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Orphan competent communities: a framework for community analysis and action

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Orphan Competent Communities: A Framework for Community Analysis and Action

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Vulnerable children in Africa have traditionally been absorbed and supported by their communities. However, in the context of AIDS and poverty, communities are increasingly stretched, compromising the quality of care available to children affected by AIDS. This calls for an understanding of the processes that best facilitate the capacity of communities to provide good quality care and support. In the interests of furthering debate and practice in this area, we seek to develop an analytical framework that builds on two inter-linked strands. Firstly, we emphasise the need to acknowledge the active coping and resilience of children affected by AIDS, rather than seeing them as passive victims. It is through taking account of children's and communities' indigenous coping strategies, and the complex dynamics between children and fostering families, that interventions have the best chance of supporting communities so that they can best facilitate resilience and well-being of AIDS-affected children under their guardianship. Secondly, we highlight six psychosocial resources that we argue should be promoted in communities to improve the quality of support available to children affected by AIDS, and thereby enhance the coping and resilience of children.

Introduction

In sub-Saharan Africa, 12 million children under the age of 18 have lost one or both parents to AIDS, and nearly 2 million children under the age of 14 are HIV positive (UNICEF, UNAIDS, WHO, & UNFPA, 2008). Millions more have been made vulnerable by AIDS-related poverty and other illness-associated stressors such as caregiving (Robson, Ansell, Huber, Gould, & van Blerk, 2006). Reference is often made to the 'orphan-care crisis' (e.g. Guest, 2001; Howard, Phillips, Matinhure, Goodman, McCurdy, & Johnson, 2006) – typecasting orphans as a problem. However, whilst the statistics are alarming and reflect the immense scale of the AIDS epidemic, a remarkable 90% of children affected by HIV and AIDS are estimated to be in the care and support of extended family members (Monasch & Boerma, 2004; UNICEF, 2003). This situation runs counter to the current

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stereotype of an 'orphan care crisis', and the frequently-made assertions that the 'traditional systems of family support' are breaking down (George, Oudenhoven, & Wazir, 2003:344; Guest, 2001).

Although extended-family networks continue to assume the primary role in orphan care and support, an increasing number of reports highlight the hardship experienced by fostering households in securing children's basic needs, including schooling, food and medical care (Nyambedha, Wandibba, & Aagaard-Hansen, 2003b; Oleke, Blystad, & Rekdal, 2005; Oni, 1995; Ssengonzi, 2009). Such struggles highlight the strain which many fostering households endure and underline the fact that neither the public sector nor communities are currently providing adequate support to the growing number of fostering households (Miller, Gruskin, Subramanian, Rajaraman, & Heymann, 2006).

There is an urgent need to earmark funds for orphan care and support. However, in agreement with Foster (2002), we believe that such funds will do most good if they target existing support strategies and psychosocial resources. This implies a need to understand, identify and strengthen latent and existing grassroots resources. Following on from this, Foster (2002) also argues that traditional fostering systems, if supported by community initiatives, will continue to meet most of these children's basic needs. His argument arises from the demonstrated ability of community-based orphan support initiatives to target and support large numbers of fostering households in sub-Saharan Africa (Drew, Makufa, & Foster, 1998; Foster, Makufa, Drew, Kambeu, & Saurombe, 1996; Nyamukapa & Gregson, 2005; Skovdal, Mwasiiji, Morrison, & Tomkins, 2008). Highlighting the viability of strengthening and supporting community initiatives, Nyambedha and Aagaard-Hansen (2007) have observed a renewed community solidarity in some settings of Kenya as a result of the AIDS epidemic, with local self-help and volunteer groups emerging in an effort to support the many children affected by AIDS.

Whilst non-governmental organisations (NGO) play a key role in facilitating community-based orphan support initiatives, it has been noted that "few agencies trust communities to make important decisions about the use of external grants" (Foster, 2002:1909). Reconciling local (community) and external (NGO) responses to orphan care remains a challenge and there is a growing concern that well-intentioned NGOs may inadvertently be undermining local efforts to cope with the epidemic. Drawing on their experience in Rwanda, Thurman, Snider, et al. (2008) argue that ill-conceived NGO services can fragment local community responses by taking over the perceived responsibility for care of children affected by AIDS. NGOs are also often guided by representations of orphans as vulnerable, poorly behaved and 'at risk' of poor mental health, representations that might not correspond with local understandings of orphanhood (Meintjes & Giese, 2006). This can lead to what local communities perceive as the unfair targeting of a single group of children (those affected by AIDS) by agencies. It is precisely such a context that can fragment local support networks and cause further marginalisation of children affected by AIDS (Meintjes & Giese, 2006; Thurman et al., 2008).

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Such inappropriate responses are often driven by the assumptions that (i) orphans are passive recipients of support, and (ii) outside agencies have the solution and that an externally imposed intervention is an appropriate way to tackle the issue. In this paper we challenge both these assumptions. We provide evidence of orphan coping and resilience, even in adverse settings, and highlight six psychosocial resources that we believe can facilitate the development of 'orphan competent communities', where local people are able to work with one another, and in partnership with support agencies, to identify support strategies and resources that are most appropriate for facilitating latent community strengths and local coping responses.

We argue that frameworks that view orphans as helpless victims or a burden are neither accurate, nor are they useful tools for action. Sustainable and meaningful action is most likely to result from approaches that seek to identify and strengthen the 'portfolio of assets' available even within poor communities (Moser, 1998). We will illustrate this with examples from Skovdal's recent research in western Kenya (Skovdal, Ogutu, Aoro, & Campbell, 2009). Furthermore, we argue that the solutions need to come from the orphans, their fostering households and host communities themselves, rather than being generated and imposed by outsiders, who often have very limited understandings of the dynamics and resources that determine children's vulnerabilities (Schenk, Ndhlovu, Tembo, Nsune, Nkhata, Walusiku et al., 2008). In developing the concept of an 'orphan competent community', we adapt Campbell's conceptualisation of a 'AIDS competent community'. We conclude by referring to a community-based capital cash transfer (CCCT) project that aims to facilitate the pathways between resilience and coping of children affected by AIDS, and what we believe are the characteristics of orphan competent communities.

The coping and resilience of children affected by AIDS

The impact of AIDS on children can be devastating, making them vulnerable to reduced access to education (D. Evans & Miguel, 2007), poor health (Andrews, Skinner, & Zuma, 2006), malnutrition (Mishra, Arnold, Otieno, Cross, & Hong, 2007), stigma (Campbell, Foulis, Maimane, & Sibiya, 2005) and challenged mental health (Cluver & Gardner, 2007). We believe that these needs are best understood and targeted through strength-based research and interventions. The concepts of coping and resilience are increasingly applied to research about children affected by AIDS in Africa (Ansell & van Blerk, 2004; Daniel, Apila, Bjorgo, & Lie, 2007; R. Evans, 2005; Fjermestad, Kvestad, Daniel, & Lie, 2008; Skovdal et al., 2009). These concepts allow us to acknowledge the active role of children in coping with adversity. They shift the emphasis away from what Ennew (2005) refers to as a current predominant focus on the 'burdens' of fostering orphans (e.g. Oburu & Palmerus, 2005; Ssengonzi, 2009) to a focus on the active and positive contributions by many fostered children to sustain the livelihoods of their host households (e.g. Abebe & Aase, 2007; Skovdal, 2009). Ungar's (2008) definition of resilience as the outcome of a process of active negotiation between individuals and their social environments provides a useful starting point for our strengths-based orientation. His dynamic understanding of the individual-community interface is a useful framework for those who

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seek to promote culturally relevant and meaningful responses to the care and support of children affected by AIDS.

In our recent research in western Kenya, we highlight the resilience of children actively engaged in coping with challenging circumstances under conditions of great adversity (Skovdal et al., 2009). We document three ways in which children do this, each of which will be discussed in turn.

1. Children cope through actively contributing to household survival, through income generating activities, and by helping to nurse sick or disabled guardians and their family members.
2. Children cope by mobilising support.
3. Children cope by constructing positive identities.

Children cope through household sustaining activities

Whilst some children are incorporated into capable and adaptive fostering households, many children end up living in ruptured and poor households, motivated to take on orphans because of their ability to contribute and sustain the household through work (Abebe & Aase, 2007; Skovdal, 2009). Some of the more vulnerable households are those with bedridden, sick (Robson et al., 2006), or ageing (Nyambedha, Wandibba, & Aagaard-Hansen, 2003a; Nyambedha et al., 2003b) members. Whilst elderly and sick foster parents might provide valuable emotional support, they might not be able to provide for children's material and physical needs (Robson et al., 2006; Young & Ansell, 2003). In such situations many children are forced to take on nursing, head of house and income generating responsibilities (Skovdal et al., 2009).

In our study, many fostered orphans made a vital contribution to their households through their participation in income generating activities. These included poultry keeping, tending of goats and cows, subsistence farming, cultivation of fruit trees, and burning of charcoal (Skovdal et al., 2009). However, none of these activities occurred without some level of negotiation with other social actors. The children often had to negotiate access to land from neighbours or their fostering household, or negotiate selling prices and make good use of the resources (e.g. animals and fruit trees) at their disposal. Similar observations have been made in Ethiopia where children worked on other people's farms and engaged in other informal work activities in towns and market places (Abebe, 2007).

Children cope by mobilising support

Many children also manage to mobilise social support. In Kenya, we found children actively asking for support from extended family members, neighbours, teachers, church, and community groups. Some support, for example emotional, food, or school materials was readily available in certain cases. Much of the social support, however, required significant negotiation, often involving reciprocity of care and support between the adults and the children (Skovdal et al., 2009). This is well illustrated by 12-year-old Kevin from Kenya, who, in order to negotiate food from his neighbours,

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helps them work their land: "If I have no food, I get it from the neighbours and in exchange I assist them in harvesting maize, sorghum and beans" (Skovdal, in press). Although the children are not always expected to reciprocate favours, they often do so in a conscious effort to nurture potentially protective social relationships.

The large number of local community groups, such as widow, women and church groups, that characterise the social landscape of many communities in Africa continue to be a valuable source of support for many vulnerable children (Nyambedha & Aagaard-Hansen, 2007). In Kenya, we also observed the capability of children to mobilise very effective friendship groups and networks through which they negotiated both emotional and practical support (Skovdal et al., 2009). Similar arrangements have also been identified by Donald and Clacherty (2005) in South Africa.

Children cope through identity construction and meanings

Identity construction shapes the way in which the children see the world and their communities and give meaning to their circumstances, and is a key dimension of coping. Woodhead (1998) reports on the active role working children play in giving meaning to difficult circumstances, enabling them to make the best of their situation and cope successfully. Similarly in Kenya, we observed how children caring for their ailing or ageing guardians drew on the positive social recognition of their responsibilities to make sense of their circumstances and to build a positive caregiver identity. This was based on their view of themselves as exercising vitally important and valuable social responsibilities within their households and communities (Skovdal & Ogutu, 2009). Children were also found to draw on previous caring experiences, suggesting that caring identities can be long-lasting (ibid.).

Towards a social psychology of coping

It is evident that the quality of care and support available to children affected by AIDS is shaped by the complex interaction between individual children and the community contexts in which they find themselves. In Kenya we found children's coping to be determined by the extent to which they negotiated support from, and participated in community life (Skovdal et al., 2009).

Children's coping is influenced by:

- I. The on-going process of negotiation between the individual and the community. This shapes the child's identity, as well as their access to local support networks and resources to tackle adversity;
- II. The quality of the community in which they live, and its ability to share resources; and
- III. Children's different abilities to negotiate community support.

This conceptualisation of coping opens up a new level of analysis, one that explores community-based activities and the impact of community relations on the coping of individuals, facilitating the

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development of more effective and context-specific policies and practices. Since children's participation and coping does not happen within a vacuum, but is dependent on the quality of their community, struggling households are best supported through the building of orphan competent communities, which we discuss below.

Orphan Competent Communities

How do we begin to conceptualise the types of communities that are mostly like to provide optimal support for orphans? Campbell's concept of the 'AIDS competent community' is one starting point (Campbell, Nair, & Maimane, 2007; Campbell, Nair, Maimane, & Gibbs, 2009, in press). She defines this as a community where people are most likely to work collaboratively to tackle the challenges of HIV/AIDS (including avoiding infection, caring for the sick, and accessing support and treatment). Reflecting the above discussions, Campbell (2003) argues that many AIDS projects in sub-Saharan Africa have had disappointing results because they have involved interventions by outside professionals who often had poor understandings of the needs, interests and worldviews of target community members. Against this background she argues that programmes should seek to identify and facilitate local community responses rather than intervening from the outside.

She argues that people are most likely to respond effectively to HIV/AIDS when they have a sense of agency and confidence in their ability to respond effectively, as well as partnerships with supportive outside agencies. She defines an AIDS competent community in terms of the following six dimensions:

- Appropriate knowledge and skills
- Opportunities for community members to discuss the challenges of AIDS, think critically about obstacles to tackling it effectively, and brainstorm ways people can work together to tackle the obstacles
- The ability to recognise and appreciate local strengths and coping resources
- A sense of confidence and agency (rather than fatalism and waiting for outsiders or the government to come and tackle the problem)
- A sense of within-community solidarity
- Ability to identify, mobilise, and access outside sources of support

This is a useful starting point for our concept of an 'orphan competent community'. However, in the case of orphans, we need to expand it with more specific reference to the material and social resources needed to support orphans, and further develop the concrete strategies required to build orphan competence. Drawing on work in Western Kenya (Skovdal, 2009; Skovdal et al., 2008; Skovdal et al., 2009), we conceptualise an orphan competent community as one in which orphans

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and their fostering households are best able to successfully negotiate and access support from their social environments (including extended family, friends, neighbours, self-help and volunteer groups, church groups, schools, NGO and government welfare services). We believe that this conceptualisation provides a useful framework for analysing the contexts in which orphan care and support programmes are located, in the interests of formulating locally appropriate intervention strategies and local responses. Reflecting upon our observations in Western Kenya, we propose six psychosocial building blocks that we believe characterise an orphan competent community.

Knowledge and Skills

Residents of orphan competent communities should acknowledge the magnitude of the HIV and AIDS epidemic and have good factual information about the disease and its impact on children. Residents should also have a sound understanding and awareness of local coping strategies and community responses to orphan care and support. These include an awareness of the activities that help children cope, and the availability of existing community services, such as community health workers and barefoot paralegals. If community members have an awareness of the challenges facing them and the knowledge and skills to follow up on these challenges, they are more likely to take ownership of the challenges posed by growing numbers of AIDS orphans. They will also see themselves as having an active role to play in tackling this issue, rather than waiting passively for government or NGOs to come and solve the problem.

Recognition of local strengths and agency

It is important for community members to recognise and have confidence in their own assets and local strengths. These include their collective ability to support orphans and their individual efforts to make a difference in their lives. An example of collective support for orphans includes community initiatives such as communal gardens cultivated by community members to generate food for orphans, or orphan day care activities to educate the youngest and non-school going children. If individuals are confident in their local strengths, they are more likely to become involved in decisions that affect the lives of children affected by AIDS. Agency and confidence in community initiatives is best facilitated through practical experiences (Cornish, 2006).

Building partnerships and access to resources

It is vital that communities have the capacity to build support partnerships with local and outside community groups and organisations that can facilitate them in supporting orphans. It is beneficial for a marginalised community to work in partnership with agencies and individuals who have the political and economic power to facilitate effective local community responses. Such alliances can generate resources that poor communities would otherwise not be able to access (Campbell, 2003). This type of 'bridging' social capital has been identified as a precondition for effective community responses to AIDS (Gillies, 1998; Szreter & Woolcock, 2004).

Solidarity and connectedness

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Communities that are characterised by sympathetic and supportive relationships provide the optimal context in which children and households affected by AIDS can negotiate support. This includes access to much-needed resources, such as land for cultivation, livestock, food, money for school-related costs, and in general, empathy. In an orphan competent community, solidarity and connectedness allow people to support each other despite differences such as position in society, or whether one fosters orphans, and work for a common purpose. Relationships of solidarity also provide favourable conditions for supportive social spaces to emerge.

Supportive Social Spaces

Community members need supportive and sympathetic social spaces in which they can collectively discuss their anxieties about the orphan issue, brainstorm ways in which they might support children affected by AIDS, and the types of support they require. Similarly, children affected by AIDS need supportive social spaces in which they can easily negotiate support and discuss issues that affect them. In many sub-Saharan African settings, local community organisations and initiatives have grown from the response to the increasing number of children affected by AIDS. Schools and church groups can provide children with supportive social spaces. Supportive social spaces can be facilitated through initiatives such as Stepping Stones (Welbourn, 1995), Community Conversations (UNDP, 2004) and Participatory Learning and Action tools (Rifkin & Pridmore, 2001). In supportive and safe social spaces, community members and children are more like to refine and develop health-enabling social identities through engaging in dialogue about their life challenges and how best to respond to these.

Positive Social Identities

Social identities arise from membership of an 'in-group' or community, and our need to locate ourselves in the environment in which we live, evolving from our desire to stand out and belong to particular social groups (Howarth, 2001, 2002). Social identities can also be imposed and, instead of being a member of an in-group, one can become a member of an out-group (Markova, 2007). Children affected by AIDS may therefore see themselves as a distinct group of children (in-group) and develop strong bonds, or be alienated by school friends due to stigma of AIDS (out-group), processes that can both hinder and facilitate coping. For this reason, efforts should be made to understand and facilitate the role of positive identities in supporting AIDS-affected children and communities.

Way forward

We believe that the six psychosocial resources highlighted above constitute factors that enhance the ability of communities to offer optimal support to AIDS-affected children, in ways that reinforce children's resilience and coping, and that build on the actual and latent strengths and resources that exist even in resource-poor communities. Our focus on children's coping and resilience is a response to the simplistic representation of children affected by AIDS as inevitably "vulnerable, scarred, and wary of life" (Kelly, 2003:61). Whilst there have been some reservations about a focus

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on coping, given the extremely negative social circumstances of many children and households (Kesby, Gwanzura-Ottmoller, & Chizororo, 2006; Rugalema, 2000), we believe that negative representations, such as those cited above, do not do justice to the remarkable engagement and ingenuity in coping which many children are able to demonstrate, even in conditions of desperation and struggle (Panter-Brick, 2002). However, we strongly believe that an emphasis on the potential resilience of children and communities should not be made without a parallel emphasis on the need for agencies to support local community responses that seek to support and bolster the capacities and strengths of children and their communities, and to strengthen and support such resilience. In this regard we have highlighted the psychosocial resources that hinder or facilitate the building of orphan competent communities. In our view, it is vital that service providers who seek to support AIDS-affected communities and children prioritise the promotion of these six psychosocial resources through participatory projects, enhanced by appropriate support alliances.

However, only a few interventions combine access to valued resources, participation and self-determination in ways that optimise the agency and competence of community members to support children (Prilleltensky, Nelson, & Peirson, 2001). It remains a challenge to develop and evaluate actionable interventions that seek to develop orphan competent communities. The first author is currently engaged in a promising CCCT project that seeks to develop orphan competence. In the project, communities (either defined geographically or because of their shared objectives) partner with a funding agency. The agency engages community members in a series of participatory processes facilitated through various participatory learning and action techniques (Rifkin & Pridmore, 2001). These techniques allow community members to critically engage and observe the circumstances that impact the lives of children affected by AIDS, which are subsequently translated into community-level action plans. These plans are funded with the aim of strengthening and supporting promising community responses to the care and support of children affected by AIDS. Early observations from this project, as well as the processes involved in implementing it, highlight the ability of CCCT to facilitate supportive social spaces, solidarity and connectedness, confidence in local strengths and ownership (Skovdal, 2006; Skovdal et al., 2008), as well as improved school attendance and performance of orphans (Mwasijaji, Webale, Skovdal, & Tomkins, 2008).

The usual problems – documented repeatedly in the community psychology literature (Cooke & Kothari, 2001; Labonte, 2004; Mansuri & Rao, 2004; White, 1996) - challenge the project, three of which are mentioned here. Firstly, as many critics have repeatedly emphasised, the boundaries of communities constantly shift, so that our target communities by no means existed as stable or fixed entities. The highly mobile nature of orphans (cf. Nyambedha & Aagaard-Hansen, 2003) has severely challenged project facilitators. Drop-out rates have been higher than originally anticipated – as youthful project participants move from one area to the next, in relation to the complex and extended geographical locations of each child's care-giving networks. Secondly we are ever conscious of well-documented warnings that community participation projects - designed to support the most marginalised members of a community - may easily be hijacked by more powerful

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community members. In our child-focused project, ceaseless efforts are made by project facilitators to ensure that adult assistance is offered in ways that support children's empowerment. Children often need adult assistance with their income generating activities, for example, for tasks such as watering plants or checking on goats whilst children are at school. However, this assistance should be offered within the context of a more general acceptance by adults of children's ownership of the project, rather than leading adults to use their participation as a stepping stone to hijacking the project for their own interests. This is not always easy to achieve. In this regard, NGO staff have an important and challenging monitoring and facilitating role as external change agents, in ensuring that the child-centred ethos of the project is recognised by adult helpers. Finally, our experience also echoes frequent warnings by researchers and health workers not to romanticise communities - to assume that community members always have the good of orphans at heart, for example. In our study community, several foster parents prevented orphans from participating in the projects because they felt it would distract them from their domestic duties in their foster homes. However, despite many challenges, the project is already yielding significant gains for some child participants, and as such serves as a promising example of ways in which child and community coping mechanisms might be supported and facilitated in ways that respect and enhance children's competencies and agency.

In summary, what transpires from our framework above is the importance of how researchers and service providers approach the needs of children affected by AIDS. If we want to support children affected by AIDS, we should begin to look at their latent coping strategies and the role of communities and households in building their resilience – moving away from seeing children as passive victims. Only then will we be able to understand the psychosocial processes that hinder or facilitate the coping of children affected by AIDS. Clearly this is a complex enterprise with many potential pitfalls, but in our view it is the approach that offers the greatest hope of success in the long term. The success of any participatory programmes seeking to enhance, strengthen or build orphan competence of a community, are dependent on the attitudes of all the people involved, right from a community level through to the donors and service providers. Finally, as factors determining the orphan competence of a community and children's agency are likely to differ across space and time, it is important for interventions and researchers to take account of the local context of children affected by AIDS on a case by case basis.

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