and youth-headed households

<table>
<thead>
<tr>
<th>Resources</th>
<th>Examples of protective factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and financial assets and material resources</td>
<td>• Inherited productive land for cultivating crops for consumption and/or sale;</td>
</tr>
<tr>
<td></td>
<td>• Livestock;</td>
</tr>
<tr>
<td></td>
<td>• Well-built house in good state of repair;</td>
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<tr>
<td></td>
<td>• Income from rental property;</td>
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<tr>
<td></td>
<td>• Capital to invest in business, agricultural inputs, or support from NGOs to establish income-generating activities such as rearing livestock;</td>
</tr>
<tr>
<td></td>
<td>• Bicycle/money for transport;</td>
</tr>
<tr>
<td></td>
<td>• Inherited financial resources;</td>
</tr>
<tr>
<td></td>
<td>• Remittances from older sibling/other relatives who are not co-resident.</td>
</tr>
<tr>
<td>Human capital</td>
<td>• Age when started caring for siblings;</td>
</tr>
<tr>
<td></td>
<td>• Previous caring experiences (e.g. for a chronically ill parent);</td>
</tr>
<tr>
<td></td>
<td>• Availability of other older siblings who are able to share care work and engage in income-generating activities;</td>
</tr>
<tr>
<td></td>
<td>• Willingness of siblings to look after each other, and close loving relationships within the family;</td>
</tr>
<tr>
<td></td>
<td>• Opportunities to develop vocational and life skills in self-care, livelihood strategies, and managing a household (e.g. personal hygiene, agriculture, business and other income-generation activities, budgeting, food preparation, childcare, etc.);</td>
</tr>
<tr>
<td></td>
<td>• Strong value placed on education;</td>
</tr>
<tr>
<td></td>
<td>• Time for private study and access to extra tuition.</td>
</tr>
<tr>
<td>Social capital</td>
<td>• Practical and emotional support and guidance from extended family members, peers, neighbours, teachers, local leaders or NGO workers/volunteers;</td>
</tr>
<tr>
<td></td>
<td>• Opportunities to participate in the community (e.g. youth groups, faith-based community, volunteer work, local celebrations and events).</td>
</tr>
<tr>
<td>Wellbeing, positive outlook and aspirations</td>
<td>• Siblings in good health and able to access healthcare;</td>
</tr>
<tr>
<td></td>
<td>• Opportunities to share experiences and feelings with peers living in similar situations and with supportive adults;</td>
</tr>
<tr>
<td></td>
<td>• Positive outlook, clear goals and aspirations for the future;</td>
</tr>
<tr>
<td></td>
<td>• Strong religious faith;</td>
</tr>
<tr>
<td></td>
<td>• Commitment to care for siblings until they are grown up and able to support themselves financially;</td>
</tr>
<tr>
<td></td>
<td>• Awareness of need to safeguard asset inheritance from unscrupulous relatives and neighbours.</td>
</tr>
</tbody>
</table>
our rights, but we don’t know them, we don’t understand them. We want more education…”

Many of the service providers identified the need for young people who live in a child- or youth-headed household to develop life skills and livelihood strategies. They saw this as a key means of building their resilience to poverty, enhancing food security, and preventing them from engaging in risky survival strategies, such as transactional sexual relations and theft, which, respectively, could expose them to HIV and other sexually transmitted infections or result in community sanctions. The young people in Tanzania who had received life-skills training from NGO workers on the topics of budgeting, personal hygiene, conserving food safely and preparing the right amount of food to avoid waste, resolving conflict with their younger siblings and living with others in the community felt that this had greatly assisted them in the transition to caring for their siblings.

The NGOs working in rural areas in Tanzania aimed to provide child- and youth-headed households with agricultural inputs like fertiliser and seeds to improve food security, although the funds for this were limited and the staff could usually assist only a few of the most vulnerable households. The project workers pointed to the challenges that young people could face in maintaining their assets if they lacked the means to invest in them. One noted:

‘Some children have been left with a house and small plots of land, but…you tell him to farm but he has no money for seed or fertiliser, so how will he farm? It is true there are some assets, but they have to be facilitated to use them.’

Some project workers explained that among the many families they supported, they tried to prioritise child- and youth-headed households facing climate-related shocks and hunger.

The NGO workers suggested that alongside agricultural inputs, young people needed training in developing sustainable livelihoods and enhancing the productivity of their inherited assets, since they were missing out on the informal education and training that their parents might have provided:

‘We think that children were [supposed] to get this agricultural education from their parents; now that their parents are not there, then we do help there instead of the parents, to educate children about agriculture.’

Indeed, the literature on the impacts of HIV and AIDS often expresses concern about the loss of the intergenerational transfer of knowledge to orphaned children, particularly regarding agricultural practices (Van Blerk et al., 2008). The evidence for such a loss of knowledge among orphaned youths is limited, however, and it has been noted that young people often receive informal training in agriculture and other life skills from a range of peers, adult relatives and community members, not just from their parents (Hadju, Ansell, Robson, Van Blerk & Chipeta, 2011).

The NGOs in Tanzania provided loans and sometimes capital for young people to start small businesses, such as rearing livestock. Service providers emphasised the importance of starting from young people’s perspectives and tailoring support to the individual needs of each young person, since their priorities and livelihood strategies depended on their interests, motivations, and the availability of existing assets and resources.

In the workshops, young people collectively ranked the material and emotional needs they had identified in interviews. They saw addressing their basic needs for food, good housing, healthcare, schooling, bedding, and financial support as crucial, before other priorities could be addressed, such as employment and obtaining a regular income or emotional support. The young people saw adequate food as their first priority, with good housing and healthcare following closely. Many were concerned about the poor quality of housing they lived in, due to their exposure to the cold, rain and mosquitoes and the risk of the house collapsing.

Most of the NGOs participating in the study provided occasional food aid, educational support, and access to healthcare for families affected by HIV, which helped to alleviate the chronic poverty and hunger these households experienced, following the reduction in household income due to parental illness or death. The young people in Kagera region received regular cash transfers from an NGO, which they highly valued as it allowed them to budget for their basic needs and concentrate on their schooling without needing to spend so much time doing paid work to support their family. While the cash transfers they received were not enough to support all their important daily needs, the young people valued being able to decide how to spend the money themselves, according to their own requirements. Rickson (age 19) explained:

‘If they had not helped us with this, my life would not have been the way it is now…. So out of that 15 000 [Tsh$], I take 4 000 for porridge and pay. There are other needs...if they give us that, we go and buy exercise books. Even food, when it is finished; we buy food and other needs like uniforms; we buy from the money they have given us.’

However, such positive experiences of receiving NGO support raise questions about the sustainability of funding streams for orphans and vulnerable children and about how the global and national politics of HIV care and support programmes play out at the local level. As noted earlier, NGO support could create dependence on external support that is only available in the short and medium term, and the withdrawal of such support could ultimately increase young people’s vulnerability to chronic poverty.

The young people who had access to land sometimes received assistance from NGO workers and their peers, such as to help prune banana and plantain trees, or to dig, plant, weed and harvest crops such as maize, potatoes, cassava and beans. The NGO workers saw their role as identifying vulnerable households and mobilising young people to assist each other with agricultural labour to improve households’ food security. One project worker explained:

‘[The NGO staff and community assistants] recognise that there is a certain child who is caring for himself/herself, and his/her farm condition is not in a good condition. So what we do is to organise
those children who are in that cluster on how we can help that child. We plan for a day to go to that family. If they have a banana farm, they remove weeds for him/her....’

Some NGO staff also provided practical assistance in renovating young people’s homes, arranging childcare to enable young mothers to complete their schooling, collecting medicines and/or providing transport to the hospital for children living with HIV.

Orphaned young people who were relatively isolated and received little external support, particularly those in Uganda, saw emotional and peer support as an important priority, once their basic needs were met. NGO workers supporting sibling-headed households through the Vijana Simama Imara (VSI) (‘Youth Standing Upright Firmly’) youth-led programme in Kagera region saw peer support as crucial in building young people’s resilience:

‘Some think they have a very heavy burden, but when they hear that their age-mates are also going through the same challenges but have managed to succeed in one way or the other, it encourages him/her.’

Young women leading self-defence clubs commented on how such activities helped to build children’s confidence to ‘stand up for themselves,’ share their problems and seek support when they were mistreated or their property was stolen:

‘After the lessons are over, they know how to stand up for themselves. If they meet someone who wants to deceive them or steal something from them they know they can go to a particular place and that there is someone there who can help them, in order for them to keep hold of their things.’

Furthermore, the youth-led VSI programme enabled young people to supplement the financial support they received from the NGO, with a small monthly allowance (1 500 Tsh) in return for voluntary work helping older people in the community, such as by fetching water and collecting wood. Alongside their allowance, a small amount (300 Tsh) was allocated to the VSI cluster’s (the village-level youth organisation) communal funds for emergencies, in order to support orphans and vulnerable children, and to the savings account, which the young people collectively decided how to spend. Proceeds from regular auctions of produce also contributed to the village-level VSI fund for orphans and vulnerable children. The VSI bank provided a means for young people to save money and take out small loans for individual or collective income-generating activities. An independent evaluation of VSI concluded that the youth-led participative orphan programme was effective in building young people’s resilience and resulted in a range of positive outcomes, including developing coping strategies, life skills, social networks with their peers and supportive adults, and making a valued contribution to the community (Clacherty & Donald, 2006).

Such youth-led collective mobilisation strategies can also help challenge the stigma surrounding orphanhood and reduce the marginalisation of child- and youth-headed households (Madoerin, 2008). Several NGO workers highlighted the need for community education in order to raise awareness of the difficulties that orphaned children face, such as stigmatisation, property-grabbing and exploitation. They felt that mobilisation was needed for the community to accept collective responsibility for children living in child- and youth-headed households and increase social support available to young people. They explained that neighbours, volunteers, and community leaders are better able to provide ongoing advice and guidance to young people than NGOs are because of their close proximity to vulnerable households in rural areas:

‘We are an NGO, but we live far away and we do not live or stay in the villages to be able to see everything that happens. But if the community is educated and have been educated that this is the problem of us all, so that they even supervise how children are brought up, this will at least make it much easier.’

NGO staff collaborated with village and ward-level orphans and vulnerable children committees, local councils and community leaders, schools and other NGOs, where possible. However, staff members identified the need for greater coordination of efforts, communication and information-sharing between all stakeholders about policies and the implementation and monitoring of interventions, to ensure that support reaches the most vulnerable children and young people.

Conclusions

The severity of the HIV epidemic in communities in Tanzania and Uganda means that young people may gain control of valuable physical assets, such as agricultural land, housing and rental accommodation, at a younger age than usual. Such physical assets represent key determining factors in the formation and viability of child- and youth-headed households in rural and urban areas in Tanzania and Uganda. Despite the risk of property-grabbing, harassment and chronic poverty, several of the child- and youth-headed households demonstrated considerable resilience by safeguarding their inherited assets, developing diverse livelihood strategies, and building social capital. In contrast, the orphaned young people who lacked physical assets and external support had often dropped out of school at a young age and were working long hours to earn enough money to support themselves and their siblings. These households often experienced food insecurity and hunger and were vulnerable to the intergenerational transmission of poverty. This was evidenced through low educational outcomes, which limited human capital in adulthood; the loss of access to or sale of their inherited assets (and the loss of a stream of future benefits); and the risk of the separation of siblings and the dispersal of the household, as young people migrated to urban areas or moved to live with foster relatives, resulting in a weakening of interdependent family ties.

Although social relations with extended family members and others in the community were sometimes detrimental to the young people’s wellbeing and security, the research highlights the importance of social networks in enabling orphaned young people to protect themselves and their property, in providing access to material and emotional

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Although social relations with extended family members and others in the community were sometimes detrimental to the young people’s wellbeing and security, the research highlights the importance of social networks in enabling orphaned young people to protect themselves and their property, in providing access to material and emotional
resources, and in enhancing their skills and capabilities to
develop sustainable livelihoods. These findings challenge
widespread assumptions and concerns among development
policymakers and practitioners that child- and youth-headed
households lack adult guidance and support, lose out on
intergenerational transfers of knowledge about livelihoods
and other life skills, and are generally disconnected from
the wider community (Thurman et al., 2008; Van Blerk et al.,
2008).

The research supports the growing literature that argues
that unconditional cash transfers and other direct means
of providing financial and material support to households
have considerable potential to alleviate the chronic poverty
that the most vulnerable children and families experi-
ence in eastern and southern Africa (Richter, 2010). As
Richter (2010) argues, such strategies need to be part of
a rights-based long term commitment to social protection
that is institutionalised in government-led structures. The
research reveals the dangers of creating dependency on
external support available only in the short and/or medium
term, which may have long term negative consequences
for building human capital in child- and youth-headed
households when funding streams come to an end. Targeted
external support could also undermine the social capital that
young people may be able to develop through their relations
with friends, neighbours and extended family members and
result in resentment and increased stigma in the community.
As Thurman et al. (2008) caution, targeting economic assist-
ance only to youth-headed households in poor communities
may cause jealousy, aggravating rather than alleviating the
marginalisation they experience.

The research shows how youth-led collective mobilisation
can facilitate the development of peer support, build young
people’s resilience and challenge stigma in the community
(Madoerin, 2008). Such youth-led approaches can be
sustained over time, if older youth, such as the young
women leading the self-defence clubs in Kagera region,
work with their younger peers to build their capacities to
lead groups and facilitate a transfer of knowledge, as they
move on to other opportunities.

The findings from Tanzania and Uganda demonstrate
the usefulness of the sustainable livelihoods framework
as a starting point for the analysis of young people’s
resilience in safeguarding inherited physical assets and
sustaining their households over time. Alongside analysis
of access to physical assets and material resources, the
research reveals the need to pay attention to individual-
level factors, such as age, gender, educational outcomes,
health and wellbeing, motivations, outlook and aspirations
for the future; human capital, such as household size, age
and capabilities of other children, caring relations, health
status and disability; and social capital, including social
networks, opportunities for participation and wider values,
beliefs and norms, such as awareness of HIV, stigma and
property-grabbing. While this study has focused on the
individual, household and community levels, it is important
to recognise that orphaned young people are situated within
a broader landscape of care in which formal social safety
nets are often severely limited, external support is subject to
global and local politics of orphanhood and changing donor
priorities, and young people’s capabilities are constrained by
wider structural inequalities in access to education, health-
care and employment opportunities and gender and genera-
tional power imbalances.

Orphaned young people may inherit a range of assets,
which vary according to locality; they adopt diverse liveli-
hood and coping strategies and have different interests,
motivations and skills in sustaining their household.
Individually tailored approaches that take a holistic perspec-
tive of young people’s lives are therefore important for
the design and targeting of interventions to support child-
and youth-headed households. External support needs to
recognise young people’s agency, as well as foster peer
support and collective mobilisation. Experiences from
Tanzania and Uganda suggest that such practices can
enhance young people’s capacity to care for their siblings
and enable them to sustain their households over time,
as well as help build more supportive social environ-
ments which challenge stigma and property-grabbing and
safeguard young people’s inheritance.

Notes

1 The categorisation of households according to ‘household
headship’ has been justifiably critiqued (see Chant, 2007; Bell
& Payne, 2009) and I acknowledge that use of the terms ‘child-
headed’ and ‘youth-headed households’ is problematic. This
research focuses on the experiences and priorities of orphaned
young people who were caring for their siblings without a
co-resident adult relative in what are often termed ‘unaccompa-
nied’ ‘child-headed households’ (i.e. where there is no co-resident
adult and all household members are under age 18 years) or
‘youth-headed households’ (where the head of the household is
aged 18–25) (Foster et al., 1997). I recognise that child-headed
and youth-headed households occupy a different socio-legal
position in terms of inheritance and access to services. Young
people’s experiences suggest, however, that caring responsibil-
ities, educational and employment status may be more signifi-
cant markers of difference than biological age-based distinctions
between under 18-year-olds and the 18- to 24-year-old age
group. Differences between older siblings’ caring responsibili-
ties and those of younger siblings are discussed elsewhere (see
Evans, 2011 and 2012).

2 Young women who had received training in self-defence
techniques and children’s rights formed self-defence clubs
for girls in their locality, where they taught their younger peers
physical self-defence techniques and discussed their rights
to protection from violence, abuse and property-grabbing.
Self-defence groups also raised young women’s awareness of
available sources of support.

3 The research conforms to the ethical protocols of the Social
Research Association and the British Sociological Association;
ethical approval was granted in 2008 and 2009 by the University
of Reading’s Research Ethics Committee.

4 In the context of children’s caring roles in Africa, self-care activi-
ties can be defined as “personal care of self, taking medication,
getting ready for school, private study, personal development,
training, developing life skills and livelihood strategies, etc.”
(Evans, 2010, p. 1481)

5 Funding for the NGO’s orphan and vulnerable children support
programme was coming to an end at the time of the research.

6 At the time of the interviews in 2008, US$1 was equivalent to
approximately 1 150 Tanzanian shillings (Tsh).
Acknowledgements — I wish to thank all the young people, community members and NGO staff in Tanzania and Uganda who participated in the study. I also thank Morten Skovdal, Marguerite Daniels, Laura Lee and the anonymous reviewers for their comments which helped to improve an earlier draft. The research was supported by a Royal Geographical Society (with the Institute of British Geographers) Small Research Grant and by the School of Human and Environmental Sciences at the University of Reading. The article also draws on analysis conducted for a Working Paper (Evans & Day, 2011) of the Chronic Poverty Research Centre (CPRC), which is funded by UKAid’s Department for International Development (DFID) for the benefit of developing countries. The CPRC gratefully acknowledges the support of DFID. The views expressed are not necessarily those of DFID; any errors remain the author’s own.

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References


Organization of the United Nations (FAO), Rome, Italy.
Challenges and coping strategies of orphaned children in Tanzania who are not adequately cared for by adults

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Orphaned children in poor rural communities sometimes have no adult who is able to care for them or else the adult caregiver is not able to provide adequate care. Tanzania remains one of the poorest countries in the world, and poverty frequently constrains foster care. Although HIV prevalence is declining, AIDS is still a major cause of orphaning. This article explores the challenges and coping strategies accompanying two possible life trajectories for orphaned children without adequate adult care: 1) that they remain in rural areas in child-headed households, or 2) that they are trafficked to an urban area. Antonovsky’s salutogenic model is used as the theoretical framework. The data come from two separate phenomenological studies with vulnerable children. In the first study, in-depth interviews were held with 12 orphaned children in a poor rural area; data concerning three child heads of households are included here. In the second study, 15 girls who were trafficked from rural areas to Dar es Salaam gave extended life-history narrations; data are included for nine of the girls who were orphaned. Loss of parents, a lack of cash, and the need to balance school attendance with food production were chronic stressors for the children heading households, while resources included income-generation strategies and the ability to negotiate with teachers for time to cultivate. For the trafficked girls chronic stressors included exploitation, long working hours, little or no pay, isolation and rape. Resources for them, although limited, included faith networks and neighbours; escape from the exploitative situation frequently involved external help. We conclude that given physical and social assets the child-headed households were able to cope with the challenges of caring for themselves and a younger child, but isolation and dependency on employers made it difficult for the trafficked girls to cope with this exploitation. The salutogenic model proved a useful tool in analysing the coping strategies of children living without adequate adult care.

Keywords: agency, care and support, child-headed households, child wellbeing, developing countries, girls, orphans and vulnerable children, salutogenic model, sub-Saharan Africa, trafficked children

Introduction

Orphaned children in sub-Saharan Africa are usually taken in by their extended family (UNICEF, 2003). UNICEF and other international institutions have identified the ‘ideal’ living arrangements for orphaned children as living under the care of an adult within their extended family (UNICEF, UNAIDS & USAID, 2004). The ‘Framework for the protection, care and support of OVC [orphans and vulnerable children] living in a world with HIV and AIDS’ has been hugely important in setting this agenda. The framework was the outcome of the first Global Partners’ Forum convened by UNICEF in 2003, in which five key strategies were outlined (see UNICEF, UNAIDS & USAID, 2004). These strategies — also adopted by the more recent ‘Joint Learning Initiative on Children and HIV/AIDS’ — focus entirely on the family and community, with little attention paid to the children who fall outside this network (Wakhweya, Dirks & Yeboah, 2008). Publications continue to stress that programmes should be aimed at providing support for children who are under the care of an adult (Hosegood, 2009; Hosegood, Floyd, Marston, Hill, McGrath, Isingo et al., 2007). While it is important to strive towards community and family care for orphaned children, it remains an ideal: policies and programmes need to acknowledge that the situations of many children fall outside this ideal. This reality includes child-headed households and orphaned children who are vulnerable to abuse, exploitation, and trafficking because the adult who is responsible for them is unable to provide adequate care.

Definition of concepts

We define orphaned children as children under the age of 18 who have lost one or both parents. Thus, a child-headed household may be defined as a household headed by a person who is under 18 years of age (see also Hosegood et al., 2007, p. 331) and one that is recognised by the community as an independent household (Luzze & Ssedyabule, 2004). In a qualitative study of 969 child-headed households in one district in Uganda, Luzze & Ssedyabule (2004) found that orphaned children living in child-headed households were poorer than orphaned children with other living arrangements, and they had lower school attendance and poorer access to social services. Many aid agencies no longer class those who care for their siblings as ‘children’ once they turn 18, even though no other circumstances have changed (Daniel, 2008). Evans
work in the homes of wealthier families. Koda (2000, p. 251), recruited by relatives or non-related adults for doing domestic from poor families, children, particularly from rural areas, are under the pretext of taking care of orphans and children family may expose orphaned children to exploitation (e.g. as
in Madhavan, 2004, p. 1444). Evans (2005) contends that instead “a normative social obligation” (Goody, 1982, cited died; such fostering lacks the element of reciprocity and is relatives feel obliged to take on children whose parents have died; such fostering lacks the element of reciprocity and is instead “a normative social obligation” (Goody, 1982, cited in Madhavan, 2004, p. 1444). Evans (2005) contends that the tradition of child fostering by members of the extended family may expose orphaned children to exploitation (e.g. as domestic servants) and abuse. According to Koda (2000), under the pretext of taking care of orphans and children from poor families, children, particularly from rural areas, are recruited by relatives or non-related adults for doing domestic work in the homes of wealthier families. Koda (2000, p. 251), describes a typical domestic servant in urban centres as “a young girl of between 9 and 18 years of age who may have been brought to her employer by a relative, a friend, a village-mate, or a child who has migrated to the urban area on her own.” Other authors (Blagbrough, 2008; Ochanda, Akinyi & Wakinya, 2011) confirm that child fostering is a factor in child trafficking. Child fostering turns to trafficking or slavery when the child is deprived of his or her basic rights, such as education, health services and the fulfilment of basic needs, and made completely dependent on the caregiver and denied the right to choose (Blagbrough, 2008).

According to United Nations (2000, p. 2) Article 3(a) trafficking in persons is:

The recruitment, transportation, transfer, harbouring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, or deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation.

Blagbrough (2008, p. 184) contends that, where children are concerned, they “do not have to be coerced to be considered as trafficked.”

Child trafficking is a very particular form of child-labour migration that involves exploitation of the migrant child. According to the United Nations (2000) protocol, only those cases of migration in which the child (at any point during the migration process) is being recruited, transported, transferred, harboured, or received for the purpose of exploitation can be called trafficking. According to Dottridge (2004), in child trafficking, victims are transported and put to another’s use, usually to make money. In short, trafficking is distinguished from migration by the existence of exploitative intention and acts at any point. The exploitation of trafficked persons may include: physical and/or mental abuse or confinement, inadequate or non-existent healthcare, poor accommodation and hazardous work, as well as forcing a child or misleading him or her with false promises in the recruitment or transportation processes (ILO-IPEC, 2002). Exploitation also includes child domestic servitude. Anti-Slavery International (1997 cited in De Lange, 2007, p. 150) defines child servitude as the “complete dependency of a child upon his or her employer for his or her wellbeing and basic necessities and withholding of wages or deferred payment for more than, or a matter of, a few weeks.”

Blagbrough (2008) notes that employers of child domestic workers may not regard themselves as exploiting the children, instead they may believe they are helping the child and her family. However, recruitment into child domestic labour is often expedited through intermediaries who commonly deceive or give “false promises about working conditions, opportunities for education and what the child’s life will be like. Typically, therefore, the way in which significant numbers of children enter domestic service can legitimately be described as trafficking” (Blagbrough, 2008, p. 184). In some cases the initiative to migrate is taken by children themselves, and although they may be more aware of the type of work they will be doing, Blagbrough (2008) argues that they are seldom aware that they will probably experience adversities.

This article merges these aspects and defines child trafficking as the recruitment (even if the child is initially willing), movement, and receipt of a child for the purpose of exploitation. Typically, child trafficking results in a loss of contact with family and complete dependency on the ‘employer,’ which increases vulnerability to exploitation.

**The Tanzanian context**

Tanzania, despite decades of development assistance, remains one of the poorest countries in the world; it is ranked 148 out of 169 in the UNDP’s Human Development Index (UNDP, 2010, p. 145). The Government of Tanzania reported that in 2007 around 33% of the population was living in poverty (United Republic of Tanzania, 2009). However, other authors suggest the figure is as high as 50% (Ndulu & Mutalemwa, 2002). The poverty level varies from one region to another, and between rural and urban areas. According to the International Monetary Fund (2006, p. 4), 87% of the poor in Tanzania live in rural areas and the absolute number of poor continues to increase due to population growth.

HIV prevalence among adults (aged 15 to 49 years) in Tanzania is declining; it was 5.6% in 2009 compared with 7.1% in 2001 (UNAIDS, 2010). There are some locations, including Makete in Iringa Region, where HIV
prevalence remains high, resulting in concurrent high levels of orphaning. Most orphaned children are absorbed by the extended family, with grandparents, aunts and uncles providing care for 90% of children without parents in sub-Saharan Africa (UNICEF, 2003). Some orphaned children, however, are left with no adult to take care of them, and in some cases the adult who is responsible for them is unable to provide adequate care due to poverty or lack of resources. Leach (2008) notes that, in Tanzania, the main constraint on adequate foster care is poverty; and Mabala (2008) comments that families may see girls as an economic burden and will seek to marry them off early, as a family survival strategy. In such cases, children may live without an adult in a household headed by a child; alternately they may accept invitations from relatives, neighbours, or friends to migrate to an urban area.

Socio-cultural factors can contribute to the vulnerability of children. The socialisation of children, especially girls, to be submissive and obedient leads children accepting abuse without questioning or seeking the help of adults. Rwezaura (2000, p. 327), writing on “the worsening status of the child in contemporary Tanzania,” notes that leading causes (of their worsening status) include gender discrimination (especially in patrilineal communities) and the fostering of children by urban relatives. Girls usually take on roles of care and domestic labour while boys frequently receive more education than girls.

The Tanzanian government ratified the Convention on the Rights of the Child (CRC) and the African Charter on the Rights and Welfare of the Child (ACRWC) and incorporated the two conventions into the Child Development Policy 1996. In late 2009, it enacted the Law of the Child Act 2009. The Anti-Trafficking in Persons Act was enacted in 2008. Under customary and some religious laws, girls, at puberty, are considered mature enough for undertaking a woman’s social roles of reproduction and household activities. In some communities, girls may be forced into marriage or asked to take full responsibility of household activities at home or as house girls in towns. According to Mbonile & Lihawa (1996), forced marriage and domestic work directly or indirectly facilitate migration and/or trafficking.

Theoretical framework

The theory of salutogenesis, used here to analyse the coping strategies of orphaned children, focuses on the origins of health rather than the origins of disease as is the case in pathogenesis. Antonovsky (1996) proposes that all human beings are somewhere along a continuum that ranges between the extremes of health and disease, and that salutogenesis is occupied with what causes people to move towards the health end of the continuum. The salutogenic model contains two key concepts — namely, generalised resistance resources (GRRs) and sense of coherence (SOC) (see also Lindström & Eriksson, 2010, pp. 18–19). GRRs are resources that help people cope successfully when faced with stressors, which may be chronic or acute (Antonovsky, 1996). GRRs can be internal or external, material or non-material, for example, as in money, self-esteem, social relations or beliefs (Lindström & Eriksson, 2010). Antonovsky (1996, p. 15) describes SOC as “a generalised orientation toward the world which perceives it...as comprehensible, manageable and meaningful”; a strong SOC will promote movement towards health and enable a person to cope with stressors. “[A] strong SOC protects against anxiety…and hopelessness, is strongly associated and positively related to health resources such as optimism, hardiness, control and coping” (Lindström & Eriksson, 2010, p. 32).

Figure 1 shows an adaptation of Mittelmark’s (2010) construction of the salutogenic model as described by Antonovsky (1996). Life situation comprises culture, social position and many other factors that may generate both stressors and GRRs. These, in turn, shape “three kinds of life experiences: consistency, underload/overload balance, and participation in socially valued decision-making” which will determine the strength of SOC (Antonovsky, 1996, p. 15). Life experiences reflect the ability to use resources available to deal with stressors in such a way that options for better health improve (Lindström & Eriksson, 2010).

Objectives

Given that most policies and programmes are centred on community and family care for orphaned children, and in the interests of acknowledging the reality that the situations of many children fall outside this ideal, this article focuses on orphaned children who are not adequately cared for by their extended family. We draw on the salutogenic model to examine the struggles and coping strategies of those orphaned children who fall outside the ‘ideal’ support network of family and community and who instead follow one of two alternative trajectories: 1) they remain in the rural area in a child-headed household, or 2) they are trafficked to urban areas to serve adults.

Methods

The findings and analysis are based on data collected for two separate phenomenological studies with vulnerable children in Tanzania. The authors, when discussing their findings, realised that some of the research participants in each study came from the same group of vulnerable children — orphaned children in poor rural areas who did not receive adequate care from adults — but who had variously followed two different trajectories. In the first study, the orphans had remained in the rural area, living in households headed by children; in the second study, they had migrated from the poor rural area and ended up in Dar es Salaam. Consequently, the authors decided to select those data from each study that relate to orphaned children without adequate adult care.

Study 1: Child-headed households

The objective of the first study was to explore the impact on social cohesion of aid targeting vulnerable children in poor communities; the data collection took place between January 2007 and November 2008 in Makete, Iringa Region, Tanzania. Initial access to the participants was through an NGO working in the area and through local government officials. Twelve children1 (aged 12–18) were purposefully selected for in-depth interviews because they
Daniel and Mathias

were information-rich and articulate about their experiences. Three of the 12 (two girls, ages 13 and 18, and one boy, age 16) were orphans heading their own households and data from these interviews are included here. All the interviews were recorded and transcribed in full (i.e. in Kiswahili as well as English), and the Kiswahili parts were translated into English. The transcriptions were coded with the help of NVivo 8 and thereafter analysed according to the key themes of the framework.

**Study 2: Trafficked girls**

The second study explored the lived experiences of girls who had been trafficked. Data collection took place from June to September 2010 in Dar es Salaam, Tanzania. Data were collected from 15 girls (ages 14 to 18) who had migrated from rural areas to Dar es Salaam. With the help of staff at the KIWOHEDE² centre, the girls were purposefully selected because they had been trafficked, exploited and abused before being rescued. The data were collected through extended life-history narrations, allowing the researcher to gain insight into the day-to-day experiences of the participating girls (Cole & Knowles, 2001). Of the 15 participants, nine were orphaned and their data are included in this article. Thematic content analysis was used to code and organise the data into units of meaning (see Cresswell, 2003). For the purposes of this article, data from the 12 relevant participants (three child-headed households and nine trafficked girls) were re-analysed using themes from the salutogenic model.

Ethical clearance for both studies was obtained from The Tanzania Commission for Science and Technology (COSTECH), which issued the research permits. Informed written consent was obtained from each of the participating children and adults after the research projects had been explained to them. In the overall study in Makete, the caregivers of the children gave written consent for the children in their care to participate, but with the children heading households, only the child’s consent was obtained. Anonymity and confidentiality were ensured both verbally and in writing. The information was repeated before each of the interviews and the informants were given the opportunity to withdraw from the study at any time should they wish to do so.

Conducting research with vulnerable children raises a number of ethical challenges (Skovdal & Abebe, 2012). Personal topics, especially those related to separation, death and abuse might be associated with pain, shame, guilt, stigma and taboos. In Makete, all of the child interviewees were given the opportunity to have one of the community leaders present should they wish, but none chose to do this. The interview was the fourth meeting between the researcher and each child informant, so some degree of rapport and trust had been established. In the Dar es Salaam study, the life history of each informant was collected over several sessions, with special sensitivity shown towards the informant’s psychosocial wellbeing.

**Findings**

**Life situation**

**Child-headed households**

The three orphaned children heading households were all caring for younger children. Stella had been looking after her younger brother (five years younger than she is) since she was 10 years old, when her mother died; although she had to drop out of school she managed to support him to stay in school. Lucy and Joseph had both continued in school while caring for younger children (cousins) who had at least one parent alive and living nearby. Each had a shamba³ and a garden for food production, and they had various strategies for earning cash to buy things they could not produce. Joseph made bricks on his shamba and the girls did day labour activities like carrying timber or building materials to earn money. Lucy and Joseph had extended family members nearby who occasionally contributed cash or moral support; Stella’s mother had moved into the area shortly before she had become ill and all her relatives had died or were living a long way away and rejected her because her mother died of AIDS. All the orphans heading households were living in very small households.
**Trafficked girls**

Before they migrated, the trafficked girls were living in rural areas. Only one of them, Wema, was without a caregiver. She was 9 years old when her mother died and was the only one in her family left to care for her disabled brother. She dropped out of school, but was unable to provide food for herself and her brother, so; they relied on the good will of neighbours. The daughter of a neighbour offered to take her to Dar es Salaam, send her to school, and find her a good place to stay. The mothers of the two paternal orphans, Semeni and Upendo, were unable to provide adequate care because of their large families and a lack of resources. Paternal relatives offered to take them to Dar es Salaam and provide a job in Semeni’s case, and secondary education in the case of Upendo. Subira and Imani were living with maternal grandparents who were too poor to provide enough food and shelter or education, and Subira had no education before migrating. Furaha and Faraja were both living with paternal uncles in large families. Faraja’s uncle was pressing her to get married, but she did not want to get married as friends who were married were living a difficult life. When relatives offered to take them to Dar es Salaam, both girls took the opportunity. Nuru was living with a cruel stepmother who frequently kept her out of school to work at home and when a friend of her mother offered to find her a job in Dar es Salaam, she agreed. Salama’s parents were diagnosed HIV-positive when she was 11 years old and she had to work to help provide for the family. After doing petty labour in her home village, she decided to go to the nearby town to find a paying job to try to meet the family’s increasing needs. She moved to another job in a bigger town to avoid the constant sexual harassment from the father of the family where she was working; then she accepted the offer from a paternal relative to provide for her secondary education in Dar es Salaam.

**Stressors and responses**

All the children referred to in this study were orphans (see Table 1); all of them had experienced the death of a parent and the grief and adversity that accompanies such a loss. In addition, all the children in both studies experienced chronic poverty and food insecurity which had worsened after their parents died. Often the lack of income resulted in poor attendance or dropping out of school completely:

> ‘While mama was still alive she was constantly sick, so I dropped out of school because there was no food in the house. When mama died there was nothing to eat because the maize in the field was not ready for harvest’ (Stella).

Salama was one of seven children. Her parents tested HIV-positive in 2003 and were told to stop heavy labour. Salama described what happened:

> ‘I and my brother started doing small business selling fried groundnuts and local fruits. Our school attendance became irregular. At the end of the academic year our school results showed poor performance and attendance. I had to repeat Standard 4 because I failed the final examination.’

Six of the trafficked girls reached Standard 7 (the end of primary school) but did not progress further because their relatives were unable or unwilling to pay for secondary education. While poverty and food insecurity were among the factors driving them away from the rural areas, the hope that they might continue their education was the strongest factor attracting them to take up offers to migrate.

**Child-headed households**

All three of the children heading households were responsible for another child. Besides managing a household, producing food, earning cash to buy items they could not produce (such as clothing, salt, sugar, oil), and doing their own school work (in the cases of Joseph and Lucy), they were responsible for the wellbeing of a younger child, ensuring his or her needs were met and that they attended school. Their numerous and conflicting roles caused tension which required creative responses to resolve. Both Lucy and Joseph experienced a conflict between the need to attend school and the need to plant and harvest crops for food production:

> ‘I have a shamba and I normally cultivate maize. Sometimes when the planting season collides with school days, I ask permission from teachers to get at least two to three days to prepare and plant my shamba’ (Joseph).

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**Table 1: Details of the participants**

<table>
<thead>
<tr>
<th>Orphans heading households</th>
<th>Pseudonym</th>
<th>Age at interview</th>
<th>Age at parent’s death</th>
<th>Orphan status</th>
<th>School level*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucy</td>
<td>13</td>
<td>9</td>
<td>Double</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Joseph</td>
<td>16</td>
<td>9</td>
<td>Double</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Stella</td>
<td>18</td>
<td>10</td>
<td>Double</td>
<td>Dropped out in Standard 4</td>
<td></td>
</tr>
<tr>
<td>Wema</td>
<td>16</td>
<td>9</td>
<td>Double</td>
<td>Dropped out in Standard 3</td>
<td></td>
</tr>
<tr>
<td>Faraja</td>
<td>16</td>
<td>N/A</td>
<td>Double</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Furaha</td>
<td>17</td>
<td>11</td>
<td>Double</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Imani</td>
<td>18</td>
<td>N/A</td>
<td>Paternal</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Subira</td>
<td>16</td>
<td>11</td>
<td>Double</td>
<td>No schooling</td>
<td></td>
</tr>
<tr>
<td>Salama</td>
<td>17</td>
<td>10*</td>
<td>Double</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Nuru</td>
<td>17</td>
<td>10</td>
<td>Paternal</td>
<td>Standard 4</td>
<td></td>
</tr>
<tr>
<td>Semeni</td>
<td>17</td>
<td>5</td>
<td>Paternal</td>
<td>Standard 7</td>
<td></td>
</tr>
<tr>
<td>Upendo</td>
<td>14</td>
<td>Before birth</td>
<td>Paternal</td>
<td>Standard 7</td>
<td></td>
</tr>
</tbody>
</table>

*Age when her parents tested HIV-positive.

†Before migration for the trafficked girls.
Joseph had planned how he himself would pay for his secondary education: he had a flock of goats that was increasing in number every year and he planned to sell a few each year to pay his school fees and buy the school supplies he needed. He also received help from his neighbours, one of whom was on the ward committee to help vulnerable children; this man linked Joseph to an NGO that gave school uniforms to him and his cousin. Lucy had received food from an NGO, but only one time, shortly after her grandmother died and when she had first started living alone. She also received school uniforms for herself and her cousin. Stella received uniforms for her brother, but nothing for herself because she had dropped out of school. When she turned 18, the NGO stopped providing a school uniform for her brother because he was then classified as living with an adult.

Stella had been heading her household for eight years at the time of the interview. In addition to the chronic stressors of poverty and food insecurity, she had experienced numerous acute stressors. She had tried several income-earning strategies, such as carrying forestry logs, carrying bricks for builders, making charcoal, and selling fruit bought in a neighbouring town. Once she borrowed money from someone at church to buy the fruit to sell, but she was robbed and the money and fruit were stolen from her house. She had to borrow from someone else to pay back the debt. Another time, after buying the fruit in the neighbouring town, she was involved in a car accident. Her upper right arm was badly broken and, after treatment, she was told to rest it for eight months: ‘To tell the truth, I was confused. I started wondering who will take care of my young brother. I started losing hope on how my life will turn out.’ She had to continue with food production on the shamba, in spite of the broken arm. Stella also experienced ongoing sexual harassment from men in the neighbourhood, but described how she dealt with this: ‘I have my own standing. If I say no, it is no.’ Stella was determined not to get married:

‘All my sisters who are married regret it — they have a bad and difficult life. My friends who went to school with me, who are now married, are worse off than me with my orphanhood: at least I can still plan for my own future.’

Trafficked girls

All the trafficked girls had been deceived: they were all made to work excessively hard, sometimes up to 20 hours a day; those who had been promised an education did not receive it and several of them were not paid, or were paid only a pittance, for the work they did. Nuru’s story is typical of several of the girls:

‘I was treated so inhumanely...the whole family was isolating me. When eating, I was not sharing the same table with the others. If it happened that the food was not enough, it was me who was suffering.…. I was told not to talk with any of her children or anyone who comes to the house. I was not paid my salary.’

The girls also experienced physical abuse, such as beatings, and psychological abuse, such as insults and false accusations. Psychological abuse was frequently the response when the girls raised the topic of schooling. When Wema asked her first employer about the opportunity for schooling as had been promised, her employer ‘told me to unbury the skeleton of my mother which will take me to school.’

Many of the trafficked girls were isolated and prevented from making contact with their families, and some were not allowed to attend church. Six of the girls were sexually abused, sometimes brutally raped, and two had become infected with HIV. Wema described what happened to her in her second job, when the father of the house, who was a policeman, began to sexually harass her:

‘During the night while I was sleeping, he entered my room and started touching my body gently. I told his wife; she said I was lying. One day I was going to the shop when three young men came, caught me and forced me to enter a guest house room, and they locked it. I think it was arranged by the father of the family. In the night he came, undressed me, took off all his clothes and raped me. I have never experienced such a painful incident. I bled so much.’

The next day when she told the wife, she was sent away with only enough money for a local commuter bus. She spent that night with some street children, but was gang raped by a group of youths. Then she met a girl who invited Wema to stay with her and promised to help her, but she later told Wema she was a prostitute. She received money from one of her clients for him to have sex with Wema. Wema was again raped, so brutally that she had to be hospitalised after being rescued. As soon as she was able, she ran away and was rescued by a woman from KIWOHEDE who found her wandering in the street.

Imani narrated how she was taken to work for an unmarried man who kept her isolated from his tenants, did not pay her (he said he would give her the money when she left), and after she had worked there for four months he began to come to her room at night and rape her. Eventually she appealed to one of the tenants who took her to the police while the ‘employer’ was out. Salama, after leaving her first job to avoid sexual harassment, had a series of jobs before working for a family where the father was a cruel man; whenever his wife and child were away, he would come to her room:

‘The first day he came and started touching me and telling me nasty stories, I could not believe it. He was a respected man. Then he continued coming naked into my room and he forced me to have sex without my consent.’

Furaha worked for a family where all the children were going to school:

‘The first-born of my employer desired to sleep with me. I refused, but he used to come at night with a small knife and rape me. I told the mother but she remained silent. I felt so humiliated.’

The girls were without resources and were often entirely dependent on their employer — many of them had not been paid and so did not even have money for bus fare; frequently they were kept isolated and could not contact their families. After realising that they had been deceived, they began to ask about the promises that had been made
to them: payment of wages and the opportunity to go to school. Such enquiries often led to angry outbursts from their employer, or for others, like Wema, dismissal without pay. All the girls held onto their dreams of education for a better life, as related by Faraja:

‘I continued doing housework and selling fish, but I was so eager to study. I knew that education was the only means that would save me from a poor life.’

Faraja once approached a girl in school uniform to ask her where she was studying and how much it cost. The girl was from KIWOHEDE and Faraja found out all the details to pass on to her employer who became furious. She then decided to run away. Those who were allowed to go to church, like Salama and Nuru, told their problems to people at church, as Nuru relates:

‘One day I explained my problems to church members. Some church members visited our home and talked to my employer.... She answered that the issues with housegirls were her internal affairs. From then on I was not allowed to go to church.’

Later the pastor’s wife told her about KIWOHEDE, communicated with the organisation and showed her the way there. Other girls were helped by neighbours or people they met in the street, and Imani was helped by one of her employer’s tenants. In all cases the girls eventually managed to get away from the exploitative situation.

The girls were asked about their future plans and also what they would advise girls like them in rural areas. Most stressed that girls should not come to town and that they should speak out if they were exploited. For example, Imani said:

‘My advice to girls who are in a vulnerable condition in rural areas is that they should not trust anybody who tells them to move to town. In urban centres life is even more difficult; they may fall into exploitation as it happened to me. For those who are already in town and are experiencing bad treatment, they should not remain silent; they have to tell faithful neighbours.’

Framing the findings within the salutogenic model
The salutogenic model provides a framework that promotes a better understanding of the coping strategies of children who find themselves without family care. This section uses the framework to examine the experiences of the children detailed above to see how they were able to use the resources available to them to make the best of the difficult circumstances they faced. As the three kinds of life experiences — consistency, underload/overload balance, and participation in socially valued decision-making (Antonovsky, 1996, p. 15) — are considered in relation to the components of sense of coherence (i.e. comprehensibility, manageability and meaningfulness), clear differences emerge between the children heading households and the trafficked girls.

Consistency and comprehensibility
Consistency occurs when life is structured, predictable and explicable (Antonovsky, 1987), that is when certain challenges can be expected and planned for. All three orphans heading households had remained in the dwelling where they lived with their parents before they died; Lucy and Joseph have continued at the same schools; and all three have continued to work their same shamba. Producing enough food to meet their needs, earning cash for things that cannot be produced, and caring for the young children in their households are predictable and ongoing challenges that they must face.

The trafficked girls, however, experienced multiple changes in their lives and a lack of consistency. Three of the girls (Wema, Salama and Subira) had several different jobs over the course of a few years; all the girls had to get used to new homes, new ways of doing things in an urban rather than a rural area, and all experienced a range of new challenges. Another breach in consistency occurred when they were faced with actions based on values other than those they had been socialised into. The girls who were sexually abused and raped found it difficult to believe that the men of the household would violate them in this way — as Salama said: ‘He was a respected man.’ Some of the girls had confided in the women who were employing them, but, instead of being supported and protected, they were accused of lying, made to leave the house or faced with silence. Mabala (2008) discusses how hard it is within a patriarchal system which protects men, to punish perpetrators of sexual abuse, particularly when the victim is dependent on the abuser; Mabala (2008) explains this silence in response to abuse as families’ attempt to hide the shame and protect their good standing.

Consistency links with the cognitive dimension of sense of coherence (SOC) — comprehensibility, the ability to understand the challenges faced. Stella and Joseph had been heading households for eight and seven years, respectively, and had a clear grasp of the challenges confronting them. Lucy was newer to the responsibilities, but clearly understood why she was living without an adult and caring for her young cousin and what such responsibility entailed. Among the trafficked girls though, there was initially a lack of comprehension. They had been promised further education or good jobs, they had high expectations of a life better than the rural situation they left behind, but they were deceived. Not only were promises of education and employment broken, but they were also exploited and treated inhumanely. Their situation was incomprehensible to them. Once they realised they had been deceived, they began to question their employers about the promises of schooling, for example. The response to such inquiries was often physical or psychological abuse.

Underload/overload balance and manageability
The underload/overload balance refers to having the resources available to meet challenges and demands (Antonovsky, 1987). Once again there is a clear difference between the experiences of the orphans heading households and the trafficked girls. All the orphans heading households had access to physical or social assets: each had a shamba and a garden for food production; Lucy and Joseph had extended family nearby who would help in a crisis; they all had means of earning cash when necessary, and Joseph had very successfully tapped into the social support available from local government and civil society.
The children’s agency can be seen as another resource: their ability to negotiate and to find alternative means of income-generation helped them to meet the challenges they faced. The trafficked girls, on the other hand, were effectively deprived of most resources; they were a long way from their extended family and friends, and they were not allowed to contact them; they were kept dependent when their employers withheld their wages. When confronted with abuse and exploitation they had few resources to utilise. Generalised resistance resources (GRRs) not only help one combat stress, but may also help one avoid it (Antonovsky [1979], cited in Lindström & Eriksson, 2010), and often the only option open to the trafficked girls was to run away. In the limited capacity available to them, they also utilised social support, for example Salama and Nuru involved members of the church in getting away from their exploitative employers.

The underload/overload balance between stressors and resources links with the behavioural dimension of SOC — manageability (Antonovsky, 1987). Unlike the trafficked girls who were raped, Stella was able to manage the sexual harassment she faced from men in her neighbourhood. Stella could see that in spite of the numerous demands on her meagre resources, she was better off in her state of orphanhood than her friends who were married and unable to manage their own lives. Joseph had planned how to use his resources for his future educational needs. However, the trafficked girls had expectations of continuing schooling, earning money to pay for their own schooling, and generally having a better life than they had previously had in the rural areas. But in Dar es Salaam they struggled to deal with the exploitation and abuse they experienced: they were not able to avoid being physically and psychologically abused. In the end, the only way to stop the exploitation was to leave the job and move away from their employer’s home. In most cases they needed help to do this. It is interesting that their advice to other girls in rural areas was to avoid getting into that situation in the first place, but also to speak out and ask for help, in other words to draw on social networks, no matter how limited.

Participation in socially valued decision-making and meaningfulness

All three orphans heading households were able to participate in socially valued decision-making; they were all caring for younger children and had to make decisions for the child’s wellbeing; they all had to make decisions about food production and earning cash. These are adult roles that were recognised and valued by the community around them. Being responsible for a younger child was both stressful and rewarding. But the trafficked girls were kept dependent, were often not allowed to participate in normal family life, and were not even permitted to make decisions about their own wellbeing, for example the violation of their person through rape.

Participation links with the motivational dimension of SOC — meaningfulness (Antonovsky, 1987), and Lindström & Eriksson (2010) identify this as the most important dimension of SOC, driving one to seek resources to strengthen the other two dimensions. Caring for a younger child motivated all the orphans heading households to persevere in solving problems and to seek the resources to provide for them. Lucy and Joseph were also strongly motivated to cope by the desire to continue their education. This desire for education as the key to a better future was also present in all the trafficked girls. Initially it was a large part of their migration strategy and after experiencing exploitation in Dar es Salaam, it drove them to question their employers’ deception and ask that the employers fulfil the promises they had made to the girls. It also motivated them to get away from the exploitation and seek a way to pursue their education. While they were unable to participate in decision-making concerning even their own personal life, they held onto the dream of further education, and this contributed to their motivation to get away from the exploitation.

Discussion

The findings from this study confirm many of the challenges experienced by orphaned and vulnerable children that have been discussed in other studies, including those in child-headed households (e.g. Luzze & Ssedyabule, 2004; Ruiz-Casares, 2009) and among those who are trafficked (e.g. Lalar, 2004; Blagbrough, 2008; UNICEF, 2011). NGOs, governments and international organisations have responded with policies and programmes to help vulnerable children; their approaches include strengthening families, and strategies like the Millennium Development Goals (MDGs) to eradicate poverty and achieve universal primary education (Steer & Levy, 2010). Wallis & Dukay (2009) have identified three stages in policy response: awareness, emergency and structural responses. While a few agencies are beginning to act at the structural level, many aid programmes are still responding at the emergency stage — and in practice this amounts to the provision of uniforms, school materials and paying school fees (Daniel, 2008). Such emergency aid may benefit those selected as recipients, but aid does not always reach the most vulnerable. All the children discussed here can be described as extremely vulnerable; however, only two (Joseph and Lucy) received sustained aid to effectively help them stay in school. In the case of the trafficked girls, eight of nine were under the responsibility of an adult relative, yet in spite of fitting the UNICEF ‘ideal,’ their families did not receive external support.

Contribution of the salutogenic model

What the salutogenic model contributes in this debate is identifying the resources the children themselves use to achieve their goals — as opposed to what international institutions and aid agencies assume they need. The children in rural areas did not have many more resources than the trafficked girls before they moved to Dar es Salaam, yet they not only avoided many of the problematic experiences the trafficked girls had, they also managed to care for themselves and a younger child (for several years in the case of Stella and Joseph). The trafficked girls even recommended that vulnerable children should rather not try to move to town, implying that they themselves would
have been better off if they had remained in the rural area. Two factors that have also been mentioned in other studies partially account for this observed difference: having an asset (in this case, a *shamba*) (cf. Ssewamala, Han & Neilands, 2009; Chowla, Ansong & Masa, 2010) and having access to social support (cf. Cluver, Fincham & Seedat, 2009; Kumakech, Cantor-Graae, Maling & Bajunirwe, 2009).

Besides identifying resources that help children cope and can be supported by government and aid agencies, the salutogenic model also identifies stressors that need to be dealt with. Several of the trafficked girls experienced severe sexual abuse. Mabala (2008) claims that adolescent girls are not safe anywhere in Dar es Salaam and he argues that most have not been prepared to deal with sexual harassment. A recent report by UNICEF (2011) indicates that a third of all girl children in Tanzania have been sexually abused by the time they reach 18 years of age. Although Tanzania has ratified the United Nations Convention on the Rights of the Child, child protection is an area that still needs strengthening.

**Agency in making the best of difficult circumstances**

The agency in the child-headed households in response to their difficult circumstances is clear: they used their labour, knowledge and skills to produce food and to earn cash; they negotiated time off with teachers; they housed, clothed, fed and cared for a younger child; and Joseph planned how to pay for his own secondary school education. These are not things for which they had received external aid under programmes to strengthen families, instead they used their agency, assets and limited social networks to reach these achievements.

Evans (2005), in another study based in Tanzania, emphasises the agency in children's migration strategies as they seek to cope with their life situation after the death of a parent. The decision by the trafficked girls to leave the rural areas were partly motivated by inadequate care by an adult family member. In many cases the caregiver was simply too poor to provide adequate physical and material care. Even when under the care of an adult family member, children may strongly resist decisions made by the adult on their behalf — such as concerning early marriage. In other words, the UNICEF ideal may be harmful to children in some cases.

All the trafficked girls had been deceived or given false promises; they all had to do excessive work; several were not paid or were paid only a pittance; some were raped and physically abused in other ways. In this article, we have used the existence of exploitation to identify the situation as trafficking. The ILO-IPEC (2002) description of what exploitation encompasses includes a number of the experiences the girls in this study lived through, such as physical abuse, confinement and being misled with false promises. Blagbrough (2008) notes that it is this very act of giving false promises that makes the recruitment of children into domestic service a form of trafficking. False promises are usually given by the intermediary who recruits the children, but the employers are often the perpetrators of further exploitation and abuse. It is this exploitation, in both the recruitment and transportation phases, and in the employment and housing of these girls, that leads us to label their experiences as being trafficked.

**Study limitations**

The data presented here came from two studies, which used different methods of collecting information. The sample from the first study (three child-headed households) was very small; other children involved in the first study were living with adults and therefore were not included in the data. However, we believe both these limitations have to some extent been overcome by the fact that both studies involved multiple contact sessions with the informants, producing detailed, in-depth insight into the participants' lived experiences which make a comparison between the studies possible; hence, even a small sample, while not generalisable to all children in Tanzania, can give insight into the phenomenon.

**Conclusions**

UNICEF and other international organisations promote an ideal situation for orphaned children as being one where they are under the care of a responsible adult. This is not always possible. This article explored the challenges and coping strategies of orphaned children from poor rural areas who were living without adult family care. Some of the orphaned children remained in the rural area living in a child-headed household; others chose to migrate to urban areas in the hope of pursuing their education and achieving a better life, but ended up being exploited to the extent that they can be described as having been ‘trafficked.’ The child heads of households did not have many more resources than the trafficked girls had known before they migrated to Dar es Salaam, yet the former group not only avoided many of the problematic experiences that the trafficked girls had, they also managed to care for themselves and a younger child. They had some basic resources (like a *shamba*) and limited social networks to draw on, and through their own agency they were able to use the resources to make the best of difficult circumstances, by producing food, negotiating time off school to harvest or plant, and providing for a younger child in the household. The exploitation that the trafficked girls experienced isolated and deprived them of potential social support and made them entirely dependent on their employer. In spite of their isolation and dependency, they all used what limited resources and social networks were available in order to escape from the exploitative situation.

The challenges faced by orphans and vulnerable children are well known, and while international organisations attempt to help orphaned children by strengthening families, the contribution of the salutogenic model is to identify those resources that children without adequate adult care actually use to cope with hardships they face.

**Recommendations**

Children's agency in coping with the adversity and vulnerability they face should be recognised by both researchers and aid agencies. Insights gained from involving children in research can inform policy and practice. To begin with,
in developing programmes to support orphaned children, there should not be an assumption that all children live with and are cared for by an adult. Next, given the significance of property and land assets in orphaned children’s coping strategies, there should be programmatic support to provide legal aid to protect these assets for children. Finally, the existing Most Vulnerable Children Committees at the ward and village level in Tanzania should be strengthened to provide a chance for children to draw attention to the strategies that work for them and to suggest how their own efforts may be best supported.

Notes

1 Forty-one children participated in three participatory activities, each an hour long, designed to build rapport between the researcher and children as well as to collect background data. The 12 children interviewed were selected from this larger group.

2 Kiota Women’s Health and Development Organisation (KIWOHEDE) aims to prevent girls from getting into child prostitution and hazardous child domestic work; it provides assistance to trafficked persons and promotes good governance.

3 Shamba is the Swahili word for an agricultural field.

4 ‘Sisters’ is used in Swahili to mean girlfriends rather than those born from the same mother.

5 These girls are deemed to have been trafficked because they were all deceived and exploited by the people who facilitated their migration or those who employed them.

Acknowledgements — The authors would like to thank all the children for their participation in the two studies. Angela Mathias would like to thank the Government of Norway through the Lånekassen for granting her a scholarship.

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Children’s caregiving of HIV-infected parents accessing treatment in western Kenya: challenges and coping strategies

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This article describes qualitative research carried out in rural western Kenya in a setting characterised by poverty and high HIV prevalence. It discusses the responsibilities and challenges that children face when becoming the primary caregiver to an HIV-infected parent enrolled in an antiretroviral therapy (ART) programme, and the coping strategies these children adopt to deal with hardship. The research draws attention to the difficulties and opportunities of strengthening home-based care services to facilitate better conditions for children to cope as caregivers. Ethnographic data was collected through a variety of qualitative research methods (in-depth interviews, focus group discussions, drama, diaries and participant observation) during five months of fieldwork in 2009. Informants included caregiving children (ages 6–16 years), HIV-infected parents, community members, school teachers, community health workers, NGO representatives, and other home-based-care stakeholders. The findings reveal that children may play a significant role in the daily healthcare of an HIV-infected parent enrolled in an ART programme. The main responsibilities of the children caring for parents on ART were intimate care and nursing, household duties, and income-generating activities. A number of social factors determine children’s ability to cope with these responsibilities, including the caregiving children’s access to nutritious food, social and emotional support, assistance from community health workers, and adequate healthcare knowledge. The level and consequences of the children’s caregiving activities as well as their ability to cope were heavily influenced by: 1) the dynamics of their parent’s health condition while on antiretroviral (ARV) medication, and 2) the context in which the child sought social and economic resources. There is an urgent need for home-based care services to look holistically at people’s needs and resources at the household level, and, in particular, to consider the hardships and coping strategies of children who live with a parent on ART.

Keywords: community caregiving, HIV/AIDS, home-based care, qualitative research, rural areas, sub-Saharan Africa

Introduction

Increased access to antiretroviral therapy (ART) in sub-Saharan Africa has strengthened, improved and prolonged life for many individuals with HIV infection (Gifford & Groessl, 2002; Wools-Kaloustian, Kimaiyod, Dierod, Sidleb, Yannoutsos & Musicke, 2006; Russell & Seeley, 2010; Campbell, Skovdal, Madanhire, Mugurungi, Gregson & Nyamukapa, 2011), offering renewed hope and reducing stigma (Farmer, Léandre & Mukherjee, 2001; Castro & Farmer, 2005). However, HIV treatment is complex and requires careful adherence to drug regimens and it is crucial for adequate nutritious food to accompany ART since the drugs impede food absorption, metabolism, nutritional distribution and excretion (Loevinsohn & Gillespie, 2003; Gillespie & Kadiyala, 2005). In contexts with inadequate access to nutritious food, ART does not always reach its potential benefits, which at times causes ill health, complications and opportunistic diseases for people living with HIV or AIDS (Gillespie & Kadiyala, 2005). ART adherence can therefore be difficult (Skovdal, Campbell, Nhongo, Nyamukapa & Gregson, 2011), leaving many people vulnerable to either defaulting on their medication schedule (even just temporarily) or to developing drug resistance, which undermines their treatment (Rosen, Fox & Gill, 2007; Bisson, Rowh, Weinstein, Gaolathe, Frank & Gross, 2008). Based on a study in rural Uganda, Russell, Seeley, Ezati, Wamai, Were & Bunnell (2007) state that the needs of HIV-infected individuals goes beyond medication, but that ART programmes must incorporate economic and social interventions that support the rebuilding of people’s lives (Russell et al., 2007; Russell & Seeley, 2010). So while the introduction of ART is a positive development — evidently strengthening lives and increasingly seen as making HIV a manageable and chronic illness (Russell et al., 2007) — it continues to require the participation of household members in caregiving for the individual living with HIV, especially in resource-limited contexts. Most of the previous research recognising the complexities of people’s life while taking ART (e.g. Rosen et al., 2007; Russell et al., 2007; Russell & Seeley, 2010) has focused on the situation of the HIV-infected individual. This study investigates similar complexities, but from the perspective of children involved as caregivers to parents on ART.

In remote rural areas of sub-Saharan Africa, healthcare facilities are often inaccessible to HIV-infected individuals...
due to lack of money for transportation and hospital fees; hence, family members frequently contribute to the daily responsibility of caregiving (Olang’o, Nyamongo & Aagaard-Hansen, 2010). In sub-Saharan Africa women have commonly carried out the responsibilities of home-based caregiving (Müller, 2005; Du Preez & Niehof, 2008). However, when adult female family members and external healthcare support are unavailable or limited, it is often a child in the household who takes on the daily role of primary caregiver. This group of children have been referred to as ‘caregiving children’ or ‘young carers’ and they are a subject of growing interest among researchers (cf. Becker, Aldridge & Dearden, 1998; Robson, 2000, 2001 and 2004; Robson, Ansell, Huber, Gould & Blerk, 2006; Becker, 2007; Dahlblom, 2009; Evans & Becker, 2009; Evans & Thomas, 2009; Skovdal & Ogutu, 2009; Skovdal, 2009 and 2010; Skovdal, Ogutu, Aoro & Campbell, 2009; Skovdal & Andreouli, 2011; Zhang, Li, Kaljee, Fang, Lin, Zhao et al., 2009).

Previous studies have identified the main responsibilities of caregiving children as intimate care and nursing, caring for siblings, taking on household responsibilities and income-generating activities (Bauman, Foster, Silver, Barman, Gamble & Muchaneta, 2006; Robson et al., 2006; Dahlblom, 2009; Skovdal & Ogutu, 2009; Skovdal, 2009 and 2010; Skovdal et al., 2009). Some researchers have further acknowledged how caregiving children’s ability to cope is influenced by their access to social resources and economic resources (i.e. Wolkow & Ferguson, 2001; Evans, 2005; Skovdal et al., 2009). More specifically, in previous research by Skovdal et al. (2009) in Bondo district in western Kenya, caregiving children were found to be coping through: 1) engagement in income-generating activities, 2) by mobilising social support, and 3) by constructing positive social identities around their caring role. Skovdal et al. (2009) emphasise that children’s ability to cope is influenced by access to local support networks and resources, the community’s ability to share resources, and the children’s ability to participate in community life and negotiate support from it. The research presented here was also carried out in rural western Kenya; however, while the research by Skovdal et al. (2009) investigated young carers more generally (i.e. children caring for the elderly, the disabled, or ailing parents or siblings), this study focused on children’s experiences of caring for an HIV-infected parent enrolled in an ART programme.

The article describes the experiences of children, who in contexts of poverty, play a key role in managing the treatment and care of a sick parent on ART, as well as how they strive to sustain the household and maintain their own wellbeing. This study explored whether the findings of previous research on the coping strategies of caregiving children (e.g. Wolkow & Ferguson, 2001; Evans, 2005; Evans & Becker, 2009; Skovdal et al., 2009) are relevant to children who care for an HIV-infected parent on ART, and/or whether additional coping strategies are adopted by this group of children in the context of ART availability.

This article highlights the strategies that children adopt in order to cope with the hardship they face when becoming a primary caregiver to an HIV-infected parent on ART. The study contributes to an understanding of how children experience a parent’s HIV-related illness and treatment, and thereby provides insight into how home-based care and ART programmes can help caregiving children cope in contexts of HIV/AIDS and poverty.

Methods

Study area

The research was conducted during five months of anthropological fieldwork in rural Bondo district, western Kenya. It was approved by the National Council for Science and Technology (Kenya) and carried out with affiliation to Maseno University and the Nyang’oma research training site, as well as the DBL Centre for Health Research and Development (Copenhagen, Denmark).

Bondo district is located in Nyanza Province, in rural western Kenya, near the shores of Lake Victoria and is inhabited by the Luo ethnic community (Olang’o et al., 2010). While overall HIV prevalence in Kenya has declined to 7.4%, HIV prevalence in Nyanza Province remains high at 15.3% (National AIDS and STI Control Programme, 2008). People living with HIV in Bondo district are able to collect free ARV medication from their local health clinic monthly. The majority of the population living in poverty rely on fishing and/or subsistence farming; however, recurring drought brings increased hardship to an already economically vulnerable population (Olang’o et al., 2010).

Sampling and data collection

The research was conducted among a sample of 10 HIV-affected households, which were closely followed for a period of five months in 2009. Key informants included 20 caregiving child (ages 6–16) and 11 HIV-infected parents enrolled in an ART programme. The households and caregiving children were identified by local community health workers according to the following criteria: a household where one or both parents were HIV-positive and on ART, and where a child was involved in the caregiving activities. Of the 10 selected households, all HIV-infected parents were enrolled in an ART programme and collected their ARV medication monthly from a local health clinic. At the time of the research, the parent in one household had disclosed her HIV-positive status, and the parents in the remaining households were concealing their HIV status from their children. Despite a lack of openness regarding the parents’ HIV status, most of the children were engaged in several caregiving activities either directly or indirectly related to their parents’ HIV-related illness and treatment.

Nine of the children were above the age of 11 years old and therefore were assumed to be able to think reflectively (see Piaget, 1929), thus they could participate more actively in the semi-structured in-depth interviews, focus group discussions, participant observation and drama (see Seal, 2004). Furthermore, inspired by Horsdal’s (1999) ‘narrative life-stories caregiving,’ the children above age 11 were asked to describe their life stories in written diaries, with a focus on possible differences in their lives before their parent became sick, their life while caregiving for their sick parent, and their life after the parent’s health had improved.
once treatment had commenced. Skovdal et al. (2009) and Evans & Becker (2009) suggest excluding children below the age of 9 because they are less likely to participate in ‘heavy’ caregiving activities and are also more difficult to include in standard research techniques. However, this study included children as young as 6 years old, through informal interviews and participant observation, in order to understand the caregiving responsibilities carried out even at a very early age. Since the children responded differently according to each method used, applying a variety of methods was an advantage because each method could reveal different perspectives from different children.

A key challenge in conducting the study pertained to parents’ lack of HIV-status disclosure. In nine of the 10 households, the parent had not had disclosed to their child — primarily to protect the child from the trauma of prematurely feeling orphaned. To respect the parents’ wishes to keep their HIV-positive status secret, the topic guide was devised so that a parent’s HIV status would not be revealed, and the purpose of the research was carefully explained to match the age of the child. For instance, the children were told that the purpose of the study was to learn about their everyday experiences and their specific experiences when helping a sick parent. Informed-consent forms were obtained from all the child participants as well as from their parent for those below the age of 18 years.

**Participant observation**

Participant observation was carried out with the children on a regular basis — during the course of the children’s daily activities and duties in their homes. Participant observation enables an intense involvement with people in their natural environment over an extended period, and, as Barth (1980) states, by participating one can gain trust and begin to understand the world from the informant’s point of view. For example, participant observation occurred during activities such as fetching water from the lake, fishing, building a hut, cooking, plaiting ropes to sell, cutting down trees for charcoal burning, searching for vegetables in the bush, and working in the maize field. Participating in these activities emphasised the physical impact of the activities as well as the psychological, economic, and social pressure that the children experienced by being responsible for generating income and finding food to sustain the family, nursing a sick parent, and performing household duties while also having to attend school.

Participant observation was an inevitable method to use to build a solid relationship with the children and thus to gain access to their life worlds. It allowed an informal means for the children to share their thoughts and experiences while engaging in the activities. Furthermore, it rendered visible and revealed new information that did not come up in the interviews, and it intensified my understanding of the problems the children faced as caregivers.

**Drama**

Towards the end of the fieldwork, the group of caregiving children, on their own initiative, prepared a 30-minute play for me as a surprise, wherein they played out their experiences as caregivers. Interestingly, during all the previous in-depth interviews, the stigma attached to HIV was very noticeable, in the sense that the children rarely mentioned HIV directly when talking about their parent’s illness. However, during the drama they felt more comfortable talking about HIV-related issues. It appeared as if the role-play gave them an opportunity to act out, unrestrained, even the most sensitive challenges involved in taking care of a parent with HIV.

**Examination of context**

To gain information about the context in which the caregiving children were living, as well as to understand the local perceptions of childhood, semi-structured interviews (see Seal, 2004) were carried out with members of the community, village elders, school teachers and school principals. Finally, in order to examine the structures, practices and challenges of implementing home-based care at a community level, in-depth interviews were carried out with 10 representatives from NGOs operating in the district as well as with representatives from the Ministry of Health and the Children’s Office. Group discussions, workshops and in-depth interviews were carried out with 50 community health workers and members of the local community. All data were collected with the support of two local research assistants who interpreted the local Dholuo language, and transcribed and translated the data into English. In order to accentuate the children’s experiences and voices, this article draws closely on this empirical data and includes excerpts from field notes and in-depth interviews.

**Data analysis**

The data analysis followed Emerson’s (1995) five phases of analysis: reading, open coding, focused coding, initial memos, and integrative memos. After reading through the transcribed data and field notes, the data were first coded into broad, open thematic categories: ‘responsibilities of caregivers for parents on ART,’ ‘challenges as caregivers for parents on ART’ and ‘coping as caregivers for parents on ART.’ Second, the data were gradually more narrowly coded into sub-themes arising from the data. A similar coding process was carried out for themes regarding home-based care.

**Findings**

Corroborating the findings of previous research (see Becker et al., 1998; Robson, 2000, 2001 and 2004; Becker, 2007; Evans & Becker, 2009; Evans & Thomas, 2009; Skovdal & Ogutu, 2009; Skovdal, 2009 and 2010), this study recognises the diverse challenges that children face when becoming caregivers. As evident in the life circumstances of Julie (a pseudonym) — a caregiving child living in an HIV-affected household in rural Bondo district (see Box 1) — throughout this study it has been clear that when parents fall sick and external support is limited, children tend to actively take over responsibility for all household duties, such as looking after siblings, providing close care and nursing for their ailing parents, and taking on an active role in generating income and finding food to sustain the entire household. These activities are often carried out
Box 1: The case of Julie — a caregiving child in an HIV-affected household in rural Bondo district, western Kenya

Julie is 14 years old and lives in a rural area of Bondo district with her mother, Michel, and her two younger sisters, Gabriella and Elisabeth (ages 6 and 10, respectively). Michel, Gabriella and Elisabeth are all infected with HIV. Fortunately, Julie is not infected.

When Julie was 10 years old, her mother and father fell seriously ill and spent nearly a year continuously bedridden and going in and out of the hospital. They both lost a great deal of weight. During this time Julie provided close care for both her mother and father, carried out most of the household duties, and looked after her two younger sisters. In order to get money for living essentials, such as food, medicine and school fees, Julie sold firewood and ropes at the market. These activities were time-consuming and at times prevented her from attending school.

After Julie’s father died in 2006, Michel, Gabriela and Elizabeth tested HIV-positive and were started on antiretroviral treatment (ART). Shortly afterwards, Michel gained weight and strengthened greatly, which allowed her to engage in the functioning of the household again and look after her children. Julie was then able to return to school.

Although Michel is still on ART it is always a challenge for the family to get enough food. At times Michel will suddenly fall sick, for days or weeks at a time, and then the children must stay home from school to nurse her, take over responsibilities in the home, and engage in income-generating activities to ensure that their basic needs are met.

by children aged between 6 and 16 years old. Generally the oldest child of the household carries out the heaviest duties; however, children of all ages tend to participate. These caregiving activities continue for different lengths of time and with different intensity, according to the circumstances of the parents’ health, whether the parents recover or die, and depending on the economic and social assistance accessible for caregiving children, for example. The caregiving children in this study had been caring for a sick parent at different levels and for different periods of time, varying from a few days to several years.

Correlation between a child’s caregiving activities and a parent’s health condition on ART

Although these activities and the lives of caregiving children at times mirror the lives of other children, it is significant to acknowledge how this group of children differs. Evans & Becker (2009) distinguish between children with light responsibilities and caregiving children with heavy and time-consuming responsibilities. Building on their notion, this study observed how caregiving children’s responsibilities change in line with their parents’ health condition after commencing ART. As stated, in sub-Saharan Africa, many HIV-infected individuals on ART face challenges in sustaining a nutritious diet, which inevitably results in instability of their health and wellbeing. Accordingly, there was a noticeable pattern throughout the research wherein the parents at times felt severely ill and were forced to be bedridden, while at other times they regained their strength. This instability of parents’ health is then reflected in their children’s caring activities.

Cross-culturally (that is, in almost all societies) the family unit been an institution for caregiving (Jan-Le Bris, 1993), while the kind of caring activities expected of family members is specifically and culturally defined and varies between contexts (Tronto, 1993). In Bondo district, the Luo social structure is based on a patrilineal lineage structure and polygyny, and has gender-based norms of care work where females are predominantly responsible for caretaking (Mboya, 1965). From interviews with community members, there was a consensus of expecting children to contribute an extra helping hand as a part of their development to learn skills that would prepare them for adult life. The caregiving children in this study have been distinctive in the sense that their activities would at times go beyond what is normally expected of children in their local context among the Luo tribe. Rather than just learning skills and contributing as an extra helping hand, when parents become bedridden the children often assumed responsibility for the continued functioning of the entire household. Viewing the household from the outside during periods where parents are strong, it may appear as a normal functioning family where the parent is taking care of the child. In light of the introduction of ART, HIV-affected households have unquestionably undergone remarkably visible improvements. However, it is crucial to acknowledge that if ART is not accompanied with adequate access to nutritious food, it can cause instability of the parents’ health, and consequently influence the roles and responsibilities of the other household members. Hence, during times where parents are weak and bedridden, the roles between parent and child might become reversed as the child becomes the caretaker as well as functions as the head of household.

Thus, children face numerous challenges when living with an HIV-infected parent in a context of poverty, include providing adequate care for their parent, taking over household duties, assuming care for younger siblings, and engaging in income-generating activities to ensure that the basic need for food and other necessities is met for the whole family — while at the same time they may endeavour to attend school. These findings mirror the circumstances for caregivers in other contexts (see Becker et al., 1998; Robson, 2000, 2001 and 2004; Robson et al., 2006; Becker, 2007; Dahiblem, 2009; Evans & Becker, 2009; Evans & Thomas, 2009; Skovdal & Ogutu, 2009; Skovdal, 2009 and 2010; Skovdal et al., 2009; Zhang et al., 2009). Among children caring for parents enrolled in an ART programme, it is especially important to recognise how the fluctuating dynamics of the parent’s health becomes reflected in the child’s caregiving activities; therefore, during periods when the parent’s condition has strengthened, the vulnerability of the caregiving child may be hidden.
The majority of children in this study experienced occasional long periods when their parents were thriving due to their enrolment in an ART programme. During these periods, the children would be relieved of intimate nursing activities and their engagement in household duties and income-generating activities lightened since their parents were now able to participate. These changes within the household frequently enabled the child to return to school. But, despite visible improvements, most of the children expressed a constant concern for their parent’s illness:

‘When she [mother] feels better, things are good, and we can return to school. But it is always there in the back of your mind, because you have the memories of what it used to be. So every day when you return from school, you are afraid that her lying on the floor again’ (in-depth interview with John, age 13).

Evidently, a child’s concerns about a parent’s health remained even during periods when the parent seemed to thrive and the circumstances within the household had changed for the better. Hence, it is important to recognise the dynamics of parents’ health while on ART, and likewise to acknowledge their children’s vulnerability and the emotional impact it has on them even during times of recovery.

**Children’s coping as caregivers**

Importantly, all the children in the study responded actively to the adversity and hardships they faced as caregivers. The conditions under which each child coped as a caregiver were influenced by the broader structures of society, such as socioeconomic circumstances, environmental challenges (e.g. drought) and health systems (e.g. implementation of home-based care programmes). However, rather than perceiving children as passive entities in the broad structural context in which they live, children’s agency as social actors should be recognised (James, Jenkins & Prout, 1998), as they indeed navigate within their given context, draw on the resources available to them, and respond actively to specific adversities. Remarkably, despite living under circumstances of extreme poverty and enduring heavy burdens of caregiving at times, each child in this study was able and willing to navigate the resources available to them — making the most out of difficult situations and finding different ways to cope with their circumstances as caregivers.

Following the mobilisation of urban youths in Guinea Bissau, Vigh (2006) used the concept of social navigation to analyse the way in which youths steer their lives in positive directions despite living in circumstances of political instability and poverty. The concept of social navigation can be used to examine the complex interaction between individual action and social forces, and the interplay between objective (or contextual) structures and subjective agency (Vigh, 2006). Elaborating on the concept of social navigation is therefore useful to analyse the ways that children navigate the social, symbolic, and economic capital available to them in their attempts to cope as caregivers.

*Navigating for social, symbolic and economic support*

Corroborating the findings of previous research, access to social resources had an influential impact on children’s resilience and coping abilities (cf. Wolkow & Ferguson, 2001; Evans, 2005). Skovdal et al. (2009) similarly found that children mobilised social support and the resources to cope while caring for a parent on ART. Members of the nuclear family, extended family members, community members, church members, friends and peers played an invaluable role in alleviating children’s burdens as caregivers, by providing economic assistance, food, encouragement and emotional support. The children in this study regularly navigated their own social networks, seeking social and economic support, as evident from in-depth interviews:

‘When she [mother] is sick I walk to my aunt; she sometimes has extra flour. But at days when she has not, I can go to Lillian [community health worker]; she has helped me with food and even water’ (Julie, age 14).

‘If I go to class and I am not feeling well, I go and tell my friends if they could have some little money, then they can contribute and give me [some] to go to the hospital with mum. We also share things that only friends share. That is how we do it in school’ (Sharon, age 13).

The school recurrently seemed to play a significant role in the lives of the caregiving children. First, providing a place for meeting their classmates and friends, the school created a forum for social networks, comfort, belongingness to a community and stability in caregiving children’s lives. Second, since the children perceived the school as a place where opportunities where given, the schools gave children hope for a better future. Previous studies in East Africa have demonstrated the significant meaning attached to school (e.g. Inkeles, 1974; Serpell, 1993; Katahoire, 1998; Stambach, 2000; Meinert, 2001). As Meinert (2001) emphasises from work in Uganda, schooling reflects values and aim at imparting versions of ‘a good life.’ Conceptually, in this study, there was a tendency for the children to express narratives that placed school attendance and school absence as two contrasting dimensions, which could lead them to contrasting future lives. There was consensus among the children who perceived school as a place for hope, dreams, and opportunities for a better future, and so a means to avoid future adversity like diseases and poverty.

*Engagement in subsistence farming and income-generating activities*

In order to sustain food for the household, the children grew vegetables on their *shamba* (a small piece of land used for subsistence farming), and when the household could produce more than they consumed, they would sell the ‘surplus’ on the market to gain income. It was clear through these activities that the children had gained useful knowledge and skills for subsistence farming and small-scale business. Those children with access to domestic animals were all able to use them to generate food and income as exemplified by a quote from a focus group discussion:

‘The donkey is good. With our donkey I can collect water to sell, or firewood...the chickens we can eat, or sell at the market if we need paraffin or medicine for mum.’
Finally, the children engaged in different forms of income-generating activities to meet their basic needs and pay for medicine and school fees. These activities included fishing, collecting water to sell, washing people’s dirty clothes by the lake, and selling charcoal or ropes. Thus, in line with previous research (Wolkow & Ferguson, 2001; Evans, 2005; Skovdal et al., 2009), it was clear that for a child caring for an HIV-infected parent on ART, access to social and economic resources was crucial for better coping with their challenges as a caregiver. Importantly, rather than passively wait for assistance, each of the children in this study actively navigated their social networks to reach out for economic resources: they approached components of their social network for assistance, actively took over the responsibilities of household duties and intimate caring, and engaged in income-generating activities. This active response to adversity must be acknowledged, understood and supported adequately; I argue that if it is not, children’s own safety and wellbeing could be compromised in their attempts to cope as caregivers.

**Motivation and reasons behind the children’s coping strategies**

To better understand caregiving children’s active response to adversity, this section draws attention to the underlying motivation behind their caring activities. Faith, positive meanings attached to caregiving, emotional attachments, and reciprocity appeared to be strong motivating factors making the children actively respond to their troubles instead of passively waiting for assistance.

**Faith and a positive meaning attached to caregiving**

Reflecting on the meanings attached to caregiving, Skovdal & Andreouli (2011) urge a move away from a focus on trauma, risk and vulnerability among caregiving children (e.g. Robson, 2001; Bauman et al., 2006) towards recognition of the social resources that enable caregiving children to ascribe more positive meanings to their circumstances, thereby helping them cope. Hence, those children who were able to draw on positive aspects of caregiving, and so construct positive caregiving identities, were better equipped at coping psychosocially (cf. Skovdal & Ogutu, 2009; Skovdal et al., 2009). Although this finding is routed in an effort to understand children’s way of coping, it is simultaneously relevant to explain the underlying reasons and motivation behind many children’s engagement as caregivers. Luo anthropologists have characterised the traditional Luo community as egalitarian, with its strong kinship bonds an essential part of society and crucial for survival during crises such as periods of food insecurity and sickness (Whisson, 1964; Mboya, 1965; Cohen & Atieno-Odhiambo, 1989; Nyambedha, 2004). The notion of *jochny* (‘people with a good heart’) was used when people helped one another (see Mboya, 1965). These traditional perceptions of good behaviour were still apparent in this study. Cultural ways of valuing caregiving as ‘good behaviour,’ can, as Skovdal & Andreouli (2011) advocate, help children construct positive caregiving identities and thereby help them cope; these same perceptions can also provide children with strong encouragement and a rationale to willingly engage in caregiving. Furthermore, faith commonly enabled the children in this study to perceive their caregiving positively; it made caring meaningful and the children received blessings for their caring activities. For example, 13-year-old John wrote this in his life-story narrative:

‘After taking care of the sick, I now know that I have a lot of God’s blessings, because if I didn’t look after the patient then he would have died. When you are caring for the sick, you might sometimes look after him until he feels much better, or he can pass away according to God’s plan. When you care for the sick person and he gets well, he will thank you, and through that you will know that you will have been showered with a lot of blessings for the kind of work that you have done as a good child. You will have gotten God’s blessings from looking after the sick.’

Having faith in God gave the children in this study the confidence that God is always by their side — offering them a sense of security and an explanation that their parents’ health was determined by God’s plan. In narratives, children often referred to God as a way of creating a purpose and meaning for their roles as caregivers. Thus, maintaining faith in God and a capacity to perceive caregiving positively seemed to be useful ways for the children to cope as well as provide reasoning and motivation for their engagement in caring activities.

**Emotional attachments and reciprocity**

Several researchers have characterised the relationships between sick parents and their children as reciprocal and interdependent, wherein parent and child alternately help one another with household duties, intimate caring, generating income and giving emotional support (Becker & Silburn, 1999; Evans & Thomas, 2009). As Tronto (1993) states, the practices of care are based on interdependence and interconnectedness between caregiver and care-receiver. In addition, caregiving usually leads to the development of close emotional bonds between carer and patient, as demonstrated in a comparative study in Namibia, Tanzania and the United Kingdom (Evans & Becker, 2009). Generally, caregivers perceive their care work as a natural part of their love, moral duty and reciprocal responsibilities towards their family (Evans & Becker, 2009). In contrast to professional healthcare, informal care is founded on love, attachment and reciprocity, as evident in a statement by 14-year-old Julie from an in-depth interview:

‘When your mum is sick, there is no way you can leave her because she is the one who gave birth to you. She loves you and you love her. You will even go to the neighbour just to get her drinking water. Sometimes when you want to take her outside for fresh air, you may not be able to because she is too heavy for you. But you want to...I go to her [mother] if I have problems. Even when she is sick she still comforts me.’

As evident in Julie’s example, emotional attachment and reciprocal comfort helped her cope emotionally. In contrast, 13-year-old John did not experience the same comfort from nursing his sick father:
‘My dad used to be very harsh and he could beat me without reason before he fell sick. So afterwards when I looked at him on the sick bed with memories of how he used to behave, it made me upset. Still I cared for him, because after all he was my dad and he needed me, so that is what I should do. He also gave me fish when I was little.’

Despite differences in parental behaviour, it was clear that all the children’s engagement in caregiving was founded on reciprocity and strong family bonds; in most cases this strengthened emotional attachments from which the child could derive emotional comfort despite a parent’s illness.

Whereas previous researchers (Evans & Becker, 2009; Skovdal & Ogutu, 2009) have highlighted these as ways of coping, the point emphasised here is that besides coping, aspects such as faith and positive meanings as well as attachments based on love, kinship obligations, and reciprocity are also key factors driving children to carry out their caregiving activities. Hence, paying attention to children’s underlying reasons for engaging in caregiving activities can help us understand not only how they coped, but also why they actively responded when faced with adversity. If the context in which they navigate does not facilitate adequate social and economic support, these same coping strategies may drive the children towards activities that compromise their own safety and wellbeing.

The challenges and potential consequences of coping strategies

Even marginal differences in the children’s access to support can have a major impact on whether their active response to adversity enables them to cope or compromise their own safety and wellbeing. Meinert (2001) relevantly states that family healthcare is often a compromise between the right thing to do in a given situation and what the family actually has the competence and resources to do. Hence, some caregiving children in this study were at times conflicted by knowing what they should do and what they could do. Although the children were usually fully aware of what was needed for their ailing parents and the entire household, and although they were usually fully capable of navigating around the social and economic resources available to them in order meet these needs and fulfil their roles as caregivers — at times, their access to support was so limited that coping was exceedingly difficult. With reference to Tronto’s (1998) words in his contextual approach to care: the caregiver’s ability to provide ‘good care’ is determined by contextual social and economic resources. Accordingly, the children’s ability to provide care and cope as caregivers were determined by the context in which they navigated for social and economic resources, which varied from child to child and also over time for each child.

Although the caregiving children in this study lived with similar circumstances, there was a marginal, but influential, asymmetrical difference between their access to social and economic resources, which influenced their coping. In short, two main components determined the degree and consequences of children’s caring activities, as observed in this study: first, the parents’ health condition on ART, and, second, the context in which the children navigated for social and economic resources. As argued, both components were dynamic and changed throughout time — inevitably making the role of a child caring for a parent on ART more complex and not always apparent. This is exemplified in several cases, discussed below.

In one household visited, an HIV-infected widow, Isabella, lived alone with her four children and regularly received money sent by her brother who worked in Nairobi. This assistance greatly helped provide for the basic needs of everyone in the household as well as financed Isabella’s occasional hospital visits. When Isabella was bedridden, her children would go to their other two uncles who lived nearby and who would give them fruit and vegetables. These four children still carried out household duties and intimate caring for their mother while their engagement in income-generating activities was very limited.

In other households visited, the children received little support from relatives and social networks: some relatives were struggling with the burdens of HIV and poverty themselves and were not able to assist, and others had passed away. In these households the children regularly engaged in various income-generating activities, such as selling firewood and ropes, fishing in Lake Victoria, or working on other people’s shamba. Furthermore, several of the girls, as young as 13 years old, were regularly exposed to transactional sex in their endeavours to support their households. In an in-depth interview, 13-year-old Sophie explained:

‘The girl just thought of how her siblings were going to spend the night with an empty stomach and she decided that it was better to sell her body and get money for food, rather than her siblings to go hungry. She was a girl in Class 5.’

Inevitably, income-generating activities can be heavy, time-consuming and compromise the health, safety and wellbeing of children (Dunkle, Jewkes, Brown, Gray, McIntyre & Harlow, 2004; Seeley & Allison, 2005; Evans & Becker, 2009). Even marginal differences in children’s access to support can have a major impact on whether their active response to adversity enables them to cope or compromises their own safety and wellbeing. This becomes apparent in a quote from an interview with 14-year-old Julie:

‘Usually my aunt can help us with food when we need. But that day she was had none left herself. After my aunt was unable to give us food, I continued walking through the bush. I knew my siblings were hungry and so was I. I knew I could sell my body and get food and even water. But I did not want to be that kind of girl.’

It is clear that Julie disassociates herself from transactional sex. Yet when no other support was available, it seemingly became her only way of ensuring food for the household. When heavy engagement in income-generating activities becomes too time-consuming, it can have a strong impact on children’s ability to attend school (Kelly, 2005; Robson & Kanyanta, 2007; Evans & Becker, 2009). In a focus group discussion, 12-year-old Sharon explained:

‘Sometimes even getting food is a problem. This will now force you to miss school and fetch for firewood, take them to Bondo to sell, then is when you can
be able to buy food.... I used to go and look for food and I bring it home. If I came back home early enough from fending, then I would go to school, but if I come back late, then I miss out on school.... When in school you even think of how you still will be going home hungry without food. Because you never ate supper, never took breakfast in the morning, and also did not eat lunch. This makes you to think about home a lot even when taking your exams.'

Some of the children’s engagement in income-generating activities at times reached a level matching the International Labour Organization’s (ILO) definition of child labour: work that is mentally, physically, socially or morally dangerous and harmful to children, and interferes with their schooling by depriving them of the opportunity to attend school, obliging them to leave school prematurely or requiring them to attempt to combine school attendance with excessively long and heavy work (see International Labour Organization, 2011).

The burden of domestic work varied according to individual circumstances such as parents’ strength and the composition of the household. Children’s participation in household duties and domestic work that does not affect their own health, personal development or schooling, is generally regarded positively since these activities contribute to children’s development, improve the welfare of their families, provide them with skills and experiences that prepare them to be productive members of society during their adult life (International Labour Organization, 2011). However, when parents become sick and bedridden, normal household duties become heavier and more time-consuming and must be combined with the tasks of intimate nursing and care. If limited or no social support is available, then these activities can reach a level where the children, rather than just learning skills and contributing as an extra helping hand, become responsible for the functioning of the entire household, which is likely to affect their school attendance and performance and/or compromise their safety and wellbeing.

In only one of 10 households visited, a parent had disclosed her HIV-positive status to her children, which enabled open communication between the family members. The HIV-infected mother advised her own children how to nurse her carefully and how to avoid HIV transmission, and at times they helped manage her treatment by reminding her to take her medication. All the other households visited were still highly stigmatised. In these households the children interviewed talked openly about other occurring diseases, such as TB, herpes and malaria, while they avoided talking directly about HIV and AIDS. They spoke openly about how their parents frequently suffered from headaches, fever, coughing, fatigue, weakness and diarrhoea and were unable to walk, but they rarely linked these symptoms directly to HIV-related illness. However, once, when fetching water with 13-year-old Emma, she explained:

‘I do not know if my mother is HIV-positive. But I think she is. I see her take medicine every day. Then I go and get her food because I know she needs it.... When she takes the medicine without food she gets weak. One day she even fainted.... I wash her in the morning.’

Despite the lack of open communication about their parents’ HIV status, the majority of the children actively engaged in HIV-related caring activities and were aware of the consequences and needs of their parents as a result of ART. However, HIV stigma impeded open communication and guidance on how to handle an HIV-infected person and avoid the risk of transmission. None of the children in this study had any special equipment or gloves when providing intimate care for sick parents. Despite the challenging circumstances and a lack of protective equipment and healthcare knowledge, all the children engaged in intimate nursing of their sick parents, which inevitably compromised their safety.

The social and material context in which children navigate influences their ability to cope. All the children in this study actively responded to adversity, approached their responsibilities with courage, showed initiative, and they capably and willingly navigated the social and economic resources available to them. When the context provided adequate conditions for open communication as well as social and economic support, the children drew on these and coped extraordinary well. However, those children unable to access adequate support were at times driven into activities that compromised their safety and wellbeing, or impacted their school attendance and performance.

Discussion

How can we facilitate better conditions for children to cope with adversity as caregivers in the context of HIV? To begin with, the role that children play in the daily healthcare of an HIV-infected parent enrolled in an ART programme must be acknowledged and attention given to how their responsibilities may play out in the given cultural context. Additionally, it must be recognised how a caregiving child’s responsibilities will be influenced by the dynamics of the parent’s health condition on ART. Next, children should be acknowledged as capable, enterprising social actors who tend to actively respond to emerging adversity once they become caregivers for a parent with HIV-related illness. As this article emphasises, children’s ability to actively respond to hardship by navigating their local context and drawing on available social and economic resources is invaluable in enabling many children cope throughout difficult circumstances. Furthermore, looking more closely at the underlying reasons behind their activities can help us understand not only how caregiving children cope, but also why they are able to respond so actively to adverse challenges. Lastly, it is important to note that if a child’s context does not provide adequate economic and social support, their strategies to cope might lead them into activities that compromise their safety and wellbeing.

In agreement with James (2007), the diversity of the caregiving children in this study demonstrates the importance of not labelling these children in one category, but rather calling attention to the multiplicity of children’s circumstances and experiences. This is best achieved by listening closely to children and seeing them as social
actors. Accordingly, although the children participating in this study all lived in similar circumstances, caring for an HIV-infected parent in impoverished conditions, even marginal differences in the context in which they navigated seemed to impact their individual abilities to cope. These circumstances differed from child to child, from household to household, and over time.

A way of strengthening a supporting context for children to cope as caregivers is through home-based care. Home-based care services are currently carried out throughout Kenya with the purpose of ensuring healthcare for HIV-infected/affected persons (National AIDS and STI Control Programme, 2011; World Health Organization, 2011). Various NGOs are involved in the local implementation of home-based care, providing services like healthcare education and equipment. ART is widely distributed throughout Kenya, making treatment increasingly available for people living with HIV. Daily healthcare is based on unpaid volunteer participation by family members as caregivers and from community health workers who volunteer in the local community. Home-based care services have the potential to strengthen communities’ capacity to deliver comprehensive support for HIV-infected individuals in their homes and thereby alleviate the daily responsibility of caregiving children. However, in this study, home-based care services tended to be asymmetrically distributed among HIV-affected households. Although NGOs provided kits with healthcare supplies, such as soap, gloves, nutrition and medicine, these appeared inconsistently distributed between households. Furthermore, there was inconsistency in the number of visits made to different households by community health workers. Some households were visited every week while others might wait one month or more without receiving a visit. This inconsistency was partly due to logistic problems, since not all community health workers had access to a bicycle and so reached fewer households per day.

Given these observations, future research might examine the relationship between community health workers and the children of HIV-infected community members. For instance, a recent study by Olang’o et al. (2010) observed an attrition rate of 33% among community health workers in Bondo district. Although these are just a few examples, due to a lack of resources and poor coordination between stakeholders, this research found that home-based care services were inadequately implemented and asymmetrically delivered to households affected by HIV.

Enhancing the coordination of home-based care workers and strengthening the supply of resources would improve the effectiveness of community health services. Regular visits from community health workers and better supplies would create a far more supportive context in which caregiving children navigate as they seek resources and support.

Previous research by Robson (2004) has pointed out how home-based care implicitly places responsibility in the home and increases children’s unpaid care work within the family. Evans & Becker (2009) state that some policies endorse family members as the dominant healthcare providers through home-based care. I suggest that situations where home-based care services are not adequately implemented, masks and reinforces the healthcare responsibility carried out on a daily basis by children. At the same time, the availability of home-based care services indeed has the potential to alleviate pressure on caregiving children.

Conclusions

In several ways, the findings corroborate previous research on children’s caregiving — especially how children manage to provide nursing care for a guardian while they take over household responsibilities and contribute to the economic survival of their household (see Donald & Claherty, 2005; Abebe & Aase, 2007; Skovdal et al., 2009). This anthropological research provides insight into the life worlds of 10 HIV-affected households by focusing on the challenges arising for children caring for an HIV-infected parent on ART, the children’s caring responsibilities, and the strategies they use to cope. It is hoped that the insights gained from this study can contribute to an understanding of children living under similar circumstances in other areas of rural sub-Saharan Africa.

Although the findings resonate with those of Skovdal et al. (2009) (particularly with regard to children’s engagement in income-generating activities, their mobilisation of social support and the construction of positive social identities as a way of coping with hardship), this article has examined the nuances of the challenges and coping strategies of children caring for a parent on ART. Two dynamic components appeared to determine the degree and consequences of the children’s caring activities as well as their ability to cope: 1) their parents’ health condition while on ART, and 2) the context in which the children sought social and economic resources.

This article has emphasised how the activities of caregiving children tend to change in line with their parent’s changing health condition when enrolled in an ART programme (oftentimes without adequate access to nutritious food). The findings illustrate that the mutual roles between parent and child may reverse: when parents fall sick, children tend to take on active responsibility for household duties, intimate caring, and income-generating activities — while drawing on resources available to them in order to cope. Emotional attachments, reciprocity, faith, and the meaning attached to caregiving all helped the children perceive their role positively and thereby cope better psychologically. Additionally, the findings can help us understand why children respond actively when facing adversity as caregivers. Individual circumstances and even minor differences in access to resources can influence a child’s capacity to cope and sustain a household during periods of a parent’s ill health. If the social context in which children navigate does not facilitate economic and social support, then children’s endeavours to cope could drive them into activities that compromise their health and safety.

This issue can be addressed through two approaches. First, attention must be given to caregiving children’s coping strategies and their strengths, ability, and willingness to respond to adversity when they become caregivers for an HIV-infected parent. Second, the given social context in
which caregiving children navigate must be understood. Initiatives targeting these areas could be a good starting point to strengthen home-based care services and ART programmes, and enhance the social and economic resources for children to draw on in their endeavours as caregivers to a parent with HIV.

Acknowledgements — I thank all the children and their families who invited me into their lives and participated in this study. I am grateful to Paul Akello and Carole Jim Akinyi for their research assistance, as well as to Jens Aagaard and Charles Olang’o for assistance, support and supervision. I am grateful for an affiliation with Maseno University and the Nyang’oma research training site. Finally, I thank Morten Skovdal and Marguerite Daniel for their comments on earlier drafts.

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References


National AIDS and STI Control Programme (NASCOP) [Kenya]


The use of rites of passage in strengthening the psychosocial wellbeing of orphaned children in Botswana

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Children who have been bereaved in the context of AIDS may experience many challenges to their psychosocial wellbeing. Programmes to help orphaned children are usually anchored in child rights. As the individual focus of rights-based approaches is inept in African collectivist culture, NGOs tend to make use of group approaches in psychosocial support programmes. One orphan-strengthening programme in Botswana, called the Ark for Children, uses rites of passage and rites of affirmation as part of a therapeutic retreat. This study explored how rites of passage and rites of affirmation contribute to psychosocial strengthening of orphaned children in Botswana. Ten orphaned children were involved in five rounds of data collection during a 16-day therapeutic retreat; and eight social workers answered questions on the effectiveness of the therapy. A supplementary document analysis was completed, which included retreat reports since 2001 and correspondence from community-based support workers and graduates of the programme. Participants reported that the rites used during the retreat helped them to commit to therapeutic transformation. During a retreat, all the participants witness and support each individual going through each rite — a process reported to foster and strengthen group formation. It was documented that the symbols used as part of the themed rites of affirmation are used by participants for years afterwards as reminders of their transformation and commitment to the group. We conclude that rites of passage can provide a powerful tool to help children commit to therapeutic transformation, build the supportive group, and enable the community to recognise and affirm that the children return as changed individuals and members of the group.

Keywords: case study, community support, HIV/AIDS, orphans, peer support, psychosocial aspects, relationships, rights-based approaches, ritual, sub-Saharan Africa

Introduction

In the context of AIDS in sub-Saharan Africa, children who have lost a parent may experience grief and social challenges as a result of their loss. While governments and nongovernmental organisations (NGOs) use a range of methods to support orphaned children psychosocially, we argue that international organisations invariably promote the rights-based approach in psychosocial care. In this article we suggest that the rights-based approach is primarily individual-based and may not fit comfortably in African cultures that tend to be collectivist. Reynaert, Bouverme-de-Bie & Vandevalde (2009) highlight three trends of rights-based approaches which contribute to this discomfort: 1) the stress on the individual autonomy of children, which frequently 2) has a divisive effect on parent/children relationships, and 3) the fact that children’s rights have become a type of global industry. Local and regional NGOs attempting to provide psychosocial support recognise that individualistic approaches are unlikely to work in Africa and often try to use more culturally appropriate approaches, such as camps and peer support.

One alternative approach to psychosocial support uses rites of passage and rites of affirmation as part of a programme to strengthen orphaned children. Rites of passage are group-based ceremonies that mark transition from one social status to another and the changes in relationships that occur as the result of transition (Turner, 1986). Initiation, for example, marks the transition from childhood to adult status. Rites of passage comprise three phases: separation, transition, and incorporation (Van Gennep, 1960). Turner (1969, p. 49) describes separation as the detachment of the group or individual from an earlier social position or state through symbolic actions, while incorporation (or re-aggregation) involves the return of the “inwardly transformed and outwardly changed” group or individual to their new place.

Transition, also known as the period of liminality, is a time of stripping away the old and constructing the new status, empowering the liminal beings to cope with their new rights and obligations (Turner, 1969 and 1992). The group process of stripping down produces “intense comradeship and egalitarianism,” which Turner describes as “communitas,” the recognition of a “generalised social bond” (Turner, 1969, pp. 95–96). For the purposes of this article we define rites of affirmation as repetitive rituals in which each member of a group, witnessed by the group, verbally or symbolically confirms the inward process of transformation. The Ark for Children programme in Botswana uses both rites of passage and rites of affirmation as part of a comprehensive programme to strengthen orphans and build them into a cohesive group of age-mates who support each other. After
The global context of psychosocial support: hegemonic rights-based approaches

Since the emergence of the United Nations Convention on the Rights of the Child (CRC) in 1989 (United Nations, 1989), international organisations like UNICEF and large international NGOs such as Save the Children have promoted a rights-based approach throughout their programming (Snipstad, Lie & Winje, 2010). The CRC has been ratified by nearly all the countries in the world, the most noticeable exception being the United States. Once governments have ratified the CRC, they are expected to integrate the clauses of the convention into their constitu-
tions and to adjust their laws and legal systems to reflect its principles. This process of legal adjustment is currently underway in most sub-Saharan countries (Skelton, 2009), and is closely monitored by the United Nations (Reynaert et al., 2009). Local and regional NGOs are obliged to incorpo-
rate rights-based approaches in their programme proposals to meet the demands of donors in order to obtain funding (Snipstad et al., 2010). With little critical questioning, “Children’s rights are presented as the new norm in policy and practice” (Reynaert et al., 2009, p. 528).

However, the individualistic approach of the CRC makes it challenging to apply within an African setting. The rights-
based approach appears to “distort the social conceptuali-
sation of childhood” (Reynaert et al., 2009, p. 523) in most African cultures as it is embedded in the Anglo-American culture of individualism, independence and autonomy (Pupavac, 2001; Snipstad et al., 2010). Instead, African traditions promote family, mutual unity and collective responsibility, and demand obedience and responsibility from children (Skelton, 2009). Customary legal statutes within African countries, such as South Africa, emphasise the group rather than the individual (Burman, 2003). Burman (2003) argues that within the African context where values are based on group rights, the (individualistic) rights-based approach is a recipe for legal and social conflict. The 1999 African Charter on the Rights and Welfare of the Child attempted to address some of the shortcomings of the CRC in relation to African traditions, and thus included articles on collective responsibilities and duties as well as the role of the extended family in raising children (Skelton, 2009).

Another criticism of child rights pointed out by Reynaert et al. (2009, p. 528) concerns the lack of consideration for the diverse social, economic and historical contexts in which the rights are to be realised.

Regional and national application of rights-based approaches

Joint efforts are made within countries by both the public and private sectors to uphold the rights-based approach as the key to successful intervention (UNICEF, 2011). However, governments and humanitarian organisations in AIDS-affected countries struggle to come up with sustain-
able large-scale interventions as the response to mass orphanning has evolved from emergency-style relief aid to structural integration (Wallis & Dukay, 2009). Psychosocial support, which tends to be provided on a small scale, is mainly initiated by NGOs, but some regional-scale programmes do exist. For example, an organisation called the ‘Regional Psycho-Social Support Initiative’ (REPSII) is favoured by UNICEF and donors like the Swedish International Development Corporation Agency (SIDA). The organisation works with local partners and has emerged as a leading provider of psychosocial services in 13 countries in southern and East Africa (Matikanya, James & Maksud, 2006), REPSII recognises that group rather than individual approaches are likely to be more effective and offers camp-based psychosocial support; it uses outdoor activities to help children open up and deal with grief although some children remain isolated and blocked. REPSII acknowledges their model is a Western one with a focus on memories, and that there is a need to develop African-based models of grief (Ruland, Finger, Williamson, Tahir, Savariaud, Schweitzer & Shears, 2005). The Memory Book programme, originally developed in the United Kingdom to help dying parents facilitate contact between their children and their families of origin, has also had widespread application in southern and East Africa (Witter & Were, 2004). Kumakech, Cantor-Graae, Maling & Bajunirwe (2009) report on a once-off, school-
based peer-support intervention to help orphaned children in one municipality in Uganda. Although this group approach successfully reduced anxiety, distress and anger among the orphaned children participating, no follow-up or repetition of the programme was mentioned.

The Botswana government ratified children’s rights in July 2001 even though the laws and policies within the country take precedence in instances where the former might conflict with the latter. Although the gap in provision of psychosocial support was recognised early, no defined programme for therapy was established. Instead, legal and policy instruments were proposed as regulations governing alternative arrangements for children in need of care. Botswana’s recent national plan of action for orphans and vulnerable children (Ministry of Local Government, 2011) draws attention to the complex dynamics that exist between young people and their families, and it seeks to ensure that young people are not assisted and supported in isolation. This results in a shift in programming focus from individual orphans and vulnerable children to family and community (Ministry of Local Government, 2011). Nevertheless, it is observed that the concurrent NGO provision of psychoso-
cial support uses the rights-based approach. For example, one of the biggest NGOs in Botswana, Botswana Christian AIDS Intervention Programme (BOCAIP), runs nine centres in the country. Several of the centres occasionally run the Masiye model of camps, where children camp for a week in the wilderness and are encouraged to share their life experiences and are presented with awareness sessions on children’s rights to motivate them to change their life for the better (Mokgadi [pers. comm.], 2011). Mokgadi (2011) argues that the rights-based strategy empowers children to assert their rights. He admits that although children’s problems tend to be multifaceted and family or community centred, little is done to work on rehabilitating the family or the community.
In the sub-Saharan African region, and specifically in Botswana, NGOs running psychosocial support programmes to help orphaned children maintain that their programmes are rights-based, yet often they have been adapted to use the group approaches which are more fitting to the African cultural environment.

**Objectives**

Given the dominance of child rights in the current context of psychosocial support, we sought to examine an alternative group approach to psychosocial support, namely the use of rites of passage and rites of affirmation in strengthening the psychosocial wellbeing of orphaned children in Botswana. The specific aims of the study included describing the process involved with the particular rites of passage and rites of affirmation, and then examining how the rites might: 1) help orphaned children commit to the transformation that happens during the strengthening programme; 2) confirm the formation and support of the group; and 3) enable the community to acknowledge and support the transformation of each individual child as well as the creation of the group.

**Case study: Ark for Children, an orphan-strengthening programme**

Botswana has a severe, generalised HIV epidemic with 25% HIV prevalence for adults in 2008 (UNAIDS, 2009). The harsh impact of the epidemic on young and middle-aged adults has left Botswana grappling with an enormous number of orphaned children (Ministry of Local Government & Department of Social Services, 2008). In 2007 the ‘National Situational Analysis on Orphans and Vulnerable Children’ recorded that 6.5% of all children had lost both parents, while 17.2% of all children had lost at least one parent (Department of Social Services, 2010). In 1998, the previous rapid assessment on the situation of orphans (AIDS/STD Unit, 1998) found that many orphans were living in absolute poverty, were denied access to basic needs and school, and were often used as a source of cheap labour. Thereafter the government introduced a system of benefits for registered orphans to ensure that they have food, clothing and school uniforms (Division of Social Welfare, 1999). Although these services have been updated to add housing in specific cases as well as free health services (including antiretroviral [ARV] treatment for those living with HIV), provision of psychosocial support has always lagged behind (Department of Social Services, 2006).

The programme to strengthen the psychosocial wellbeing of orphaned children which was explored by this study was developed by a NGO called People and Nature Trust under its programme Ark for Children, and it has been implemented in selected villages since 2001 (Ark for Children, 2006a: see Box 1 for a references list of documents used as data). The psychological problems associated with orphanhood, such as abuse, stigma, isolation and marginalisation, were identified some time ago (AIDS/STD Unit, 1998), but it was only in 2006 that the Botswana government began to provide systematic group-based psychosocial services to adolescents (Department of Social Services, 2007). It is currently rolling out the Ark for Children programme in phases in 10 selected districts (Ark for Children & Department of Social Services, 2008). The Ark approach provides a group-centred method to help orphaned adolescents understand and overcome their loss and to redefine their life objectives and coping strategies through a relatively brief, cost-effective and culturally grounded therapeutic experience. The programme is packaged as two components: a wilderness-based therapeutic retreat lasting 16 days at a time, for up to 40 adolescents from the same village, and a three-year follow-up support programme (Ark for Children, 2006a). Thamuku & Daniel (in press) describe in detail the structure of the retreat and the therapeutic techniques used.

As mentioned, as part of the retreat the programme uses both rites of passage and rites of affirmation to strengthen orphans psychosocially and build them into a cohesive group of age-mates who support each other (People and Nature Trust, 2007). The retreat as a whole forms the overarching rite of passage. It involves a separation phase as the children are taken away from the village into the wilderness; a phase of transition, liminality, and ‘communitas’ while the children undergo therapy during the retreat; and a re-aggregation (incorporation) phase on their return to their home village. During the retreat five smaller rites of affirmation help the participants commit to therapeutic transformation; these rites are called: My Vow, Piercing Grief, Self-Strengthening, The Graduation Ceremony, and My Light. (Details of these rites are described in the findings section.)

Ark for Children is an example of a locally developed psychosocial support programme founded on some of the African values identified by Skelton (2009) and Burman (2003). Throughout the retreat and follow-up programme, the emphasis is on the group: therapy is largely (though not entirely) group-based and the follow-up activities promote the group, both as a source of support and as a place where the members have responsibilities to others (Thamuku & Daniel, in press). The retreat, as a rite of passage, has many similarities to historical Setswana initiation, and this link with cultural traditions is recognised by the community. Historically, initiation was the process through which children were transformed into adults and moulded into a mophato or age set (Schatzer, 1953). The age sets established ‘fictive’ kinship relationships between those who were initiated together (Evans-Pritchard, 1940), and while there has been a marked decline in the practice of initiation in Botswana, it still exists in a few places, most notably in Mochudi village (Mosothwane, 2001).

**Methods**

The findings and analysis presented here are based on data collected between January and April 2008 as part of a larger study. The data comprise both primary data collected through semi-structured questionnaires and secondary data in the form of NGO documents, reports and correspondence pertaining to the Ark for Children programme since 2001. The documents used as data for the study are listed in Box 1. Initial access to the participants was through the Ark programme. There were two sample groups: children participating in the therapeutic retreat and social workers who had facilitated the therapy for between one and four years.
The children were purposefully selected. Initially all 44 orphaned adolescents on the retreat were included in the sample in order to avoid feelings of exclusion among the children; later, 10 were selected on the basis that their answers were representative of the group and that they were reasonably articulate. The children were aged between 13 and 15 and were all in Standard 7, the last year of primary school. All the data collection with children was through semi-structured questionnaires conducted on the Ark for Children retreat premises. The facilitators posed questions to the group, and each child wrote down his or her answers separately. The data were collected in five rounds. This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2 This investigation employs only the data relating to their answers separately. The data were collected in five rounds.2

In the larger study, thematic content analysis of the data involved both deductive theory-driven coding and inductive coding in order to develop the themes (see Fereday & Muir-Cochrane, 2008). Inductive coding followed Attride-Stirling’s (2001) method of thematic network analysis. In reading and rereading the data, additional themes emerged, which Attride-Stirling (2001) would call the basic themes; these were then grouped into clusters of similar issues or organising themes. Two of the larger study’s organising themes, namely ‘rites of passage’ and ‘rites of affirmation,’ have been used for this investigation. The documents analysed include retreat reports since 2001 and correspondence from community-based support workers as well as from graduates of the programme.

Findings

After describing the rites of passage, we give a brief explanation of each themed rite of affirmation and share the meanings as experienced by the 10 participating orphaned children. Additional analytic views are drawn from the social workers’ responses and our analysis of reports and newsletters pertaining to the Ark programme.

Rites of passage

1. The separation

It is the community that authorises and releases the children for the retreat, permitting that they be separated to be given a life-transforming experience (Ark & Mark, 2011a). Prior to the children’s departure, awareness and community mobilisation meetings are conducted to allow the community a time to affirm that the orphaned children and their families...
are experiencing hardship and require intervention (Ark & Mark, 2011a). Having understood that the Ark for Children programme can help the orphaned children deal with the adversity they face, they release the children to participate in the retreat (Ark & Mark, 2011b). At the time of departure, the caregivers and community leaders gather to see the children off to the wilderness for life-training, giving them hugs and handshakes to wish them luck (Ark & Mark, 2011b).

2. Liminality
In the Ark for Children approach, the practice of taking the children away from the village is meant to: 1) allow the children time off from the distractions and oppressive environment of normal life; 2) provide them with time for reflection and focus; and 3) allow undisturbed time and space where these ‘lonely’ children may form a unified kinship group (People and Nature Trust, 2007). At the retreat, to promote interaction and solidarity among the members, the group is divided into two smaller groups, which alternate between participation in intensive therapy and nature-based activities. During the retreat the children actively face the memories of painful and traumatic experiences (Ark & Mark, 2011b); and as a group the children work together to construct resolutions for each challenge the members reveal (Ark & Mark, 2011c).

3. Re-aggregation
The return of the ‘graduates’ is marked by a big welcome ceremony in the community, with the gathering including the district commissioner, council secretary, head of social welfare services, school representatives, the village chief and other community members. In 2010, the Kgatleng District Council reported that at the time of re-aggregation for cohort four of the graduates, the district commissioner and the main chief of Bakgatla tribe honoured the occasion with their presence; they gave speeches of encouragement while the audience stood in solemnity and respect to receive the chief’s call for community support and his charge to the graduates. Furthermore, the graduates were provided the opportunity for delivering speeches, drama, poems and songs to give the crowd a taste of their experience in the wilderness and declare their commitment to change and to address their problems in different ways. In Thamaga village, Ark for Children (2006b) reported excitement during the occasion: ululations, traditional dancing, and the chief’s speech of welcome and support. In 2010, Tlokweneng District Council reported a significant speech given by the graduates’ representative to relate their experience of transition in the wilderness, their commitment to change, and their request that the community watch them and guide them if they should falter; the graduate’s words were received by the village chief of Batlokwa who assured them of the community’s support.

Rites of affirmation
The rites of affirmation are enacted repeatedly to facilitate assimilation of the orphans’ resolution to restructure their life and their commitment to behavioural change (Ark & Mark, 2011c). The kinship group created is strengthened daily through openness between the members, the enactment of the rites of affirmation as witnessed by the group (described below), and the evening social activities.

‘My Vow’
The children enact the rite of affirmation themed ‘My Vow’ in three phases of therapy. First, according to Ark & Mark (2011c), at the time of registration, before beginning the therapy sessions, the children enact this rite to mark their commitment to being a member of the group. During the second enactment, using a reformulated vow some five days into the therapeutic retreat, the children actively seal their commitment to resolutions developed to confront their psychosocial problems (Ark for Children, 2005a). The participating children usually reveal living with a range of difficult situations, including verbal abuse, sexual abuse, physical abuse, trauma, rejection and stigma, poverty and behavioural difficulties (Ministry of Local Government & Department of Social Services, 2008). During the graduation ceremony each enacts the vow for the third time to publically commit to reshaping their own life in a positive way (Ark & Mark, 2011c).

The children in the study described different meanings and feelings when they took their vows during the three phases. All the children viewed the first phase as a public declaration and admission that they face challenges in life and are committed to being a member of the Ark cohort for the sake of receiving help. One participant wrote:

‘I found it important to join Ark for Children programme so that I can deal with the problems that I have. I have problems. I have heard a lot from the counsellors that the programme can help me.’

Others highlighted that the first phase means committing to the set rules of the retreat, especially to attend all the therapy sessions and being open to receiving help. Some children explained that during the enactment they were afraid and unsure, and yet they wanted to do it. The first vow is concluded by pasting ‘palm signatures’ on paper using water paint. These palm prints are then pinned on a tree or wall and are visible to everyone as a constant reminder of the commitment they made (Ark & Mark, 2011a). One social worker stated:

‘I like it that we give them the liberty to express themselves as they want. This reflects their true feelings about joining the programme. You can see this from the group excitement and attention.’

Furthermore, the social workers report that this rite is enacted with loud welcomes voiced by the other group members.

Most of the children viewed the second phase of ‘My Vow’ as carrying a more direct and deeper personal meaning since it is about each individual’s decision to address their problems. Eight of the 10 study participants stated that they enacted it in order to pledge before the group their commitment to behaviour change and to confronting their different problems. At the time of enactment the group assures them support by saying aloud a phrase of encouragement: ‘O tlaa kgona molekane!’: this is followed by a round of applause. The direct meaning of the statement is ‘You will achieve your goal, age mate’ (Ark & Mark, 2011a). One child confirmed

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this anticipated group support in his response: *I have said my many problems and through this vow I will work with my friends to deal with the problems.*

Most of the children said that taking vows made them feel like they were making serious decisions about their life, and that *the retreat is not a place to play but to decide for oneself.* The social workers added that the formulation of the vow by the group brings a sense of ownership and unity. One social worker observed that children often refer to the vow in order to advise and guide others when they notice unwelcome behaviour during the retreat. Likewise, a social worker stated: *Seeing their commitment to the vow I use it throughout the rest of the retreat as a standard to address any lack of cooperation and misbehaviour.*

By the time of the graduation ceremony the number of witnesses will have increased: the number of age mates observing as witnesses may have doubled, adults offering other services during the retreat will arrive for the ceremony, and several guests including district commissioners, councillors, council secretaries and chiefs will also travel to attend the ceremony (Ark & Mark & Department of Social Services, 2009). As the audience of witnesses increases and important adults will be around to crown and congratulate them, the social workers observed that some children show mixed feelings of excitement, tension and fearfulness when they say their vows. The graduation is regarded with great awe and solemnity, yet a mood of excitement and achievement also dominates as the children dance, dramatise their retreat experiences, and flash out poems and ululations (Ark & Mark, 2011c). One child wrote: *Many people watch you and I don’t want to make a mistake before them; I have to say what I am going to do.* Another wrote: *It is an exciting day that shows everyone that I have grown and have been strengthened.*

Reports from the three-year home follow-up support effort reveal the importance the children give the vow rite. In a newsletter (Ark for Children, 2005b) one boy wrote that the vow ‘rings in his mind’ all the time and motivates him to take action regarding his life; in the same newsletter some children forwarded complaints about other members’ inconsistency in attending cohort meetings — but one stated, *We use our vow to remind them.* The children attribute such great significance to the vows that they repeatedly suggest that follow-up-activity meetings should end with a similar commitment (noted by Hukuntsi Sub-District, 2009).

*Piercing Grief*

Each child recites these words in front of their group as they enact the rite ‘Piercing Grief:\n\n*I have pierced the hard shell of my grief\nI have passed through the bitter fruit of my loss\nIn so doing am I not whole?\nI have let go of my pain. I do not know today, what the future holds for me\nBut whatever comes to me, I will face it\nAs the whole person that I am meant to be’ (see Ark & Mark, 2011c).

This rite takes place after the children have gone through three intensive sessions unveiling their trauma of loss, these being: art therapy using the workbook ‘Grieving Someone Special,’ individual therapy, and a group session on ‘sharing the pain of loss’ (Ark & Mark, 2011c). To prepare for ‘Piercing Grief’ each child goes into the wilderness to find a seed they consider very hard to break (e.g. the morama), representing the hard shell of their grief. The seed is then pierced through with a hot piece of wire to make a hole. When they enact the rite, they string the hard, pierced seed on a leather string (Ark & Mark, 2011c).

When explaining the meaning of the rite the children said:
\- *By putting the string through, I am showing that I took out all the puss of my pain, and I am relieved.*
\- *I managed to tell the story of my loss and it was not easy, just as the shell is hard to penetrate.*
\- *I mean I know what to do with the constant thinking about my mum.*
\- *I have aired out my entire problem.*

Many expressed that the enactment of this rite gave them a feeling of great achievement. Piercing the hard shell of the seed is not as easy as stringing it before the group, hence the children experience the hardness of the core before the relief at enactment (Ark for Children, 2007): *When children string on the seed, we observe that it makes them feel they have overcome and have control* (noted by Hukuntsi Sub-District, 2009). Each child is affirmed by the group as each asks aloud *Am I not whole?* The question is followed by a round of applause, giving the child a sense of pride in their achievement (Ark & Mark, 2011c).

*Self-Strengthening*

A piece of heartwood picked up in the wilderness is used to represent the strength that lies within the individual. Each child finds a piece of heartwood in the wilderness, cleans and varnishes it, leaving it shiny and beautiful. This rite is done at the conclusion of the therapy sessions, just before graduation day. It aims to allow children an opportunity to publicly affirm and confirm the strength that they feel inside (Ark & Mark, 2011c). Each participant stands before the group and declares:

*I have known something of the harshness of the world! And yet I endure…\nLike this token of the piece of hard wood, I am strong.\nAs I live and grow, I will change.\nBut always, inside, if I look,\nI will find this core of strength which is what endures in me.\nAm I not empowered and strengthened?*

The group then responds as witnesses: *You are indeed, strong!* (Ark & Mark, 2011b).

The participants explained that like the piece of heartwood which remained when the mother tree was destroyed, life had been harsh and unfair to them; they had experienced the loss of many of their family members, yet they were not diminished. They related different meanings for the different phases of preparation for this rite’s symbol. Four of the 10 orphans mentioned that by enacting the rite they were showing that they had rubbed away their problems just as they scrubbed and cleaned the piece of wood. When asked about their sincere feelings concerning the rite, one said:
My heart has gained strength like the piece of heartwood. I am also a beautiful heart, not as ugly as before.’ Another said: ‘This counselling has cleaned my heart, and I will treasure this heartwood as my new heart.’ One added that it represented how they treasure themselves.

The hard seed and the piece of heartwood forming part of each child’s necklace were highly treasured. Several of the evaluation reports for the caregivers’ workshops around the country reveal the significance attributed to the symbolic object. After giving the caregivers an explanation of symbolism of the rites, one exclaimed:

‘Oh...no wonder, my grandson nowadays withdraws away from fights within the house, and several times I have seen him quietly holding on to this piece of heartwood’ (noted by Kgatleng District Council, 2010).

Graduation

The graduation ceremony is conducted with its own symbols of growth and unity of the created kin, namely: a T-shirt for each, a beret, and an open ring of kin unity (see Ark & Mark, 2011c). The graduation is a big celebration marked with music, poems, and drama which all carry the message of their 16-day experience. All 10 of the children regarded the graduation as a symbol of achievement. One wrote: ‘I felt like a university student, I have learnt a lot.’ Among the symbols mentioned, all children seemed to attach most significance to the beret and the ring. They all wrote that the beret symbolised their readiness to go back to the community and protect their lives. Two explained this meaning with reference to soldiers: ‘Like soldiers, we are all wearing berets; we are saying we will fight for our lives.’

The Ark for Children (2002) also records instances where two children wrote letters to the social workers questing a replacement beret as a relative had taken theirs away. One wrote: ‘I feel different when everyone is in their uniform; I want to feel part of the group.’ Furthermore, reports by some community volunteers affirmed that T-shirts and berets are regarded as a symbol of unity and belonging, and are worn in special activities of group support (Kgetsana, 2004; Mokome, 2006). At all funerals for deceased group members, cohorts pay tribute to their lost ones by taking part in burial ceremonies wearing full uniform (Mokome, 2006). In Tonota village, all 12 cohorts of graduates (401 children) gathered in uniform for a performance during the Day of the African Child (Phologolo, 2007). In Lerala village, five cohorts (149 children) conducted a ceremony where they gave tree seedlings to the community from their community project and were recognised in uniform (Ark for Children, 2006b). During these special gatherings, community leaders will give encouraging speeches to the kinship group and repeatedly affirm the changes they have observed in them in comparison with children who have not been through the programme (Ark for Children, 2006b).

The ‘kinship rings’ are made of pieces of copper wire, prepared by the children themselves. They hold their individual rings high during the graduation, and, as they close the ring of wire, they declare in unity: ‘We are one cohort, we are a complete ring, I am part of the cohort, and therefore I close this ring to complete the circle.’ Following this, they sing the song: ‘Will the circle be unbroken... We all can stand together.’

Several children said that the ring would always remind them that they belong to the group and that if they were ever absent from the meetings there would be an unfilled gap. During the enactment of this rite the children would string the ring onto the leather necklace along with the pierced seed and piece of heartwood; next, leading adults would place the completed necklace around each child’s neck.

The social workers regarded the graduation as ‘a very important occasion,’ ‘the climax of the 16-day experience’ and ‘a celebration of achievement.’ One said that the morning of graduation day is always filled with excitement and energy; the children seem recharged and happiness illuminates the place. Another stated that the children walk proudly in their uniform and they search for the best trousers to wear with the T-shirts, and the members lend each other trousers to give the appearance of oneness.

‘My Light’

This is the last rite of passage conducted for the purposes of saying goodbye to one another, appreciating the group and appreciating the change that each has experienced (Ark & Mark, 2011c). It is done the last night before departure. The group silently forms a circle in the darkness and each child is given a chance to light a candle and pass a message of appreciation to the group. The rest of the group members listen in silence to whatever is said, to take in and reflect on each individual’s speech (Ark for Children, 2006b; Ark & Mark, 2011b).

Feedback on the experience of the rite ‘My Light’ differed between the social workers and the children. Many of the social workers saw it as a solemn ceremony, which often triggers children to cry, possibly as a sign of regression. Contrary to this, one child stated that she cried during the ceremony because she was overwhelmed by her sense of achievement: ‘I know I came in as a naughty fighting person, now I learnt where my behaviour comes from, and the group helped me to change; they say I have changed.’

Ark & Mark (2011a) cite that the mood projected by the social workers during the enactment of the rite is easily picked up by the children. Furthermore, the ‘My Light’ rite should be done with a moderate mood of excitement, spirit of pondering and reflection and sincerity in the messages given (Ark & Mark, 2011a). All the participating children should write that the rite symbolises having been in darkness in the harshness of life, but now they are in the light and are ready to address their life issues. One added: ‘I used my friend’s candle to light mine because the group has given me the light.’ One social worker appreciated how each child’s speech constituted rich feedback about the 16-day experience: ‘I get to my tent and write [what I remember of] the speeches; they are of great value on assessing the impact of the 16 days.’

Discussion

Psychosocial wellbeing refers to both social and mental health aspects of wellbeing. Sebone (2009) writing about mental health in Botswana identifies the following characteristics as
important for psychological wellbeing: a sense of self-appreciation, a sense of belonging to a social group, the ability to use available resources to meet basic needs, the capacity to cope with adversity and adapt to change.

**Self-appreciation**
A sense of self-appreciation is closely linked to self-esteem and confidence, as described by Betancourt, Meyers-Ohki, Stulac, Barrera, Mushashi & Beardslee (2011) in a study which mentions indicators like strength, lack of fear, and an ability to understand others. Several of the rites of affirmation contribute to a sense of self-appreciation. In the ‘My Vow’ rite, one of the participating children specifically referred to having grown and been strengthened; the wording of the ‘Self-Strengthening’ rite includes references to strengthening and empowering, and the children’s responses invariably indicate a sense of self-esteem and appreciation.

**Belonging to a social group**
This characteristic of psychosocial wellbeing is perhaps the one most strongly developed by both the rites of passage and the rites of affirmation used in the retreat. In initiation, during the time of transition, the participants experienced pain and, as the wounds began to heal, they received instruction about their new institutionalised roles (cf. Comaroff, 1985). While the pain during initiation was physical, due to circumcision (boys) or a cut on the inside of the thigh (girls), during the therapeutic retreat the pain is psychological as the children speak to the therapist and to their age mates about their grief and loss as well as about their experiences of abuse. The orphaned children on retreat also receive instruction as their wounds begin to heal, in this case about how to deal with the problems they face. Turner (1992, p. 50) terms this ‘reconstruction’ and notes that another positive effect of enduring pain together is “intense comradeship” among the liminal beings which he calls ‘communitas’ (Turner, 1969, pp. 95–96). During the therapeutic retreat, ‘communitas’ is deliberately fostered as the children are formed into a cohesive created kinship group. This group then provides support when the child faces challenges back home, and each child in turn, as a member of the group, supports others when they need it.

During re-aggregation in the Setswana initiation ceremony, special clothing was worn as a visible symbol of new identity (Comaroff, 1985); likewise, graduates of the retreat will wear uniform berets and T-shirts to symbolise their transformation and also to clearly show off their membership in the kinship group. In initiation, the adults welcome the youngsters back as ‘strangers,’ thus acknowledging the children as a member of the group. This group then provides support when the child faces challenges back home, and each child in turn, as a member of the group, supports others when they need it.

**The ability to use available resources to meet needs**
The supportive group becomes a resource to the children once they return home to their village. Likewise, the symbols used to reinforce the affirmation can be taken back home by the child as a reminder of that affirmation. The hard seed, pierced to symbolise ‘piercing grief,’ is a visible form of the idea (Turner, 1986) that the child has ‘passed through the bitter fruit of loss,’ ‘let go of pain’ and is now whole. Likewise, the heartwood symbolises empowerment and strengthening. The symbols act as reminders of these meanings, months and even years after the retreat, as suggested in the grandmother’s report of her grandson gripping his heartwood during family conflicts.

**The capacity to cope with adversity and adapt to change**
All the children attending the retreat have lost a parent and have to deal with grief and bereavement. The ‘Piercing Grief’ rite is the culmination of several therapeutic techniques to help the children face and cope with loss. The children’s quotes above show that they are able to talk about their grief, identify other problems associated with their loss (like constant thinking about their mother), and move on with a great sense of achievement. Bereavement frequently leads to changes (in living arrangements, for example), and orphaned children may face many other adversities, such as abuse and exclusion.

The rites, when enacted by all the children attending a retreat, are repetitive — as up to 40 children enact each rite individually and then receive affirmation from the group. Kapferer (2005) notes that the repetitive nature of rites helps slow down and suspend chaotic reality, giving participants the opportunity to adjust to the processes and dynamics of life. So, for example, a child who has felt victimised and abused, affirms that she was ‘empowered and strengthened’ during the self-strengthening rite, and then she hears those words repeated again and again until they become part of her. This goes hand in hand with the other aspect of affirmation. Each child makes a commitment in front of other members of the group and they also make pledges to the group. The other members of the group participate in affirming and encouraging the one making the commitment; for example, the first time ‘My Vow’ is enacted, the rest of the group gives ‘loud welcomes,’ and when the rite of ‘Piercing Grief’ is enacted, as the child asks ‘Am I not whole?’ the group gives a positive affirmation followed by a round of applause. Hunter (2007, p. 162) notes that “commitments made in public gatherings were stronger than those made in private”; and Kearney (2009, p. 84) contends that rituals “require participation that can be witnessed”; and, being publically recognised, achievements cannot be denied.

The ongoing strength of the rituals is evident in reports of how they are used during the three years of follow-up; the vow, for example, has been used by witnesses, both adults and age mates of the kinship group, to remind a graduate of the commitment they made. ‘My Light’ is another rite that allows the children to appreciate the group and be affirmed as a member of the group.
of virtuality, mentioned by Kapferer (2005), namely the space to visualise the adjusted reality: that is, the child in the example above would visualise herself as empowered and strengthened in situations where previously she was abused.

Collective rites versus individual rights
The main resource to succeed in giving care and protection to children is the traditional care system, which emphasises collectiveness (Snipstad et al., 2010). The rites approach emphasises community and group involvement, where the community is given an opportunity to appreciate children’s challenges and authorise their participation in the group-based therapy; the group serves as a support system and a platform of child strengthening; the rites of affirmation are witnessed and authenticated by the group; and the community receives the cohort back home at the re-aggregation phase, and is given feedback and prepared to support the children. In contrast, rights-based approaches, while they may be done in groups (like during the REPSSI and BOCAIP psychosocial support camps), focus not on commitment and responsibility to group and community, but mainly on the happiness of the individual child (Mokgadi, 2011). The rights-based approach calls everyone’s attention to the needs of the child while ignoring the safety net of family and age mates that also need support (Pupavac, 2001).

The rites used during the retreat help children make the best of difficult life circumstances. The children participate in constructing the created kinship group by committing to supporting and being supported by other members of the group, both during the retreat and once they are back home. They publicly declare that they are dealing with grief, facing their problems and being transformed; and, in turn, they actively witness other members making such declarations and affirming their transformation. Documents show that the graduates mutually give and receive support when they return to their home village. The group will also remind individual members about their commitment to transformation as well as give the individual a sense of belonging. This sense of belonging is reinforced when the group appears together in uniform at public ceremonies, such as during funerals or the celebration of the Day of the African Child. The participating children embrace the symbols and use them to affirm transformation — for example, the boy who used his symbolic heartwood during family conflicts to remind himself that he was empowered and strengthened.

Conclusions
While the rights-based approach is seen as the new norm in policy and practice for children’s psychosocial interventions, governments and NGOs, aware that the individualism of the rights approach is inept in African cultural settings, adopt group approaches to psychosocial support. The Ark for Children programme utilises rites of passage and rites of affirmation as part of its psychosocial-strengthening approach. During the therapeutic retreat, orphaned children use rites of affirmation to declare that they have been transformed, while members of the group witness the declaration, thereby helping each child commit to the transformation. The repetition of the rites by each member of the group, affirmed each time by the group as a whole, creates a cohesive group and a supportive cohort, which has been found to provide ongoing support once the children return to their home village. The community is involved in the larger rite of passage, sending the children off to the retreat and welcoming them back with a collective ceremony in which the children describe their transformation, and when the community recognises and affirms that the children have returned as changed individuals, now part of a cohesive group.

Rites of passage and rites of affirmation promote psychosocial wellbeing in participating children by fostering a sense of self-appreciation as well as a strong sense of belonging to the group. They also improve children’s capacity to use available resources to meet their needs and enable children to cope with personal adversity and adapt to change.

Notes
1 Setswana denotes the language and the culture. Although there are some minority ethnic groups in Botswana, the Tswana tribe is dominant numerically and politically, and hence Setswana culture is also dominant.
2 Questions to the orphaned children:
   Round 1: Have you ever discussed the experience of the death of your parents in depth with anyone close to you? How did they respond? Did you feel able to share this experience? Kindly give reasons.
   Rounds 2 and 3: What issues did the group members share that are similar to your experiences? What issues of your life experience did you share with the group? Is there anything in the discussions that made you feel reluctant to share? Please explain the solutions that you have constructed so far to confront your problems. How did the group help you come up with solutions during group discussions or role plays?
   Round 4: The workbook titled ‘When someone very special dies’ follows certain themes. Each page has a question (Q), a space for the child to respond, and an affirming statement (A) at the bottom of the page. The themes include: ‘losses,’ ‘my special loss,’ ‘expressing your feelings and thoughts,’ ‘rituals’ and ‘help.’ 
   Round 5: Do you think the therapy helped other children in the group? Kindly give examples. How did the therapy help you? How did working with the group help you deal with the loss of your parents? Which of the symbols used in the rites is most important to you? How and why is it important to you? Explain how the other rites are important to you.
3 Questions to the social workers:
   Explain how you see the effectiveness of the therapeutic techniques which the methodology applies to help children ameliorate the effects of loss and grief. In particular, refer to the group discussions, role plays, workbooks, and individual counseling. In your experience, which of the therapeutic techniques work well? Please explain. In your experience, which of the therapeutic techniques do not work well? Please explain. In your experience, does the group approach enhance the therapeutic process? In what way? In your view, how does the enactment of rites impact on the children?

Acknowledgements — The authors would like to thank all the orphaned children who participated in the research, the social workers who responded to the questionnaire and the Ark & Mark Trust for access to the relevant documents.
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‘Read me to resilience’: Exploring the use of cultural stories to boost the positive adjustment of children orphaned by AIDS

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The study explored whether and how culturally sensitive stories can encourage resilience in young children orphaned by AIDS. The purpose of the investigation was allied to the paradigm of positive psychology, which focuses on the promotion of potential strengths to buffer children against adversity, as well as on social ecological understandings of resilience, which emphasise that social ecologies have a duty to facilitate children's positive adjustment to adversity. A pre–post-intervention evaluation was used to gather qualitative data on orphaned children's resilience to AIDS-related adversity by employing participatory visual methods. The intervention, called Read-me-to-Resilience (Rm2R), consisted of telling 22 culturally sensitive stories to the children. We compared the pre- and post-intervention data for each participant before thematically analysing the total findings. Our analysis indicates that the children's resilience had been bolstered in the period between the pre-test and post-test. We conclude that culturally relevant stories could be used by South African caregivers, service providers, and educators as an accessible, inexpensive and ready-made tool to directly empower children who have been orphaned by AIDS.

Keywords: folktales, HIV/AIDS, participatory visual methods, protective resources, psychological development, social ecology, South Africa, storytelling

Introduction

In South Africa, the HIV epidemic has contributed to a significant increase in the number of orphans — which are currently estimated to numbered about 1.9 million (UNAIDS, 2010) and predicted to rise to 2.3 million by 2020 (Actuarial Society of South Africa, 2005). The exact number of children orphaned because of AIDS is almost impossible to say, but these statistics point to the severity of the situation and confirm a serious threat to the wellbeing of South African children and youths. A growing body of research indicates that orphanhood due to AIDS places children at risk in terms of their psychosocial development (Bhargava, 2005; Cluver & Gardner, 2007; Operario, Pettifor, Cluver, MacPhail & Rees, 2007), their educational opportunities (UNICEF, 2006; Akwara, Noubary, Ah Ken, Johnson, Yates, Windfrey et al., 2010), their financial stability (Monasch & Ties Boerma, 2004; Collins & Leibbrandt, 2007) and their general wellbeing (Makame, Ani & McGregor, 2002; Shear & Shair, 2005).

Adding to the complexity of the problem, help is often not at hand for these children (UNICEF & UNAIDS, 2010). Even if support were readily available, it is questionable whether many orphans would be referred for psychological help, since death tends to be a taboo subject in traditional African communities (Atwine, Cantor-Graae & Bajunirwe, 2005) and psychological support is not readily accessible to the majority of South Africans of all ages. In the absence of support to help make sense of and adjust to a parent’s death, many orphans internalise this trauma. Internalising the trauma of parental death can lead to depression, stress, withdrawal and low self-esteem (Dowdney, 2000). There is also evidence that children who are orphaned are more likely to suffer exploitation and abuse, often at the hands of their caregivers (Stein, 2003; UNAIDS, 2009).

Consequently, children orphaned by AIDS are subject to a whole “spectrum of vulnerability” (Boiler & Carroll, 2004, p. 1) and are in need of a range of psychosocial and material interventions to improve their wellbeing. Although schools have been recognised as possible nodes of care and support for HIV-infected or affected children, including orphans (Giese, 2004), and even though the mooted ‘Draft Integrated Strategy on HIV and AIDS’ from the Department of Basic Education (2010) emphasises the care and support mandate of schools, evidence presented in the literature suggests that schools will struggle to provide or facilitate access to the required services in the short term (Cohen, 2002; Moletsane, 2004; Wood, 2009). The Minister of Education (Motshekga, 2010) herself argued that education in South Africa, particularly in the more disadvantaged communities (which are the hardest hit by the HIV epidemic), is in crisis and may not have the
capacity to respond to the needs of children whose vulnerability has increased because of HIV and AIDS. Similarly, in most sub-Saharan countries, health and welfare organisations and ministries are severely challenged in their efforts to implement policies for the provision of treatment, care and support to children orphaned by AIDS (UNAIDS, 2009). Stein (2003) highlights that many countries position children orphaned by AIDS as a threat to national security and the economy, rather than concentrating on providing them with the real help that they need. Bray (2003) agrees that these children are often represented in the media and literature in a way that increases and reinforces their stigmatisation and marginalisation, drawing attention away from the trauma they endure when their material and psychosocial needs are not met.

We are likewise concerned that official responses to the needs of this vulnerable group of children will not be delivered quickly and effectively enough to help them cope with the adversities they face. A few South African interventions (e.g. Circles of Care: Cook & Du Toit, 2004; the Memory Box Project: Denis, 2004) have been designed to enable children orphaned by AIDS to cope resiliently. These interventions operate from a positive psychology paradigm that focuses on the promotion of potential strengths to buffer children against adversity (Seligman, 2005; Donald, Lazarus & Loewana, 2007). This observation led us to contemplate how we could design an intervention that would elicit resiliency in this vulnerable group of children.

Based on our experience of using bibliotherapy with individual clients, and based on information in the literature about the use of stories as a therapeutic tool to enhance coping responses (i.e. Bergner, 2007; Brink, 2008), we decided to investigate how the telling of culturally sensitive metaphorical stories or folktales could encourage children orphaned by AIDS towards resilience. By empowering children through the reading of stories, caregivers, psychotherapists, educators and other service providers could provide an inexpensive, accessible and protective resource for building resilience in children orphaned by AIDS.

The article first explains our understanding of resilience and the importance that culture plays in resilience-enhancing efforts to reduce the vulnerability of children facing HIV-related adversity. The potential of cultural stories as a resilience-enhancing tool is explicated and justified. We then describe the participatory methods used in the study before critically discussing the findings. Finally, the limitations of the study are elucidated and tentative suggestions are made for further investigation of the usefulness of cultural stories as a resilience-enhancing intervention for children who have been orphaned by AIDS.

Enhancing the resilience of children orphaned by AIDS

If AIDS orphans are seen as active members of the community rather than just victims, their lives can be given purpose and dignity. Many children already function as heads of households and as caregivers. They are a vital part of the solution and should be supported in planning and carrying out efforts to lessen the impact of AIDS in their families and communities (Avert, 2011).

This statement encapsulates our own thinking around the empowerment of vulnerable groups. Interventions are needed that will help build up coping responses in children, rather than ones focused on doing things to and for children. Research has defined resilience as a process of recovering from, adapting to, and/or remaining strong in the face of adversity (Masten, 2001). A key requirement of resilience is the presence of risk (such as the material, social and emotional risks experienced by children orphaned by AIDS), which predicts negative outcomes. When children adjust positively despite these risks, resilience is inferred (Luthar, Cicchetti & Becker, 2000). Masten (2001) made the point that resilience is probably more prevalent than early researchers predicted, and recent research supports the notion that children living in adverse contexts are capable of acquiring agency to improve their life situations (Skovdal, Ogutu, Aoro & Campbell, 2009; Skovdal & Andreouli, 2011). We proceed from the viewpoint that orphans face considerable risk and are more vulnerable than other populations, although we recognise that not all children exposed to risk and adversity develop problems (Boyden & Mann, 2005). Nevertheless, we are cognisant that positive adaptations in behavioural terms may obfuscate psychological distress (Luthar et al., 2000).

Current understandings of resilience have moved away from person-focused notions of positive adjustment, which foist the responsibility to adapt on individuals, towards recognition that positive adjustment is an ecologically embedded process that requires input from both youths and their social ecologies (Masten & Wright, 2010; Ungar, 2011). In his explanation of the theory of the social ecology of resilience, Ungar (2012) emphasises that positive adjustment is a contextualised process that is facilitated by social ecologies (e.g. families, schools, communities and governments). This does not imply that children at risk should become passive recipients of support, but rather that social ecologies and children collaboratively transact to promote youths’ resilience.

The theory of the social ecology of resilience acknowledges that the process of adjusting well to adversity is complex and variable (Luthar et al., 2000), partly because the process is sensitive to contextual support. Broadly summarised, such support for youths entails the encouragement of attachment relationships, a provision of opportunities to take action and experience success, guidance that teaches socially appropriate self-regulation, assistance to make positive meaning of one’s life experiences, and the promotion of problem-solving skills (Masten & Wright, 2010). As process-oriented understandings of resilience have flourished, researchers have urged sensitivity to how the culture of a given social ecology shapes the processes of resilience, including attention to “indigenous coping strategies” (Ungar, 2012, p. 15). Thus, from a social ecological perspective of resilience, interventions to promote resilience should foreground local resilience-promoting resources and consider culturally sensitive measurements of resilience (Masten, 2011).

This social ecological understanding of resilience informed the Rm2R intervention, partly because it resonates with our belief that communities have a duty to
collaborate with children towards their own positive adaptation, and partly because its sensitivity to indigenous culture aligns well with recent emphasis on cultural heritage in South African studies of resilience. Previous South African studies acknowledge that resilience is nurtured by multiple resources that are rooted in cultural resources (Theron & Theron, 2010), such as religion (Theron, 2007), oral stories (Theron, Stuart & Mitchell, 2011), cultural values and traditions (Dass-Brasifald, 2005; Ebersohn, 2007; Phasha, 2010; Theron & Malindri, 2010), and cultural pride (Phasha, 2010). This understanding led us to wonder how we could support the development of ‘resilient coping’ in children orphaned by AIDS in a culturally relevant way that is accessible, inexpensive, and does not require complicated infrastructure to implement. In other words, in a way that could be easily used by teachers and caregivers without specific training and as part of a normal school curriculum or care programme. Exploring the literature about resilience theory, it became apparent that something as simple as storytelling could help children orphaned by AIDS to access their inner, hidden strengths (Bergner, 2007; Brink, 2008) and enhance personal and cultural protective factors that promote resilient coping.

**How cultural stories could boost resilience**

The benefits of metaphorical storytelling have been demonstrated in individual or family psychotherapeutic interactions (Arad, 2004; Brown, 2006; Bergner, 2007; Brink, 2008) and expressly recommended when counseling people of African descent (Maréé & Du Toit, 2011). However, to the best of our knowledge, it has not been tested in non-familial group contexts, or specifically with groups of children orphaned by AIDS. In African cultures, traditional folktales (isiXhosa: iintsomi) and storytelling are a cultural practice (Maréé & Du Toit, 2011). These folk stories can boost personal resilience in several ways: 1) through the provision of moral lessons; 2) through the promotion of emotional healing and new ways of thinking; and, 3) through metaphors about positive adjustment.

Many African folktales have moral lessons (African Cultural Centre, 2011). Often, the stories are about small animals battling against large ones, or ordinary people fighting against characters with supernatural power or superior physical strength. The animals, birds and mythological creatures often take on the human characteristics of greed, jealousy, honesty, loneliness, etc., and through these metaphorical stories, valuable life lessons can be conveyed (see Table 1 for more detailed examples).

Research has shown that storytelling has the potential to contribute to emotional healing on a subconscious level, thereby enabling resilience (Brown, 2006; Bergner, 2007; Brink, 2008). Often, this is embedded in story-based examples of resilience-promoting processes (like attachment or problem-solving). Other work has shown that fictional literature can help people cope more resiliently with the effects of depression, trauma and grief (Jones, 2001). Use of the literature to promote wellbeing is often referred to as bibliotherapy, which Morgan & Roberts (2010, p. 207) describe as “therapeutic reading.” As children listen to a story and identify with the characters, they can learn new ways of thinking about and coping with their problems, becoming more hopeful and therefore better able to adjust to adversity (Jones, 2001; Iaquinta & Hipsky, 2006; Morgan & Roberts, 2010).

Metaphors of positive adjustment found in stories can also enable children towards resilience (Schore, 2003; Bergner, 2007; Brink, 2008). Based on previous research, we wished to further explore the work begun by Jones (2001) on the use of fiction to foster resilient coping in children who are bereaved. We theorised that indigenous African stories that model attachment, problem-solving, agency and mastery, positive meaning-making and hope, and self-regulation would offer orphans an alternative schema that potentiates resilience (Utsey, Bolden, Lanier & Williams, 2007). Local folktales seem an appropriate choice of fiction, given that Morgan & Roberts (2010) urge researchers and mental-health practitioners to consider the culture in which a child is embedded, and to use this to influence which stories will be used to make up bibliotherapy content.

**Methods**

The purpose of this preliminary study was to determine the potential of cultural stories to boost the resilience of groups of vulnerable children, such as those orphaned by AIDS. We collected 30 stories in Xhosa by engaging the collaboration of several community members who were active in community development projects in a township in the Nelson Mandela Metropole (Eastern Cape Province, South Africa). They were asked to approach mature community members who might recollect stories they had heard as children and that had made them feel ‘enabled’ or strong. These stories were then translated into English and given to a multiracial panel of psychologists to judge which ones might be the most suitable for building resilience. Twenty-two stories were then selected and translated back into Xhosa and compared with the original story to ensure that the essence of the story had not been changed in the translation. Table 1 indicates how these stories were evaluated by the team of independent psychologists as being able to boost positive coping in children facing adversity.

The stories were told in Xhosa in a lively manner by a researcher, who kept field notes and a reflective diary (see Nieuwenhuis, 2007). Stories were mostly told on a Sunday afternoon at an orphanage (to a group of 22 children) and on a Thursday afternoon at an aftercare centre (to a group of 10 children) for a period of about 15 minutes. The children all listened attentively to the stories. Twenty-two stories were told, one story per week, after which the researcher left, without discussing the story or interacting with the children in any other way. This process was strictly adhered to because we wanted to test the effects of the stories on the participants’ resilience — and, should the reader bond warmly with the participants, this attachment would influence resilience, given that human relationships are known to encourage resilience (Masten & Wright, 2010). However, we accept that this might be a limitation of the study, since the regular attendance by the storyteller may have given the children a sense of stability and adult attention. Even though the interaction was limited, there was
Table 1: Summary of how the cultural stories might boost resilience in the children orphaned by AIDS

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<th>Resilience-promoting themes</th>
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<tbody>
<tr>
<td><strong>Self as enabling</strong></td>
<td>Ten stories (Stories 1, 2, 8, 9, 10, 11, 13, 17, 20 and 22) presented protagonists and/or themes that communicated a message that one’s personal qualities provide strength and are enabling. These personal strengths included warm-heartedness, an ability to follow instructions, and curiosity. These stories encouraged confidence in a personal ability to solve problems, and many of the stories emphasised this confidence in one’s own ability. This is illustrated by an excerpt from Story 22: ‘In one of the villages in the Eastern Cape, one couple had only one child. This was a girl child. She was very dark in complexion, with big red eyes. She had long protruding teeth. Her neck was like a long pole that had been inserted between those wide shoulders. She was so unusually tall for a girl. Her arms formed brackets, and she had big muscular legs. One would think that she was an unusual creature or that she was disabled…. She was teased by others in her area because of her ugliness. Even her nickname ‘Instant Poison’ was also from people in the area, because they said she was like poison. She used to say, ‘Even if you are beautiful, your beauty does nothing for me. I can do anything I want to do myself, there’s nothing that I can’t do because I am ugly. I am far better than most of you.’ Her belief in her own ability led to her being able to save her community…’ And the story ends with: ‘Her parents were very happy for her. Their child was the first black woman to lead an army and come back triumphant.’ The stories also encouraged clear thinking and problem-solving as enabling. For example, in Story 11, a spotted warbler named Ngcede triumphed over a powerful eagle because he used his intellect to compensate for his physical puniness and in so doing outwitted the great eagle. And, in Story 17, an ant triumphs over a majestic lion, despite its physical vulnerability, by using its wit. Likewise, these stories emphasised the importance of agency. Although there were also themes about enabling communities and having supportive family or friends, these stories illustrated how the child protagonists made good use of the supports offered to them, and/or how they negotiated for support.</td>
<td></td>
</tr>
<tr>
<td>Community as enabling</td>
<td>Six of the stories (Stories 1, 3, 5, 14, 16 and 18) illustrated that communities could be relied on to ‘help beat the odds.’ In four of the stories, help came from elders in the community: the elders provided shelter, information, and/or food that enabled the protagonist in each story to adapt to difficult circumstances and cope with these. In one (Story 16) there was pertinent reference to neighbours who were enabling: ‘Ntsingselo was a 12-year-old boy who lived in one of the villages in the Bathenjini area across the Nciba River. He was staying with his grandmother Mamvulane. His parents died when he was three years old; they died of pneumoconiosis [a lung disease]. His grandmother was struggling to make ends meet and there was no one who was prepared to offer them help. There were, however, a few neighbours who gave them a few things that they could help them with. In those days there were no old age grants.’</td>
<td></td>
</tr>
<tr>
<td>Family as enabling</td>
<td>Three of the stories (Stories 9, 16 and 18) presented protagonists and/or themes that communicated a message that family members can be relied on for support. These stories referred to ancestral family members or extended family members: for example, orphaned children coped because of remaining family, such as a father figure (Stories 9 and 18), an ancestral mother-figure (Story 9), or a granny (Story 16). All six stories suggested the importance of bonding, and that even in case of an extremely troubled home environment, a good relationship with a family member is enabling.</td>
<td></td>
</tr>
<tr>
<td>Friends as enabling</td>
<td>Eight of the stories (Stories 2, 4, 5, 6, 12, 16, 19 and 20) presented protagonists and/or themes that communicated a message indicating that relational bonds (such as friendship) buffer risk. These bonds facilitate high expectations, encouragement to participate in meaningful activities, counsel or advice, and having an identity as a survivor as opposed to being a victim. For example, in Story 2, the main character Mankepe was saved by the children in the village. Because there was a connection between her and the other children in the village, they went out of their way to rescue her when she was in grave danger.</td>
<td></td>
</tr>
<tr>
<td>Cultural practice and beliefs as enabling</td>
<td>Eleven of the stories (Stories 2, 4, 6, 8, 9, 12, 13, 15, 16, 18 and 21) presented protagonists and/or themes in terms of cultural frames which are deeply invested with spirituality/religion, magic, and music. These stories also emphasised the importance of collectivism and generosity as resilience-promoting resources. For example, in Story 12, Sikhahloni had to call for divine intervention when the boys were chased by the cannibals: ‘This time the boys came to a swiftly flowing river that barred their way; and thinking that this was surely the end, they turned in despair to Sikhahloni and said ‘Save us, save us little chief!’ Seeing their plight he called out, ‘Water, water, water, please open up before us, for the cannibals are close behind.’ This time Khanjapa the python, guardian of the river, rose from the depths, and, striking the water with an enormous tail, divided it, leaving a pathway to the other side. The boys lost no time in getting across, and they threw themselves onto the grass to recover their breath as the water closed again behind them. The cannibals, however, were so near when all this happened that they heard Sikhahloni’s call for help and saw the water let them through.’ As in other similar stories, this excerpt illustrates story content that uses cultural beliefs and practices to encourage hope when all seems lost, and to encourage spiritual dependence as a pathway to enablement. In Story 18, the children are taught by their father that working together will benefit them more than working individually: ‘He asked them to take some sticks from the ones that were left and give them to him. He then made them into a bundle. He gave the bundle to the first so that he could try and break it, but he couldn’t; he then gave it to each one of them, they all couldn’t break the bundle. After he had passed the bundle to all of them, he then told them that if they could stick together like that bundle of sticks, nothing, not even their enemies, could break them and nothing could overpower them.’</td>
<td></td>
</tr>
</tbody>
</table>
nonetheless interaction in that they met each other regularly over a specific period.

Study design
The purpose of the study required us to use an evaluation design in order to determine whether the reading of the stories had made any discernible difference in the resilient coping of children. We therefore chose to employ a pre-test, post-test evaluation design (Leedy & Ormrod, 2005) to measure the resilience of the participants before and after the intervention. A visual, participatory qualitative approach was followed, since we believed that this would offer greater understanding of the meanings that the participants had constructed about their world and experiences (cf. Creswell, 2005; Denzin & Lincoln, 2005), and because we were sensitive to the need for culturally sensitive measurement of resilience (Masten, 2011).

Participants
To recruit participants, we invited local children to form an advisory panel (as used by Theron [2007] and Ungar, Brown, Liebenberg, Othman, Kwong, Armstrong & Gilgun [2007]) to help identify children orphaned by AIDS and thus at risk for non-resilient outcomes. The criteria for final selection was that the children should be single or double orphans whose parent(s) had died of an HIV-related illness, and be between the ages of 9 and 14. Thirty-two children (22 living at a local orphanage, and 10 in foster care in the community) took the pre-test, but only 20 completed both the pre-test and post-test and the intervention. Such attrition when working with children in care is not unusual, since children in an orphanage may be moved into foster care, and those in foster care are often moved between relatives living in different places. The 20 children included in the study comprised eight boys and 12 girls who were all living in the orphanage. Four were double orphans; the other 16 were single orphans who had been abandoned by their surviving parent and with whom they had no contact.

Data generation
We employed a visual participatory approach that foregrounded the draw-and-talk or draw-and-write method (see Mitchell, Theron, Stuart, Smith & Campbell, 2011), in that we invited children to make two drawings and explain the meaning of these. Our choice of this method was encouraged by its reported alignment with African ethics (see Theron et al., 2011) and Africentric counselling style (Maree & Du Toit, 2011); its non-reliance on linguistic skill (Mitchell, 2008), which is important in South Africa where most children are barely literate; and successful use in prior studies with black South African youths (e.g. Govender & Reddy, 2011; Malindi & Theron, 2011). Drawings also have a reputation for generating information in a non-threatening way (Malchiodi, 1997; Ndlovu, 2001). All this suggested the potential for cultural and contextual sensitivity in our measurement of resilience (cf. Masten, 2011).

First, the children were asked to respond to the following prompt: ‘Think about your life now. Draw a picture that will show me what your life is like. Remember that how well you draw is not important.’ They were then asked to explain the symbolic drawing, either orally (recorded and later transcribed) or by adding a written explanation. The field researcher was a native Xhosa speaker who could explain the instructions in the children’s first language. Since the children were all Xhosa-speaking, they were invited to explain in their mother tongue (if they wished), but the general level of literacy was very poor in either language. Nevertheless, the explanations provide situated knowledge, or knowledge interpreted and perceived through each child’s social ecological context (Stuart, 2004).

Second, we asked the children to ‘draw a person in the rain’ and then explain their drawing. The ‘Draw-a-Person-in-the-Rain’ (DPIR) method is a projective technique imported from North America and used mostly by psychologists and social workers to interpretively assess the illustrated figure’s protection (or lack of it) against the rain as an indication of the drawer’s need for protection against current adversity, and, hence, is used as an indication of the degree of resilience present. In clinical applications, the drawing is scored and interpreted according to specific indicators. Thus, the reliability and validity to reveal the interaction between stressors and coping responses in the participants was established in an American context (see Carney, 1992; Kravits, McAllister-Black, Grant & Kirk, 2008). However, we chose not to interpret the children’s drawings clinically. Instead, we thematically analysed the contents and explanations of the drawings and used the analysis to deduce the children’s experience of risk (based on the drawn presence of, or reference to, threatening weather phenomena such as lightning, thick clouds, etc.) and protection (based on the drawn presence of, or reference to, protective clothing or paraphernalia or shelter). Theron (2004) used the DPIR method in a similar thematic manner to draw conclusions about resilience in South African youths with learning disabilities. We employed this technique as a means to triangulate the analysis of the symbolic drawings and the written descriptions. The pre-test was administered one week prior to the children’s participation in Rm2R; an identical post-test was conducted one week after the children’s participation in Rm2R had ended, which was about 26 weeks later since no stories were read during the school break.

Data analysis
We scrutinised each child’s symbolic drawing (i.e. as a drawing illustrating the child’s life) and the narrative explanation, both pre-test and post-test. We followed a-priori coding by using the seven themes that Ungar et al. (2007) reported as implicit to resilience processes in children across cultures. Table 2 presents the indicators of resilience. It is evident that the themes in the stories identified as being able to boost resilience resonate with these indicators (see Table 1). Following consensus, we compared the coding of the pre-test and post-test drawings to describe conclusions about the children’s level of resilience following their participation in the Rm2R intervention.

For the thematic analysis, we independently compared the pre-test and post-test drawings for each participant, looking for symbols of protection and/or vulnerability in each drawing. Only the indicators that we all agreed on as symbolising resilience or a lack of resilience were included...
Table 2: Factors necessary to enhance resilience in youths

| 1. Access to material resources | The availability of financial, medical and educational resources and other resources to fulfil basic human needs, such as food, clothing and shelter, as well as employment opportunities. |
| 2. Access to supportive relationships | The presence of a supportive relationship network within the family, community, at school, or among work colleagues or mentors. |
| 3. Development of a desirable personal identity and positive self-concept | An awareness of life purpose, personal strengths or weaknesses, aspirations and beliefs, values, spiritual and religious identification, and good self-esteem. Personal characteristics included: a positive attitude, the ability to remain cheerful, and enthusiasm. |
| 4. Experience of personal power and control | A sense of self-reliance and internal locus of control, sense of agency to effect positive change in social/physical environment and to access health promoting resources. Personal characteristics include: positive future orientation, goal directed, internal locus of control, perseverance, optimism, assertiveness. |
| 5. Adherence to cultural traditions | Knowledge of and ability and opportunity to adhere to cultural practices, values and beliefs. |
| 6. Experience of social justice | The formation of a meaningful role in a community, bringing with it acceptance and social justice. |
| 7. Experience of a sense of cohesion with others | An ability to balance personal interests with one’s responsibility to the community and to a greater good; a feeling of being part of something larger than oneself; engaging appropriately with others, according to cultural and community expectations, without losing one’s own sense of identity. Personal characteristics included: empathy and a desire for love, a sense of obligation and responsibility. |

Adapted from Ungar et al. (2007)

in the analysis. For example, drawings with thick clouds, lightening, or drenching rain were interpreted as symbolic of vulnerability. Protective clothing (e.g. a raincoat, a hat), protective paraphernalia (e.g. an umbrella), or shelter against the rain (e.g. a tree) indicated adjustment to the stressor (rain). This thematic analysis was ratified by an independent researcher (who is also a research psychologist). As with the symbolic life drawings, we compared the coding of the pre-test and post-test drawings to draw conclusions about the children’s levels of resilience following their participation in the Rm2R intervention.

**Trustworthiness**

Trustworthiness of the findings was enhanced by means of triangulation of the data sources, prolonged engagement, detailed or dense description of the research process, coding and re-coding by three researchers, consensus on the final themes and categories that emerged, and preservation of the raw material as an audit trail (see Leedy & Ormrod, 2005). In addition, we presented our emerging analysis to researchers with experience in studies of resilience and asked them to comment critically: their comments influenced our conclusions.

**Ethics**

In keeping with ethical requirements (Creswell, 2009), the children and the caregivers signed assent/consent forms stating they had been informed about the purpose of the study; that they knew confidentiality would be ensured; and that they understood their participation was voluntary and they were free to withdraw at any time. Furthermore, the children were aware that we might make use of their drawings in research publications. The researcher who read the stories kept in close contact with the houseparent at the orphanage and with the caregiver at the aftercare centre that the foster children attended to ensure that any sign of emotional stress exhibited as a result of the testing/storytelling could be identified. Counselling/therapeutic services were secured for that eventuality, but these were not utilised because the houseparent/caregiver reported no distress in the participants. In order to receive ethical clearance from the university review boards, the study design had to make provision for ensuring the psychological/emotional wellbeing of the child participants, and both boards were satisfied that such measures were in place.

**Findings and discussion**

Two themes emerged from the data analysis of the symbolic drawings: there appeared to be evidence of increased self-esteem in the children, as well as more positive relations with others, which created a sense of love and caring amid hardship. These are both indicators of resilience (Ungar et al., 2007) and part of the resilience-promoting promoting processes of agency and mastery, and attachment (Masten & Wright, 2010). We found substantial evidence of these indicators post-test, but not pre-test, which encouraged us to conclude, albeit cautiously, that the Rm2R intervention had facilitated positive adaptation in the participating children. The symbolic contents of the DPIR post-test further supported this working hypothesis.

**The symbolic life drawings**

As explained under the methodology section, all the drawings and their written explanations were compared pre- and post-intervention for each participant. However, space does not allow for the presentation of such a copious amount of data here. Therefore, we highlighted the themes that were repeatedly discerned in the drawings and written explanations. These themes are discussed with reference to specific drawings and descriptions by the participants, and controlled against relevant literature.
Theme 1: Indications of increased positive self-concept
Many of the drawings portrayed development of an increased and more positive sense of self between the pre- and post-tests. For example, Participant 4 drew a boy playing soccer both times (Figure 1), but the pre-test drawing shows him in stick-form with an incomplete face, whereas the post-test contains a large portrait with full facial features; his accompanying narrative says he is always happy and laughing. The larger and more life-like figure is indicative of a heightened sense of identity and better self-esteem (Furth, 2002).

Participant 7 (pre-test) drew himself in what he says is a car, parked outside a house (Figure 2). It almost looks as if he is in prison, and the stick-like person could indicate low self-esteem (cf. Malchiodi, 1998). However, his post-test drawing portrays him as a tall, strong person with full facial features; his explanation includes his name and that he likes to play soccer. It would seem that he is now proud of who he is and has developed a stronger sense of identity.

Participant 8 drew similar pictures pre-and post-test, but the second drawing has a more life-like face and has a smiling sun shining on her. Her detailed written explanation gives us insight into her life (see Figure 3).

Participant 16 also showed more self-awareness and seemed more in touch with his emotions, both positive and negative, in his post-test explanation:
Pre-test: ‘I draw me and my friends playing skipping rope and we are showing happiness.’
Post-test: ‘My name in NN. I stay at S. Sometimes I am happy, other times I am not. I like to play with other children. I don’t like to be upset because when that happens I stop speaking to other people. I like to dream about my future. At school, I dance.’

This participant’s post-test explanation gives voice to self-knowledge and suggests he is future-oriented; both are qualities associated with a more positive self-concept and constructive adjustment to hardship (Baumgardner & Crothers, 2010).

These examples are typical of many of the participants’ drawings and explanations at the time of the post-test, where the development of an identity was indicated through drawings of larger, full-faced figures and the mention of a participant’s name, hobbies, friends and achievements. The pre-test drawings tended to be more anonymous, often with no mention of who the participant is, where they live, or what they like to do. Given the developmental level of the children in the study (ages 9–14), they could be expected to produce visually realistic drawings (Krampen, 1991). Therefore, one can deduce that the drawing of a stick figure with no discernable features is more indicative of the child’s emotions and sense of identity than suggestive of an inability to draw. Ungar et al. (2007) found that the presence of a desirable personal identity and positive self-concept was a strong indicator for resilient coping in children. Masten & Wright (2010) report this as integral to the resilience-promoting mechanism of agency and mastery.

In the post-test drawings and explanations, the children’s development of a positive personal identity and self-concept could be further deduced from allusions to self-awareness, an adherence to specific values and beliefs, and signs of a positive and enthusiastic approach to life. A sense of self-worth helps the child feel more hope, agency and personal control — all strong indicators of resilience (Masten & Wright, 2010; Brooks, 2011). Feeling more in control of one’s personal circumstances was well evidenced in the drawings of a few participants. For example, for the pre-test, Participant 6 drew a girl crying in front of two empty houses (Figure 4), suggestive of the grief he was experiencing at the death of his parents, and the need to distance himself from his emotions by portraying someone else as being heartbroken. However, by the time of the post-test he seemed more in touch with his emotions and was able to express anger. He drew a large self-portrait and explained that he became very angry when a bully had stolen his meat at Sunday lunch and so he had fought with him. Although fighting is not the most socially appropriate response, his reaction suggests agency and indicates he felt that he could take action and stand up for himself.

Theme 2: More positive relations with others
In the pre-test drawings and narratives, the participants tended to refer to the orphanage as a ‘house’ instead of a...
home. None of the children mentioned that they loved their caregiver; instead, they were more emotional when they thought about their parents, often described as either dead or sick. This indicates that the children at the orphanage did not identify themselves as part of a family unit. However, in the post-test narratives some participants referred to the people at their orphanage as ‘family.’ For example: ‘I live at…I love my family there because they take care of me when I need something’ (Participant 15) and ‘I have drawn myself watering my mom’s garden at S’ (Participant 2).

Many of the post-test drawings and narratives depicted friends as very important to the children. Several participants (i.e. 4, 5, 7, 16, 11, 20 and 22) mentioned that they all shared and played together. Figure 5 illustrates the development of one child’s feelings of being alone and victimised by bullies, to feeling a sense of cohesion with the other children in the home.

Positive relationships are a powerful protective factor for vulnerable children (Criss, Pettit, Bates, Dodge & Lapp, 2002; Saewyc, Wang, Chittenden, Murphy & The Mc-Creary Centre Society, 2006; Ungar et al., 2007; Masten & Wright, 2010). Indeed, Luther (2006) expounds that constructive relationships are probably the most powerful protective resource in the development of resilience. The aforementioned studies indicated that resilience is enhanced and adversity buffered by: a feeling of connectedness to teachers, friends and family; having a
Figure 4: The pre-test and post-test drawings of Participant 6

Figure 5: The pre-test and post-test drawings of Participant 22
confidante at home; and having friends who are a positive influence. The fact that the children seemed to be enjoying enhanced peer and caregiver relationships post-intervention indicates that their resilience had been bolstered. The pre-test drawing in Figure 6 shows the participant playing with a friend and thinking about her future at school, which is indicative of a resilient response; but her post-test drawing is even more indicative of cohesion with her extended family members. Perhaps she can now see a future outside of the home and feels better connected to this extended family.

A spiritual relationship was important for some of the children who seemed to find comfort in putting their trust in God. For example, the post-test explanation of Participant 3 states: ‘God took care of my health and now I have a new family.’ Cultural assets, such as religion and spiritual connections, are important factors in the development of resilience (Masten & Wright, 2010; Theron & Theron, 2010). Filbert & Flynn (2010) found that the more cultural assets that children living in residential care had, the lower the incidence of maladaptive coping responses.

The ‘Draw a person in the rain’ (DPIR) method
Thematic analysis of the drawings generated by the DPIR method indicates growth in the participants’ capacity for resilience, post-intervention. Table 3 gives a sample of the analyses.

Despite many signs of enhanced protection in the drawings, a number of participants drew themselves without feet, which might connote feelings of instability (Brink, 1997 and 2008), or with inadequate protection against the rain. The continued presence of risk in the post-test drawings urges respect for concern that behavioural adaptation may mask psychological pain (see Luthar et al., 2000). Children must learn to navigate rapidly changing social ecological systems (Berkes, Colding & Folke, 2003); orphaned children in particular are subjected to social, familial and financial instability (Cluver & Gardner, 2007), therefore it is understandable that their degree of coping may fluctuate on a daily basis, and/or that pain may be omnipresent even when they appear to cope. For example, the pre-test drawing of Participant 21 (Figure 7) shows protection against the rain, but in her post-test drawing she omitted the umbrella. Nonetheless, the rain and clouds were fewer/smaller, indicating she felt a lesser degree of adversity and was better able to withstand. The second drawing also depicts a person with feet, which is potentially indicative of improved stability. In effect, all the post-test drawings either showed some increase in degree of protection against adversity or indicated decreased feelings of vulnerability.

Figure 6: The pre-test and post-test drawings and explanations of Participant 15
Conclusions

It is not an easy or straightforward matter to measure resilience (or even to infer it), given the complex and dynamic nature of the phenomenon (Luthar et al., 2000; Masten & Wright, 2010). However, the comparison of the pre-test and post-test drawings suggests that the participants experienced an increase in two of the main protective processes for coping with adversity, namely high self-esteem (as indicative of mastery and agency) and a sense of cohesion with others who care (suggesting attachment processes) (see Masten & Wright, 2010). The baseline assessment of the children’s resilience (i.e. findings pertaining to the pre-test drawings) suggests that most of the participating children were struggling to adjust to troubled lives. The post-test findings suggest that the children’s sense of agency/mastery and attachment were now more robust — thereby indicating resilience (cf. Ungar et al., 2007; Masten & Wright, 2010), which by implication highlights the salience of partnerships between social

Table 3: Examples of ‘Draw-a-Person-In-the-Rain’ (DPIR) analyses

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pre-intervention</th>
<th>Post-intervention</th>
<th>Displays increased resilience?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Many clouds and large drops of rain; umbrella not protecting the person (but held to side); no feet (instability) or hands are noticeable.</td>
<td>Smaller and fewer raindrops; umbrella over head of the person; hands are discernible.</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td>Drops almost as big as a small person; no hair or umbrella.</td>
<td>Only two raindrops; hair is protecting the head; a larger person, but hands and feet are now missing.</td>
<td>Yes — but person/illustrator is possibly feeling unstable?</td>
</tr>
<tr>
<td>7</td>
<td>Lots of rain; no protection.</td>
<td>Less rain, but hands are missing and the person is shown in side profile now.</td>
<td>Some suggestion of increased capacity to resile (i.e. to abandon his/her course of action).</td>
</tr>
<tr>
<td>11</td>
<td>Heavy rain; umbrella not held over head.</td>
<td>No rain visible; umbrella overhead.</td>
<td>Yes</td>
</tr>
<tr>
<td>14</td>
<td>Huge drops of rain engulfing the person; no umbrella.</td>
<td>Few drops and person is holding an umbrella.</td>
<td>Yes</td>
</tr>
<tr>
<td>15</td>
<td>Person is standing under huge drops of rain, which are engulfing him/her; no protection; no hands.</td>
<td>Rain has lessened, but still no protection; no feet.</td>
<td>Some suggestion of increased capacity to resile.</td>
</tr>
<tr>
<td>19</td>
<td>Person is almost drowning in rain; no feet.</td>
<td>Rain is falling only on the person’s head; feet have been added.</td>
<td>Yes</td>
</tr>
<tr>
<td>20</td>
<td>Large clouds and many large raindrops; no protection against the rain.</td>
<td>Clouds have gone and the rain is almost invisible; the person has thick head of hair to protect the head.</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Figure 7: The pre-test and post-test drawings of Participant 21
ecologies and children towards resilience. Since this was not an experimental study, we cannot definitively claim that the children’s participation in Rm2R was responsible for an improvement in their resilience. The nature of our study meant we could not control all possible influences, both negative and positive. For example, excerpts from the diary of the researcher who read the stories indicate obvious factors that could have contributed either to increasing the adversity experienced by the children, or to fostering their resilience. Various stressors, such as material deprivation and relationship instability, were described:

‘Sometimes I would arrive early and I could see how they had to survive under the conditions. There were 65 children in that home and they slept in groups of 10 since there were not enough rooms, sometimes sharing two to a bed. During lunchtimes, they would run and push one another to be first in line, and they often fought over food’ (researcher’s field notes, 20/10/2010).

‘During the process, I learnt that these children really appreciated my visits and they wanted to know me better. They would ask me questions about my life and children, and I began to feel uneasy that I could not interact freely with them, due to the nature of the study. Some of them asked to come to my home. One day I could not go when I was supposed to and some of them said they thought I had abandoned them’ (researcher’s field notes, 15/06/2010).

However, the researcher also noted factors that were potentially resilience-enhancing in the children’s circumstances:

‘The older ones (15 and above) also played a significant role in the house as they were responsible for the younger ones in terms of washing their clothes, comforting them when they are crying, etc. It appeared as if everybody had a role to play in the house’ (researcher’s field notes, 12/03/2010).

‘These children were all attending school. They were also exposed to different people who came to assist them with their needs, for example, visitors from overseas/university students to assist with the homework, some sponsors would host braais for them, others take them to the beach, church people would come and fellowship with them…. The children were involved in sports, as sports medals were displayed in the lounge’ (researcher’s field notes, 14/2/2010).

Therefore, many intervening variables could not be controlled for; indeed, it would be very difficult to control for variables such as relationships with external family members, the degree of economic hardship experienced, or the experience of abuse and neglect, and physical or mental impairment. Thus, we are cautious in making conclusions about the resilience-promoting potential of the Rm2R intervention itself. Nevertheless, the findings emerging from this preliminary study encourage us to repeat the study with a larger cohort of children who have been made vulnerable by orphanhood, and so use the new findings to corroborate these preliminary ones. Continued study of the value of the Rm2R intervention also needs to heed the concern stated by Luther et al. (2000) — namely, that researchers must be sensitive to the psychological (and not just behavioural) functioning of children when pronouncing that a child is ‘resilient.’

An interesting and unsolicited finding that emerged from our discussion with the caregiver at the orphanage was that the children would enact the story later in the day; hence, we wonder whether this also contributed to the development of resilience. From the perspective of resilience theory, self-esteem should be based on “a pro-social values system, a realistic sense of oneself and one’s capacities, and an awareness of personal responsibility” (Alvord & Grados, 2005, p. 240). Using drama in an educational way can develop skills in goal-setting, values clarification, problem-solving and identification of personal strengths and talents, all of which contribute to meeting the requirements voiced by these authors. By re-enacting the story told to them, children can identify with the characters, perhaps experiencing some of the power and strength typically portrayed.

The telling of stories could be followed up with opportunities for engaging with the children; especially, this would be a useful tool for enhancing the coping responses of orphans. For example, one might ask the children which characteristics of the characters they identified with, and to visually portray these in drawings; to re-enact the story in their own words; to make up similar stories portraying themselves as the main characters; and to identify and discuss the values that the stories convey.

Although the telling of stories by itself seems an appropriate way to enhance resilient coping in children, culturally relevant stories could be used by caregivers and teachers in a variety of ways to enhance resilient coping responses particularly in children orphaned by AIDS. We recommend further research in this area in order to meet an urgent need for interventions that will support the increasing number of orphaned and made vulnerable by AIDS, so that they may develop a higher degree of resilient coping.

Notes

1 Defined as any child under the age of 18 who has lost one or both parents to HIV-related illness.

2 Although the focus of this study is on children orphaned by AIDS, the findings are applicable to all children facing a severe form of adversity and who would therefore benefit from increased resilience.

3 Initially we included a control group comprised of children in foster care. However, this set of children seemed to have had an increased level of resilience at the start, perhaps because they faced greater emotional and economic adversity than the children in residential care did; thus, we decided not to use the findings pertaining to this group. In addition, many variables could likewise not be controlled for and the sample size was limited, reducing the validity of a quasi-experimental study.

Acknowledgements — The authors would like to acknowledge the funding provided by SANPAD for this study.

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References


Coping with hardship through friendship: the importance of peer social capital among children affected by HIV in Kenya

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Children living in households affected by HIV face numerous challenges as they take on significant household-sustaining and caregiving roles, often in conditions of poverty. To respond to their hardships, we must identify and understand the support systems they are already part of. For this reason, and to emphasise the agentic capabilities of children, this article explores how vulnerable children cope with hardship through peer social capital. The study draws on the perspectives of 48 HIV-affected and caregiving children who through PhotoVoice and draw-and-write exercises produced 184 photographs and 56 drawings, each accompanied with a written reflection. The themes emerging from the essays reveal that schools provide children with a useful platform to establish and draw on a mix of friendship structures. The children were found to strategically establish formalised friendship groups that have the explicit purpose of members supporting each other during times of hardship. The children also formed more natural friendship groups based on mutual attraction, with the implicit expectation that they will help each other out during times of hardship. In practice, the study found that children help each other through sharing (e.g. schools material and food) as well as through practical support (e.g. with domestic duties, securing food, and income-generation) — thus demonstrating that children are able to both accumulate and benefit from ‘peer social capital.’ The study concludes that a key coping strategy of HIV-affected and caregiving children is to mobilise and participate in friendship groups which are characterised by sharing and reciprocity of support. Development responses to support children affected by the HIV epidemic need to take heed of children’s ability to draw on peer social capital.

**Keywords:** community support, HIV/AIDS, participatory action research, PhotoVoice, social networks, sub-Saharan Africa, visual methods

**Introduction**

As parents fall ill from HIV, children may find themselves taking on significant household-sustaining and caregiving roles, often in contexts of poverty, which may compromise their education and psychosocial wellbeing (Skovdal & Ogutu, 2009). This is a cause for concern, encouraging both local and international organisations to develop strategies and responses that promote the wellbeing and growth of children affected by HIV. While service delivery organisations can play an important role in facilitating supportive and health-enabling environments for children affected by HIV, such efforts must resonate with children’s agency and consider innate support systems. It is against this background, and in the interest of highlighting the opportunities for social participation that schools can provide for HIV-affected and caregiving children, that this article explores the nature of children’s peer relations, looking explicitly at how they are formed and the ways they can be drawn upon by vulnerable children to successfully deal with hardship.

Extensive research from the ‘global North’ has highlighted the importance of peer groups in promoting reciprocity, collaboration and acceptance (Hartrup, 1983; Parker & Asher, 1993) and made great efforts to map out the organisation and dimensions of peer relations (see Brown, 2004; Gest, Graham-Bermann & Hartup, 2001), yet little research has explicitly focused on the importance of friendship for HIV-affected children in sub-Saharan Africa. The wider HIV/AIDS-related literature however does allude to the importance of friendships in a number of different ways. First, studies have expressed, albeit briefly and in passing, that friendships may be an invaluable source of support for HIV-affected children (Murray, 2010) and that peer connections might serve as a protective factor in helping HIV-affected children build resilience (Cluver, Bowes & Gardner, 2010; Wild, Flisher & Robertson, 2011).

Second, studies exploring children’s experiences of HIV and AIDS have highlighted that children express concern that they might lose their friends. This has been demonstrated for example in studies that report on children moving in with extended family members to help them cope with the impact of HIV and AIDS, leaving their friendship groups behind (Evans, 2005; Skovdal, 2011a). In Lesotho and Malawi, one study found that children who migrate to stay with extended family following the deaths of their parents mentioned missing their friends and feeling isolated before new friendship groups had been established, forming...
part of the negative aspects of moving (Van Blerk & Ansell, 2006). But it is not migration alone that forces children to leave their friendship groups. Children who stay in their local community but drop out of school in order to cope with significant care and household-sustaining responsibilities (as their parents fall ill or die) have also been found to feel isolated after losing their friends (Skovdal & Ogutu, 2009; Yanagisawa, Poudel & Jimba, 2010). A study of orphaned children heading households in Uganda found children with extensive care and home duties struggling to nurture their friendships, primarily because they had to drop out of school and were busy generating income for their household (Dalen, Nakitende & Musisi, 2009). These studies all indicate that HIV-affected children value their friendships, but give no further background about what it is about these friendships that is so valuable.

Third, studies have found that children and youths, who may not necessarily be affected by HIV and AIDS themselves, represent and describe their HIV-affected peers as having supportive friendship groups. In Malawi, for example, young people suggested that HIV-affected youths had friends and peer groups who would provide them with advice and encouragement to adopt healthy attitudes and behaviours (Wright, Lubben & Mkandawire, 2007). Similar observations have been made in Zimbabwe where children aged 10 to 12 years spoke about the importance of friends in providing HIV-affected children with a break from their care and household-sustaining duties. The children also suggested that friends may go and help HIV-affected children with their care and household-sustaining duties (Campbell, Skovdal, Mupambireyi & Gregson, 2010). These studies have alluded to three possible networks, or forms of social capital, that can positively impact children's coping. These are: 1) the close friends of HIV- and AIDS-affected children (bonding social capital); 2) peers from the wider community (bridging social capital); and, 3) schools or other organisations facilitating peer-support (linking social capital). We now turn to use this brief review as a platform to develop a 'peer social capital' framework.

Towards a ‘peer social capital’ framework
The concept of social capital (see Bourdieu, 1986; Coleman, 1988; Putnam, 2000) is increasingly used to understand the social psychological resources that children — at a micro-level — invest in and actively negotiate access to in dealing with life circumstances (Morrow, 1999; Barry, 2011). Coleman (1988 and 1990), combining the rationality of individuals and the social structures in which they are located, argues that children and young people actively develop friendship groups who can offer support in times of hardship. He goes on to argue that once friendship groups have been established, children and young people are ready to go to great lengths to sustain their friendships, particularly throughout adolescence and in times of domestic turmoil, where friendship networks can take on greater significance than the family (Coleman, 1990). Barry (2011), drawing on the work of Coleman and other social-capital theorists in relation to young carers in the United Kingdom, found friends to feature highly in the lives of young carers. The positive impact of having close friends was not only about having someone to talk to about their home situation, it was also about giving them the opportunity to be like other children and youths, escaping their caring role, to be free from worries (Barry, 2011).

As evidenced by the work of Barry and Coleman referred to above, theories of social capital provide a useful platform to investigate the importance of friendships for children to cope with hardship. However, social capital is by no means a straightforward concept. The theory of social capital has a significant intellectual history and has been pulled in different directions. In this article we draw on three varieties, or social psychological processes, of social capital as characterised by key theorists (cf. Putnam, 2000; Woolcock, 2001; Szreter, 2002). The first one relates to bonding...
A second process of social capital relates to bridging social capital, where people interact with social networks beyond their own social group, but within a similar setting. Bridging social capital is based on the premise that no social groups are located in a vacuum, but will be influenced by other social networks. For example, children who are part of a peer group, characterised by support and trust, do not function in isolation. Peer groups interact with each other, for better or for worse. A peer group of HIV-affected children for example may be ostracised and bullied by children and youths from another peer group in the local area, which can have a negative influence on their psychological coping and ability to navigate for support (Cluver & Orkin, 2009). Morrow (1999) states that if children are to ‘get on’ (i.e. move beyond just getting by), they must gain the support of and work in partnership with other social networks.

A third category of social capital has been referred to as linking social capital. Linking social capital relates to the interaction between people and networks across social strata and institutionalised power hierarchies with the aim of accessing support and leveraging resources (Szreter & Woolcock, 2004). For HIV-affected children, educational establishments and international organisations (through teachers and social workers) provide the linkages and opportunities for children to develop new peer relations (thus linking social capital).

‘Peer social capital’ may therefore relate to the opportunities and social resources that are available for HIV-affected children to develop close friendships (i.e. bonding social capital), be supported by peers from their school environment and wider community (i.e. bridging social capital) and participate in peer-support activities, facilitated by teachers, social workers or NGO staff (i.e. linking social capital). A ‘peer social capital’ framework can place greater emphasis on the role of friendship and peer-support in enabling or restricting children’s coping with hardship. It also points towards some of the dynamics that need to be considered for any responses looking to facilitate children’s coping through peer support and friendship.

Although this study alludes to the importance and relevance of HIV stigma in undermining friendships (negative bridging social capital) as well as the role of schools and international organisations in facilitating peer-supportive social spaces (linking social capital), the overall aim of this study is to explore how children actively organise themselves into friendship groups (generate bonding social capital) and make productive use of them to cope with hardship (utilise bonding social capital). In doing so, this study highlights their agency and latent coping strategies.

Methods

The study received approval from the Research Ethics Committee of the London School of Economics and Political Science, as well as the Department for Gender, Children and Social Development in Kenya. Observing the ethical guidelines of the British Psychological Society (2004), informed and written consent was obtained from all participants and their guardians with the agreement that confidentiality would be ensured. We therefore use pseudonyms throughout.

Study population and sampling

The study was conducted in the Bondo district of western Kenya. The district borders Lake Victoria and is predominantly inhabited by the Luo ethnic group who primarily engage in fishing and subsistence farming. Bondo is characterised by frequent droughts and laterite soils with poor water-retention capacity, which contribute to high levels of poverty and food insecurity (Government of Kenya, 2006). This, coupled with seasonal migration to fishing villages, has encouraged local people to engage in transactional sex, contributing to the rapid spread of HIV in the district. HIV prevalence in the district is conservatively estimated at 13.7%, still twice the national average of 7.4% (National AIDS Control Council, 2006; National AIDS and STI Control Programme/Ministry of Health, 2008; UNAIDS, 2008). The district was carved out of Siaya district in May 1998, which meant that the building of a district infrastructure and administration took precedence at the peak of the HIV epidemic. This resulted in a delayed response to the epidemic. Over the past decade, the district has therefore experienced an influx of nongovernmental organisations and bilateral support to help the district and its local population respond to HIV and AIDS. However, the combination of poverty, the early onset of HIV infection or AIDS illness and a delayed response to the management of HIV has led to a surge in the number of HIV- or AIDS-affected children in the district. A survey done by Nyambedha, Wandibba & Aagaard-Hansen (2003) in Bondo district found that one out of three children (33.6% of the 724 sample size) had lost one or both parents, and one out of nine children had lost both biological parents.

This study forms part of a participatory action research project that set up with two youth clubs for 48 caregiving children (between the ages of 12 and 17) in two rural communities in western Kenya. The sociodemographic characteristics of the children, as well as whom they care for, are presented in Table 1. The children and youths met weekly or fortnightly to spend time with children of similar circumstances, either through workshops, sports or income-generating activities as part of a life-skills programme. The youth clubs were facilitated by a local NGO and provided a platform to recruit and engage with HIV-affected and caregiving children for the purpose of this study. As the material drawn upon in this study was gathered at the very start of the project, the youth clubs do not feature as a source of social capital, and the children’s perspectives are likely to reflect innate ties and networks and not those generated from their participation in the youth clubs.
In our interest to do research “with children rather than on or for children” (Matthews, Limb & Taylor, 1998, p. 312), PhotoVoice was used a research method. PhotoVoice is a participatory research methodology that enables children to share their life experiences as well as reflect and develop perspectives on life challenges by producing and reflecting on images (Wang & Burris, 1997; Wang, 2006). PhotoVoice is traditionally used to involve lay-people and encourage them to identity challenges to their health and wellbeing, with the aim of increasing the awareness of policymakers. Here, PhotoVoice is used to highlight coping strategies, arguing that such a focus will bring forward both life challenges and indicators for action and change that are aligned with local resources (Skovdal, 2011b).

Through a series of workshops — facilitated by local NGO staff in the local Dholuo language — the children were sensitised to the PhotoVoice project. They were informed that the purpose of the exercise was to explore their coping strategies and they were taught how to use the disposable cameras. We also discussed some of the ethical implications of using PhotoVoice (for examples, see: Gold, 1989; Wang & Redwood-Jones, 2001; Skovdal & Abebe, 2012). Through these discussions it was agreed by the children to not take undignified photos of parents or guardians who may be ill and bedridden. It was also agreed that if photos were to be taken inside their homes, these photos should be staged or acted (as opposed to a snapshot of ‘reality’). If children wanted to take photos of people, they were asked to first seek permission and consent to do so. In the workshops, the children practiced what they had to say in order to obtain informed consent. If the children wanted to share a story, but for ethical reasons or time constraints were unable to take the photo, they were encouraged to draw the scene and write a story about that.

The children had the disposable cameras for two weeks and were provided with four guiding questions: 1) What is good about your life? 2) Who helps you? 3) What keeps you strong? and 4) What needs to change? All 48 cameras were returned, but one camera turned out to be faulty and the child was given a new camera and a chance to repeat the exercise. After all the photographs had been developed, the children were gathered in a workshop setting and encouraged to select up to six photographs that would tell a story about how they get by, things they lack, and/or someone who is important to them. The children were then invited to reflect on their photographs and write down their reflections. To prompt the children, they were given three questions: 1) ‘I want to share this photo because…’; 2) ‘What is the real story this photo tells?’; and 3) ‘How does this story relate your life and/or the lives of people in your neighbourhood?’

This exercise generated a total of 184 photographs and 56 drawings, each accompanied with a written reflection. We draw on these written stories in this article. However, to exemplify the kind of photos the children produced, we have included a couple of the pictures in our presentation of findings (see Figures 1 and 2). The stories were translated from Dholuo into English and imported into Atlas.Ti — a qualitative data analysis software package. Following the steps of Attride-Stirling’s (2001) thematic network analysis, text segments were coded with an interpretive title and subsequently clustered into basic themes. As we do not seek to report on all of the themes emerging from this analysis, the coding framework was revisited, this time guided by the literature presented in this article in order to explore how the codes making reference to friendship were interconnected. Through this process, 13 basic themes were identified, each of which were clustered into three organising themes, covering: 1) how the school environment provides children with opportunities to form close friendship groups; 2) how the children coped through sharing; and 3) how the children coped by helping each other more practically at home.

As we seek to map out the stock of resources and perspectives articulated by our informants in an exploratory manner, it is not our aim to draw links between individual children’s accounts and their personal backgrounds (e.g. social and orphan status, number of friendship groups). However, we try to distinguish between majority and minority views, by clarifying whether the perspectives were held by many of the children or only some. Next, we discuss the primary themes emerging from this study with the aim of answering the research question: How do HIV-affected and caregiving children cope with hardship through friendship?

Findings

The combination of poverty and HIV can have catastrophic consequences for how children experience their schooling

### Table 1: Sociodemographic characteristics of the participating caregiving children (n = 48), Bondo district, western Kenya

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girls</td>
<td>28</td>
<td>58</td>
</tr>
<tr>
<td>Boys</td>
<td>20</td>
<td>42</td>
</tr>
<tr>
<td>Age group:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12–14 years</td>
<td>29</td>
<td>60</td>
</tr>
<tr>
<td>15–17 years</td>
<td>19</td>
<td>40</td>
</tr>
<tr>
<td>Orphan status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paternal orphan (child has lost father)</td>
<td>30</td>
<td>63</td>
</tr>
<tr>
<td>Double orphan (child has lost both parents)</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Social orphan (child is vulnerable to poverty and parental illness)</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Maternal orphan (child has lost mother)</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Guardian (whom the child lives with):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>24</td>
<td>50</td>
</tr>
<tr>
<td>Grandmother</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>Aunt</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Sister</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>No one</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Care recipient (whom the child currently cares for):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>25</td>
<td>52</td>
</tr>
<tr>
<td>Grandmother</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Aunt</td>
<td>7</td>
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<tr>
<td>Grandfather</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Neighbour</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sister</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
and peer relations. As parents fall ill from HIV or other related illnesses and require around-the-clock care and support, it is often the children of the household who step in. For example, one boy described his escalating experiences of caring for his mother, which eventually resulted in him having to drop out of school temporarily:

‘I drew a picture of my mother to share with you the kind of caring I did for her. I was caring a lot for my mother; I was washing her, bathing her, washing her feet, cooking for and feeding her. I had to ensure that she was asleep before I did. I only slept for a little while and woke up early to clean the house, washed her and fed her before going to school. But I had to drop school at some point; it was really bad for me. I left school at one time to be with her all the time and that wasn’t good for me at all’ (Mark, age 13).

Not only do children like Mark drop out of school temporarily to provide care, some are denied the opportunity to go to school in the first place because the associated costs are unattainable for many families. Some children have the assets necessary to generate income that will allow them to attend school. In one of her written stories, 15-year-old Mildren explained how she grew and sold crops so that she could afford to go to school. However, rather than telling us that the school was providing her with invaluable life skills and knowledge, which is one of the primary aims of educational establishments, Mildren, when explaining the importance of going to school, placed her emphasis on how the school has helped her develop friendships:

‘At home we grow a variety of crops and we benefit a lot from the farm. We harvest and sell the crops to get money which we use to pay for school. This has helped me to socialise and meet many friends’ (Mildren, age 15).

Despite the fact that many of the caregiving children had experienced stigmatisation and bullying from peer groups at their school, many of our informants, like Mark, were deeply unhappy about having to drop out of school. Having noted this, there were occasions where children, like Everline, expressed bullying as a reason why some children did not want to go to school:

‘Sometimes I did not go to school because groups of children there who have never cared just talk bad about your name. They joke about the condition of your parent’ (Everline, age 14).

The experiences of our informants, as illustrated by Mark, Mildren and Everline (above), confirm what has been previously described in the literature. First, that HIV stigma may result in the bullying of HIV-affected children by other peers (a type of negative bridging social capital). Second, that HIV-affected children on the whole value going to school (a form of linking social capital), socialising with peers, and developing friendships (bonding social capital). But how are these friendship groups organised?

**Children generate bonding social capital through mobilising friendship groups**

Schools provide children with a space to identify and develop friendship groups based on mutual understanding, respect and support, loyalty, trust and fun. These friendship groups appear to be organised through a mix of formalised and informal friendship structures which transcend the school environment where they are formed.

**Formalised friendship groups**

A number of children spoke about being part of groups that were formed by children themselves on the mutual understanding that the group members would help each other during times of hardship. Often the groups were formed at school and with school friends, having the primary purpose of making sure that everyone in the group was able to attend school and do well in class. As 12-year-old Kevin highlighted, this more formal approach to mobilising friendship groups is rooted in their observations of the achievements of adult community-based groups in their local communities. Kevin and his peers knew that through team and collaborative work they were more likely to succeed at school:

‘It is good if we are in a group while being taught in school as there is an understanding amongst us and we can learn better. In our exams we do better than others from various areas and schools. I took this photo because of the good relationship we have amongst us, we cooperate. Team work helps. Being in a group has helped women in a village where they were weeding as a group, harvesting, and this ensured that their crops did well and they got a good harvest’ (Kevin, age 12).

But the support groups often extend beyond school-based encouragement and work. As 15-year-old Millicent highlighted, being part of a support group made a huge difference to her. She explained how her fellow group members, because of their shared love and respect, were able to assist her and her mother through a difficult time, providing them with both practical and emotional support through home visits:

‘I want to talk about this photo because these school children have formed a group, which I am a part of. We help each other. I once had a problem and they helped me through a difficult time. They regularly came to visit my mother and they also helped me fetching water and firewood. This photo shows us that we should love and visit each other, because if we respect one another we can assist one another. If I have problems, my fellow children help me. This picture shows that while some have plenty of things, a friend may have less and we can always join hands, so small fundraising to help someone through a situation’ (Millicent, age 15).

Thus Millicent recommended that friends ‘join hands’ in these more formal structures, since such structures can help someone through times of hardship.

**Informal friendship groups**

In addition to, or instead of, these more formalised friendship groups, children also form smaller and more naturally occurring friendship groups that ascend out of mutual attraction, with parity governing their social exchanges. Seventeen-year-old Fanuel took a photo of his three best friends (Figure 1) and described how important they were to
him, both in helping him generate income, but also through encouragement and advice:

‘This picture shows three school children. These children come from the village where I live and go to the same school as me. I took a photo of them because they are happy and because I love them. They are important to me because they help me live well. The boy carrying a schoolbag on the photo is a close friend of mine; I love him very much because he takes the time to teach me many things and helps me with my studies. If he sees me playing and have left studies, he reminds me to go back to the books and says — Son of Alego, you came here to learn, learn, and this will help you in the future. Some friends when they see me playing, they just join me and encourage play. The other two boys I also love, because if they find me working they will join me and help me, even if it is hard work. They do help me and encourage me by saying that there is nowhere in the world where work is easy, saying that I should be prepared to work. And whenever I hear these wise words from them, I become happy and that is why I took a photo of them’ (Fanuel, age 17).

Fanuel loved his friends and appreciated the fact that they wanted what is best for him and helped him stay focused on living well and responsibly. Similarly, 15-year-old Janet expressed affection for a small group of close friends. For Janet, friends enabled her to escape her caregiving role temporarily. She was appreciative of the fun she could have with her friends as well as the opportunities to confide in them:

‘The people on this photo usually come around to my place. We play together, we chat, we play as a group, and have fun. The photo reminds me of how at times I can become very happy with my friends and the stories we share’ (Janet, age 15).

While the children greatly valued the benefits of more formal friendship structures, it is clear from both Fanuel and Janet that smaller and more naturally occurring friendship groups based on mutual attraction offered a level of intimacy and shared happiness that larger and more formalised friendship structures, based on mutual commitment to support each other during times of hardship, do not provide. Although we have presented these two types of friendship structures separately, the children are not part of either structure in isolation, but rather draw on both structures interchangeably as a way of optimising their bonding social capital. Having established the organisation of supportive peer relations, we now outline how friendship groups practically utilise this bonding social capital to cope with hardship.

**Friends share what they have**

One way friends help each other is through sharing. As 12-year-old Lucy suggested, friendship starts with sharing:

‘I want to talk about this photo [Figure 2] because they are my schoolmates. The one with the red jumper is my neighbour. It shows my classmates and children from other classes. I took the photo of them because of our good relationships and it reminds me of how we help one another and can share most things amongst each other’ (Lucy, age 12).

One way to sustain your participation in a friendship group is therefore to share and help out during times of hardship. Although the sharing of joys, pains, feelings and fun is fundamental to all friendships and relationships, in this particular context of poverty and disease, sharing more material items becomes symbolic of the quality of a friendship.

**Friends share school materials**

The school environment is the primary space for children to share and establish friendships. A number of children spoke about how friends helped them obtain school materials in times of need. Both Clare and Millicent explained that if they lacked anything in school, their school-attending friends would share their own items with them:

‘I want to talk about this photo because on it is my schoolmate and friend. She is also my neighbour. The photo reminds me of our good relationship; if I lack a pencil, I can share with her, the same goes for books’ (Clare, age 12).

‘I wish to talk about this photo as it shows my friends. My friends are good, they help me in school because at times I may lack a pen and if I go to anyone of them and ask them, they always give me one’ (Millicent, age 15).
The children also spoke about the importance of sharing food, helping them to overcome food insecurity and to diversify their diet. Fifteen-year-old Carren, in highlighting the importance of friends in helping caregiving children cope with hardship, told how she could go and ask her friends for vegetables to cook if she was short of food:

‘The photo shows how important friends are to one’s life. These friends of mine can help me in various ways. Some of them cultivate vegetables, and if I don’t have food, I can go to them and ask them if they can help me. They will give me some vegetables to go and cook’ (Carren, age 15).

These subsections have highlighted sharing as a key strategy for HIV-affected and caregiving children to access the food and items they otherwise lack, illustrating that sharing is an integral part of friendship in this particular context.

**Friends help each other in practical ways**

Another way friends help each other cope with hardship is through practical support. They do this by assisting with household chores and caring duties as well as securing food and income-generation.

**Friends assist with domestic responsibilities**

As parents or guardians fall ill and children take on more and more responsibilities, it becomes increasingly difficult for the children to balance all their domestic and caring responsibilities with their social life and schooling. One way to overcome this challenge was to carry out these duties and responsibilities with a friend, making it a social activity:

‘I took this picture of my friend whom I always go with whenever we need to fetch something, like fetching water and firewood. We always go to the places together’ (William, age 14).

However, for some children the household chores and caring duties escalate and become so difficult that their friends decide to step in and help out. This was illustrated by Janet who stated that children in the community related well to each other, highlighting a sense of solidarity and understanding for the hardship that some children endure.

As such, Janet’s friends occasionally helped her fetch water, releasing her for some of her duties as a caregiver:

‘In our area, where we live, my fellow school children sometimes come to me, we play together, some love me very much and sometimes bring me water. The photo shows us how fellow children and others help me and bring for me water. We children relate well to one another in the community. At times they assist me and that is why I took this photo, to remind me of that’ (Janet, age 15).

But friends were not only found to help out with fetching firewood and water. Fifteen-year-old Paddy described how his friends, during times when his mother was ill, had assisted him with cooking, cleaning and washing clothes:

‘These children are my friends and they also help me when my mother is sick. They assist me with washing clothes, cooking, cleaning and fetching of water’ (Paddy, age 15).

**Friends assist with food and income-generation**

As parents or guardians fell ill, many children assumed responsibility for their home allotment (shamba) and livestock, which are key livelihood assets. In addition to helping out with domestic duties and the caregiving of a friend’s parent, the children supported each other in providing for and sustaining their households. Fifteen-year-old Pascal for example took a photo of a friend who helped him during periods of hardship and parental illness, explaining that this friend not only assisted him with caring for his mother, but also helped look after their goats:

‘This photo shows my friend who assists me at times when my mother is sick. He comes to help me doing certain duties, such as washing clothes, utensils, tethering the goats and cleaning the homestead’ (Pascal, age 15).

Sixteen-year-old Zeddy also took a photo of one of his friends to show how important his friends were in helping him cope with his life’s challenges. Zeddy struggled in school and spent many hours completing household duties. Assisting him was his friend, who despite coming from another community, would make the journey to come and help Zeddy with homework and working on the farm:

‘This is my friend and he assists me in school, even at home, despite the fact he lives in Lale, far away from us. He helps me with weeding, clearing the compound and in the farm. I also help him in ways he wants’ (Zeddy, age 16).

Zeddy importantly highlights the reciprocity involved in nurturing and accessing these supportive friendships. Zeddy pointed out that the help he received was not charity, but an outcome of his support of his friend. Not all caregiving children however are able to keep the sharing and support reciprocal, and this can have a devastating impact on their friendships. Seventeen-year-old Felicity explained how one of her friends, who had previously helped her out, got tired of supporting Felicity and broke all ties with her:

‘There was a certain child called Mercy in our village, that was coming to help me. We also spent
During times of hardship (we have called these implicit expectation that they would help each other out friendships naturally based on mutual attraction, with the each other cope with hardship in different ways. The tuite bonding social capital. In practice, the children helped and supporting each other, they are more likely to cope from peer social capital.

Aside from illustrating how the agentic capabilities of children in this context help HIV-affected and caregiving children draw on peer social capital to cope with hardship, the findings also point towards some of the contextual factors that enable children to draw on their friendship networks during times of hardship. The school environment is clearly conducive for the development of close friendships and meeting like-minded peers who can lend a hand and share what they have during times of hardship. Although schools are often perceived as simply spaces of learning, we suggest that the school environment is a key space for the development of peer social capital. This being noted, schools are also a conducive environment for the generation of HIV stigma and the bullying of children affected by HIV (cf. Cluver et al., 2010).

Another contextual factor relates to the local understandings and expectations of friendship. Friendships in this poverty-stricken context appeared characterised by sharing and mutual support. While it can be argued that sharing between friends is a natural trait of friendship and may not pertain to their needs as caregiving and HIV-affected children, sharing in this context appeared to be integral to how the children evaluated the quality of a friendship. A final contextual factor contributing to these coping-enabling friendships relates to the children’s observations and imitation of how adult members of community groups support each other by working together as a team and formally commit to reciprocity and sharing. Nyambedha & Aagaard-Hansen (2007) looked into the emergence of community groups in Bondo district and they argue that although duol and siwindhi, which are concepts signifying unity and solidarity within a lineage under the authority of elders, are no longer practiced in the traditional sense, new structures (e.g. church and community groups — thanks to church and donor assistance) dominate the way communities provide care and support for people affected by HIV or AIDS, including children. Unlike the traditional system, the current system transcends kinship patterns and other traditional and gendered relations in Luo social life — responding to contemporary challenges, including HIV and AIDS (Nyambedha & Aagaard-Hansen, 2007). It appears that children in this context will draw on this new structure and way of providing community support as they negotiate support from their friends.

These two contextual factors appear to have arisen from local responses to poverty and the HIV epidemic. This suggests that although the interaction between poverty and HIV is devastating for entire communities, children in these communities are able to adopt new practices (e.g. mobilise support from formalised support networks and their close friendship groups) and build on existing norms (e.g. friendship...
is characterised by material sharing and reciprocity) that help them cope. One might even suggest that the HIV epidemic has provided children and communities with new opportunities for social participation and social change.

A limitation of using PhotoVoice in this study is that it did not involve a formal dialogue, in the form of an interview, between the children and the researcher. Although the children wrote about reciprocity, perhaps indicating that the children within their friendship groups were both vulnerable and in need of support, we cannot comment on whether the children formed the friendship groups based on their individual life experiences and identities. Webb (2007) noted a tendency of orphaned children to form friendship groups as a result of stigma and discrimination, however; he warns that this may contribute to a social stratification of society.

The exploratory nature of the study leaves questions unanswered, but opens up opportunities for further investigation. Does the size of the friendship groups matter? Do children with many friends cope better? How do children who have just moved into a new area and joined a new school access these supportive peer groups? Is it a shared identity that nurtures these friendships?

Despite many unanswered questions, we conclude that ‘peer social capital,’ understood as the norms and practices that children draw on and adopt to secure benefits through membership in formalised and/or informal friendship groups, plays a key role in enabling HIV-affected and caregiving children cope with difficult circumstances. This coping strategy illustrates children’s agency in responding to hardship and must be considered by programme planners and policy actors, together with an appreciation of the contextual factors that enable children to mobilise and participate in friendship networks.

Acknowledgements — We thank the children who participated in this study. We also thank Cellestine Aoro for her help with facilitating the PhotoVoice project.

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References


Skovdal and Ogutu


Schoolchildren affected by HIV in rural South Africa: schools as environments that enable or limit coping

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The importance of psychosocial support for the wellbeing of children made vulnerable by HIV is a frequently discussed topic in the fields of education and HIV-related social science research. For children to juggle both the demands of education and the impacts of HIV is an enormous challenge. Against this background, schools have been hailed as potential sources of support, yet we know little about how the school environment can provide support, which might reflect the lack of input from schoolchildren themselves. This article explores how schoolchildren made vulnerable due to HIV and AIDS might cope and even thrive in a rural school environment in South Africa. I argue that schoolchildren’s own contributions and abilities are fundamental to accelerate their coping strategies, allowing them to step back from vulnerability and so gain perspective about it. An inductive analysis makes use of data generated from a method of participatory photography (PhotoVoice), conducted with schoolchildren aged 16–18 years at a rural school in KwaZulu-Natal Province. The article draws on the concept of appreciative inquiry as a framework for examining coping strategies among schoolchildren made vulnerable by HIV. The findings point to the schoolchildren’s ability to identify and access resources that will encourage them to cope with HIV-related adversities in their own lives. The participants revealed an ability to point out perceived social and structural challenges that have a dominant influence on their coping strategies.

Keywords: appreciative inquiry, assets, coping, PhotoVoice, psychosocial aspects, research methods, rural settings, visual participatory methods

Introduction

International policies and the academic literature have positioned schools as nodes of care and support. The idea of ‘caring schools’ has developed along with children’s increasing vulnerability due to HIV and AIDS and other factors (UNESCO, 2008; UNICEF, 2011). In South Africa, a number of policy documents have been developed in response to the challenges faced by children affected by HIV. These documents include phrases such as ‘schools as inclusive centres’ (Department of Basic Education & MIET Africa, 2010); ‘friendly schools, caring schools, healthy schools’ (UNESCO, 2008); and ‘schools as nodes of care and support’ (Soul City Institute for Health and Development Communication, 2006) — phrases that have been repeated in the peer-reviewed literature (Kendall, 2007; Kendall & O’Gara, 2007; Williams, 2010). Although best known for promoting academic excellence, schools can serve as a platform for nurturing young people, and they provide a framework through which care and support is available. As indicated by Wood & Hillman (2008, p. 186), “Schools should try to create an environment in which children feel loved, secure and valued, since many of them may not receive this support at home.”

There is growing recognition of the need for children’s participation in decisions relating to their lives (McCee & Greenfield, 2011). Hence, schoolchildren need to be consulted about their needs, as their own interpretations provide important insight into many contemporary issues, including children’s coping strategies. Of importance to this study was schoolchildren’s experience of care and support in the age of HIV and AIDS, and how their experiences might enable them to cope with adversity in a rural school context. While I appreciate the role that the school plays in providing care and support to schoolchildren made vulnerable by the HIV epidemic (see Davis & Wright, 2008; Khanare, 2009), I argue that coping differs from one person to another.

This article employs appreciative inquiry (AI) (Cooperrider & Srivasta, 1987) to frame a discussion of children’s coping strategies in the age of HIV and AIDS in a rural school setting in South Africa. AI challenges the problem-oriented approach that is often applied by research, and the concept recognises people as having the potential to become agents of their own lives. For instance, AI may help draw attention to important but otherwise ‘hidden sources of coping’ (Grant & Humphries, 2006).

As a tool for development and inquiry, AI focuses on “what is possible rather than what is wrong” or impossible (Van Buskirk, 2002, p. 67). AI as a tool for inquiry is premised on and appreciates schoolchildren’s agency by focusing on the processes and ability of pupils to identify the enablers...
of and barriers to coping. I chose this framework because it contrasts with the commonplace notion that vulnerable schoolchildren are ‘a problem,’ needy and in need of support from outsiders, with the appreciative proposition of valuing the active role they play in managing their everyday lives. In this connection Poku (2006, p. 113) writes: “Coping can be developed through previous experience, observing others, a perception of one’s own biological disposition and social persuasion.”

Folkman & Lazarus (1985) note that coping is a complex phenomenon involving a multiplicity of processes. In the same way, Schwarzer & Schwarzer (1996) indicate that coping with an adversity includes numerous ways of dealing with diverse persons and environment transactions as well as the conflicts between them. A primary tenet in this article is that efforts to cope with HIV-related issues are embedded in a rich social context (i.e. school). Therefore, by including the schoolchildren, harnessing and appreciating the positive role they can play in recognising their own coping strategies we can demystify the complexities.

Thoughts, feelings and actions make up the coping strategies that are called upon to varying extents in particular circumstances (Poku, 2006). Efforts to improve and expand the role of the school require the understanding of heterogeneity (Folkman & Lazarus, 1985) in children’s coping with hardship. While some great strides are being made in policies and practices concerning HIV-related care and support, much more needs to be done to understand and enable individuals, particularly vulnerable schoolchildren, to survive in a world shaken by HIV and AIDS (Ogden, Esim & Grown, 2006). This article contributes to ongoing debates about the plurality and fluidity of people’s coping strategies. It is premised on the AI approach and uses the visual method PhotoVoice to highlight schoolchildren’s agency in (re)creating their own coping strategies in a school context.

**The construction of care and support in relation to schooling**

Reflecting the dominant understandings of educators’ perceptions about schools as centres of care and support, particularly in the context of HIV and AIDS, many research findings have described the emotional and financial cost to teachers. Teacher burnout with regard to the care and support of schoolchildren who are vulnerable has been reported by studies in several countries, such as China (Huang, 2008), South Africa (Ramokhoase, 2005; Bhana, Morrell, Epstein & Moletsane, 2006; Theron, 2007; Parag, 2009) and Lesotho (Ntaote, 2011). A didactic school environment can also contribute to a perception that only adults and teachers contribute to these care and support responsibilities (Abebe & Skovdal, 2010). In contrast, there is evidence that this so-called ‘adult support’ does not always meet the needs of schoolchildren made vulnerable because of HIV and AIDS (Van Dijk & Van Driel, 2009).

Teachers are struggling to offer care and support to schoolchildren — not only because of resource constraints, but also because of victimising representations of ‘needy’ children (Rolon-Dow, 2005; Skovdal, 2010). Such discourse portrays schoolchildren affected by HIV as passive or ‘a problem.’ This in turn makes it harder for the children to exercise their agentic capabilities. Such attitudes contradict the argument of Eley (2004) who asserts that care that is more extensive, effective, and supportive of vulnerable schoolchildren must not be developed from a perspective of simply seeing them as deficient or needy.

The success of school-based interventions depends on interaction between all school community members, including schoolchildren who are vulnerable. Significant progress has been made towards the inclusion of young people in intervention programmes, something deemed necessary for a sustainable and effective response to the needs of young people. This is best illustrated by Shiller (2009) who explored relation-building practices in a poor urban community in New York City. Her findings reveal that students were motivated by a desire to be engaged through holding students to high expectations and creating an environment that would address their needs. With these students, care meant understanding their lives outside school and viewing them as assets rather than feeling sorry for them.

**Reciprocity and children’s agency**

In many sub-Saharan countries, it has been recognised that many schoolchildren made vulnerable due to HIV and AIDS juggle the experience of being a ‘young carer’ and a pupil at school. Such experience should be identified as a potential asset to the school. In Lesotho, in the absence of parents or secondary caregivers (such as extended family and neighbours) due to HIV-related issues, young people often take on the primary role of support for their surviving and younger family members (Morojele, 2011). Similar findings have been reported from rural areas of Zambia (Esu, Williams, Schenk, Motepe, Zulu, Bweupe & Weiss, 2006). A study of young carers in a rural community in Zimbabwe found that children involved in anti-AIDS school clubs were admired and respected by their peers for their efforts to care for their ailing parents (Campbell, Skovdal, Mupambireyi & Gregson, 2010).

It is evident that the coping capacity of schoolchildren made vulnerable by HIV and AIDS involves “critical care praxis” (Rolon-Dow, 2005, p. 104) wherein the children’s experiences are seen not simply as obstacles to personal functioning and schoolwork but also as assets and resources that teachers might make use of. By recognising the role that many young people are actually performing in their homes, teachers and schools could learn from and harness young people’s skills (Davis & Wright, 2008).

**Participatory visual methodology**

In an effort to recognise the skills and attributes of young people who must care for household members affected by HIV, the research sought to draw connections between young people’s skills in this regard and what schools and teachers can do to further support them. To do this, I used a method of participatory photography called PhotoVoice. Fargas-Malet, McSherry, Larkin & Robinson (2010) provide a brief up-to-date examination of participatory methodology, highlighting the capacity to more fully incorporate indigenous and minority populations into the process of knowledge construction. Other researchers have paired
this with visual methods; as a result, visual participatory methods have caught the eye of many researchers dealing with the ‘cultural embeddedness’ of HIV and AIDS among young people (e.g. Olivier, Wood & De Lange, 2007; Park, Mitchell & De Lange, 2007; Balfour, Mitchell & Moletsane, 2008). Therefore visual participatory methods have been chosen by researchers for their merits when engaging with young people, as this offers a forum for sharing and voicing experiences.

Sullivan (2010) contends that visual participatory methods provide a sense of enjoyment in the research activities. The participants in this study learnt visual skills while they actively produced visual artefacts (photographs). They had an opportunity to choose what to talk about and to say which experiences were important to them, to give them space to think about and reflect on their own lives in relation to coping with issues relating to HIV and AIDS.

Research context

The study was undertaken in uMgungundlovu district in KwaZulu-Natal (KZN) Province, South Africa. South Africa registered a decrease in HIV prevalence between 2007 and 2009, with national HIV prevalence estimated at 29.4% (UNAIDS, 2010). Among the different provinces, KZN has the highest level of HIV prevalence (39.5%); uMgungundlovu district is the second most-populous area in KZN, with over one million citizens, and has an estimated level of HIV prevalence of 40.9%, which is well above both the national and provincial estimates (Department of Health, 2010).

A large proportion of the district’s inhabitants live in rural areas, where there is little social and physical infrastructure for households and often inadequate or no sanitation and poor access to clean water and health facilities. Over 60% of the population is unemployed, and close to 70% of those who are working earn less than R1 500 per month (Education and Training Unit, 2011). Roughly half the population is under age 20 years. Consequently, schools in the rural areas are severely challenged in responding adequately to the needs of children (Khanare, 2009).

Data relating to the coping strategies of schoolchildren made vulnerable by HIV and AIDS were generated over four months in 2011 at two rural schools. The inclusion criterion for the schools was its location in a rural community with a high level of HIV prevalence. Ten Grade 11 pupils (boys and girls) were purposively selected at each school. The teachers informed me that many schoolchildren at the schools were from households with no regular income, some lived in child-headed households, and some were orphaned. Although these issues were considered relevant to the study, they were not prescriptive measures for participation. The participants were purposively selected to target information-rich sources (see Nieuwenhuis, 2007).

Data collection

While some of the participants had used digital cameras previously, none had training in PhotoVoice. I engaged the participants in formal PhotoVoice training based on my previous experience with qualitative research and by drawing on the practical suggestions of other researchers (e.g. Wang, 2006; Mitchell, 2011). The participants received technical instruction in how to use a camera and the ethical guidelines of photography were also discussed. Due to limited time with the participants, a group of five pupils at each school were given 45 minutes to take photographs depicting their experiences of coping with HIV and AIDS in a school setting. To this end, I used the following prompt: ‘Take photos to represent your experiences of coping with the adversities of HIV and AIDS in your school.’ Afterwards, the participants were asked to briefly explain the photographs in a 10–15 minute individual presentation to the whole group. The presentations included explanations of each photo and its intended meaning, ensuring a conversational dialogue between the participants and myself as researcher. The presentations and discussions were video recorded and later transcribed verbatim.

The data were analysed through an inductive and iterative process (Nieuwenhuis, 2007; Vaughan, 2010). Given that PhotoVoice is well situated to participatory-oriented analysis, the participants took part in the data analysis. Thus, selecting the photographs, contextualising the photo-narratives, and codifying the issues, themes or theories occurred during our group discussions. To analyse the data, I adopted the three-step process described by Wang (2006). First, the participants were asked to select and talk about photographs that they felt were most relevant and significant to coping strategies in the context of HIV and AIDS. Second, the participants were instructed to take a critical stance towards their photographs through the mnemonic ‘SHOWed’ (see Wang, 2006, p. 151):

- What do you see here?
- What is really happening here?
- How does this item relate to our lives?
- Why does this situation, concern, or strength exist?
- What can we do about it?

Third, the participants codified the issues and themes that arose from the group discussions. As a group, they generated a collaborative (written) understanding of what they felt constitutes care, support and coping. And finally their responses were categorised according to attributes concerning coping-enabling opportunities and coping-inhibiting dynamics within the school environment.

Permission to undertake the study was obtained from the KZN Department of Education. Informed consent was obtained from the school principals and various teachers, parents and students. The purpose of the study was explained to the Grade 11 children and they participated voluntarily; they were free to withdraw from the study at any time or to not respond to particular activities if they felt uncomfortable with them. Furthermore, I gained permission from the specific participants whose photos are reported on here. The participants devised their own pseudonyms.

Findings and discussion

This discussion values and appreciates the active role that young people play in coping with HIV-related issues in a rural school context, by employing the lens of appreciative inquiry (AI). AI also presented compelling potential for the participants to ‘step up’ and identify both the enablers and barriers to coping with HIV and AIDS in a rural context. The
findings are presented in two sections: first, by detailing the participants’ perceived coping-enabling opportunities within the school context, and, second, by describing the perceived social and structural factors inhibiting development of their coping with HIV-related adversities in a school context.

Coping-enabling opportunities within the school environment

The participants’ coping strategies leaned towards the support they got from other people, particularly friends and peers. They seemed to derive clear and realistic expectations from peers and friends. There was no obvious difference in the responses of females and males — both appeared equally likely to approach their peers for support. Hence, the schoolchildren most obviously reflected an ability to cope with adversities in the school through their articulation of having supportive friends:

‘I have a friend by the name of Maroses who helps me when I am sad because of problems at home; so Maroses comforts me so that I do not feel like I am lonely here at school’ (Sunflower, age 16).

‘This is my friend [in Photo 1]. He is more than a friend to me, he is like my brother, he knows the situation at home and I know his situation too; we are now like family and we help each other through difficult times’ (Terminator, age 17).

Some participants sought supportive friends as enabling their own schooling. For some participants, such as Romeo and Romero, supportive friendships were seen as a possible way to achieve their personal goals and dreams:

‘On this photo [Photo 2] it’s when I was playing with my friend showing love on whatever the situation he was facing, I’m on his side. It was a time of laughing [despite] all our problems we are facing at school or even at our homes. Each and every day we work together with my friend to achieve our goals or our dreams so that we can be something in life or we can have a better future. Even if my friend is HIV-positive, there is no need to forsake him, I still have to show love, care and support on everything he is doing or we are doing’ (Romeo, age 17).

‘Each and everyone have a goal to achieve and even if you are poor you want to move away from that situation you are in or [do it] for your children. In this photo [Photo 3] it’s when we work together with my friend to achieve our goals or our dreams; it is upon to us that we can be something better in life or we can have a better future than our parents. Care and support to us also mean influencing our friends to work hard; we should not wait [for] that to come from the teacher’ (Romero, age 17).

The data revealed a process whereby individual children connect with others as they anticipate and cope with everyday challenges in their school-life. As noted in the excerpts above, coping spans from being highly individualised to being coordinated or shared with others, such as when friends share similar appraisals of their difficulties and their approaches to coping. This corroborates the findings of Kosciulek (2007) who noted that coping is socially constructed, with emphasis placed on the ability to mobilise
as many resources as possible. In the broader context of HIV and AIDS and the school environment, schoolchildren are likely to turn to their peers: the participants demonstrated agency through their ability to identify friends at school who held clear and realistic expectations regarding shared life goals, such as completing their studies.

An identification or discovery of resources is closely related to the concept of AI. People talk to one another about their accrued experiences, as well as ask for ‘ideas’ and ‘opinions of what could be’ (Grant & Humphries, 2006). The schoolchildren were able to seek assistance or assist their peers as a means to (at least temporarily) forget devastating situations in their respective homes. Thus, working together in this way creates an avenue for young people’s active participation in a response to the impacts of HIV and AIDS, in the school context and beyond. The participants’ responses show that they viewed other pupils’ contributions as key to coping with the adversities of HIV and AIDS.

As implied, coping seldom takes place in a social vacuum. Not surprisingly, the participants identified teachers as assets that they could draw from in the context of coping with personal adversity. The everyday presence of teachers, and their distinctive values and beliefs, are apt to assist the coping strategies of vulnerable pupils, as indicated by the participants:

‘I took this photo [Photo 4] in Mrs Z’s office. She is our queen mother, all the learners come to her when they have problems; even teachers tell us to go to her when we report our problems to them. One day I had a serious problem at home and I was not doing well with my schoolwork; she even told me she will bring the social worker to check my home as well as [check on] me how [and how I] react to my studies’ (Dollar, age 15).

Another participant said:

‘If I have a problem, I normally go to my dearest teacher; she sits alone in the office waiting for us. I love her because she is so down to earth; she listens to all the learners’ stories. Not even on one day she will shout at us like other teachers’ (Thobela, age 16).

This participant clearly saw the teacher as a resource to facilitate students’ coping. As one part of a ‘conception of good,’ the participants acknowledged the capacity of teachers to make basic resources available to them in order to cope with HIV-related issues in the school context:

‘At school we have learners who need help, like those who need some food and clothes; some teaches give them food and organise uniforms for them for visitors who normally visit our school. I told this teacher about my problems and she often tells me not to stress’ (Starlight, age 15).

‘There are teachers’ cars found at school. These cars are more helpful to the emergencies times that prevail in our school, because the clinic is far; sometimes when some learners are sick, the teachers’ cars are used’ (Sweet Potato, age 19).

In these responses, it is apparent that coping encompasses a range of services and teachers’ ethos are important to adequately help pupils with coping while in schools. Many of the participants chose to present photos that showed the perceived qualities of the “person’s personality or character” (Davis & Wright, 2008, p. 27). For instance, coping with HIV-related adversity was helped by teachers with qualities like listening skills and sensitivity to pupils’ needs; such an environment provided the schoolchildren with greater opportunity for coping.

The participants also sought support from other sources, such as faith-based organisations and peer-education programmes:

‘As a Christian I normally go to church; I chose a church because this is where I get strength to carry on, it is so powerful there and there is no gossiping there about the sick, we all support each other to be strong. We sometimes share sessions on HIV/AIDS with other organisations from other churches or volunteers’ (Menzi, age 16).

‘There is also a project in my school called Mayikhethele [‘Your Choice’]. Peer educators motivate us about HIV, teach us life skills like how to cope with your studies and peer pressure’ (Maroses, age 18).

These comments demonstrate that HIV-affected schoolchildren may locate assets beyond the school setting to improve their coping capacity and wellbeing (cf. Williams, 2010). Thus, by identifying organisations outside the school environment, schoolchildren are capable of acting out against the challenges of HIV by drawing from resources other than teachers and peers alone.

Central to AI is the notion of best of practice — since an organisation that attempts to appreciate what is best in itself will discover more that is good (Seel, 2000). The participants’ coping strategies, as revealed thus far, were helped by teachers’ best practices in the school setting. If the pupils were listened to, they could express their feelings and state what coping-enabling resources they had identified, whether internal or external ones (cf. Raskind, Goldberg, Higgins & Herman, 2003).

Approachability is often considered a dominantly feminine characteristic. Previous studies have documented women’s substantial involvement in the household in
terms of safeguarding the education of children who are vulnerable, particularly in AIDS-afflicted rural areas (e.g. Nyamukapa, Foster & Gregson, 2003; Oleke, Blystad, Fylkesnes & Tunwini, 2007; Lund & Agyei-Mesah, 2008). In this study, interestingly, Menzi, a Zulu boy, and Tabbly Mounty, a Zulu girl, each chose a male teacher as someone approachable in their school rather than one of their female teachers. By situating male teachers as approachable and kind, the participants were challenging cultural discourses that implicitly or explicitly equate men with being largely uncaring (O’Neill, 1997). In a school context, the quality of ‘caring’ may variously entail educators’ duty to human rights, empathy, and emotional involvement to the benefit of schoolchildren (Morrell & Jewkes, 2011).

So far, the discussion has illustrated how the use of AI enabled the participants to express their views about HIV-related coping-enabling opportunities with the school environment. The findings indicate the complexity with which these pupils understood their circumstances in relation to these opportunities. The next section highlights their ability to identify coping-inhibiting factors within the school setting.

**Coping-inhibiting factors in the school environment**

Applying AI not only brought out positive coping strategies, as experienced by the participants, but also allowed them to identify barriers to their coping strategies in schools in the context of HIV and AIDS. AI does not focus excessively on “warm, fuzzy group hugs” (Grant & Humphries, 2006, p. 403), but rather uncovers multidimensional meanings of appreciation. For example, schoolchildren made vulnerable by HIV and AIDS may be conscious of barriers to their coping strategies and thereby transform them into best practice. As such, it makes the argument for re-engaging with inquiry imperative. Hence, this section highlights these schoolchildren’s ability to identify coping-inhibiting factors within their school environment. Likewise, these findings reveal factors that warrant scrutiny within the school environment in order to enhance the learners’ coping strategies.

Contrary to early discussion about teachers as essential for developing schoolchildren’s own ability to cope with HIV and AIDS, the majority of participants were adamant that they would never share their HIV-related problems with teachers, no matter how much they would like to. For instance, teachers who lack listening skills and personable qualities and who appear insensitive might strain pupils who otherwise endeavour to cope with their challenging situation. Accordingly, one participant said about her photo:

*This is me [in Photo 5]; I was so sad to what has been said to my friend whom I know they have problems at home. Sometimes teachers ask funny questions in the class and other learners laugh at you, like — Why didn’t you comb your hair? Have you bathed? — and so on’ (Teddy Bear, age 17).*

Another girl also mentioned unpleasant days at school:

*I was disappointed by my teacher. Once upon a time I told my teacher I need to go home early because my mum is sick; my teacher was not an answer to my problem, the only thing she said was — You are full of craziness and laziness you are never going to be able to pass. This photo represents the pain of ignorance; they [teachers] take us for granted’ (Proteah, age 17).*

These quotes show a teacher’s insensitivity and ignorance as an obvious barrier to the girl’s coping. The lack of support from teachers was perceived throughout the participants’ responses as being a key, but not sole, source of their own inability to cope. In the defence of teachers, however, there is extensive research literature on the extent of teachers’ emotional stress and burnout within the school environment (e.g. Ramokhoase, 2005; Bhana *et al.*, 2006; Theron, 2007; Parag, 2009; Morojele, 2011).

There is an added element to schoolchildren’s concerns about coping-inhibiting factors: schoolchildren who experience being bullied and abused by other schoolchildren (a somewhat familiar phenomenon in the school context) is particularly straining. Some of the participants’ photos and narrations indicated this type of bullying by peers:

*‘There was this group of two girls who happen to be my classmates. They always saying nasty things about me. I am worried because the other girl is my ‘home-girl’ and knows the conditions at home’ (Proteah, age 17).*

*‘Sometimes it is very difficult to cope in school, meaning I cannot cope with HIV and AIDS as long as other people tease me about my poverty condition. You see this group of learners tease me about where I come from, about my family — that we are so poor we do not have anything — and I really feel bad. Everything is not so good’ (Myke, age 16).*

These participants are reflecting on how bullying impacts them in a myriad of adverse contexts — in classrooms and at home; this in turn impacts their ability to cope with life’s adversities. The participants also highlighted poverty as a factor that hinders coping with HIV and AIDS. Moreover, poverty can be accompanied by feelings of isolation, withdrawal, and a lack of self-esteem or self-confidence, especially among young people affected by HIV (Van Niekerk & Kopelman, 2005).

Another appraisal of the participants’ responses reveals poor implementation of policies that aim to support and
protect schoolchildren. This shortcoming creates an environment that causes more strain and pressure on schoolchildren who are trying to cope using their own resources. The most significant identification of this point is the participants’ reflection on corporal punishment. This pupil’s point is simple but stark:

‘I was sick having flu, but I decided to come to school even though I was not feeling one-hundred percent good. I was beaten by my principal and I told him that I had brought with me a reporting letter of why I was not at school the day before. Damage has already been done as I was not given a chance to explain’ (Tabby Mounty, age 17).

The school realm in which schoolchildren live denotes the gap between policies and practice. It is well known that corporal punishment in South African schools has been abolished (Republic of South Africa, 1996). However, the actuality of such policy is far from the experience of many schoolchildren. Not surprisingly, Tabby Mounty’s explanation of her photos implies that the violation of some policies could have a negative influence on students’ coping with HIV-related adversities.

A closer look at the South African Schools Act (Republic of South Africa, 1996), the national policy on HIV/AIDS for learners and educators in public schools, and students and educators in further education and training institutions (Department of Education, 2003), as well as Curriculum 2005 and the Revised National Curriculum (Department of Education, 2005), illustrates how teachers contribute towards the holistic development of all children (Prinsloo, 2007; UNESCO, 2008). Teachers should act in the best interests of the children, including many made vulnerable by HIV and AIDS.

Conclusions

The discussion has illustrated how using appreciative inquiry (AI) enabled the participating schoolchildren to express their own views about coping-inhibiting factors within their school environment. Borrowing from Grant & Humphries (2006), ‘appreciation’ could also mean ‘to know’ and ‘to be conscious of’ the complexity with which these schoolchildren understood their context relative to HIV-related coping abilities and opportunities.

The concept of a ‘caring school’ is plural and fluid, and could be defined as including all stakeholders among whom a school is situated. This research employed AI to examine how schoolchildren in a rural context in South Africa coped with HIV-related adversities. Taking a wide range of research evidence into account, I suggest that schoolchildren appreciate and acknowledge the efforts made by their school peers in response to such adversities. Peers comfort each other during times of trouble, whether at home or at school.

Several successful coping mechanisms derived from the schoolchildren’s efforts and willingness to join a peer-education programme, where they said they learnt much about life skills. Thus, peer-education programmes will be relevant to schoolchildren’s lives in and outside of school, and these need to be strengthened as an alternative, educative tool for enabling schoolchildren’s coping strategies.

The participants depicted some teachers as resources through which they could become more resilient and adaptable to changing conditions. To these schoolchildren, coping-enabling strategies were also embedded in the concept of teachers’ ‘best practices’: teachers who listened to them and were sensitive to their needs could accelerate how they coped in the school environment.

AI also provided an opportunity for the participants to become conscious of and identify specific coping-inhibiting factors within the school environment. Some pupils said they still felt vulnerable to bullying by their peers. Another impediment identified by them was teachers who lack listening skills and personable qualities, as they appear insensitive to the needs of schoolchildren affected by HIV.

Poor implementation of policies intended to support and protect schoolchildren was also evident as a barrier to coping with adversity, as it creates an environment that causes more strain and pressure on schoolchildren who otherwise endeavour to cope.

In deflecting attention away from the seemingly negative issues shared by the participants, I may have lost a valuable opportunity to learn more about their constraints to coping with HIV-related adversity in the school context. AI became an exercise to expose the schoolchildren to enablers and inhibitors of their coping strategies in school and in the context of HIV and AIDS. The use of the concepts of ‘appreciating’ (valuing the best of what there is), ‘envisioning’ (what might be), ‘dialoguing’ (what should be) and ‘innovating’ (what will be) provides an effective approach for the development of coping and agency among schoolchildren. By employing the PhotoVoice technique they were able to create and recreate their coping strategies within the school context. This tool provided a social setting where the participants individually and collectively discussed what worked for them and what could work for them in terms of coping with HIV-related issues in the school context.

By building on already existing resources, young people can be supported by equipping them with the skills necessary for meeting a range of their own and their peers’ care needs. While their own efforts and peer-based resources must not be taken for granted, schoolchildren should also be supported through opportunities outside of school life.

Acknowledgements — With great thanks to Marguerite Daniel, Morten Skovdal, Cynthia Kulongowski and the anonymous reviewers for their very helpful comments and feedback. Special thanks to the pupils and staff at the two schools participating in this study, and to my colleagues and friends at the University of KwaZulu-Natal (UKZN) and Nelson Mandela Metropolitan University (NMMU) (South Africa). I am also very grateful to Prof. Naydene De Lange, my doctoral supervisor, for her intellectual insight and constant encouragement. I gratefully acknowledge the National Research Foundation (South Africa) and the UKZN School of Education Research Office for financial support of the current PhD project on which this article is based on. The ideas expressed in the article are the responsibility of the author alone.

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References


How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma

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Introduction

The situation of people living with HIV has changed dramatically following the rollout of antiretroviral therapy (ART). ART has shifted HIV infection from being a terminal disease to a chronic illness. The improved availability of ART and associated services has helped suppress the replication of the virus in many HIV-infected people, enabling them to return to socially and financially productive lives. There is some debate about how this normalisation of HIV infection, ART, and children’s psychosocial wellbeing, including from the perspective of adolescents themselves. Two qualitative studies were carried out, in Botswana and Tanzania, in 2011: 16 adolescents and three healthcare workers were enrolled in Botswana, and 12 adolescents and two healthcare workers were enrolled in Tanzania. The data were collected through individual and group interviews as well as participant observation. The recorded interviews were transcribed and analysed using thematic network analysis. The findings indicate that HIV-status disclosure enabled adolescents to engage effectively with their ART treatment and support groups, which in turn provided them with a sense of confidence and control over their lives. Although the adolescents in the two studies were still experiencing stigma from peers and community members, most did not internalise these experiences in a negative way, but retained hope for the future and felt pity for those untested and uninformed of their own HIV status. We conclude that disclosure and good HIV-related services provide an important platform for HIV-infected adolescents to resist and cope with HIV stigma.

Keywords: Botswana, HIV/AIDS, medication adherence, qualitative research, social support, Tanzania, thematic network analysis, treatment support, youths

HIV-related stigma has a major impact on the health and psychosocial wellbeing of HIV-infected children and youths. While there is some debate about the extent to which improved access to antiretroviral therapy (ART) contributes to a reduction in HIV stigma, we know little about how adolescents who know their HIV status and who are enrolled in ART experience and cope with stigma. The aim of the research was to understand and identify the pathways between HIV-status disclosure, ART, and children’s psychosocial wellbeing, including from the perspective of adolescents themselves. Two qualitative studies were carried out, in Botswana and Tanzania, in 2011: 16 adolescents and three healthcare workers were enrolled in Botswana, and 12 adolescents and two healthcare workers were enrolled in Tanzania. The data were collected through individual and group interviews as well as participant observation. The recorded interviews were transcribed and analysed using thematic network analysis. The findings indicate that HIV-status disclosure enabled adolescents to engage effectively with their ART treatment and support groups, which in turn provided them with a sense of confidence and control over their lives. Although the adolescents in the two studies were still experiencing stigma from peers and community members, most did not internalise these experiences in a negative way, but retained hope for the future and felt pity for those untested and uninformed of their own HIV status. We conclude that disclosure and good HIV-related services provide an important platform for HIV-infected adolescents to resist and cope with HIV stigma.

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Introduction

The situation of people living with HIV has changed dramatically following the rollout of antiretroviral therapy (ART). ART has shifted HIV infection from being a terminal disease to a chronic illness. The improved availability of ART and associated services has helped suppress the replication of the virus in many HIV-infected people, enabling them to return to socially and financially productive lives. There is some debate about how this normalisation of HIV infection and AIDS illness may impact HIV stigma. Commentators from Botswana (Wolfe, Weiser, Leiter, Percy-De Korte, Phaladze et al., 2008), Kenya (Kaai, Sama, Luchters, Geibel, Munyao, Mandaliya et al., 2007), Haiti (Castro & Farmer, 2005) and Mozambique (Pearson, Micek, Pfeiffer, Montoya, Matediane, Jonasse et al., 2009) have argued that improved access to ART is associated with reduced levels of HIV stigma. A Tanzanian study found that ART contributed to a degree of normalisation of HIV infection, yet it continues to be stigmatised as a ‘moral disease,’ which undermines disclosure and voluntary counselling and testing (Roura, Urassa, Busza, Mbata, Wringe & Zaba, 2009; Roura, Wringe, Busza, Mbata & Zaba, 2009).

Reconciling this debate, a recent study by Campbell, Skovdal, Madanhire, Gregson & Nyamukapa (2011) found that the improved availability of ART in Zimbabwe did not necessarily reduce the presence of stigma, but provided people living with HIV (PLHIV) — through their ability to take control of their own health and return to living socially and economically productive lives — with the opportunity to resist and challenge stigmatising attitudes. They did so by constructing an empowering distinction between ‘us’ (the self-identified PLHIV who live positive and productive lives) and ‘them’ (the stigmatising, ignorant and untested others). As we are unaware of any previous study discussing the interface between ART access for adolescents and their ability to cope with stigma, we sought to build on that finding in relation to adolescents in Tanzania and Botswana, and to explore how HIV-infected adolescents on ART manage to cope with HIV stigma.

HIV stigma and adolescent health and wellbeing

Several studies have highlighted how fear, ignorance and a lack of basic knowledge about HIV and AIDS contribute to the stigmatisation of PLHIV (e.g. Campbell, Fouls, Mainman & Sibiya, 2005; Holzemer & Uys, 2005; Mutalemwa, Kisoa, Nyigo, Barongo, Malecela & Kisinha, 2008; Nyblade, MacQuarrie, Kwasigabo, Jain, Kajula, Philip et al., 2008; Akande, 2010). Children and adolescents living with HIV, as well as children living with family members with HIV, are likewise subjected to gossip, discrimination and hostility because of their association with HIV (Goffman,
1963; Deacon & Stephney, 2007). Although HIV stigma is often defined as “an attribute that is deeply discrediting,” this article concurs that stigma should be discussed in the “language of relationships not attributes” (Goffman, 1963, p. 3).

A literature review by Deacon & Stephney (2007) highlights studies that show that children are affected by HIV stigma in a number of ways. Children can be affected directly (when the child is the subject of stigma) and indirectly (when caregivers are the subject of stigma). Most studies to date have looked at the indirect impact. For example, stigma has been found to influence the decision of parents or caregivers to not tell their child that he or she is HIV-positive — undermining the child’s ART adherence (Bikaako-Kajura, Luyirika, Purcell, Downing, Kaharuza, Mermin et al., 2006). Parents or caregivers with HIV-infected children on ART, and who struggle to facilitate the child’s ART adherence, might refrain from seeking support from neighbours or other community members because of non-disclosure and fear of stigma (Hejoaka, 2009; Skovdal, Campbell, Madanhire, Nyamukapa & Gregson, 2011).

**The mental health of children and youths with HIV infection**

Living with HIV and the pressure to comply with a treatment regimen is undoubtedly stressful. A number of studies have highlighted the psychological distress experienced by HIV-infected children and youths. Research in North America suggests that adolescents living with perinatally acquired HIV have higher rates of psychiatric illness than their uninfected peers (Koenig, Nesheim & Abramowitz, 2011; Malee, Tassiopoulous, Huo, Siberry, Williams, Hazra et al., 2011). This can further impact disease progression, as studies of HIV-positive adults in the United States found evidence that stress and traumatic life events are associated with non-adherence to antiretroviral medication (Mugavero, Ostermann, Whetten, Leserman, Swartz, Stangl & Thielman, 2006; Leserman, Ironson, O’Cleirigh, Fordiani & Balbin, 2008). A literature review examining the role of depression, stress, and trauma in HIV-disease progression reports that psychosocial factors negatively affect disease progression. Whether it is depression that puts a person at greater risk of disease progression, or rather disease progression that causes increased risk of depression, is still under debate (Leserman, 2008). Interestingly, however, recent evidence suggests that children and adolescents who live with someone who is HIV-positive and who are not infected with HIV themselves, have greater mental health problems than their HIV-infected peers (Malee et al., 2011). Malee et al. (2011) proposed that this difference may be explained by the immediate enrolment of HIV-infected children and youths into treatment support networks — an opportunity for support generally unavailable to HIV-affected children and youths.

Only a few studies have examined the mental health challenges of children and youths living with HIV in sub-Saharan Africa (e.g. Menon, Glazebrook, Campain & Ngoma, 2007; Li, Jaspan, O’Brien, Rabie, Cotton & Nattrass, 2010; Petersen, Bhana, Myeza, Alicea, John, Holst et al., 2010). A study by Petersen et al. (2010) found that over half of their South African study participants showed signs of internalised stigma, and they argue that stigma can also lead to the inability of HIV-infected children to express their distress. The study also found that factors associated with coping with distress included the availability of life-prolonging medications, strong family social support, and extensive supportive networks (Petersen et al., 2010).

**The importance of disclosure to children and youths with HIV infection**

Despite the fact that non-disclosure of HIV status to HIV-infected children is a common barrier to their ART adherence (Nabukeera-Barungi, Kalyesubula, Kekitiinwa, Byakika-Tusiime & Musoke, 2007; Polisset, Ametonou, Arville, Aho & Perez, 2009), several studies have reported low levels of disclosure to children about their own HIV-positive status (Biadgilign, Deribew, Amberbir, Escudero & Deribe, 2011; Kallem, Renner, Chebremichael & Paintsil, 2011; Vaz, Maman, Eng, Barbarin, Tshikandu & Behets, 2011). Parents or caregivers may choose not to disclose a child’s own HIV-positive status to the child for a number of reasons. These include fear of discrimination towards the family if the child reveals their status to others, fear of being judged by the child, as well the perception that young children are unable to understand the implications of being HIV-positive and taking ART (Vaz, Corneli, Dulyx, Rennie, Omba, Kitetele & Behets, 2008; Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui, 2010). A study by Vaz et al. (2011) found that some caregivers provide children with deflecting information about the child’s health, such as including some information about the disease but avoidance of naming the disease. Vreeman et al. (2010) report on a Kenyan study that explored the perceived positive impacts of disclosing HIV status to children. They found that despite caregivers’ fears of telling a child about his or her own HIV-positive status, they nonetheless perceived positive impacts from disclosure, including the child’s improved ART adherence and access to supportive networks. Observations made in Uganda (Bikaako-Kajura et al., 2006) and Zambia (Menon et al., 2007) where children knew about their HIV infection and were enrolled in an ART programme found that disclosure was related to good adherence, and the children had fewer emotional problems compared to those who had not been disclosed to.

Only a few studies have sought children’s and adolescents’ perspectives on the perceived impact of their HIV-status disclosure. Through their work with HIV-positive youths in the Democratic Republic of Congo, Vaz et al. (2008) and Vaz, Eng, Maman, Tsikandu & Behets (2010) concluded that a large majority of children and youths prefer to know their HIV status, despite the fact they may feel sad and afraid immediately after the disclosure. Furthermore, a study in Brazil (Abadía-Barrero & Castro, 2006) shows how non-disclosure can create confusion and mistrust in children, compromising knowledge of the disease and leading to increased HIV-risk behaviour.

This brief review of previous research highlights the importance of understanding and identifying the pathways between HIV-status disclosure, ART and children’s psychosocial wellbeing, not least from the perspective of adolescents themselves. Against this background, and in our
interest to highlight the ‘agentic’ capabilities of African youths, we report on studies that bring forward the perspectives of adolescents, and we explore how, in the context of ART and disclosure, HIV-positive adolescents in Botswana and Tanzania find opportunities for managing their lives and coping with HIV stigma.

Methods

The article draws on the findings of two qualitative studies, conducted between June and September 2011, in Tanzania and Botswana. Both were guided by a phenomenological study design which sought to explore the lived experiences of HIV-infected adolescents. Initially the separate studies had slightly different objectives, with the study in Botswana focusing on what contributes to HIV-positive adolescents capacity to thrive, and the study in Tanzania focusing on how HIV-positive adolescents thrive despite the stigma they face. But in the process of analysing the data, we noticed many similar findings, despite being research conducted in two different countries; consequently, we identified the similar themes and reanalysed the data.

Both studies received approval from the Norwegian Social Sciences Data Services. In addition, the Tanzanian study received approval from the National Institute of Medical Research (NIMR) of Tanzania, while clearance for the Botswana study was granted by the Ministry of Health in Botswana and the Regional Committee for Medical and Health Research in Norway. Rigid ethical guidelines were followed to ensure the participants’ confidentiality and anonymity. The participants were informed that participation was voluntary and that they could withdraw or refuse to answer any question without consequences. Written and informed consent was obtained from the participants, and written or oral consent was obtained from the caregivers of participants under the age of 18 years.

Study locations and participants

Botswana is a landlocked country with approximately two million people (CIA, 2011). Botswana has the second-highest level of HIV prevalence in the world (24.8%) for the age group 15–49 years, and it has approximately 16 000 children aged 0–14 with HIV infection (UNAIDS, 2010). Botswana introduced an ART programme in 2002, aiming to offer treatment to all HIV-positive citizens who needed it (AVERT, 2011); by 2009, ART coverage exceeded 90% of those eligible (UNAIDS, 2010). Tanzania is a more populous country, with an estimated 42.7 million people. HIV prevalence in Tanzania is estimated at 5.6%, which includes between 83 000 and 240 000 HIV-infected children aged 0–14 (UNAIDS, 2010). Tanzania initiated an ART programme in 2002, and has since reached an estimated coverage of 32% of adults and 17% of children eligible for treatment (UNAIDS, 2010). The study in Tanzania was carried out within an organisation called ‘Pastoral Activities and Services for people with AIDS Dar es Salaam Archdiocese’ (PASADA), which offers medical and psychosocial support for people living with HIV or AIDS, including children and adolescents. The study in Botswana was conducted at two different sites: a hospice in an urban setting and a hospital in a rural setting. As we found few differences in the findings from the rural and urban settings, the data from the two areas were analysed together.

All the participants were purposefully recruited with help from staff who worked at the sites. Adolescents on ART and whom the NGO or healthcare staff deemed to be articulate and communicative were invited to participate in the study. All the participating adolescents had their HIV status previously disclosed to them. The study in Tanzania included 12 HIV-positive adolescents (7 girls and 5 boys) between the ages of 12 and 14, and interviews with two healthcare staff members. In Botswana, 16 adolescents (10 girls and 6 boys) between the ages of 12 and 20 were enrolled in the study, and three healthcare staff members were interviewed to explore their perspectives on adolescents coping with ART treatment and HIV stigma. The names used here are pseudonyms.

Data collection and analysis

In both countries the data were obtained through individual interviews with the adolescents. The Botswana study included two focus group discussions in addition to the individual interviews. Semi-structured interview guides were used for all the interviews. The interview guide used in Botswana covered the positive resources in the adolescents’ lives, their relationships with family and friends, their experience and thoughts about disclosure, and how they handled stigmatisation. In Tanzania the interview guide covered forms and effects of stigma, and coping mechanisms related to stigma. In order to gain additional information about the adolescents’ environment, to observe how they interacted with each other and as part of the selection procedure for the individual interviews we also drew on participant observation. We participated actively in group activities and seminars organised by the healthcare facilities in Botswana and PASADA in Tanzania. Participation enabled us to form an understanding of adolescents’ environment and their relationships to each other; in Tanzania it also helped the researcher to select participants for the individual interviews. All interviews were recorded. As the study in Botswana was conducted by a non- Setswana speaker, translators were used to facilitate the individual and group interviews with the exception of one interview where the girl being interviewed felt confident enough to carry out the interview in English. The translators used were healthcare staff working at the healthcare facilities. Interviews were transcribed and translated from Setswana into English. The Setswana parts of the interviews were transcribed by a local student. The Setswana transcriptions were then translated back into English by a second local student, without the opportunity to see the transcription of the English parts of the interviews, to make sure his translation would not be coloured by this. The interviews in Tanzania were conducted by the researcher in Swahili, and translated into English by the researcher herself.

The data were analysed using thematic network analysis based on Attride-Stirling’s (2001) four analytic steps: 1) coding the material; 2) identifying themes; 3) constructing the networks, and 4) describing and exploring the thematic networks. Data from the studies in Tanzania and Botswana
were initially analysed separately and analysis began through basic coding of the transcripts. Data from both studies were then reanalysed within the framework of this article’s aims and objectives. Thirty basic themes emerged, which, through an iterative process involving all the authors of this article, were clustered into 12 organising and more interpretative themes, which in turn were grouped together to make the four global themes that guide the structure of our findings section. On the basis of this analytical exercise, Table 1 was developed by adding a ‘B’ (for Botswana) and/or a ‘T’ (for Tanzania) in brackets after each basic theme, to indicate from which locality the basic themes had emerged.

Findings

Stigma impacts on the lived experiences of HIV-infected adolescents who are enrolled in ART programmes in Botswana and Tanzania. Most of the adolescents reported experiencing various forms of HIV stigma, such as verbal abuse (for example, being called degrading names), being labelled (for example, being given a red ribbon to wear as a sign of disease), and being pointed at. The adolescents also felt that people gossiped about their HIV status, and they sometimes felt discriminated against or rejected by friends and family members. This is exemplified by 14-year-old Lina from Tanzania:

‘My stepmother disclosed my status to everybody; she even told her relatives that I am HIV-positive. It reached a time when I was isolated on a sleeping mat; I was sleeping on the floor while the children of my stepmother were sleeping on the bed…. Other times I was served food on a plate that we used for feeding the chickens and sometimes on a plate with a hole, while her children were served on the good plates.’

In addition to having to deal with stigma, some adolescents reported worrying about getting enough food; time in school lost due to opportunistic infections; and some had also experienced the loss of close family members to AIDS. Despite these challenges and the stigmatising attitudes of

<table>
<thead>
<tr>
<th>Basic themes</th>
<th>Organising themes</th>
<th>Global themes</th>
</tr>
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<tbody>
<tr>
<td>Initiates antiretroviral therapy (ART) (B, T)</td>
<td>The availability of medication</td>
<td>1. Improved HIV services</td>
</tr>
<tr>
<td>Uses/desires counselling services (B)</td>
<td>Treatment support services</td>
<td></td>
</tr>
<tr>
<td>Has hospital check-ups (B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joins ‘Teen Club’/support group (B, T)</td>
<td></td>
<td></td>
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<tr>
<td>Life finally makes sense (B)</td>
<td>To be informed about their HIV status helps adolescents understand their life situation</td>
<td>2. To be disclosed to, and to disclose one’s HIV status to others</td>
</tr>
<tr>
<td>Knows the purpose of hospital visits (B)</td>
<td>When disclosed to, adolescents are able to take control over their life</td>
<td></td>
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<tr>
<td>Adolescent wants to know his/her own HIV status (B, T)</td>
<td></td>
<td></td>
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<tr>
<td>Knows the importance of ART and how to adhere to the medication (B, T)</td>
<td></td>
<td></td>
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<tr>
<td>Knows how to live healthily and positively (B)</td>
<td>Adolescents are strategic about whom they declare their HIV status to</td>
<td></td>
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<tr>
<td>Does not disclose to any friend (B, T)</td>
<td></td>
<td></td>
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<tr>
<td>Does not disclose to anyone outside the family (B, T)</td>
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<td>Only discloses to trustworthy people (B, T)</td>
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<tr>
<td>Advised by caregiver to not disclose (T)</td>
<td></td>
<td></td>
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<tr>
<td>Has friends from the support group (B, T)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to share problems with others (B, T)</td>
<td>Adolescents thrive as a result of their friendships</td>
<td>3. Adolescents’ engagement with their social environment</td>
</tr>
<tr>
<td>Adolescent gains knowledge and learns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engages in sports and other leisure activities</td>
<td></td>
<td></td>
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<tr>
<td>with friends (B, T)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent has good friends in school (B, T)</td>
<td>Adolescents seek help</td>
<td></td>
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<tr>
<td>Adolescent visits social workers (B, T)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent reports stigma to adults (B, T)</td>
<td>Adolescents ‘fight back’ against stigma</td>
<td></td>
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<tr>
<td>Adolescent confronts the stigmatizers (B)</td>
<td></td>
<td></td>
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<tr>
<td>Adolescent stigmatises the stigmatizers (B)</td>
<td></td>
<td></td>
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<tr>
<td>Adolescent ignores those who stigmatize him/her (B, T)</td>
<td></td>
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<tr>
<td>Adolescent is supported by their immediate family (B, T)</td>
<td>Has family support</td>
<td></td>
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<tr>
<td>Adolescent is supported by their extended family (B, T)</td>
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<tr>
<td>Some adolescents turn to God (T)</td>
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<td></td>
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<tr>
<td>Believes it is a strength to know one’s HIV status (B, T)</td>
<td>Seeks religion</td>
<td>4. Adolescents’ individual sense-making</td>
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<tr>
<td>Adolescent knows he/she is not to blame for the HIV infection (B)</td>
<td>Some HIV-infected adolescents find confidence despite their misfortune</td>
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<tr>
<td>Continues schooling and education (B, T)</td>
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<tr>
<td>Is able to plan for the future (B, T)</td>
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people around them, four pathways for coping with stigma, emerged from our analyses. These four pathways relate to:

- improved HIV-related services;
- to be disclosed to, and to disclose HIV status to others;
- adolescents’ engagement with their social environment; and,
- adolescents’ individual sense-making (see Table 1).

Improved HIV services

In both Botswana and Tanzania ART services are provided free to all citizens eligible for treatment. Availability of medications contributed to a feeling of safety for many of the adolescents interviewed in both Botswana and Tanzania. ART was reported as very important in their lives and was related to being able to live a long life. Adolescents interviewed in Tanzania explicitly mentioned how their CD4 cell counts had been low before initiating ART, and how their health situation had improved after being enrolled in an ART programme. ‘The ART has helped me as I take them as I was directed by doctors. My CD4 [count] was down before starting the ART; I am happy my health is improving and my CD4 count is up’ (Pili, age 14, Tanzania).

A boy from Tanzania told a similar story:

‘I was very ill to the point where I couldn’t walk; my aunt used to carry me to the hospital. Since I started the ART, my health has improved. I thank God I am alive and I can do other things on my own, like going to school and coming to the hospital’ (Hamis, age 12, Tanzania).

In both Botswana and Tanzania available treatment and support services that were mentioned included counselling services, hospital check-ups and support groups. Counselling services were talked about as a place where the adolescents could ask questions regarding their health, HIV and general life issues. Most adolescents saw it as very important not to miss their scheduled hospital check-ups. However, one of the healthcare staff in Botswana reported that a common worry among the adolescents was that the hospital check-ups interfered with their school days. This resulted in having to explain to their friends why they had to miss school on these days, without disclosing their status.

The support groups seemed to be an important resource for the adolescents in both Botswana and Tanzania. In Botswana the adolescents had access to ‘Teen Club,’ a peer support group for HIV-positive teenagers. Teen Club can be found in several places in Botswana. The programme combines knowledge and information on various themes (with health personnel available to answer questions) and sports and games activities. In Tanzania the adolescents were engaged in different group activities, such as singing, dancing, drawing, painting, pottery, sports activities and seminars. The seminars covered a variety of themes, for example, a seminar on managing stigma was attended by the researcher. In both countries the adolescents reported that the groups helped them in several aspects of life such as reducing stress when they had problems at home, and for some it was also the only place where they had friends. They gained knowledge about HIV, even advanced biomedical knowledge (as Pili demonstrated in the quote above about her CD4 count), medication, stigma, reproductive health, how to protect themselves from re-infection and others from infection, and also knowledge in terms of respect for others. It was also a place where they could be open with each other and about their status. Kasigo (age 19) from Botswana explained that ‘in Teen Club we are just open to talk to everyone,’ ‘...share the problems...’, ‘...to share something same...’. They met others in the same situation; they had fun together, and supported each other. Thobo (age 19) from Botswana expressed that ‘our team united us.’ The support groups also provided them with social skills to deal with the impact of stigma, as expressed by a boy in Tanzania:

‘The seminars which I get from PASADA and also the grieving session which I attended, have taught me how to handle myself and avoid self-stigma’ (Raul, age 14, Tanzania).

The importance of adolescents obtaining information on how to live healthily with ART was also articulated by healthcare staff. For example, one staff member in Botswana said that obtaining knowledge on how to adhere to ART is a prerequisite for adolescents to take control of their health:

‘The best thing we are doing here is information... when they are well kept with information they can do whatever they think in the right manner’ (health-care worker, Botswana).

These examples show that HIV services such as ART, counselling and support groups are important resources for the adolescents, enabling them to improve their health through knowledge and participation.

To be disclosed to and to disclose to others

Disclosure was important from both the perspective of being disclosed to, and to disclose own status to others. Knowing their own HIV status helps adolescents understand their life situation; by knowing the purpose of hospital check-ups and medication regimes, life finally makes sense. All the participants in the study had their status disclosed. However, several of the Batswana participants reported feelings of confusion and anger before they were disclosed to because they had to attend hospital check-ups and take medications without knowing why:

‘I used to find myself at the hospital without knowing what was happening’ (Henry, age 12, Botswana).

As Henry described, several of the Tanzanian participants experienced having to go for hospital check-ups without knowing why; they did not know that HIV was the reason that they sometimes had to go to hospital, they thought they were being treated for what they called ‘normal diseases.’ Some adolescents reported that they refused to take their medications, or used the medication incorrectly before disclosure because they did not know the real purpose for taking the medication or the way the medication should be administered. A Motswana girl explained about experiences of complacency, failing to see the purpose of repeatedly taking the same medication; she got angry and refused to take them. One Tanzanian girl described her experience as follows:

‘I took the ART for some months and I felt fine, so I stopped taking them because I felt I was no longer ill. My grandmother insisted I had to keep on taking
In contrast, a Motswana girl explained that before she knew her status, she sometimes took additional doses of ART during the day if she had a headache or a stomach ache, because she had been told that the tablets would make her feel better. As the adolescents came to know their status and why they were on treatment, they were in a position to take control of their lives. All the adolescents in both Botswana and Tanzania wanted to know their status, even though many felt sad, shocked and lost hope at the moment of disclosure. When disclosed to this helped the adolescents to understand the importance of ART and how to adhere to treatment.

Most of the Batswana participants pointed out the importance of how disclosure helped them to live healthily and positively:

‘Because now I know my status and when I grow up I can take care of myself. If I didn’t know…I wouldn’t be caring about myself’ (Marea, age 14, Botswana).

The Tanzanian adolescents did not explicitly mention being able to live healthily and positively as a result of disclosure, but they, like the Batswana participants, saw the importance of protecting themselves and others from transmission of the virus.

Knowing their status made the adolescents aware of what people around them thought about being HIV-positive. It gave them the choice of whether or not to disclose their status to others, and to consider to whom they would disclose their status. Our data show that adolescents are strategic about declaring their HIV status. Most participants would not disclose their status to people outside their family, like friends and other community members. In Tanzania most of the participants were advised by their caregivers not to tell others. Fear of stigma and other people’s lack of knowledge about transmission of the disease contributed to the adolescents choosing to keep their status a secret, as described by Kisura from Tanzania:

‘People in my neighbourhood do not know that I am HIV-positive, because I was told by my grandmother not to disclose my status to anyone in order to avoid stigma’ (Kisura, age 12, Tanzania).

The adolescents in Botswana did not report that caregivers told them to keep their status a secret, but in most cases they chose to not disclose their status because of fear of stigma. Furthermore, two of the three health-care staff interviewed in Botswana said they recommended children and adolescents to keep their status within their family until they grew older and were able to defend themselves from stigma:

‘I think they still have to keep it within the family…at that age they are still fragile minds…until the adolescent grows up, coming to a state where they can also defend themselves verbally’ (healthcare worker, Botswana).

Due to the fear of being stigmatised, many chose to keep their status secret. However, a few of the participants in both Botswana and Tanzania had disclosed their status to some friends they considered trustworthy, and had positive experiences with this. They could get support and understanding from these friends; one girl explained that ‘I told because I felt better after I told them…so that they can understand’ (Marea, age 14, Botswana). Furthermore, in Tanzania some of the adolescents also disclosed their status to their teachers, because they could provide them with social support in cases of stigmatisation at school.

What these findings suggest is that it was crucial for HIV-infected adolescents to know their HIV status. It provided them with opportunities to take care of themselves, to protect others, adhere to treatment, to choose whom to disclose their status to and to seek social support from.

Adolescents’ engagement with their social environment

Support from friends in the support groups and at school was mentioned by many of the participants, in both countries, and they seemed to thrive as a result of their friendships. However, the information they would share with their friends was different regarding which friends they were with. With the friends in the support groups they were able to be open about their HIV status and share their problems because they were with others in the same situation. When we participated in these groups during our stay in the field, we got the impression that the adolescents really enjoyed each other’s company; they were chatting, laughing, dancing, playing and joking. Furthermore they seemed very confident to speak in front of each other and the adults that were present in the group, even when we, as researchers coming from the ‘outside’ were present. With friends they had not disclosed their status to; they would talk about issues other than HIV. A Tanzanian girl explained that being with her friends helped her:

‘I like staying with my friends because it helps me to avoid self-stigma, and also we are learning from each other, because we have different ways of understanding things’ (Sara, age 14, Tanzania).

In Botswana the participants did not mention gaining knowledge from each other, but friends were the ones they could engage with in leisure activities and seek support from. Engaging in sports activities was important for many of the adolescents, and many of the Batswana participants said their sport made their day good. Taking part in sports activities included being part of a team or taking part in competitions.

In cases of stigmatisation or being bullied the adolescents would seek support from adults, like caregivers, social workers and teachers. This suggests that they were able to make use of the resources they had available in their environment. One teenager explained that she would seek help from teachers when experiencing discrimination from other students:

‘When I was still in school I used to face cases of discrimination from other students, which led me to tell my teacher to help me’ (Kefilwe, age 19, Botswana).
Adolescents from Tanzania would also turn to their teacher for help as mentioned in the section about disclosure.

As we noted initially, most adolescents in these studies had experienced stigmatisation. The participants from both Botswana and Tanzania thought the reasons for stigmatising included lack of knowledge about HIV and how it is transmitted. James from Tanzania explained how he responded to stigma:

‘I usually ignore those who stigmatisme and I see them as fools, since they do not know what they are doing’ (James, age 14, Tanzania).

James found strength in knowing the facts about HIV, and that he knew that those stigmatising him did this out of ignorance. One of the Batswana participants suggested telling the person stigmatising how it feels to be stigmatised. Some of the Batswana participants also explained that some of the people stigmatising didn’t know their own status, and might as well be HIV-positive themselves.

Many of the adolescents experienced support from both immediate and extended family. For most of the Batswana participants, their immediate families were often the most important source of support. For the Tanzanian participants the importance of their family was implicit in their statements as illustrated by Bibiana who described what happened when her aunt did not give her enough food:

‘Sometimes my mother gave me her portion of food when I was given little; my mother could stay without eating and give her food to me to make sure I was satisfied’ (Bibiana, age 14, Tanzania).

The participants from Tanzania also reported that family, both immediate and extended, was important when it came to following up treatment such as taking their medicines and caring for them if they got ill, paying school fees, bus fares, providing food and clothes among others.

Many of the Tanzanian participants had lost their biological parents and were living with their extended family; this also applied to some of the Batswana participants. For these the extended family was very important. One boy had lost his mother and explained how his uncle was a very important source of support for him:

‘[My uncle] made that promise after my mother was buried; he told me — I’m going to support you in good and difficult times — and right now he still is’ (Thobo, age 19, Botswana).

However, not everyone experienced support from their extended family when they needed it. Juma from Tanzania described his experience:

‘After my father’s death we had a family meeting, where my family refused to let me to stay with them. They told me they would support me wherever I was, but it wasn’t so. Due to lack of support from my relatives, sometimes I had to walk long distances to school due to lack of bus fare. I wish my parents had left a will, it could have helped me’ (Juma, age 14, Tanzania).

Due to lack of support from his extended family, Juma experienced difficulties in his everyday life.

Another source of support mentioned was religion. One participant mentioned religion was important to her as she believed that it could cure her illness:

‘I am a good Christian and I believe that through God I will be healed, and I have been attending the healing sessions’ (Bibiana, age 14, Tanzania).

Statements like the one above did not come up in the interviews with the Batswana participants; however, one boy said that he liked to go to church, because he found it was a good place to be.

The adolescents in the two studies had a range of different social relationships including with caregivers, immediate family, extended family, friends in their support groups, friends at school, teachers, healthcare staff and spiritual relationships like turning to God. We suggest that the adolescents’ engagement with their social environment helped them thrive in spite of challenges such as stigma.

Adolescents’ individual sense-making

Some of the Batswana participants reported that knowing their status was a strength to them, and they somehow managed to find confidence in their misfortune. One boy stated that ‘we have self-esteem because we know our status’ (Tebogo, age 19, Botswana). They pointed to those out there, who were stigmatising without even knowing their own status (as mentioned in the previous section), one girl saying that ‘at least I know my status’ (Kefilwe, age 19, Botswana). Juma from Tanzania explained how he thought a man was being punished for treating him in a bad way:

‘One of our neighbours pointed his finger at me, saying to the other people in the street...look at that child, he is HIV-positive.... Then I met him one day at PASADA, I couldn’t believe he was also HIV-positive. From then I believed that if a person does bad things to others, God will punish him, the way the man was punished. Unfortunately, that person is dead, but I am still alive’ (Juma, age 14, Tanzania).

Furthermore, both in Botswana and Tanzania, some of the participants said they knew it was not their fault they were HIV-positive, they knew they had been born with it and that they were not to blame: ‘I have been born with the virus’ (Tabia, age 14, Botswana). This knowledge, and also knowing that the people stigmatising ‘did not know what they were talking about’, contributed to helping them deal with stigma. They believed that knowing their status they were better off than those who didn’t know as the knowledge enabled them to take care of themselves and know what they were heading for, compared to those who didn’t know.

All the participants in the studies had hopes and dreams for their future. School was mentioned as an important aspect for many of the adolescents, and many saw it as significant in order to be able to continue with further education. A Tanzanian boy explained:

‘I need support for school fees, as my aunt is not in a position to assist me with everything I need. I will appreciate if I get any kind of support, as I really want to study to fulfil my dreams’ (Raul, age 14, Tanzania).

Like Raul, all the other participants reported specifically on what they would like to do or to be in the future. Participants from Botswana mentioned a range of careers that they would like to pursue, such as teacher, doctor, policeman,
carpenter, singer and football player. One girl also had a dream of one day building a big house for her mother. The participants from Tanzania had similar goals.

In spite of challenges, most of the adolescents managed to make life meaningful as they had plans and hopes for the future. Many believed that they could overcome the obstacles they were facing, and some found strength in knowing their status and the reality that they were not to blame for being HIV-positive, they were born with it.

Discussion

Supportive context
All the participating adolescents knew their HIV-positive status and all were accessing ART and other support services. As stated in our introduction, only a small proportion of HIV-positive children in sub-Saharan Africa are told their status (Biadgilign et al., 2011; Kallem et al., 2011; Vaz et al., 2011) — making the participants in our studies an unusual group. Adolescents in our studies reported that disclosure contributed significantly to their adherence to ART, confirming the findings of other studies that have explored the links between disclosure and adherence (Bikaako-Kajura et al., 2006; Menon et al., 2007). The availability of ART has given adolescents the opportunity to live their lives fully and take control of their health and wellbeing. A recent study from Zimbabwe also found the availability of ART to contribute to a ‘normalisation’ of HIV, showing that it is possible to live a close to normal life in spite of being HIV-positive (Campbell et al., 2011). ART is accompanied by other services, such as counselling and support groups. In both our studies the social support groups provided by the treatment system seemed to enable the adolescents to form meaningful social relationships with other adolescents in the same situation, leading to a feeling of fellowship or being united as a group. Being part of a group seemed to make the adolescents strong and to create confidence. Furthermore, the support groups gave access to important information about issues such as HIV, ART, reproductive health and stigma.

We found that disclosure was a key factor for the adolescents in order to be able to access or make use of the different services that the treatment system could offer. For instance, in order to be a member of the Teen Club in Botswana the adolescents had to know their status. Campbell, Skovdal, Mupambireyi, Madanhire, Nyamukapa & Gregson (2012) report similar findings in Zimbabwe, where children were found to be more likely to actively participate in their treatment regimens when disclosed to. Recent studies recommend a systematic approach to inform and advise caregivers of HIV-positive children and adolescents about the disclosure process (Biadgilign et al., 2011; Kallem et al., 2011; Vaz et al., 2011). Our findings from Botswana and Tanzania support Menon et al. (2007) when they suggest that emotional and peer support could be facilitated by disclosure.

According to Petersen et al. (2010), adolescents with strong family support, and extensive social support networks, tend to cope better. In our studies from Botswana and Tanzania, family and friends were seen as important resources of support by the adolescents. Many of the adolescents were coping well in their situation, and we suggest that in these studies, similar to Petersen et al. (2010), it is evident that support from family and extensive networks contributes to coping.

Adolescents’ agency
Many of the adolescents in our studies actively accessed and used the resources (such as treatment services) available to them. As mentioned above, disclosure was a key factor in being able to effectively use many of the services the treatment system could offer, but we also found that disclosure could give life new meaning in the sense that the adolescents understood their life situation. It was commonly reported that before they were told about their status, they found themselves in a situation where they didn’t understand the reason for their medication regimes and hospital check-ups. After disclosure life finally made sense in the way that they found their treatment meaningful, and wanted to adhere to it to keep themselves healthy. Furthermore, many of them seemed to be able to apply the knowledge about HIV, ART and stigma to their own life situations and people surrounding them. The obtained knowledge enabled them to manage and to take control of their lives and to look positively towards the future.

In addition to making use of the available treatment system, many also actively sought support from friends, family, teachers, and healthcare staff. Several studies concerning disclosure to children and adolescents with HIV, report that one of the barriers to disclosure is that the caregiver fears that the child or adolescent will tell someone outside the family about his/her status, which could lead to stigmatisation (Vaz et al., 2008; Vreeman et al., 2010). Even though many of the participants in our studies chose to keep their status a secret, only disclosing to family members, some did choose to disclose their status to a few close friends. The rationale for this was that it felt good that someone knew, and for their friends to be aware and to understand their situation. Disclosing to some close friends did not lead to stigmatisation for these participants but instead to feelings of support and being understood. By disclosing to the adolescents they are given the opportunity to decide who outside the family, if any, should know their status. This could contribute to the adolescents being able to access social support also outside the family and the support groups within the treatment system. Another reason reported in the literature for not disclosing a child’s status, is the fear of being judged by the child (Vaz et al., 2008; Vreeman et al., 2010) but our findings show that what was important to the adolescents was that they knew they themselves were not to blame for their HIV status; this contributed to their ability to handle HIV stigma.

Resisting and coping with stigma
In spite of experiencing stigma, many of the adolescents appeared to have the necessary resources to cope with it. By knowing their status and being part of a treatment system the adolescents somehow managed to develop
strategies to deal with the challenges of stigmatisation. For example, the adolescents were in a position to decide who they would choose to disclose to. Sometimes the adolescents disclosed to teachers in order to seek their help when experiencing stigma and discrimination at school, other times they made a conscious decision to keep their status secret, which is a coping mechanism in its own right. This has also been observed by Thupayagale-Tshweneage (2010) who found adolescents in Botswana kept their HIV status and ART adherence a secret as a way of dealing with stigma related to HIV.

The knowledge they obtained through the treatment system helped them create a form of individual sense making, to know the reality, such as how the virus is transmitted, and get confirmation that being HIV-positive was not their fault, but something they had been born with. In addition, some of the adolescents found strength in knowing their own status. Knowing their status made them able to take care of themselves, but they also pointed out that there were people ‘out there’ who did not know their status, and that the ones stigmatising might be HIV-positive themselves without knowing. As a strategy to resist stigma, the adolescents felt sorry for those untested and in the dark about their HIV status. These findings echo a study in Zimbabwe (Campbell et al., 2012), which observed that adults on ART, in an attempt to cope with stigma, made a distinction between ‘us’ (the HIV-positive) and ‘them’ (those who do not know their HIV status).

Implications of the findings and recommendations

The findings from these studies underline the importance of disclosing adolescents’ HIV status to them, as well as promoting access to treatment services including ART and social support. We have found that disclosure contributes to enabling adolescents to actively participate in their own treatment regimen; they gain important knowledge, confidence and a desire to adhere to their treatment, which furthermore enable them to cope with stress in life such as stigma and discrimination. There is much to learn from HIV-positive adolescents themselves regarding their own situation.

Study limitations

The Botswana and the Tanzania studies each had a relatively small number of participants and findings cannot be generalised. However, the phenomenological approach has provided insight into the lived experiences of HIV-positive adolescents, and found that the experiences and responses of adolescents from two different countries have been remarkably similar. This study has not explored how HIV-positive adolescents unaware of their HIV status and not on ART cope with stigma, or whether the age of disclosure and the length of time they have known their HIV status affect their ability to cope. These questions could provide a focus for future research.

Conclusions

The research shows that ART and disclosure opened up new opportunities for the HIV-positive adolescents to improve their health and enable them to live social and productive lives. Disclosure gave them a better understanding of their life situation and the desire to adhere to treatment. Disclosure made adhering to ART meaningful, and by adhering to treatment the adolescents managed to take better control of their lives. Through treatment and support services they gained detailed knowledge about their condition and how to manage their medication. Being part of a support group for adolescents in similar circumstances enabled a sense of openness and nurtured their confidence. Thus, the social context and the psychosocial resources it facilitated enabled HIV-positive adolescents to: 1) seek support from friends, family, teachers and healthcare staff in times of need, and 2) resist internalised stigma by seeing themselves as better off than those who have not been tested and are unaware of their HIV status.

Notes

1 Setswana is the predominant language in Botswana. Motswana refers to one citizen and Batswana refers to several citizens.
2 CD4+ T cells are the main components of the cellular immune system; CD4+ T cells are destroyed or impaired by the HIV virus, leading to immune deficiency.

Acknowledgements — We would like to thank all the adolescents who participated in the two studies and the staff at the various participating institutions for facilitating the research.

The authors — Vivian Midtbe and Violet Shirima both completed an MPhil in international health promotion at the Department of Health Promotion and Development, University of Bergen, in 2012. This article is based on data collected for their master’s theses. Morten Skovdal is a community health psychologist writing about children’s health and community responses to HIV. He is with the Department of Health Promotion and Development at the University of Bergen and a visiting scholar at the London School of Economics and Political Science. Marguerite Daniel is an associate professor in the Department of Health Promotion and Development at the University of Bergen.

References


Strategies to bring about change: a longitudinal study on challenges and coping strategies of orphans and vulnerable children and adolescents in Namibia

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Longitudinal research provides insight about the life trajectories of children, the challenges that children experience in different phases of their lives, and the way children cope with these challenges. The article examines the perspectives of 14 orphaned or vulnerable children, initially aged 9 to 12 years (in grades 3 and 4), concerning changes in their difficulties and coping strategies. The children participated in the research in 2003 and again in a follow-up study in 2010 to 2012. Focus group discussions with the children/adolescents were used, as well as child-orientated methods such as drawings, and in-depth interviews with the adolescents and caregivers. Most of the participants described their life situation as better at the time of the 2010/12 study than it had been in 2003. In general, they were receiving more financial support than before from their immediate and extended family or were supporting themselves. One important change since 2003 was that nine of the 14 had since received a state-provided child welfare grant for at least some years. Also, those who said they had previously experienced mistreatment had since left these home situations. The children’s agency in making positive changes to their life situations is described by the participants. As adolescents, they tried to access family support by actively asking for financial assistance, and in return they generally felt obligated to support the family once they began earning an income. The strategies they most used to get away from abusive home situations were to inform a relative about the mistreatment or to run away. Children’s and adolescents’ limitations concerning strategies for improving their adverse living situations are also discussed.

Keywords: coping, family relationships, longitudinal study, resilience, social capital, sub-Saharan Africa

Introduction

It is estimated that there were 155 000 orphaned children aged 0–17 years in Namibia in 2008 — 15% of the child population — with 69 000 of these believed to be orphaned because of AIDS (Ministry of Health and Social Services [MOHSS], 2009). Various authors have predicted or observed many adversities in the lives of children orphaned in the context of HIV. Besides adversities such as limited access to schooling and healthcare, abuse, stigmatisation, homelessness, a high risk of exploitation and emotional problems (Booysen & Arntz, 2002; Bicego, Rutstein & Johnson, 2003; Nyambedha, Wandibba & Aagaard-Hansen, 2003; Shetty & Powell, 2003; Cluver & Gardner, 2007), some also predict that orphaned children are at risk of becoming dysfunctional or criminal adults (Matshalaga & Powell, 2002; Schönteig, 2002).

How do children orphaned in the context of HIV perceive the challenges they face in their life trajectory? And how do they cope with these challenges? This study examines the perspectives of 14 orphaned and vulnerable children concerning challenges to their wellbeing and the scope of their coping strategies. The children, initially aged 9 to 12 years, participated in the research in 2003 (see Van der Brug, 2007), and then again in a follow-up study in 2010 to 2012. As adolescents, they commented on the changes in their lives and on factors that had facilitated improvements.

This study forms part of a growing body of research that highlights the topics of resilience and coping in order to understand the wellbeing of children and adolescents affected by the HIV epidemic. Various aspects of resilience have been addressed in these studies. For example, Skovdal & Andreouli (2011) found that social recognition of the agency of caregiving children in Kenya led children to constructing a positive identity that facilitated resilience. In Uganda, openness and disclosure (e.g. through adults talking about sex and death to children) were found to serve as protective factors to enhance resilience (Daniel, Apila, Bjorgo & Lie, 2007). Attention to coping and resilience helps to identify the qualities that children use to deal with adversity along with the support structures that are available to them. This information can be used to increase the effectiveness of policies aiming to improve children's wellbeing.

The longitudinal approach of this study offers an impression of some of the long-term implications of orphanhood and HIV, in addition to the problems and difficulties that children and adolescents face in different phases of their lives. Previous researchers have stressed the importance of longitudinal studies for understanding the experiences of...
children in the context of HIV (e.g. Li, Naar-King, Barnett, Stanton, Fang & Thurston, 2008), yet few studies have used a longitudinal approach to study the impact of the HIV epidemic on children. One longitudinal study, by Yamba (2005), is a description of the life trajectory of siblings in Zambia who lost their parents to AIDS. Yamba (2005) argues that the lives of children may take an unfortunate turn in the context of the HIV epidemic, as when due a lack of care the Zambian siblings ended up living in a child-headed household; she states that this situation shows how sufficient support for orphans and vulnerable children is lacking in many rural areas of Africa. The following sections describe the concept of resilience as defined in this study, and the focus is on the extended family as a support structure for orphaned and vulnerable children in Namibia.

**Resilience and vulnerability**

Studies of orphans in the context of the HIV epidemic have been enriched by examining the vulnerability of children more generally — not orphanhood per se — and through attention to the coping and resilience of children. The interface of the social and the individual is emphasised in different discourses on childhood. For example, within the discourse on children's agency, Hickey & James (1993) stress that children are both social actors and part of a world with social-cultural structures which are determined by adults. The resilience of children can be defined in a similar way. In Carrey & Ungar's (2007) definition of resilience, the individual's strengths as well as the physical and social capital of the individual's families and communities are considered important. Camfield (2012) refers to such an understanding of resilience as 'relational,' with a central role given to the social relationships of children. She recommends an exploration of children's access to social and material resources and to the 'social competencies' which enable them to convert these resources into wellbeing outcomes, as well as attention to how children's social networks may either support or threaten their wellbeing. Social coping strategies, as described by Skovdal (2011), are based on a similar understanding of resilience. These strategies are "located within a social context that allows children to exercise agency as they navigate and actively negotiate support" (Skovdal, 2011, p. 260). Caregiving children in Kenya, for example, were found to cope by engaging in income-generating activities, mobilising social support, and constructing positive social identities. Thus, children's coping is determined by their ability to participate in community life (Skovdal, Ogutu, Aoro & Campbell, 2009). In this article, such an understanding of resilience is used to explore the coping strategies of children and adolescents, specifically how children and adolescents actively participate with and try to influence their supportive social environment.

The children that participated in this study were either orphaned or vulnerable children, which gives insight in whether orphaning brings particularly vulnerabilities to young people. The policies of governments and aid agencies have shifted from a focus on orphans in the context of HIV and AIDS to concern for all children affected by the pandemic (hence the term 'orphans and vulnerable children'). Meintjes & Giese (2006) question why a somewhat singular focus on orphanhood in the context of HIV and AIDS still persists despite these developments. Besides, the definitions used by governments and aid organisations are often not in accordance with local notions of orphanhood and vulnerability. Consequently “notions of ‘the orphan’ can obscure the vulnerabilities of children more generally, especially the children living in poverty” (Meintjes & Giese, 2006, p. 408). In a study of 60 households in 36 African countries, Akwara, Noubary, Ken, Johnson, Yates, Winfrey et al. (2010) show that orphanhood and co-residence with a chronically ill or HIV-positive adult are not universally robust measures of child vulnerability; instead, they content that household wealth should be seen as a key predictor of child vulnerability.

**The extended family as a support structure**

This study explores the importance of the extended and immediate family as a social resource, and how children interact with their social context in order to cope with difficult circumstances. The extended family is still a common pattern of organisation of households in rural areas of Namibia (UNICEF, 1995). In the central north, where this research took place, the most common carers of orphans and vulnerable children are maternal grandmothers or aunts (Social Impact Assessment and Policy Analysis Cooperation [SIAPAC], 2002) since receiving children within the mother’s family is related to the matri-lineal structure of the Ovambo community (Malan, 1980). Almost half of all Namibian orphans live in the rural central northern area (SIAPAC, 2002). Not only orphaned children are taken care of by the extended family, but also non-orphaned children. In Namibia, only one quarter of all children live with both parents, and 36% of all children do not live with either parent (UNICEF, 2011). Almost half of all children in the central north region of the country live with no parent (MOHSS, 2008). Factors contributing to this trend are a low rate of marriage and labour migration from northern Namibia into other parts of the country (National Planning Commission, 2010). This indicates that in the domain of orphans, vulnerability is not caused just by living without one or both parents. The costs of caring for (orphaned) children are shared by different family members, while poverty is not uncommon in these households. In Namibia, poverty is concentrated in the rural areas as 32% of rural households are considered poor. Especially, pensioner households are at high risk of poverty, with a poverty rate of 47.5% among them; often these households care for children with no additional income source (Central Bureau of Statistics, 2008).

Several scholars have studied the strength of the extended family in relation to the care of orphans in the context of HIV, and they have debated whether this system is able to cope. Foster (2000) developed indicators of strength and relative weakness among African families and found that families that cared for orphans suffered more weaknesses than those not caring for orphans. Chirwa (2002) however argues that communities in Malawi employ innovative and complex strategies of orphan care within the existing extended family structure. Abebe & Aase (2007) propose a contextual understanding of the ‘orphan burden’ and argue that care for orphaned children is dependent on...
the profile of the extended family (i.e. ‘rupturing, transient, adaptive or capable’). Recent reviews of the role of families in care for children affected by HIV or AIDS emphasise the importance of efforts to strengthen families to support children affected by HIV (Hosegood, 2009; Richter, Sherr, Adato, Belsey, Chandan, Desmond et al., 2009). One of the most important policies in Namibia to tackle child poverty and assist families in the costs of care is the social welfare grant system. Two types of cash transfers are most common for orphans and vulnerable children. Child maintenance grants (CMG) are paid to a biological parent of a child who is under age 18 years and whose spouse 1) is receiving an old age or disability grant, 2) has died, or 3) is in prison,1 and who is implicitly conditional on a child’s school attendance. The foster care grant (FCG) is paid to any person who undertakes the temporary care of a child who has been placed in his or her custody.2 The number of recipients of child welfare grants has rapidly increased in Namibia — from 9 739 in 2003 to 113 995 in 2010 (Ministry of Gender Equality and Child Welfare [MGECW], 2010). Namibia has also instituted school feeding programmes and an exemption of the payment of ‘school fees’ (school development-fund contributions) for child welfare grant recipients. However, many schools still expect these children to pay school fees (MGECW, 2010). Many children indicate that they often suffer due to an inability to pay for school-related expenses (National Planning Commission, 2010). In a study of the impacts of social cash transfers (such as pensions and child welfare grants) in Namibia, Levine, Van der Berg & Yu (2011) conclude that these transfers play an important role in alleviating poverty, especially for the very poor. They also expect that the poverty-reducing effects of the child grant are likely to increase as access is being expanded rapidly. However, these grants are mainly allotted to orphaned children, while the wider group of children living in poverty is not being reached (National Planning Commission, 2010). A report on the effectiveness of child welfare grants in Namibia (MGECW, 2010) recommends that the CMG should be adjusted to become a mean-tested grant for all poor and vulnerable children in the country.

Methods

Study location and participants

The longitudinal study took place in 2003 and during 2010 to 2012 in north-central Namibia, an area heavily affected by the HIV epidemic. Sentinel surveys in the area where the research took place showed 30% HIV prevalence among pregnant woman attending antenatal care clinics in 2002, and 25% prevalence in 2010 (MOHSS, 2010). The study took place in a rural village consisting of widely spaced homesteads. The income in these households derives from different sources, such as agriculture for own use, jobs for pay, and different trading activities (see Mendelsohn, El Obeid & Roberts, 2000). Children are considered important labourers in many households, as they may participate in agricultural activities, collecting firewood and water, cooking, ploughing and tending animals.

An afterschool Kidsclub was started in 2003 at the village’s primary school. Due to the sensitivity of the research topic it was not possible to interview children in their home situation. Fourteen children in grades 3 to 4, ages 9–12 years, participated in the Kidsclub, which met on a regular basis. The children were selected by the teachers. Since the teaching staff did not know the background of all pupils in their class and the school had only began to register orphans and vulnerable children in 2004,2 they selected supposed orphans based on their poor clothing and lack of food. Eleven children participating in the study were orphans4 (five double orphans and six single orphans) and three were non-orphans; they all came from poor households; one had a physically handicapped parent and one had a mentally ill parent. In 2010 to 2012, the same children, now adolescents (ages 18–21 in 2012), participated again in the research.

The lack of openness about HIV made it difficult to determine if children had lost a parent to AIDS or to other causes. In 2003, one caregiver revealed that the mother of her orphaned granddaughter had died of AIDS. In the 2010/12 study, two caregivers mentioned AIDS as the cause of death of one or both of the parents of the child they were taking care of. When the adolescents were asked about the cause of death of their parents, some said they did not to know the cause of death or they did not want to talk about it; others mentioned non-stigmatised causes, such as a car accident or malaria. Most explained that they only knew their parent died of an illness, but they expressed a wish to be told the type of illness. One girl openly informed me that both her parents had died of AIDS.

Data collection and analysis

Qualitative research methods were used to acquire insight into the experiences and perceptions of the participants. The first part of the research (‘the 2003 study’) took place from November 2003 until February 2004. Obedience and respect for adults are often emphasised to children in rural northern Namibia, as in other parts of southern Africa (Levine, Michaels & Back, 1992). Consequently, the children were not accustomed to talking with an adult about their experiences and feelings. Meeting with children as a group over a longer period provided an opportunity to build confidence and trust between the participants and researcher. Group interviews took place during the Kidsclub meetings, and child-orientated research methods like drawings were used. The children were also visited at home twice and their caregivers were interviewed. The themes of the group discussions and drawings were selected by the researcher in consultation with the children. The first themes were aimed at getting insight into the daily lives of the children, especially their positive experiences; later, children were given the opportunity to express difficult aspects of their lives. The drawing exercise was done in a group, but the drawings produced were discussed individually with the children, with the aim of starting a conversation. Children who were too shy to talk during the group interviews seemed more at ease and able to express themselves in a drawing; thus, topics that had not been mentioned during group interviews sometimes came out in the drawings. Drawings offers the advantage of being less open to critique and judgement.
than verbal answers to a question would be (O’Kane, 1998); children can participate in research through drawings by creating images that are about themselves (Christensen & James, 1999).

In the follow-up study (‘the 2010/12 study’) the 14 adolescents were individually interviewed in July and August 2010. Five caregivers were interviewed as well. In addition, four focus group discussions took place with six adolescents who were together in the same junior secondary school (grades 9 and 10). In September and October 2011, the 14 adolescents were interviewed again, as well as three caregivers. Finally, seven adolescents and two employees of the Ministry of Gender Equality and Child Welfare participated in individual interviews in June 2012. All the interviews were recorded and later transcribed; only the group interviews in 2003 were written down immediately. The transcripts from the 2010/12 study were read in their entirety, then coded, categorised in broader themes and compared with the findings of the 2003 study.

The 2003 study focused on the perceptions of orphans and vulnerable children concerning their living and care arrangements, and the difficulties they experienced due to their life circumstances. The 2010/12 study paid attention to several themes: whether the challenges the adolescents experienced before still existed, whether the adolescents felt their life circumstances had improved, and how they defined the ‘improvements.’ The analysis of data pertaining to the children’s coping strategies differentiated between two types of strategies: 1) strategies that children and adolescents use to improve their life circumstances, and 2) coping strategies and styles used to emotionally handle their problems (e.g. acceptance of a life situation, sharing with friends, and trying not to think about their problems). The article focuses on how the children actively influenced their available social resources to bring about positive change, thus the discussion does not elaborate on their particular coping strategies.

**Ethics**

Research permission for both studies was obtained from the Namibian Ministry of Education; ethical clearance for the 2010/12 study was obtained from the VU University Amsterdam. In the 2003 study, the caregivers were asked for either written consent for their child to participate, or verbal consent when the caretakers did not return the consent form. The children were asked for consent verbally. It was explained before all sessions that participation was voluntary and that they could withdraw at anytime, and the children’s anonymity and confidentiality were ensured. Finally, in the 2010/12 study, informed written consent was obtained from the adolescents.

By participating in follow-up research the adolescents were re-identified as ‘orphans.’ For some participants this process was ambivalent. One of the participants, Samuel, chose places for the interviews where he could not be seen by others. Not only being identified by others as ‘orphaned,’ but also talking and thus being reminded about his late parents was uncomfortable for Samuel. He explained:

‘It makes me feel bad and sometimes I feel like not responding to some of your questions...like things about my parents. I like to be asked, but about new things in my life.’

During the 2003 study, the children didn’t like to be labelled as an ‘orphan’ by others, since orphanhood is associated with poverty, even though not all orphaned children come from poor households. Some of the orphaned children were bullied by other children at school because they ‘looked’ poor. Except for Samuel, by 2010 the adolescents were mostly less concerned about being identified as orphaned. They seemed to realise that many young people had lost their parents, and they advised each other during discussions at school how to deal with the adversities related to the loss of one’s parents.

Most of the adolescents appreciated the chance to participate in the research. They stayed in contact with the researcher by sending text messages and stopping by. The caregivers were also pleased to be included; they felt that the follow-up showed that the researcher had a genuine interest in the children. The adolescents’ appreciation was partly caused by the fact that participating in the research was beneficial for them. For instance, they received some gifts, a party was organised for them, and they turned to the researcher for small requests such as cellphone credit. Participation was also seen as encouraging by many of the participants, as the researcher showed interest in their life situations. Nelao expressed this, saying: ‘When you are asking me questions I can see that there are people that care about me.’

**Findings and discussion**

The first part of the findings section describes changes in the children’s perspectives on the difficulties in their living and care arrangements, the impact of child welfare grants on their financial situation, and how the young people evaluated the changes in their lives and what had facilitated improvements. The second part explores the agency of children and adolescents in terms of the way they manoeuvre in the support system of an extended family and the strategies they might use to get away from mistreatment within the family.

1. From childhood into adolescence: A changed situation?

**Challenges in living and care arrangements in 2003 and 2010/12**

In 2003, all the children reported that they lived in a household with immediate or extended family (see Table 1). Each of the orphaned children had been taken in by a grandmother, aunt or great aunt; the three non-orphaned children lived with one or both parents. Several children described insecurity with their care and living arrangements (e.g. lack of food, uncertainty about their care arrangements, mistreatment within the household) as well as a high workload. Due to a lack of food, several children said they had trouble concentrating at school because of their low energy level. Ester said:

‘Sometimes you are looking at the teacher, but you didn’t hear anything, you are just thinking about food. Your mind is not in the class. Sometimes they
ask you — Do you understand? Then I say — Yes — But I didn’t hear anything.’

Households cope with food shortages by eating fewer meals a day. Aleta’s household could barely afford one meal a day during some months of the year, when the millet was finished. As part of a study by the National Planning Commission (2010), focus groups with children were conducted. Children mentioned poverty as a central issue, with hunger being one of its components. Poverty affects both orphaned and non-orphaned children. The rate of poverty among children in Namibia is estimated at 43.4%, with little difference in the average level of poverty for orphans (45.3%) or for non-orphaned children (42.9%) (Central Bureau of Statistics, 2008). With the loss of one or both parents the security of the children’s care arrangements had decreased. The orphaned children especially worried that their current caretaker might die, as had their parent; they wondered where they would live if their current caregiver died and they were afraid that their position would be worse in a new household. Paulus related:

‘If my grandmother dies I have nowhere to stay because I don’t know if the housemaid will chase
me; I have no idea. But I don’t think anybody wants to take that responsibility.’

With the loss of adults due to HIV in the household, the children (particularly girls) often experienced a heavy load of household chores and agricultural tasks. Some children also worked in the fields of other households to earn money for their own household. Most indicated that they had little time for homework. Another prominent problem for some children was living in an abusive home situation (discussed further in the next section).

In 2010/12, most of the adolescents were connected to the same household as they had been in 2003. They were variously still living in the household, had moved away to nearby small towns for a job or to attend boarding school, or had joined a nunnery. The children’s mobility was noted: three orphaned girls had moved into new households five or six times. Reasons for changing households within the extended family were: as a consequence of the death of a caretaker, to assist in another household, because of mistreatment or exploitation, for better access to school, or to take care of their own child. Many difficulties that the children had faced during childhood did not continue into adolescence. For example, only Aleta, who was now heading a household herself, said she experienced a lack of food; she only had enough millet to get through four months of the year and otherwise had to rely on help from the community. Largely, the adolescents no longer experienced heavy workloads and they had enough time for homework. Some argued that their workload had not decreased but that they were able to better organise their time; others felt they had fewer tasks to do. Only Lena, who stayed at home after she dropped out of school, felt she had too many chores and was often shouted at by her parents for not finishing her work on time. In general, the adolescents reported less experience of mistreatment in their households (as discussed in the next section). The orphaned adolescents who were depending on an elderly caregiver were more worried than in 2003 about the loss of their caretaker, due to the increased health problems of these caregivers. The adolescents were concerned that there would be nobody to give them money or pay their school fees or were concerned about where they could stay.

New challenges had arisen in the course of adolescence as well. Only four of the total 14 were attending or had completed senior secondary school. The others (both orphaned and non-orphaned) had dropped out of school because of failing grades or because of pregnancy. They did not have money to attend NAMCOL in order to improve their grades, and the families of the two girls who had given birth refused to pay their school fees (’school development fund’) so that they could continue their schooling. Other studies have similarly described the poverty and lost educational opportunities experienced by orphaned adolescents (e.g. Harms, Jack, Ssebunnya & Kizza, 2010). These troubles are in accordance with general trends in Namibia. In 2008, only 40% of all young people were able to move into senior secondary school (grade 11) (National Planning Commission, 2010). Not completing secondary school has adverse implications: early leavers are much more likely to spend the rest of their lives in poverty (National Planning Commission, 2010). One boy who dropped out of school was employed by a garage; however, others said they had difficulty finding a job. This finding corresponds with national statistics showing a high level of unemployment among 15–19-year-olds (approximately 67%) (Ministry of Labour and Social Welfare [MOLSW], 2006).

Access to child welfare grants contributes to improved circumstances

At the time of the 2003 study, none of the children were receiving a child welfare grant, but several families had started the application procedure, and one family had gotten confirmation that the grant was approved.

In the 2010/12 study, the caregivers of eight orphaned adolescents and one non-orphaned adolescent reported that they received a child welfare grant or had received it in the past (if the adolescent had since left school). By this time, some families had endured a long application procedure, as long as five years. While caretakers had initiated the application, the child had joined for registration. Importantly, receiving the grant helped households cope with the cost of caring for an orphaned child:

‘That time [2003], there were problems. It was difficult for our mother to afford things like clothes. Our mother was always stressed because of school fees. I think it has changed because the government had introduced an organisation for orphans. My mother keeps the money for us and buys clothes and pays our school fees’ (Joseph).

The grants seemed to have a poverty-reducing effect on the households. Frieda said she planned to move in with an aunt in case her grandmother died, because: ‘She has an income; she gets the grant for her children because her husband died.’ However, grants did not necessarily reach all the children. Claudia and Frieda could not receive one because of missing documents (e.g. a parent’s death certificate). Three others suggested that their caretaker or parent used the funds for their own expenses. Emilia stated: ‘I get a social grant, but my father spends the money and when I ask for the money he gets angry.’ Samuel explained: ‘My aunt appeared to love me but it was not true, it was just because of the money she received for me. She was using it as her salary.’

The Ministry of Gender Equality and Child Welfare in Namibia tries to limit the misuse of child welfare grants. Principals and teachers are encouraged to check that these social grants are spent on schoolchildren and to report misuse. When teachers fill in school progress reports (a necessary document to prolong a child welfare grant), they must evaluate the physical appearance of the child and report whether the child has a school uniform. In 2012 the ministry introduced an identification card for orphans and vulnerable children in order to monitor the distribution of child welfare grants.

The adolescents’ evaluation of their living circumstances

Security and safety were important issues for the adolescents when they evaluated their life circumstances. They frequently mentioned economic security, access
to education, treatment in the household, and personal development (see Table 1). Eight adolescents considered their life circumstances to be better than they were at the time of the first study: they did not experience mistreatment any longer; they felt their financial situation had improved because they started working; or there was more financial support available from a caretaker. Others described their situation as being as good as when they were young. Three adolescents mentioned that some aspects of their lives were better before, but other things were better now. They related how they had once been in school but had since dropped out and experienced being at home negatively while their peers were going to school, or they could not forget about their mistreatment at home as well as they could in the past. However, they all felt their financial situation had improved because more people could support them now than before. Some adolescents mentioned their personal development as well: they could now take care of themselves, differentiate between good and bad, study more and acquire skills, and they knew what they wanted to do in the future. Some mentioned that their own behaviour had led to improved life circumstances. Joseph said: ‘What I did for myself is that I tried to study hard and reached the standard [grade] where I am now.’

2. Strategies to bring about change

The extended family as a support system

During the 2003 study, the costs of caring for an orphaned child appeared to be shared by different family members. The main provider would be the person that the orphan stayed with, such as a grandmother or aunt, while extra support might come from a surviving parent, aunt, uncle or cousins. The orphaned children mentioned the loss of financial and material support as a consequence of the death of their parent; they recalled how their parent would buy them clothes and food and pay for their school fees. By the time of the 2010/12 study, in most cases the caregiver was still the main provider, with extra support sometimes received from relatives. Older siblings might also be contributing. However, most of the orphaned adolescents still missed the support they’d had from their deceased parents: ‘If my parents would have been alive, they could have given me money to go back to school’ (Paulus). The support of parents was seen as given out of love, while some perceived the support of extended family members as given out of social pressure. Others did not see a difference between themselves and non-orphaned adolescents because they considered the support from home as sufficient, or because the father who passed away was not supporting them before his death. Insufficient financial support from caretakers was also mentioned by two non-orphaned adolescents. When they compared their situations with that of others they found that some peers were in a better position because their parents could pay for NAMCOL or tertiary education, for example. Besides financial support, the family is an essential network for the acquisition of jobs as well. The two boys that were working (one had a temporary job) got their jobs through family members. Samuel said: ‘I have decided to look for a job. I will wait and see if my family members will give me a job’ [2010]. And later: ‘An uncle of mine called me and he gave me a job’ [2011].

How do adolescents manoeuvre within this system of extended family support? The adolescents actively asked for financial support from different family members. Children who were performing well in school appeared more likely to be supported than children who performed poorly. Joseph said: ‘Right now I get a lot of support from my family. If people see that you are doing alright [in school], they will give.’ However, the adolescents were not always successful in receiving financial support as their requests were sometimes refused: ‘I still have problems. When I ask my brother for something, he doesn’t want to give, just as other people do’ (Frieda). The system clearly has a reciprocal character: as soon as young people have an income they are expected to support relatives. The adolescents in this study seemed to want to meet these expectations. They hoped to financially support their siblings, caregivers and other relatives in the future. Paulus, who was working at a garage, was already supporting his family: ‘I take bread and sugar home, and when someone asks for shoes, I will buy them.’ Other studies have likewise found a perceived obligation to support family members in return. In a study on the resilience and wellbeing of Ethiopian children, Camfield (2012) describes this feeling of obligation to support caretakers and states that it might influence children’s choice of life pathways and thereby reduce an ability to focus on educational outcomes. In this study, the adolescents’ dependency on support from extended family members was also experienced as a burden. Most of the adolescents wanted to have a job in the future and so become financially independent: ‘The parents that were supposed to help you, they are not there anymore, so you have to study hard, get a job and help yourself’ (Joseph).

Strategies to leave situations of mistreatment

At the time of the 2003 study, the children reported variable experiences with the way they were treated within their households. Some indicated they were treated fairly, while others reported maltreatment. Violence in the domestic setting is common in Namibia (National Planning Commission, 2010). In a study on violence in southern African countries, 70% of 1 100 Namibian men and 73% of 1 400 Namibian women said that violence against women was a problem in their community (Andersson, Ho-Foster, Mitchell, Scheepers & Goldstein, 2007). In focus group discussions conducted by the National Planning Commission (2010) in Namibia, children reported varying levels of verbal and physical abuse in the family. The aid agency Lifeline/Childline operates a counselling service for children and young people in Namibia. Data from 2006 show that, aside from suicidal thoughts, child abuse was the most common reason for seeking assistance (Lifeline/Childline Namibia, 2007). The children interviewed in the 2003 study mentioned insults, beatings, and a high workload. Nelao explained:

‘I feel so bad when somebody does not treat me the same as the ones who are having their own mothers. In our house, there are some children that
are treated well, and others that are treated badly. We, who are orphans, we are not treated the same. Maybe it is just the way of other people treating you bad when you lost both your parents. Sometimes they say — There is no food for you here. Maybe you can look for your father and mother if they have food.'

The follow-up study in 2010/12 gave insight into the life trajectories of children who live in situations of mistreatment. Three girls said they had lived in abusive households in 2003, but they moved out one or two years later. These girls remembered the mistreatment clearly. Claudia still had scars from beatings by her aunt; when she asked her aunt for school fees, she was told to go to the grave of her father. Gertrud remembered how her drunken caregiver would wake her up at night and force her to cook. Other girls had entered an abusive situation in a later stage of their lives. Emilia was physically abused by her father after he became disabled, lost his job, and moved back to his family. Aleta said she was beaten with an iron stick and insulted by her grandmother. The stress of raising children in a situation with little resources can contribute to maltreatment of the children. For instance, Aleta’s grandmother claimed that Aleta became rebellious and did not listen to her; in 2010, Aleta herself said:

‘Some days I don’t eat. There is food but my grandmother has bad manners. She says that when my father was working he never helped and it is my father that brought the disease [HIV] to the house. I become angry when she says I must not eat because I am not the one who brings food in the house.’

When children live in situations where they are mistreated, they seem to lack possibilities to exercise their agency. However, most of the children/adolescents actively tried to change their situation by informing an adult (mainly a relative) about the mistreatment or by running away. Nelao turned to her older sister:

‘I told my sister I was not treated well. And then, one day, she went to my grandmother’s house and slept there, maybe for a week, and she found out it was true. She took me to Ondangwa’ (2006, age 13).

Gertrud left her home at age 12 (in 2004) because she was not treated well:

‘I used to live at my great grandmother’s house before and I went back myself. I would be left alone in the house and was afraid, and then I decided to go back.’

Emilia’s sister arranged for her to move in with an aunt so she could enrol at NAMCOL and get away from her abusive father. In 2010 Aleta and her brother ran away to a friend of her late mother. They stayed on a few months but returned because their family wanted them to stay with their grandmother and help her with agricultural and household tasks. A social worker and church people had intervened, and so the situation improved for some months. When the mistreatment started again, the neighbours warned the regional counsellor, who forced the grandmother to leave the household. Aleta became head of the household. Although she was not mistreated any more, she was now responsible for growing food and caring for her younger brothers. Besides the cost of these strategies, there are clear limitations to children’s possibilities for leaving abusive home situations. Running away is not socially acceptable, and, in a practical sense, children are only able to run away when there is a nearby household that can take them in. Moreover, informing a relative only has effect when the relative can be contacted, and when the relative decides to act. For example, Claudia had never informed her mother about her abusive situation when she came to visit because her aunt was always around; only after her mother saw her wounds during a holiday at home did she keep Claudia home.

Conclusions

The samples of this qualitative study were small, which limits the validity of generalisations from the findings. However, the longitudinal and in-depth character of the study provides insight into the perspectives of orphaned and vulnerable children and adolescents from a highly HIV-affected area in northern Namibia. Contrary to some past predictions about the ‘orphan crisis’ or about orphans’ potential to become dysfunctional adults (Matshalaga & Powell, 2002), most of the adolescents evaluated their situation as being better at the time of the follow-up study than it had been during the initial phase of the research. The adolescents used different indicators to evaluate their life circumstances: they reported having more financial support than before or that they were supporting themselves; several had left abusive home situations; and all mentioned the positive impact of their own actions and decisions, such as studying hard at school. An important change in 2010/12 was the adolescents’ access to state social welfare grants, which are meant to support families in meeting the costs of caring for orphaned or vulnerable children in the household. Nine of the 14 children had received a grant for at least some years; however, not all had benefitted from the grant since their caregiver had used the money for his or her own expenses.

The challenges that the children/adolescents said they experienced in 2003 and in 2010 to 2012 can be interpreted as a lack of security and safety within their living and care arrangements. In 2003, the children mentioned, among other problems, a lack of food, worries about the loss of their caretaker, and being mistreated in their household. At the time of the 2010/12 study, the adolescents described fewer problems. However, they expressed being largely still worried about the potential loss of care, and some had experienced new challenges, such as limited educational opportunities due to a lack of financial support and unemployment. The research highlights the importance of addressing vulnerability among all children, yet especially children living in poverty, and not focusing solely on orphanhood — as is also stressed by authors Meintjes & Giese (2006); this is a valid starting point of policies for orphans and vulnerable children. Most of the above-mentioned challenges seem to be poverty-related and are experienced by both orphaned and non-orphaned children and adolescents. The orphaned adolescent’s own perceptions of whether their situation was similar to non-orphaned
peers appeared dependent on the level of support they received at home. Some emphasised that there was no difference with non-orphans because their support at home felt sufficient, while others felt they had lost out on educational opportunities due to the death of their parent, and they missed a parent’s protection when they experienced abusive home situations.

The extended family is the social context in which these children are taken care of. This study shows that children navigate within, and actively participate with, such a social context in order to improve their situation. The adolescents expressed their agency by asking for financial support from relatives. They recognised the reciprocal character of support from a family, and expressed intentions to support their family in return once they began to earn an income. Many wished to become financially independent, and thereby less dependent on their family’s support. They tried to escape abusive home situations by informing a relative about the mistreatment, or they ran away to a related household. These coping strategies have limitations and are not always successful, however. Requested financial support is often refused, for example. And, running away is not socially acceptable, and is only possible when a related household is nearby. Also, the person whom they inform about their mistreatment may not necessarily assist them.

The findings show that a lack of financial support and educational opportunities, as well as unsafe living and care arrangements, were vital issues for the participants, both in childhood and adolescence. Policies and practices that aim to improve the wellbeing of children who are orphans and vulnerable should address these issues, with an aim to strengthen the resilience that is portrayed by children. Namibia has several policies that focus on improving the financial support of children, including their access to education, such as through social welfare grants. Child protection issues are mostly addressed by the Woman and Child Protection Unit (WACPU) and by social workers. However, these networks do not seem to be sufficient yet. A study by the National Planning Commission (2010) indicates that the status and operations of the WACPU need attention. The Ministry of Gender and Child Welfare has reported a severe shortage of social workers (MGECW, 2010). In the area where this research took place, only a few social workers were responsible for services to a large area. They felt overburdened and were mainly occupied with investigations relating to foster care grants, leaving little time for child-protection issues. The coping strategies that children mentioned in this study, such as informing a relative about maltreatment, can give insight in the structures that should be strengthened or developed on a community level to prevent child abuse. Examples of support structures to benefit children are: the appointment of trustworthy community workers to whom children can turn to for confidential help; awareness-raising within communities; providing caregivers with information and assistance about caring for foster children, as well as about the legal consequences of child abuse; and the training of headmen, lay counsellors, school staff and church workers.

Notes
1 The CMG is means tested and restricted to applicants with a monthly income of less than N$1 000. Since 2000 the value of the grant has been N$200 for the first child and N$100 for each additional child. The grant may be extended until the child turns 21, on condition that the child continues secondary schooling.
2 The value of the FCG is the same as the CMG.
3 Registration records for 2004 showed that 30% percent of the pupils in grades 3 and 4 were orphans. In 2011 the proportion of orphaned school children in grades 3 to 4 in this school was still 30%.
4 In Namibia an orphan is defined as an individual up to the age of 18 years that has lost one or both biological parents (MOHSS, 2002).
5 All names are pseudonyms.
6 NAMCOL is an educational institution where students can repeat subjects in cases where the student has twice failed either grade 10 or grade 12.

Acknowledgements — I would like to thank all the children and their caregivers who participated in this study, and the interpreters Sarah, Ossor, Nelao, Neami, Lena and Veronika for their help. I also extend thanks to IBIS and Positive Vibes, as well as the school principal, for assistance with this project.

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Questioning the use-value of social relationships: care and support of youths affected by HIV in child-headed households in Port Elizabeth, South Africa

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The opinion that the extended family can fulfil its supportive role in assisting child-headed households continues to exist. How these households encounter support, what this support entails, and how they experience this support is an under-researched subject. Most research literature on this topic emphasises child-headed households' material and financial support. However, although financial support is vital, emotional support to cope with the loss of loved ones, or with loneliness and insecurity, is also much needed, as well as adult assistance in obtaining formal support, such as social welfare grants. Thus, to what extent are child-headed households capable of capitalising on existing (extended) family and community members' care and support? This article addresses this question by exploring the 'use-value' of social relationships among child-headed households in Port Elizabeth, South Africa. The coping strategies of the child-headed households are discussed and analysed, indicating the children's interpretations and valuation of social relationships and support, whether this increased their potential access to other resources, and whether this support could be considered sufficient. Despite some exceptions, we argue that support from relatives or neighbours is often ambiguous and of little use-value from the viewpoint of a child-headed household. Insights from these findings might be of interest to those involved in support programmes for these households, including the assignment of an adult mentor — which is based on the assumption that existing networks of extended family and community members will help orphaned and vulnerable children to cope.

Keywords: community support, coping strategies, exploratory research, families, orphans and vulnerable children, social capital, sub-Saharan Africa

Introduction

The case of Mona shows that children who become orphaned cannot always rely on the support of extended family members and they have to be wary about the intentions of community members:

Mona lived with her father and stepmother in a modest two-bedroom house in one of the townships of Port Elizabeth. Although they did not have much money, for Mona it was enough, and she was happy. However, her father died in early 2000, when she was 12 years old. Shortly afterwards (after her stepmother moved out), relatives tried to take over the house. They were not interested in her fate though. When some neighbours became aware of her relatives' intentions, they informed the ward councillor for the district she resided in. Together they prevented her relatives from taking the house. Mona had been living alone for more than four years when a neighbouring family offered to foster her. Mona had occasionally stayed with this family, as she was sometimes afraid to be alone because of safety issues. Mona told a teacher about this, who informed a social worker, who in turn assisted Mona's neighbours in applying for a foster care grant. Mona was initially happy to live with them. She felt safe and taken care of. Within a few months, however, she was struggling with her position in that family. There were constant conflicts with her foster parents. As a result, she was often in poor spirits and seldom wanted to talk during our meetings. According to Mona, she was repeatedly reminded that she did not belong to that household. Because she did not feel welcome, the in-fighting worsened. Mona decided to move back to her own house. As a result, she no longer received any support. She could only depend on herself.

Although the community members were aware of Mona's situation and seemed concerned, this did not lead to further action or structural support for her for several years. According to Mona, she received very little actual support from any of her neighbours, and she was frustrated by the total lack of assistance from relatives.

This article discusses other cases of youngsters in similar situations, living in so-called child-headed households in a township area of Port Elizabeth, South Africa. We focus on how these children experience the support they receive from extended family and community members, and whether this support is sufficient to cope with the loss of loved ones, or with loneliness and insecurity.
on whether and how the social relationships of child-headed households contribute to their capability to cope, with emphasis placed on the children’s interpretations and valuations of the support.

**Children affected by AIDS and child-headed households in South Africa**

Although HIV incidence is decreasing in South Africa, the HIV epidemic remains one of the largest in the world (UNAIDS, 2010). The number of orphaned children rose strikingly from 3 million (16.4% of children in South Africa) in 2002 (Meintjes, Hall, Marera & Boulle, 2010) to almost 4 million in 2008 (Meintjes & Hall, 2010). The government in South Africa started to rollout antiretroviral (ARV) medication in 2004, attaining 31% effective coverage by 2009 (Abayomi, Somers, Grewal, Sissolak, Bassa, Maartens et al., 2011). With the current rollout of antiretroviral treatment (ART), the number of orphans should decline by more than half a million by 2020, which will still leave 3.1 million children who have lost one or both parents (Anema, Au-Yeung, Joffres, Kaida, Vasarhelyi, Kanters et al., 2011).

The number of child-headed households (consisting of children under the age of 18) in South Africa rose strikingly in the period from 1995 to 2005 (Richter & Desmond, 2008). However, according to the analysis of Meintjes et al. (2010) the number of child-headed households did not increase in the period from 2000 to 2007. It is apparently difficult to enumerate child-headed, as communities may be reluctant to acknowledge their existence (Roaikvam, 2005) and such households may be under-represented in surveys because an adult is generally required to complete the household questionnaire (Monasch & Boerma, 2004). The main problem with estimates of the number of child-headed households in South Africa is that they are based on household surveys that are not designed with the objective of determining the number of child-headed households. Besides this, although reliable figures are difficult to obtain, little is known about the characteristics of support and assistance to these households.

It is generally agreed that it is better for orphaned children to be supported by their families or by people in their own communities, rather than cared for in an institution (UNICEF, 2004). It is often stressed that members of the extended family will take care of children who have lost their parents. Foster (2004, p. 67) argues that in the past the sense of responsibility of extended families in southern Africa was "almost without limits." Although this may be a romanticised view, child-rearing was traditionally a collective responsibility of the whole family and the extended family has always played an important role in supporting its members. In general, kinship obligations are viewed as determining who will take care of whom. However, particularly in South Africa, many demographic and social transformations have taken place, influencing family and community life. The HIV epidemic, chronic poverty, apartheid, and migrant labour are often given as factors that have severely weakened the extended family structure (see Sloth-Nielsen, 2003; Foster, 2004; Madhavan, 2004; Germann, 2005).

The opinion that the extended family can still fulfil its supportive role continues to exist. Some argue that, as a consequence of the changes and challenges, the shape or form of the support may have altered (Foster, Makufa, Drew & Kralovec, 1997; Mathambo & Gibbs, 2009). In this line of reasoning, child-headed households are sometimes referred to as a 'new coping mechanism of the extended family.' Foster et al. (1997) were the first to point this out, as their research on child-headed households in Zimbabwe showed that most households are supported and visited by extended family members. What this 'support' entails, however, is unclear. In a more recent account, Meintjes et al. (2010) also argue that most children in child-headed households are taken care of by relatives, based on data from the 2006 General Household Survey. They calculated that most child-headed households (77.4%) rely on remittances as their main source of income, rather than on grants (6.8%).

Although Meintjes et al. (2010) draw the conclusion that child-headed households are consequently not isolated from relatives, it is unknown to what extent these relations contribute to children's coping and whether this support is sufficient and secure.

Internationally, there has been much discussion about the most appropriate response to children affected by HIV and AIDS who are not fostered by relatives or community members. Although child-headed households are not viewed in most of these discussions as an ideal care option for (orphaned) children, these households are considered unavoidable. A number of international lobby groups have pushed for the legal recognition of child-headed households, with provision for ‘appropriate’ support and assistance (International Social Service & UNICEF, 2004; UNICEF, 2007). This is also the case in South Africa, where discussions on child-headed households were intensified during revisions of the Child Care Act of 1983. The new Children's Act states that child-headed households should be legally recognised as a placement option for (orphaned) children, with suitable adult support given in the form of ‘household mentors’ (Republic of South Africa, 2006). This means that a child-headed household should be placed under the general supervision of a designated adult or nongovernmental organisation (NGO), which may then collect and administer any financial grant or assistance to which the household is entitled. A child-headed household is defined as a household where a child aged 16 to 18 years has adopted the role of caregiver because the parent or caregiver has died, is terminally ill, or has abandoned the household. Note that the Child Care Act does not consider a child living alone as a child-headed household, and that not all household members in a child-headed household need to be under the age of 18.

South Africa has a comprehensive social security package, including social grants for ‘vulnerable’ adults and children. The child support grant (CSG) and the foster care grant (FCG) are most relevant for youngsters in child-headed households. The FCG is a component of the foster-care system, which was designed to intervene in the lives of children in need of protection against abuse or neglect. The government encourages people from the community or extended family to take in orphaned children by offering them FCG incentives, thereby implying that problems among orphaned children are dominantly material (Meintjes,
Budlender, Giese & Johnson, 2003). The caregivers of children up to age 16 years old can apply for a CSG after a means test.3 The CSG currently amounts to R250/month per child (R200 at the time of our study). ‘Caregivers’ are those persons that provide the primary care for the child and they need not be a biological parent or related to them in any way. Initially, the age range of eligibility for the CSG was 0–7 years old, but this has been extended over the years. In May 2010 it included all children under the age of 16 years. And since 2012 the grant includes all eligible children under the age of 18 (Jamieson, Mahery & Seyisi-Tom, 2010).

It is very difficult for youngsters in child-headed households to access grants, however. First of all, this relates to the age of the oldest child in the household. When the oldest child is under the age of 18, he or she cannot apply for a FCG for a younger sibling. To apply for a CSG, a caregiver must be over the age of 16, which makes the CSG more easily accessible.4 However, child-headed households also have difficulty accessing the CSG (see Van Dijk, 2008; Meintjes et al., 2010). Recognising these issues, the Children’s Act (2010, section 137) states that ‘household mentors’ should be able to access grants for child-headed households, as mentioned above.

Cop in child-headed households

Children in difficult circumstances are often portrayed as vulnerable, powerless and victims. However, viewing children as victims in need of rescue denies children agency (White, 2003; Skovdal & Campbell, 2010). Children who live in so-called difficult circumstances may not want to be ‘rescued,’ but rather supported in gaining more control over their lives (White, 2003). This does not mean that the difficult circumstances of many children are acceptable, but viewing children and young people as victims is not effective in supporting children in their effort to cope (Boyden & Mann, 2005; Van Dijk, 2008).

Research on how children and young people cope in the developing world is relatively new. Studies that deal with coping in child-headed households often do not directly take children into account. For example, viewing child-headed households as a ‘new coping mechanism of extended families’ says nothing about children’s coping. Furthermore, when looking at coping in child-headed households, it is vital not solely to consider the level of wellbeing of the members of the household (Sen, 1983) as this may merely reflect the view of whoever is doing the measuring (Kabeer, 2005). In the case of child-headed households, these are mainly the views of adults. Therefore, in this article we focus on children’s own interpretations and valuation of social relationships and support.

The capability to cope is strongly influenced by social support since individuals who receive social support are more inclined to believe that they can deal with adverse situations (have a sense of agency) and therefore they will seek further social support (Meursing, 1997). Yet, the availability of social relationships “does not tell us what the person can, in fact, do” with these relationships (Sen, 1983, p. 160). Thus, the significance of social relationships depends on its “use-value” (Foley & Edwards, 1999, p. 146). This means that a certain relationship is only valuable when it contributes to the capability to cope. Children in child-headed households have to cope with a multitude of problems, yet in the above-mentioned studies and in the Children’s Act, coping with material problems seems central.

In this article, we focus on the actors that are predominantly expected to offer support to child-headed households — namely, the (extended) family and community members. We define the use-value of social relationships in terms of their contribution to children’s coping. To assess this, we considered children’s interpretations of the motivations of the providers of support, the type of support, and how this may contribute to their coping capabilities. When children have a sense of agency they are more likely to ask for and receive support. Hence, this article focuses on children’s support-seeking capabilities. We first discuss the research rationale, objectives and methodology. Next, we explore the use-value of children’s social relationships.

Study context

This study deals with the coping capabilities of youngsters in child-headed households in Ibhayi, a township area of Port Elizabeth, South Africa. The Eastern Cape Province is among the poorest provinces, with 7 million inhabitants who are primarily Xhosa-speaking. The province has the second highest percentage of children living in poverty and one of the highest percentages of child-headed households (Meintjes, John-Langba & Berry, 2008). The objective of the exploratory research was to gain insight into coping in child-headed households, from the perspectives of the children and young people themselves.

Research design

The research involved three periods of ethnographic fieldwork totalling 18 months: from December 2003 to March 2004; from July 2004 to May 2005; and from March to May 2006. Staff of the Ubuntu Education Fund (UEF), a local NGO, were involved in locating child-headed households and acted as interpreters. The main criterion in selection of the participants was that the participant had previously or currently lived in a child-headed household. One aim of the study was to define child-headed households. According to most definitions, when one of the household members is over the age of 18, a household is not considered child-headed (anymore) (Meintjes et al., 2010). This means that a child-headed household can turn into an adult-headed household overnight without changes in the composition of the household. As a result, the household loses its special status, which may be related to a particular state and access to other support (Van Dijk, 2008). By also involving households where one of the ‘children’ who assumed the caring role was age 18 or older, it became clear that such households experience the same problems as households where all members are under age 18. Additionally, youngsters who are under or above the age of 18 may be viewed as social minors by the community (Kuhanen, Shemeikka, Notkola & Nghixulifwa, 2008; Van Dijk & Van Driel, 2009; Van Dijk, 2011). One could argue that young parents may face similar problems as child-headed households. However, young men and women who have become parents are perceived as more adult than those...
who have not had children. Furthermore, most sibling heads of households do not actually have a choice in taking over the parental role. Besides the difficulties they may experience in adjusting to their new role, they must also drastically adapt their future plans (Van Dijk, 2008). The criterion of biological age of the household head for defining a child-headed household is therefore an arbitrary one.

Twenty child-headed households participated in this study. When the household became child-headed, in 13 of these households the oldest person was under the age of 18, in five households the oldest person was between the ages of 18 and 21, and in two households the oldest person was older than age 21.

Methods

Data collection
We have done 77 one-to-one interviews with 22 individuals in 20 child-headed households. In all cases, the oldest member of the household was the one most involved in the study. In some cases, younger children were present during the interviews, which provided an opportunity to observe their interactions. In addition, during the third period of fieldwork, some of the younger children were involved in group discussions. As input for one of these group discussions, they were given disposable cameras and asked to take pictures of important people in their lives. In seven cases, with the approval of the youngsters, neighbours and relatives were interviewed. Furthermore, five in-depth interviews were conducted with people who worked either for UEF or for another community-based organisation. These interviews aimed at gaining insight into the care needs of child-headed households, the possibilities of supporting them, and the potential obstacles in providing them with support. Most of the interviews were recorded and then transcribed verbatim.

Data analysis
The findings were analysed by means of open coding. These codes were categorised into three broad themes: 1) the child-headed household members’ access to material and social assets, 2) their room to manoeuvre in order to gain these, and 3) their resulting coping strategies. In this article, we focus on social assets (social relationships and support) and how these contributed to the children ‘room to manoeuvre’ in terms of employing their coping strategies. Room to manoeuvre includes ‘sense of agency,’ defined here as a belief in the ability to act. We concentrate on the children’s views and interpretations of the support received and their capabilities to access additional support, thereby offering insight into their sense of agency, which goes beyond the actual support received. To validate the findings, during the third period of fieldwork, the findings were discussed with the respondents, the interpreters and in a group discussion with workers from UEF.

Ethical considerations
Ethical approval and funding was given by the Netherlands Foundation for the Advancement of Tropical Research (NWO/WOTRO). Although all research involves ethical considerations, it is often argued that research with children requires extra precautions (Schenk & Williamson, 2005). The main concerns in childhood-related research are the issues of informed consent, of protection and of maximising the possible benefits. In order to ensure voluntary participation, consent was viewed as a continuous process. This meant that, following their initial consent to participate in the study, every interview started with asking youngsters if they still wanted to participate.

Although the findings of this research project will possibly benefit youngsters in similar situations in the future, those participating did not benefit immediately. After discussing the issue with staff at UEF, we agreed that they should receive some incentive when participating in the research. The participating youngsters received small material incentives after every interview (a few Rand and/or a loaf of bread). By involving experienced child counsellors, who acted as interpreters, they were protected emotionally. Moreover, the participants were given the option to be involved in the counselling programme at UEF. In this way, a potentially continuous counselling relationship was established.

Findings and discussion
We discuss the children’s interpretations of support received from (extended) family and community members, starting with the relationships with their remaining parents. Before we proceed with the analysis of how the youngsters interpreted and valued the social relationships and support, we present information on the living conditions, needs and challenges facing the child-headed households.

Table 1 shows the composition of the households, the ages of the household heads and of the siblings at the time we met, the age of the child when he/she became head of the household, and the ages of any biological children of the household heads. In 15 households, the oldest sibling had one or more younger siblings to take care of. In four cases the household consisted of only one person, and in one case the household consisted of an 18-year-old household head and his 20-year-old cousin. Except for that household, all the youngsters in the child-headed households were siblings, although they did not always share the same biological father.

For most of the children, talking about the illness or death of a caregiver was very difficult. For this reason, and because some children took care of a severely ill parent, the precise age at which a child became the head of the household was sometimes uncertain. Accordingly, some of the children were heads of households at a younger age than is shown in Table 1. We include two households headed by young people that were considerably older than the other child household heads. These are Sindy and Linda, as they were respectively 26 and 25 years old when becoming caregivers for their siblings. These two households are included in the sample because both were relatively large; the households faced very economically challenging situations; and finally the older ages of the household heads proved to be very useful in analysing the influence of social age on coping. At the start of the study, most of the households had been child-headed for at least one year.
Table 1: Composition of the child-headed households and their access to social welfare grants (FCG = foster care grant; CSG = child support grant)

<table>
<thead>
<tr>
<th>Pseudonym of the child household head</th>
<th>Gender</th>
<th>Age of the household head (years)</th>
<th>Age of the household head at start of child-headed household (years)</th>
<th>Ages of siblings (years)</th>
<th>Ages of the household head’s biological children</th>
<th>Eligible for the FCG?*</th>
<th>Receiving a FCG?**</th>
<th>Eligible for the CSG?*</th>
<th>Receiving a CSG?**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zack</td>
<td>M</td>
<td>18</td>
<td>16</td>
<td>20</td>
<td></td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mona</td>
<td>F</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nick</td>
<td>M</td>
<td>18</td>
<td>16</td>
<td>15</td>
<td></td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lauren</td>
<td>F</td>
<td>19</td>
<td>17</td>
<td>17, 16, 14</td>
<td></td>
<td>Yes (3)</td>
<td>Yes (3)</td>
<td></td>
<td></td>
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<tr>
<td>Aidan</td>
<td>M</td>
<td>18</td>
<td>18</td>
<td>14, 11</td>
<td></td>
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<td>No</td>
<td>Yes (1)</td>
<td>Yes (1)</td>
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<tr>
<td>Marc and Janin</td>
<td>M, F</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td></td>
<td></td>
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<td>F</td>
<td>19</td>
<td>18</td>
<td>9, 8</td>
<td></td>
<td>Yes (2)</td>
<td>No</td>
<td>Yes (2)</td>
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<tr>
<td>Nell</td>
<td>F</td>
<td>22</td>
<td>16</td>
<td>16, 14, 9, 7</td>
<td>2 years</td>
<td>Yes (4)</td>
<td>No</td>
<td>Yes (3)</td>
<td>Yes (1)</td>
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<tr>
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<td>M</td>
<td>15</td>
<td>15</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phoebe</td>
<td>F</td>
<td>20</td>
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<td>14, 13, 6, 2</td>
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<td>Todd</td>
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<td>14</td>
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</tr>
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<td>M</td>
<td>18</td>
<td>17</td>
<td></td>
<td></td>
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<td>F</td>
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<td>17</td>
<td>17</td>
<td></td>
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<tr>
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<td>F</td>
<td>19</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tara</td>
<td>F</td>
<td>14</td>
<td>14</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Morton</td>
<td>M</td>
<td>21</td>
<td>21</td>
<td>18</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>F</td>
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<td>19</td>
<td>9</td>
<td></td>
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<td>Yes (1)</td>
<td>No</td>
</tr>
<tr>
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<td>F</td>
<td>23</td>
<td>17</td>
<td>19, 15, 10</td>
<td></td>
<td>Yes (2)</td>
<td>No</td>
<td>Yes (1)</td>
<td>No</td>
</tr>
</tbody>
</table>

*Yes* means that they are eligible; the number in parenthesis shows for how many grants they are eligible.

**Yes** means that they receive one or more grants; the number in parenthesis shows how many grants are received by the household.
More than material needs

Children in child-headed households are often poorer than children in adult-headed households (Donald & Clacherty, 2005). In our study, most child-headed households lived in very challenging circumstances. They lived in houses in very poor and unsafe conditions, were mostly unable to fulfil their nutritional requirements, and were in urgent need of material support. Moreover, they expressed a serious need for emotional support. Most of them had gone through very difficult periods, particularly when their caregiver was ill or dying. In five cases, they had taken care of their dying parent. Talking about the time when they had to care for their parents evoked much anxiety and sadness, especially when they did not receive much support from relatives or community members.

Almost none of the parents had talked with their children about their approaching death. This aggravated the shock and anxiety the youngsters felt when their parent died, as they worried about who would care for them after the parent’s death. This is illustrated by the following quote of a young man who had just turned 18 at the time his mother died:

‘So I was shocked…I asked at that stage, why? Why? Why did God take my mother, because she was my only hope? …I didn’t cry…. It was like I was dry inside...I had a sore thing here [points to his chest]. It was like something stuck in me and it wouldn’t go past my throat. It was too deep. When they buried her, it was the time I cried’ (male, age 18).

Initially he felt shocked and angry that he was left by himself. Other participants had the same response: they felt shock without crying. One boy recalled the day his father died:

‘I went to the room and I just covered him with the blanket. I didn’t cry then…. When he passed away here at home I didn’t think he passed away. I just thought he went out to do his piece job…. The day of my father’s funeral I lost all hope, like inside me something died, I was angry. When I started to cry I didn’t stop for the whole day. My tears made my face sore and I felt nothing inside me, nothing, just dead’ (male, age 16).

Besides parents not raising the subject of death, relatives also silenced the subject, advising children not to cry and to forget. Many children said they never talked about their parent(s) anymore. The covering up of emotional and psychological hurt by silencing the subject may inflict ‘hidden wounds,’ causing complex emotional and psychosocial trauma (Daniel, 2005).

Besides the unresolved grief over their parent(s) death, the oldest siblings had difficulties in fulfilling the ‘parenting’ role. They felt uncertain and anxious about being able to care for their younger siblings due to a lack of resources. Furthermore, raising and disciplining younger siblings was challenging as the younger siblings did not always accept their authority. Meanwhile, they highly valued advice from an adult about running a household or guidance on raising children. However, most indicated they were unable to share their problems with an adult.

In short, child-headed households have both material and emotional needs. The latter, however, receives less attention in both research and policy. Emotional needs include support when grieving, as well as lending an ear and offering advice about running a household and raising young siblings.

(Un)supportive parents

In 13 of the households, the oldest child still had one parent living, and in four of the households one or more of the younger siblings had a parent who was still alive. However, most of these children did not feel supported by their remaining parents. Biological parents are obliged by law to support their children financially through ‘paying maintenance’ (according to the Maintenance Act, 1998). Parents who are not financially able are not required to do so, which means that the living parents of the children in this study may not have been able to support their children financially. However, in the youngsters’ views, many parents should have been able to do so as they had a paying job or received a social grant.

If they perceived their parent(s) as able to offer financial support, they sometimes assumed a new partner to be the reason for not doing so. For example, Therah (age 18) lived alone since her mother died when she was 17. Her biological father was still alive and she sometimes had contact with him. Before her mother died, her father had paid some maintenance; however, after her parent died her father did not give Therah any financial support and she assumed that his new wife prevented him from doing so:

‘He got a wife now; his wife doesn’t like me and my father takes her word…before my mother died he used to come here and give some money to my mother, but not me...she keeps my father’s money....’

Although some children tended to blame the new partners rather than their parents, others were angry or frustrated with the parent for not supporting them. The parents of Nell (age 22) had left their younger children (at the time, ages 10, 8, 3 and 1) in Nell’s care from the time she was 16 for several weeks or months at a time:

‘My mom does not care about anything. If you would see her you would cry; she’s as thin as a stick….she is always drunk and she is really suffering…. She doesn’t even know her little boy....’

The little boy is Nell’s youngest brother who was only 1 year old when Nell became the main carer. Her mother’s alcoholism was the main reason why she no longer cared for her children. Nell talked about her father with less bitterness, however. According to her, he was caring for the children because he would at least bring some food when he came to their house.

Of the 17 households in which one or more of the siblings had at least one remaining parent, only in four cases did this parent support their child on a regular basis, according to the children. This was the case with Lauren, who had lived with her three siblings (ages 12, 14 and 15) and her mother before she died when Lauren was age 17. The four of them shared the same biological father, who had divorced their mother and lived elsewhere. They kept regular contact
and he supported them financially. However, he did not support them in other important ways according to Lauren. He did not visit them regularly, it was difficult to reach him when they had a problem, and he did not offer any advice or guidance. Lauren particularly wished he would spend time with her brothers, who expressed a need for this. Also, as her brothers were approaching the age of initiation to manhood, she felt they needed their father.

In three cases, the biological parent of a younger sibling provided some sort of support to the household. This was the case with Stephen (age 15) who lived with his younger brother Nkosi (age 11) after they lost their mother with whom they had both lived. Stephen's father had died a few years before their mother, but Nkosi's father was still alive. He visited both children daily and supported them financially. He would give them money for school materials or clothes, and brought them groceries every week. Before their mother died, he also contributed financially. He supported the brothers equally and Stephen argued that he was like a father to him. Furthermore, Stephen and Nkosi regularly visited the relatives of Nkosi’s father, such as Nkosi’s grandmother. Nkosi’s father thus played an important role in both brothers’ lives.

In contrast, in two other households only the biological children of the living parent received support. This was the case with Aidan and his brothers who had lived with their mother before she died. Aidan (age 18) did not share a biological father with his brothers (ages 11 and 14). Both his and his brothers’ father were alive. Aidan did not receive support from his father, but his brothers did get some financial support from their father. This was also the case with Noleta (age 19), who had a different father than her brother (age 8) and sister (age 9). The three of them had lived together since their mother had died. Noleta’s father did not provide any support whatsoever, but her two siblings’ father did support them financially. He gave Noleta R150/ month for groceries. Although, in both cases, the biological father may only have intended to support his own children, both Aidan and Noleta were also helped by the support.

In most cases, the children were not subsequently double orphaned. Factors leading to the establishment of child-headed households are hence more complex than parental death. Most of the remaining parents among the participants hardly provided either material or emotional support to their children. Children seek excuses for the lack of support from their remaining parent, which means that they expect support from them. Social relationships with some remaining parents offered access to support due to the households’ complex compositions.

Where is the extended family?
All the youngsters could name living aunts and uncles and also knew their whereabouts. Fifteen of the households had regular contact with relatives. This ranged from being invited to funerals, to occasional visits. Although relatives were consequently aware of the situations the children lived in, this did not result in continuous or sufficient support, according to the children. The relatives sometimes lived far away, although in 14 cases at least some relatives resided in the Port Elizabeth area or even in the same neighbourhood. This was the case with some of Stephen’s relatives whom we referred to above. Stephen (age 15) and Nkosi (age 11) knew that their deceased mother’s brothers and sisters lived nearby, but the brothers did not have any contact with them. Stephen therefore argued that these relatives were not really his family: ‘I cannot even call them family; I just see them as other people, because there is nothing that they do for us…..’ Also, the relatives seldom visited and did not support their mother when she was ill. In other words, the relationship between their mother and relatives had not been very close. This points to the possible importance of family relationships before parents die. In case parents do not have strong family relationships, children might not be supported by them. On the other hand, Aidan (age 18), who stated he was not supported by relatives, argued that his mother did have good relationships with her relatives before she died:

‘No one takes care of us: no one phoned to ask how we are, nothing. I feel very angry about this because when my mother was alive she was taking care of them. She was a faithful person.’

Aidan was particularly angry with his mother’s relatives because his mother used to support them when she was alive. Although Aidan reported that nobody offered him any support, he did receive monthly groceries from his aunt, who was his mother’s sister. However, he and his brothers often went without food or money for days. His interpretation that he was not really supported resulted from his need to talk to somebody and to be taken seriously. Without consultation, his aunt let out two rooms of the house where he and his brothers lived. Furthermore, while he was absent for two weeks to visit relatives in a rural area, his two younger brothers stayed with her. When he returned, his aunt kept his brothers in her care, arguing that he could not care for them. Aidan, however, wanted his brothers to move back in with him.

Aidan did not understand why his aunt only wanted to care for his younger brothers and not for him. The aunt may have thought Aidan was old enough to care for himself. As a result, however, Aidan was worse off. He could no longer access the CSG (see Table 1) or receive support from his brother’s father, which were his only sources of income.

When we visited Aidan in 2007 (two years later), one of his brothers (now age 16) had moved back in with him. According to Aidan, his aunt did not want his brother living with her anymore, as he was disobedient and had started smoking marijuana. Aidan often expressed anger towards his aunt:

“She is a traitor to me…. No one seems to care about me, not even my dad…. I feel angry about that. I will forgive her, but I will never forget what she did to us. She is so bad and has made my life to hurt. I have no words to say the pain I sometimes feel.’

Something similar happened to Norah. Since the time her mother died when she was age 17 (in 1999), she took care of her three siblings (ages 5, 11 and 14). When she turned 18, she wanted to apply for social grants and needed her siblings’ birth certificates to do so. Her aunt kept the papers but claimed that they had been lost and suggested that the
two youngest children should come live with her. Norah agreed, as she could not take care of them without income from the grants. Because Norah wanted her siblings to live with her, she decided to apply for the birth certificates and social grants again. However, she was unable to apply for grants, as the first requirement is that the children live with the applicant.

The above narratives indicate that family relations altered with the death of the parent, and instead of becoming supportive, these relations could become a threat. Feelings of abandonment and a lack of consultation about their immediate living circumstances impacted the children’s sense of agency, causing emotional distress due to separation from their siblings and because of mistreatment, as they saw it, by those from whom they expected assistance.

**Neighbours helping out**

Besides the expectation that extended family members should support orphaned children, in Xhosa culture, community members are also expected to share their wealth with poorer members of the community. This type of support is in accordance with the local perception of the spirit of *ubuntu*. In most cases indeed, the children received some support from close neighbours. There were different forms of support, but helping with food was the most common. In 10 of the child-headed households, the children received food from neighbours, ranging from a loaf of bread to full supper. Most of them indicated that they had to do something in return — for example, they were sent on errands or helped in the household. As a result, some perceived the food they received from neighbours as compensation rather than support. On the other hand, Skovdal Ogutu, Aoro & Campbell (2009) found that children may also reciprocate favours in a conscious effort to nurture potentially protective social relationships. This is probably dependent on the type of relationship they have with a neighbour. For example, Zack (age 18) willingly helped his old neighbour, a woman whom he visited regularly and helped by washing dishes or doing shopping. The neighbour often cooked for two, treating Zack as her own child. Zack seemed to feel very close to her too. According to her, other neighbours also gave him food; but according to Zack, the other neighbours did not give him food or help in any other way. It thus appears that although community members may think that youngsters are supported by other neighbours, this is not necessarily the case.

In most cases, the children ate the food they received from others in their own homes. Some of the younger children, however, such as Marc and Janin (both aged 13) and Nick’s younger brother Bathi (age 15), indicated that they had supper at a neighbour’s house. Bathi liked to eat there, sometimes watched TV and felt welcome in the home. In these cases, the material support may have consequently fulfilled emotional needs. Some youngsters indicated more clearly that they received emotional or moral support from neighbours, teachers or friends. Lauren was able to talk with two teachers about her problems, and they would offer her advice. Lauren lived with her three younger siblings, and so she really appreciated her teachers’ support. Two other participants also said they had a good relationship with a teacher; while for most of the children such emotional support was less evident.

There were cases of community support of which the children appeared unaware. This was the case with Therah: one day during an interview, we were interrupted by an older female neighbour who came over because she thought we might be interested in buying Therah’s house. Another neighbour had stolen the ownership documents and tried to sell the house to the ward councillor. According to the neighbour, she had prevented Therah’s house from being sold to other neighbours. Surprisingly, Therah did not know that her neighbours helped in this way, as they hadn’t told her what they were doing. The same happened to Mona, whom we mentioned at the beginning of the article. She, too, was not aware of the intervention by community members to prevent family members from appropriating her house.

Although Stephen (age 15) and Nkosi (age 11) were not supported by the relatives of their mother, they were supported by Nkosi’s father. Furthermore, a friend of their deceased mother, Leah, who lived nearby, also visited them daily, offering support in running their household. According to Leah, before their mother died, she asked Leah to care for her children. The children related that Leah acted like a mother, whose support they very much appreciated.

Whereas the support of community members was not structural or sufficient, it helped child-headed households to survive. Furthermore, although some youngsters claimed they received no support from relatives, almost all households received some support from neighbours.

**Coping capabilities**

Having discussed the participants’ needs, the support they received and their interpretations of this, we return to the question of whether social relationships contributed to their capacity to cope. Three of the 20 households claimed to be materially supported by relatives in the form of monthly groceries and payment of school fees. However, although this type of support helped them run their households, it was not considered secure as it would periodically or indefinitely stop. Although most of the child-headed households received some support from neighbours, it was rather unpredictable and unstable, according to them. This meant that the youngsters did not know whether they would have food on the table every day. Lauren and her siblings and Stephen and Nkosi were the only households that managed quite well, despite their grief and worries about caring for their sibling(s).

The youngsters’ interpretations of support, which influenced their sense of agency, depended on the quality of the relationships and on their assessment of a person’s ability to offer support. When the children felt accepted or loved by the provider of support, they were more positive about its quality, irrespective of how minimal the actual support was. Another factor in their interpretation was whether they were consulted or involved in the support-related decisions by relatives which affected their lives. By their accounts they were rarely consulted about care arrangements or interventions. Irrespective of the motives of relatives or neighbours in not supporting and involving them
(more), the negative interpretations of youngsters influence their sense of agency and, consequently, whether they seek further support, such as access to grants.

Nine households were eligible for one or more foster care grants (FCGs), but only one household received a FCG (Table 1). This was the household of Lauren, who was supported in the application process by an acquaintance of her late mother. Nine households were eligible for one or more child support grants (CSGs), of which five households received one or more CSG (R180/month at the time of the fieldwork).

To apply for a FCG or CSG, the applicant needs to have an identity document (ID), the birth certificates of the child (or children) for whom he or she is applying, and the death certificate of the former caregiver. Many people in South Africa do not have these documents. Children in child-headed households are less likely to have such documents than children who live in adult-headed households (Donald & Clacherty, 2005). Some youngsters indicated that they had these papers in the past, but these had since been lost, stolen or kept by relatives. As in Norah’s case, discussed above, relatives were sometimes reluctant to return these documents.

Youngsters who want to apply for an ID need to have a birth certificate, which many of the participants did not have. To apply for one’s birth certificate, one needs to search the medical records of the hospital where one was born, or one can go to one’s (former) school to get papers proving one’s identity. Most of the youngsters in the study never approached the required authorities to seek formal support. One important reason for this appeared to be their difficulty communicating with older people as they need to show respect, are not expected to ask for something in a direct manner, and are not perceived as able to speak for themselves. This was the reason Zack (age 18) did not return to the Department of Social Development after his first visit to the office:

‘They will tell us that we must go home and come back with an older person, don’t come and waste our time….’

According to him, the older person is ‘the one who can explain everything to the social workers.’ Others also argued that they needed someone to accompany them to the different authorities. For example, Peter (age 18) wanted to apply for an ID for which he first needed to obtain papers from his former school. However, he didn’t go to his old school because he argued that he needed an older person to accompany him:

‘Somebody who goes there with me, because if I go alone and then they don’t understand…they will ask me, where are your parents?’

From the above, besides the money required to obtain the right documents, senior back-up is needed in accessing formal support. However, except for Lauren, none of the youngsters were assisted by relatives or community members in the application process. In some instances, the actions of relatives seem to have hindered the youngsters in applying for grants, such as in cases where they kept their documents or removed younger siblings from the household. This resulted in a sense of powerlessness and lack of control over their situation, in turn preventing them from applying for formal support or asking for informal support, either material or emotional. People working in the community confirmed that ‘children’ are not taken seriously when they apply for assistance alone or are even told to go away. The perceived ignorance of younger people does not relate so much to biological age (as many of these ‘children’ were over the age of 18) but rather to local understandings of childhood.

As a result, the youngsters appeared to have a low sense of agency with regard to seeking formal support. They were also reluctant to approach relatives for support, although they often felt entitled to such support. However, asking for formal support or support from relatives is also complicated as children are not expected to communicate in a direct manner with seniors. However, not seeking support from relatives was also a conscious strategy. Some children did not expect to receive support; they perceived their relatives as too poor, or they wanted to save their requests for even worse times. This implies that they did not want to ask for support too often as relatives or neighbours may have gotten ‘tired’ of them and become less inclined to help. In these cases, a reluctance to ask for support related less to a poor sense of agency than to well-considered reasons or motives.

Conclusions

This study assessed the use-value of support networks from the viewpoint and experiences of child-headed households. As our study shows, the idealised image of the capacities of the extended family and community to support children in need does not correspond to the everyday realities of youngsters in child-headed households. By definition, the presence of social relationships is not positively related to a certain quantity or quality of support.

Not surprisingly, youngsters' perceptions about the type of support they need differ from those of adults. When they need other forms of support or when their expectations of support contrast with the actual support, youngsters may feel unsupported. Constant worry about whether they can manage, emotional problems related to the death of a caregiver, and insecurity and frustration due to not being listened to, all contribute to a low level of confidence in others as well as themselves. This state is likely to be aggravated by their social status as ‘children,’ which limits their room to manoeuvre in seeking and asking for support. Overall, those participants who received support, which they interpreted positively, were more hopeful about their future and their own capabilities. Positive interpretations of support largely related to feeling cared for or loved, and this positively influenced their sense of agency and consequently their coping capabilities.

The social relationships of most of the child-headed households in our study appeared to not contribute positively to their room to manoeuvre and sense of agency: youngsters did not have the sense that they were able to seek formal or informal support. In other words, their social relationships seemed to have little use-value in terms of accessing material and emotional support.
The current provision in the Child Care Act for a proposed mentorship scheme is only intended to help those who cannot access formal support due to their biological age. However, youngsters above the age of 18 also have difficulties accessing support. Statistics show that there is a striking rise in sibling-households headed by young adults (aged 18 to 24) (Richter & Desmond, 2008). More attention to these households in the Child Care Act is justified by the fact that children below the age of 18 are also part of these ‘youth-headed households’ and are hence directly affected by measures aimed to assist these households. Grants monies should not only serve the needs of dependent siblings, but also those of the young household heads themselves, as well as those children who live alone.

While access to grants via an adult mentor would be of considerable support to child-headed households, more attention to their overall needs is crucial. Support for accessing grants should include an adult willing to accommodate them to authorities, such as going to municipal services to arrange identity cards. Other important needs are a chance to be listened to, receiving advice on running a household and raising younger siblings, and planning initiatives into adulthood.

Despite limited ‘room to manoeuvre,’ the youngsters in the child-headed households managed to survive and deal with their precarious situations. Notwithstanding many restrictions in the children’s capabilities, the findings show that the youngsters had well-considered reasons and motives for their strategies. In order to assess whether child-headed households are a viable living arrangement for children affected by HIV, assessing the use-value of social relationships in terms of potential support — from their own points of view — proves fundamental.

Notes
1. All names used here are pseudonyms.
2. Of the 30 000 households that participated in the 2006 survey, only 156 households were identified as ‘child-only’. As McIntjes et al. (2010) acknowledge, this severely limits the power of analysis of child-only household characteristics, such as their dependence on remittances.
3. In 2010, caregivers were eligible if they were single and had an income not higher than R2 500 per month; for married couples, the combined income could not be above R5 000 per month.
4. To apply for the grant, a person must have an identity document that is only provided from the age of 16 onwards.
5. For more about the diverse and complex reasons for establishment of child-headed households, see also Van Dijk, 2008, pp. 143–145.

Acknowledgements — We thank Marguerite Daniel and Morten Skovdal for taking the initiative for this special issue and for their useful feedback on an earlier version of this article. We are grateful for financial assistance for the research from the Netherlands Foundation for the Advancement of Tropical Research (WOTRO), part of the Netherlands Organisation for Scientific Research (NWO).

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