# The black, white and grey of rainbow children coping with HIV/AIDS.

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## Abstract

*This article explores the complexity of the inquiry process concerning South African children coping with the effects of HIV/AIDS. The aim is to start a debate on this issue and to review coping literature relating to children and HIV/AIDS. The article makes use of the metaphor of a tapestry, in order to convey the intricacies, complexities and multiplicity of facets of this process. The article commences with a rationale for the exploration, and assumes that understanding these children's coping might facilitate early identification and support of their psychosocial stress, as well as increase their resilience. The article subsequently explores what coping is by integrating the different theoretical standpoints and the assumptions of the authors. It illustrates how our current theoretical constructions of the coping process fall short in understanding the unique coping process in South African children who are dealing with HIV/AIDS. This is done by sustaining the tapestry metaphor, posing rhetorical questions and also by referring to some observations made in the initial phase of this research process. However, the article also illuminates the contributions that generic coping theories can make in the construction of a theoretical framework for understanding coping in this context, namely the transactional coping process, individual experiences of stress, the coping repertoire of children, and the fact that children under threat revert to primary emotional coping strategies. They also depend on adult support to assist them in coping. Protective factors that might buffer the effects of trauma are explored. The article next relates the complexities of HIV/AIDS to the coping of traumatised South African children. It concludes with the notion of not being a 'comfort' text (because there are more questions than answers), but it underscores the need for persistence in the inquiry process.*

## Introduction

The much-lauded South African rainbow nation is threatened by the presence of the HIV/AIDS pandemic. How does a child cope if the colour has gone from her life? How does a boy consumed by unwarranted guilt on account of a parent's death handle everyday life without carefree play?

Not much has been published on children coping with HIV/AIDS in South Africa. We do not presume to present models or programmes for coping. Our aim is to enter the debate on

children's coping with HIV/AIDS. We seek to explore some of the questions entangled in the lives of South African children infected and affected by HIV/AIDS.[86] These questions are (1) what is coping? (2) how do children cope? and (3) how could traumatised South African children cope with the effects of HIV/AIDS?

HIV/AIDS constitutes a chronic stressor in the lives of many South African children. They live with the stress of being without the familiar care of a mother. They have to bear hardship and responsibility on account of parents' unemployment. They face being stigmatised by peers and treated as social outcasts. They are burdened by grief for lost family members, lost homes and lost opportunities. Traumatised children are prone to feelings of inadequacy and depression and may suffer Post Traumatic Stress Disorder (Ndethiu, 2001a). The early identification of such psycho-social stress could lead to timely support and care. Effective coping reinforces a sense of competence and encourages coping responses in future (Zeitlin & Williamson, 1994). Thus, the cared for children of today have a better chance of becoming the resilient adults of tomorrow.

What are the black and white HIV/AIDS facts South African children have to cope with? We highlight some of the effects of HIV/AIDS to contextualise the predicament of these vulnerable children (UNAIDSb, 2000; Hepburn, 2001; Foster & Williamson, 2000; Hunter & Fall, 1998; Coombe & Kelly, 2001; Goliber, 2000; Hay, 2001; Fox, 2001; Ndethiu, 2000b; Kelly, 2000b; Smart, 1999, Hunter & Williamson, 2001).

- **Demographic effects**: Half of South Africa's 38,8 million population (16,3 million) are children. An estimated 61% of them live in poverty. Because of the close association between poverty levels and HIV infection this figure can serve as a proxy for the number of HIV/AIDS affected children. AIDS-related illnesses and mortality among adults are adversely affecting dependency ratios. In sub-Saharan Africa children under the age of five are expected to outnumber adults over the age of 44. Higher infection rates and mortality in women are shifting the gender ratios in some age groups.
- **Health effects:** Children living in infected communities suffer from poor nutrition and ill health, and show signs of failure to thrive. Children's nutritional status suffers in rural areas that are dependent on household labour for subsistence agricultural production. Where social services, hospital and home-care systems are stretched or absent vulnerable children have inadequate access to health care. Infected children have to battle the symptoms of the illness, including diminishing strength and advancing death. Common illnesses (measles, diarrhoea and respiratory infections) are more severe, frequent and persistent.
- **Family-life effects:** The traditional structure of households is changing in affected communities and vulnerable children are required to adapt to the demands of non-traditional families and deepening poverty. The loss of a mother as primary family caregiver has a profound effect on children's wellbeing. As young or middle-aged fathers and mothers die, grandparents take over the full-time care of young children and the latter assume unfamiliar adult roles at home for which they are ill-prepared. Sometimes they are the primary caretakers of their infected elders, assuming adult responsibilities, washing, cooking for and feeding sick elders and younger siblings, taking care of cattle, and growing mealies for sustenance. A common consequence of strain and pressure exerted on weaker households is a

[86] *Infected children* may have been infected vertically, sexually or as the result of unsafe sex. *Affected children* may be abandoned or orphaned as a result of HIV/AIDS, may be from an HIV infected family, may be vulnerable to becoming HIV infected, or may be from an uninfected family in an affected community (Smart, 2001).

drastic reduction in the family's ability to care for and protect its children, who become prey to neglect and abuse.

- **Welfare effects:** Economically children and their families are hard hit. On account of poor health productive members of the family are often unable to continue work. Families are impoverished and rendered more vulnerable by the costs of illness and care. Their meagre funds are used to buy local medicines and palliative care, leaving less for food, housing, clothing and education. Even when caregivers attempt to protect children by not discussing economic difficulties with them, the children are attuned to their emotional environment and readily adopt the anxiety, fear and frustration that accompany financial strain.
- **Educational effects:** A marked decline in school attendance already characterises the South African education landscape. HIV-infected children shy away from disclosure There are many causes, among them illness, morbidity and death, fear of discovery and shaming at school, increased demands for child labour, including caring for sick relatives (both within and outside homes), and inability to pay school fees. The long-term impact of poor early childhood development and limited literacy on South Africa's social, economic and political systems is inestimable.
- **Psychosocial effects:** Children's psychosocial distress and trauma is often not as visible as that of their health, education and economic needs, but it is of fundamental importance. The psychosocial challenges children face include coping with grief, loss of identity (self-, family- and cultural identity), coping with shame, stigmatisation and fear of abandonment, rejection, death.
- **Orphanhood effects:** The disruption of families and death of parents and close relastives have created an unprecedented number of destitute and abandoned South African children. By some calculations, on current mortality trends, orphans will comprise 9-12% of South Africa's total population by 2015. Orphans may live in child-headed households with older siblings looking after younger ones, thus assuming parenting roles they are ill prepared for, others are taken care of by communities, some are placed in institutions, and still others lose all contact with carers and become street children. In such circumstances even uninfected children, lacking nurture and sustenance and needing to feed themselves or others, run a high risk of becoming infected through abuse or prostitution.

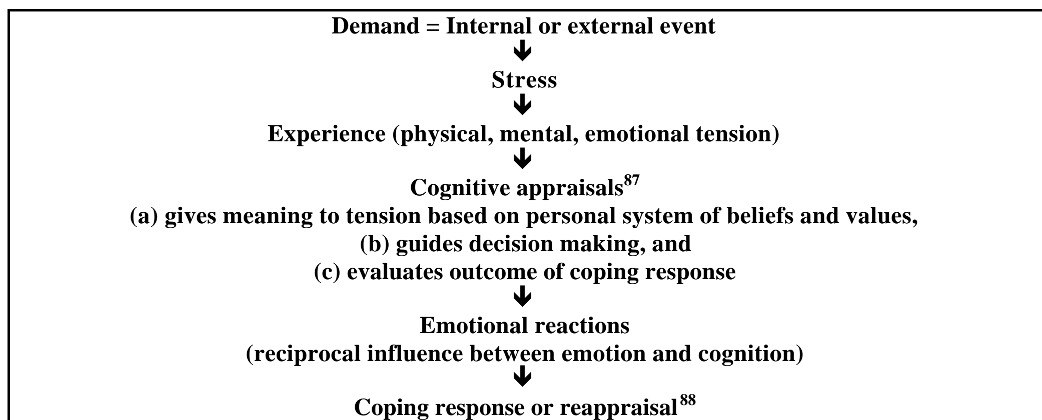
These stark black and white data omit the grey areas where the children themselves live out their lives. In exploring the shadows a tapestry of psychosocial emotions and interactions can be constructed. We seek to understand how the children see themselves, how they feel, what they think, believe and ultimately do in the face of HIV/AIDS. The process depicted in this article forms the first phase of a larger Participatory Learning Assessment (PLA) project aimed at understanding the coping experiences of HIV/AIDS infected and affected children in South Africa.

# What is coping?

There is a comprehensive body of coping literature representing various perspectives (Snyder, 1999; Zeitlin & Williamson, 1994; Lazarus & Folkman, 1984; Salovey & Sluyter, 1997; Ozer & Bandura, 1990). At its most basic conception, coping implies adaptation by an individual to demands. Our assumptions defining coping are based on literature review, interviews with experts and our professional experience as educational psychologists.

- Our approach to coping is eco-systemic (Donald, Lazarus & Lolwana, 1997). Coping is framed as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. Coping is what people do when they successfully manage transactions with their environment.
- Coping is our reaction to the question: what do I do? Before one can cope other psychosocial processes occur, not necessarily sequentially or consciously, in answer to the following questions: Who am I (identity formation)? How and what do I feel (emotion regulation)? How and what do I think (cognitive regulation)? What are my beliefs (normative regulation)?
- Coping is acquired by learned adaptive actions. Children are unique individuals but they learn by following examples. Significant others (parents, aunts, grandmothers, older siblings, teachers, social workers) cue children on coping options. Diversity in traditional beliefs, rural or urban settings, and socio-economic resources determine a variety of coping responses.
- Depending on the person and the situation a coping response can be located on a continuum from consistently ineffective to consistently effective. Characteristically people prefer certain coping responses to others (coping style).
- Some people are more resilient in matching available resources with specific environmental demands on them. Protective factors in the environment (a child's disposition, a responsive family milieu and external support for the child and family) could act as buffers against the impact of stressors on a child.
- The fundamental process of coping is the same for everyone, although people differ in age, gender, culture, and socioeconomic situation. The transactional coping process in Figure 1 illustrates these universal stages.

**Figure 1: Stages in the transactional coping process**



(Adapted from Zeitlin & Williamson, 1994).

According to the transactional coping process the environment makes constant demands on the individual. The individual experiences these demands as stress (anxiety, tension). The individual has to decide how to manage the stress. The outcome of decision-making is either a

[87] Even young children make appraisals according to their developmental stage (Zeitlin & Williamson, 1994).
[88] *Reappraisal* is the result of a changed belief because of new information or new perceptions (Lazarus & Folkman, 1984).

coping response or reappraisal. (For example, a boy's infection may become less threatening to his teachers when the teachers acquire knowledge that encourages them to believe his presence is not harmful to others).

A certain coping response will influence the child's environment. It may in turn present new demands on the individual or alleviate the stress. The evaluation of the effectiveness of the outcome should be based on its developmental appropriateness, its applicability to the situation, and the outcome generated.

The following example illustrates the reciprocity in the transactional coping process. A girl with an infected mother may decide to cope with trauma by having sexual relations with a teacher. Her choice increases her susceptibility to infection, yet provides her with lunch money and passing grades. Her stigmatised family, seeking social acceptance, may strengthen her acquaintance with an admired community figure. If she becomes pregnant, or infected, or both, she may be abandoned by the teacher and add her personal trauma to the distress already experienced by the family.

# How do children cope?

Children's coping equals the integration and application of developmental skills (motor control, communication, cognitive and socio-emotional skills) into their daily living (Miller & Byrnes, 2001; Zeitlin & Williamson, 1994). In fact a primary developmental task in childhood is to transform early adaptive behaviours into mature coping styles (Masten & Coatsworth, 1998; Salovey & Sluyter, 1997).

In their initial dependent life phase children's transactions are more reflexive and universally undifferentiated – crying, cooing and sucking are examples. Children's motor, affective, and cognitive skills are refined as their central nervous systems mature and they acquire experiences in the environment.[89] The presence of stress is natural. Stress creates tension and motivates a child to develop by interaction with the environment. Thus by learning to cope children gradually gain more autonomy and interdependence. Because of their limited coping repertoires, children's coping is a simplified version of the mature transactional coping process portrayed in Figure 1.

As stated we do not assume that all children cope in the same way. A four-year-old Tswana boy living in rural Bushbuckridge with his unemployed aunt will not cope in the same way as an eleven-year-old Zulu girl living in a state institution in Durban. The differences in their ages may mean that he would prefer to be comforted and she might focus on solving problems. The difference in their gender may lead to her preferring to talk with peers and for him to choose to play out his grief, anger and frustration with sand, stones and water. Based on their environment he may find support from an established kinship network, whereas she may find solace from social workers. Culturally they will both be influenced by the accepted rituals and beliefs ingrained in their separate communities.

According to resilience theory children should have access to resources (internal and external) to cope effectively – to change what they can, or make the best choices regarding things they cannot change. Figure 2 illustrates the interrelatedness between protective factors that might buffer the effects of trauma on a child (Kilmer, Cowen & Wyman, 2001; Garmezy & Rutter, 1988). These protective factors become crucial when children are under threat (Ndthiu, 2001).

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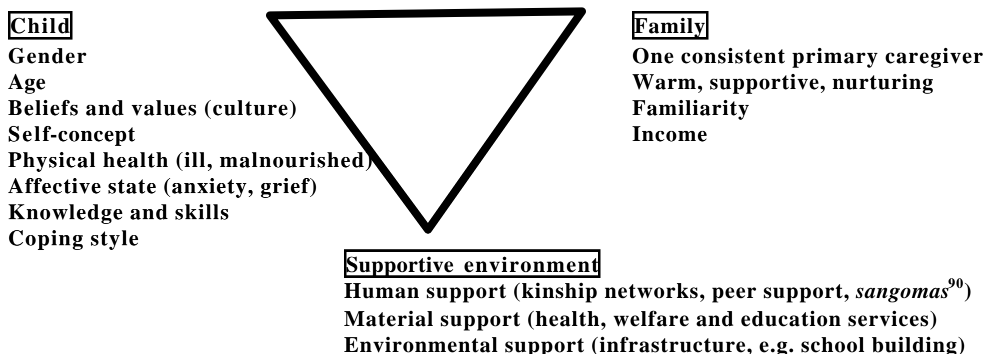
[89] Zeitlin & Williamson, 1994.

**Figure 2: Protective factors that act as buffers to the effects of trauma on children**




Based on Figure 2, ideally we should explore the coping of boys and girls in all age groups, representing a range of different family circumstances, in both urban and rural areas, including all cultural South African groups. Realistically, we know that this is not a viable research strategy. Our research observations, interpretations and reflections should therefore be guided by our knowledge of this complexity and diversity. We strive to remind ourselves continuously of the larger tapestry and not get lost in multiple grey threads.

# How could traumatised South African children cope with the effect of HIV/AIDS?

Mentally and emotionally children lack the capacity to manage demands of the magnitude HIV/AIDS presents. Poverty, malnutrition and illness probably inhibit the maturation of children's central nervous systems. If their development is stunted this would predictably have a detrimental effect on their ability to acquire coping skills.

In times of crisis children revert to primary emotional coping strategies. Their dependence on adult support to assist them in coping is critical. Traumatised children in Rwanda and Thailand found the environmental and personal demands unmanageable (Devine & Graham, 2001; Ndethiu, 2001a). Children survived in zombie-like states. By means of emotional detachment they separated themselves psychologically from the harsh reality of their daily lives. Unidentified and unsupported the outcome of this psychological trance could predict a future of emotions, cognition and behaviour in discord.

Following the 1998 bombing in Nairobi a model was developed to train teachers and caregivers of traumatised children (Bovard, Mwiti and Oasis Counseling Center Writing Staff, 1998; Bovard & Pfefferbaum, 2000). In Table 1 we present this model's interpretation of traumatised children's coping.

Table 1 integrates the essence of the transactional process (Figure 1) with protective factors (Figure 2). The emphasis is on emotion, basic solutions and support from adult caregivers for children's effective coping. In the absence of such support (child-headed households, abandoned orphans, street children) children's repeated experiences of helplessness will result in despair at their lack of control. Experiencing that they consistently cope ineffectively may

[90] A *sangoma* is a South African traditional healer. Besides remedies, traditionally they also offer counselling.

generate an unwillingness to try managing similar situations, may bring about additional stress and create feelings of inadequacy.

**Table 1: Coping stages of traumatised children**

| Stage One | Stage Two (similar to stage one, but less intense) |
|---|---|
| • Initial shock<br>• High level of distress (anxiety, helplessness) | • Less crippling emotional state<br>• Poor solutions may be maintained because they lack other options<br>• Support from adults means that fears can be voiced and options explored |

HIV/AIDS triggers multiple anxieties in a child. Stressors may be environmental demands such as exclusion from school, or having to find money for a funeral. Internal challenges may be bewilderment at drastic changes in family circumstances, profound grief at the loss of a mother, or having to suppress expressions of sadness because the father does not cry in public. The challenges could be the physical changes of a weakening body. More often than not the stressors co-exist in the tension-fraught lives of children poorly equipped to deal with these demands.

A child may experience anguish trying to find out what is happening to her when she is removed from a familiar community and placed in institutional care. She will wonder how these changes will affect her wellbeing: Who will cuddle her now? Who will tell her comforting stories? Where will she get food? What will happen to her brothers and sisters? Will she see her grandparents again? What is expected of her now?

Cultural beliefs and values are fundamental guidelines in the subsequent cognitive process of determining what an event means. We assume that certain universal principles of coping will be relevant across cultures. Yet we acknowledge that traditional indigenous coping in South Africa will probably differ from the much-published American frameworks of coping. Coping cannot be separated from its particular context. (This is reflected in our contextualisation of the predicament of vulnerable children in South Africa.) Therefore we anticipate that South African children's coping will differ from that of their counterparts elsewhere. Little documentation of indigenous coping beliefs and practices exists (UNAIDSA, 2000). We wonder if a child deprived of community care (not to mention maternal care) has sufficient exposure to traditional beliefs and values to inform her coping responses? We also question if young children in the process of determining who they are (forming their identities) will be able to assess their capability to cope?

A child's perception of stress is closely linked to reactions in the family unit. When a mother dies after a long period of deterioration the whole family is affected by a range of feelings. A little boy's perception may be in accordance with a single individual's reaction (the unfamiliar sight of his crying father means he perceives the particular event as harmful and threatening). Or he could follow the example of the whole family (he does not talk about the reason for his mother's death, because no one else is disclosing her status). Another way would be for him to focus on how the family members react to one another (he is afraid because all his worried sisters and brothers argue about their future).

In the subsequent decision-making phase of cognitive appraisal another child may ask herself what she can do. (What can I do to stop my hunger?). Older children will be able to appraise cost effects in terms of time and effort. (It will be quicker and easier for me to beg for food than

to grow and harvest it myself.) Children will have certain expectations regarding their decisions. (If I take food from aunt Nomsa's cupboard I won't be hungry anymore, but she may be angry.)

The subsequent implementation of decision constitutes the observable outcome of the coping process. What a child does is the only indicator of the unobserved psychological processes that preceded the coping response. Developmentally we presume that younger children may cope by expressing their emotions of insecurity, bewilderment and sadness. We wonder if this expression of emotion is accommodated within cultural coping beliefs? Emotionally younger children will also seek solace and support. We question whether traditional kinship systems can be maintained when whole communities are devastated by HIV/AIDS? Where will children seek solace and support? Do teachers, *sangomas* and community leaders support children? Are they able to mobilise and sustain support networks for children (Bovard, Mwiti & Oasis Counseling Center Writing Staff, 1998)?

We wonder if some traumatised children might be able to cope in a problem-solving fashion? Can a child put aside anxiety, fear, anger and sadness and solve problems logically? Or does a child cope by merely continuing with daily activities like fetching water, maybe attending school, merely surviving within a specific environment? Does an institutionalised child know to whom to go for comfort?

Physiological coping is common in children, even more so in those traumatised (Ndethiu, 2001a). If a child does not know how to express his feelings of helplessness or worry, and how to act to alleviate such feelings, a child can naturally reach out for comfort by means of somatic symptoms such as headaches, pains and allergies.

Will rural children make use of nature in their coping? Will urban children be more prone to escape their fear, pain and frustration by turning to high-risk avenues such as child prostitution or drugs?

And we wonder whether traumatised children cope at all? The words of a colleague quoting a counsellor echo in our minds: there are children who merely "swallow their despair" (Coombe, 2001).

To continue this debate we propose the following lines of future inquiry:

- an inquiry into existing cultural coping practices in South Africa;
- case studies exploring and describing children's coping with HIV/AIDS;
- ecosystemic descriptions of community-based coping practices as supportive environments;
- inquiries exploring the relationship between coping and consistency of caring;
- case studies exploring and describing the manifestation of protective factors in South African communities;
- an inquiry into the role of leaders (e.g. *sangomas*, teachers, faith-based leaders) in supporting children's coping with HIV/AIDS;
- an analysis of the relationship between children's care placement (e.g. extended family, foster care, institution) on their coping strategies;
- an analysis of the relationship between coping and independent variables such as age, gender, disability, health status and socio-economic background.

# Conclusion

This research is in the exploratory phase of trying to understand the coping experiences of South African children with HIV/AIDS. So far this process has brought us to this particular stage in which we observed the resilience of vulnerable children. During several field visits we sought to discover some of the colours of a psychosocial coping tapestry. We saw children stubbornly refusing to let go of colour. In a rural community we played with boys and girls aglow in the presence of caring volunteers. In an urban hospital setting we saw children flourishing under the loving supervision of grandmothers and aunts who had taken over their care. We talked with a ten-year-old boy who proudly displayed a homework assignment on a torn piece of paper. We were privy to black moments also: a young boy desperately crying for his mother in a shelter for abandoned children, a fifteen-year-old girl in a hospice struggling with the pain of AIDS without the comfort of her family.

Reflecting on our discussion it is clear that our answers are not black and white. We have to admit that in fact we have no answers. Our attempt at producing answers is merely a tapestry of multiple questions possibly pointing the way to future inquiry into the phenomenon of coping. We concur with the vision of Patti Lather (1997, 51) when she advocates working against the 'comfort text' that may provide the consolation of certainty and set meanings and the romance of knowledge as a cure. This article reflects the complexities of research processes in which we seek to find answers, but only tend to find more questions. We do, however believe that our journey has started by weaving together some of the questions regarding children's coping.

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