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Published in:
African Journal of AIDS Research

DOI:
[10.2989/16085906.2012.734975](https://doi.org/10.2989/16085906.2012.734975)

Publication date:
2012

Document version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Skovdal, M., & Daniel, M. (2012). Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa. *African Journal of AIDS Research*, 11(3), 153-164.
<https://doi.org/10.2989/16085906.2012.734975>

— 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, Mupambireyi & Gregson, 2010; Campbell, Skovdal, Mupambireyi, 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, Fotso, 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 & Ableidinger, 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; Boyden, 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; Boyden, 1997; Nsamenang, 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 aid 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

progressively define their membership of an adult society. Piaget's stages theory has contributed to thinking that interprets children's perspectives according to their developmental level and sees children as incomplete, 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 biomedically 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 & Kj rholt (2009) that dichotomising children as *either* active agents or passive victims is problematic and undermines the possibility for what Kesby, Gwanzura-Ottmoller & 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. Nyambedha, 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 psychosocial 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 grandmothers 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, Lopman, 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, 2005; Daniel, Apila, Bjorgo & 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, Sebunnya & Jack, 2009; Betancourt, Rubin-Smith, Beardslee, Stulac, 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 recognise 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 recognise 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 mobilise 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 recognising 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 recognising their agency; for example, the young people prioritised the provision of basic needs ahead of employment or emotional support. Evans also demonstrates the role that youth-led collective mobilisation 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 Ogutu** (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 each other's aid in times of needs.

Second, employing 'appreciative inquiry' to frame the discussion of adolescents coping strategies, **Khanare** (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, Khanare 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 Ogutu, Khanare 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 digital 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

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

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.

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