

CHAPTER 2

Situating the study within a conceptual framework by reviewing pertinent literature

2.1 Introduction

The aim of my study was to explore, understand and describe how children negotiated pathways to well-being while affected by HIV&AIDS. In the previous chapter, I outlined the structure of this inquiry by providing an overview of the focus, guiding questions and rationale. I expounded the research design and methodology that underlined my approach to this study. Furthermore, I described the core concepts and terminologies that framed this inquiry.

I begin Chapter 2 by foregrounding my conceptual framework, which was constructed from the main themes that were highlighted from a review of the relevant literature. I regard this underpinning conceptual framework of key constructs, concepts and theories as central to the relevance and understanding of this study. I do this by juxtaposing the constructs of resilience and coping with the core elements of positive psychology: positive and enabling systems and positive intrapersonal characteristics. I provide a strengths-based perspective in addressing the psychosocial and emotional concerns of children affected by HIV&AIDS, I frame my understandings from an ecosystemic standpoint.

In Section 2.5, I substantiate the relevance of the underpinning conceptual framework by reviewing the literature. I begin the literature review by highlighting empirically based research on the challenges, stressors, risks, and vulnerabilities facing children and families, and specifically the psychological and psychosocial consequences of HIV&AIDS for children. Thereafter I explore the literature based on experiences of well-being in adversity as well as resilient adaptation and coping. In my review of selected literature, I attempted to emphasise the limitations in empirical studies that pertain to children's experiences of well-being while living in a context of HIV&AIDS. I situate my study in the gaps that I encountered in the empirical literature that examined a specific group of children's positive adaptation while living in a context of multiple adversities related to HIV&AIDS.

2.2 A conceptual framework

The purpose of this section is to offer a conceptual framework for integrating critical concepts that will inform this study. I aim to illustrate how key concepts that were highlighted in the review of the literature are interrelated. These concepts emerged from my review of multiple sources on HIV&AIDS, together with the forms of institutional care and elements of positive psychology that are conducive to well-being. Figure 2.1 is an illustration of the conceptual framework.

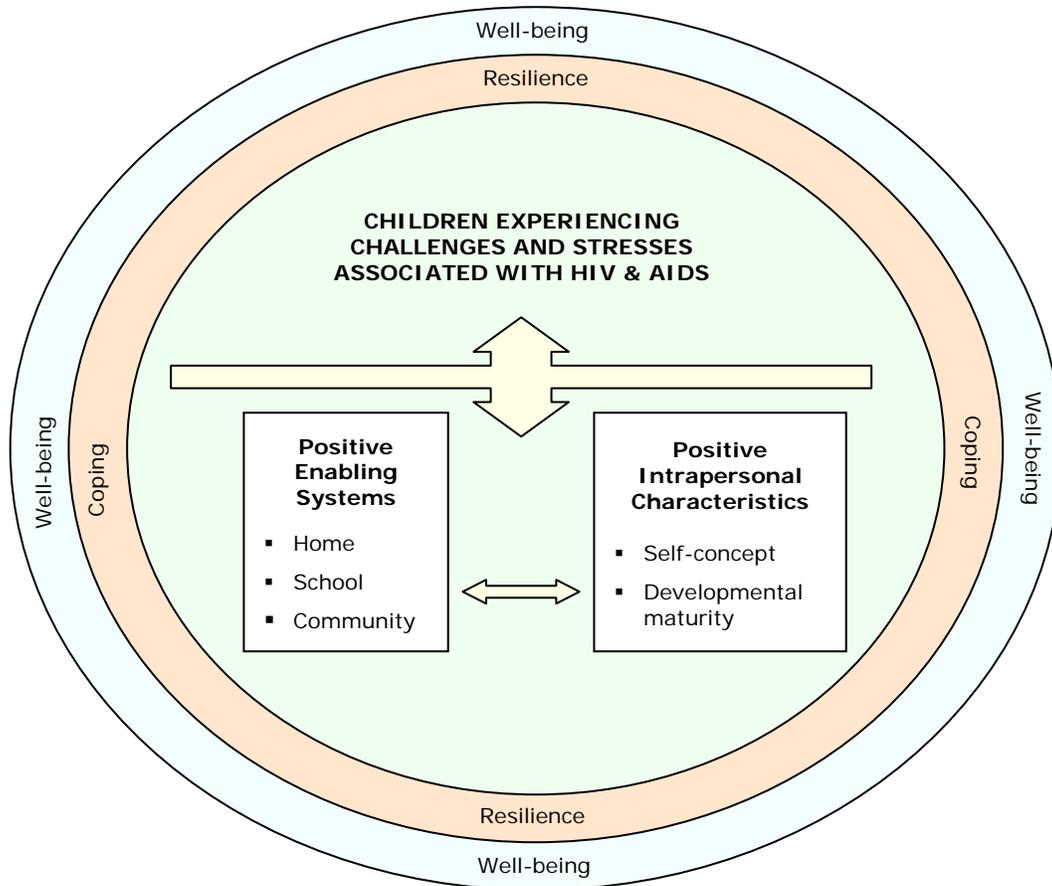


Figure 2.1: Conceptual framework

2.2.1 Adopting a positive approach to supporting children affected by HIV&AIDS

Amidst an array of studies documenting the psychological and psychosocial deficits in children from a needs-based approach (Cluver & Gardner, 2006; Gosling, Burns & Hirst, 2004; Pivnick & Villegas, 2000; Landry & Smith, 1998), I posit a study that incorporates a strengths-based perspective from a positive psychology approach in understanding children's challenges and stressors. As stated in Chapter 1, I suggest that adjustment to the

stressors that are associated with living in a context of chronic adversity may be enhanced by resilience factors as defined by positive psychology. I go on to explain my stance.

By adopting a positive approach, I subscribe to the views of Seligman and Peterson (2003), who foreground human strengths against a backdrop of adversity, distress and pathology, in advocating a positive psychology approach. In this study, I concur with the opinion of Masten (2001:235), who states that resilience does not come from rare and special qualities, but from the everyday magic *"of ordinary, normative human resources in the minds, brains and bodies of children, in their families and relationships and in their communities"*.

Currently there is a worldwide paradigm shift towards a notion of an increased positive approach to psychology and medicine. The enticement of the positive approach (Positive Psychology) lies in Seligman and Peterson's (2003) determined stance that human strengths tend to act as buffer against psychological stress and illness; they go on to remind us that the basis of psychology is not only the study of disease and weakness (psychological distress among children, adolescents affected by AIDS). Rather, it is also about building human strengths. Furthermore, Keyes (2007) claims that mental health does not only imply the absence of illness or the presence of psychological or emotional well-being. He argues for the development of social well-being arising from active participation in a society where one is anchored and feels a sense of belonging.

Advancing a positive outlook in no way denies the existence of suffering, loss, distress and trauma among children affected by HIV&AIDS. Rather, death, loss, separation, trauma and psychological and emotional consequences are inherent (Miller & Harvey, 2001). They will remain deeply entrenched and ingrained in the lives of individuals affected by HIV&AIDS in the decades to come. Adopting a positive approach implies recognising and addressing the wide range of adversities that confront people and individuals affected by HIV&AIDS. From an asset-based approach (Ebersöhn & Eloff, 2003, 2006) advancing a positive outlook is about identifying and mobilising strengths, resources and capacities to address the negativity. In addition, Miller and Harvey (2001) propose that a psychology of loss can help to illuminate one of the central themes of positive psychology- showcasing human skills that emphasise human strengths and optimal functioning. However paradoxical the interface of positive psychology and a psychology of loss might seem, it could lead to a new way of discovering and understanding for both these areas (Miller & Harvey, 2001).

In my conceptual framework, I consider the constructs of resilience and coping as they bear relevance to the study. I would like to point out that I do not believe that the conceptual

framework that I advocate is fixed and rigid. Rather, I regard my understanding of the interrelatedness of a set of concepts as dynamic and relevant in a particular moment in time due to the complexity and multilayered nuances in the field of HIV&AIDS in an African context. It is for this reason that I do not adopt resilience and coping theories in their totality, but rather highlight aspects of these theories that inform my study. In so doing, I assume the term *resilient adaptation* in my meaning-making approach.

2.2.1.1 Resilient adaptation

In the context of this study, the concept of resilience represents the manifestation of positive adaptation despite significant life adversity (Luthar, 2003:xxix). Integral to this description is the view that instead of a specific trait or child characteristic (Rutter, 2000; Werner, 2000; Garmezy, 1983), I advocate that resilience in this study refers to a process that is inferred from the interrelatedness of extreme adversity (risk) and the relative positive adaptation in spite of the stress within an ecosystemic context.

Generally resilience refers to the process of overcoming the negative effects of risk exposure, coping successfully with traumatic experiences and avoiding the negative trajectories that are usually associated with risk (Fergus & Zimmerman, 2005). Over the years, different streams of thinking about resilience have marked the literature base. For example, Block and Block (1980) described resilience in terms of ego-resiliency as existing on a continuum where it is implied that ego-resiliency lies at one end of a continuum with the other end being ego-brittleness. Block and Block's (1980) description enforces resilience as a personality characteristic that is not related to stress. Masten (2001) also describes resilience in terms of a variable-focused and person-focused approach. In these descriptions is the view of resilience as occurring or developing as a static entity. Related to my study, resilience, described solely as a personality characteristic, may not be relevant, as it does not consider the effects of adversity, stress or the context of the resilience manifestations.

Rutter (2000), Werner (2000) and Garmezy (1991) contemplated resilience as a characteristic of some children from at-risk environments, hence resilience in terms of life stressors in the presence of protective factors. Although the transactional nature of resilience may be distinguished as incorporating a personal characteristic, such a depiction also places an emphasis on engagement with the environment which is linked to secure attachment and effective problem-solving skills. In this case, resilience is influenced by the individual's characteristics and environmental factors and emphasises the coping strategies

required of an individual in the developmental environment. In addition, it seems that to engage successfully with the environment in order to secure resilient outcomes requires a relationship with a significant adult (Beardslee & Podorefsky, 1988). Therefore, protective factors, which are inclusive of both individual characteristics, enabling environmental factors and positive relationships, may be considered essential elements for enhancing positive adaptation and reducing risk.

In the field of resilience and coping, there is a move towards an increased emphasis on theory and research moving beyond the prediction of adaptation to understanding the processes underlying adaptation (Luthar, Cicchetti & Becker, 2000; Sandler, Wolchik & Ayers, 2008), as it seems that it is not enough to simplistically identify and list risk and protective factors. According to Sandler *et al.* (2008), the processes of adaptation can be studied using both quantitative and qualitative approaches. These researchers propose a contextual resilience framework to explain how bereaved individuals change over time. They proposed that an individual has four basic needs: safety, control, self-worth and belongingness. It is argued that protective resources affect these needs to promote resilience, and that these resources come from multiple levels: individual, microsystem, cultural and community levels.

This framework incorporates key concepts from the broader literature on resilience in the face of multiple adversities (Luthar, 2003; Rutter 2000), including a conceptualisation of positive well-being together with the problems and aspects of resilient outcomes, a focus on personal and environmental risk and protective factors, and a study of the process of adaptation (Sandler *et al.*, 2008). Emphasising the context and the community, Eloff (2008) suggests that resilience should also be conceptualised as embracing a collective identity. Therefore, there appears to be general consensus that children and resilience should not be studied independently from their context or setting as they are inherently bound to each other and thereby influence outcomes (Eloff, 2008; Sandler *et al.*, 2008; Grotberg, 2003; Luthar *et al.*, 2000).

The context of HIV&AIDS is primarily one of poverty, discrimination and uncertainty. While living in chronic and cumulative adversity, there seems to be little chance for hope amongst the most severely affected people. From a first world perspective, developmental psychologists have shown that resilience is common among children growing up in disadvantaged conditions (Masten, 2001) and that positive emotions can act as the building blocks of resilience that may reduce physical illness (Fredrickson, 2001). Strengths function as a buffer against adversity and against psychological disorders and they may be the key to resilience (Kaplan, 2006; Masten, 2001).

There are multiple and sometimes unexpected pathways to resilience (Bonanno, 2004), and one such pathway may be associated with promotive factors such as assets and resources (Fergus & Zimmerman, 2005; Ebersöhn & Eloff, 2003, 2006). In this case, assets are considered the positive factors that reside within the individual such as competence, coping skills and self-efficacy, which are also seen as protective factors. Protective factor research has consistently shown that the development of resiliency is the process of healthy human development based on and growing out of nurturing, participatory relationships that are grounded in trust and respect. Resources are also positive factors that help individuals overcome risk but they may be regarded as external to the individual. In this sense, resources include parental support, adult mentoring or community organisations that promote positive individual development. Notably, the concept of resources emphasises the social environmental influences on individual health and development and thereby situates resilience in an ecological context, away from an individualistic manner (Fergus & Zimmerman, 2005:399-400; Masten & Reed, 2005; Dutra, Forehand, Armistead, Brody, Mose, Morse & Clark, 2000).

While employing individual assets and community-based resources are ways of enhancing resilient outcomes, another pathway to resilience has been described as hardiness (Bonanno 2004). Amongst others, hardiness as a pathway to resilience implies having a meaningful purpose in life and believing in one's ability to influence the environment. In this case hardiness, implying growth from both positive and negative experiences, may be considered a protective factor. Considering the protective factor implications in my study, psychological resilience would refer to the child's capacity to withstand stressors which would be manifested as mainly positive moods, interactions and relationships.

Generally, with regard to the construct of resilience, there seems to be a lack of consensus regarding: the age domain covered by the construct, the circumstances in which it occurs, its definition, its boundaries and the adaptive behaviours it describes (Mandleco & Peery, 2000). Given the controversies and debate that surround a common description of the multidimensional nature of resilience, I submit that for the purposes of this study, I would adhere to demonstrating resilience in terms of children's positive adaptation in the face of risk rather than to advocate resilience as a flawless scientific construct. As a fundamental approach to this study, the conceptualisation of resilience from the field of positive psychology bears immense relevance. The conceptual framework that I adopt integrates aspects of resilience from a positive psychology paradigm featuring risk and protective factors resulting in what I term resilient adaptation. I also use this term to subsume coping efforts. Underlying this thought is the notion that strengths function as a buffer against

adversity and against psychological disorders and that they may be the key to resilience (Masten, 2001).

2.2.1.2 Coping efforts as they relate to resilient adaptation

Although coping ability may initially seem to be a synonym for resilience, it should be regarded as a separate construct. Coping is viewed as one of the factors affecting resilience when stress is especially high or adversity especially strong (as is the case of the children facing multiple adversities in my study). In this regard, coping has been conceptualised as: constantly changing cognitive and behavioral efforts to manage specific external and/or internal domains that are appraised as taxing or exceeding the resources of the person (Lazarus & Folkman, 1984). In this conceptualisation, a distinction is made between problem-focused coping and emotion-focused coping.

Problem-focused and emotion-focused coping strategies are examples of the responses an individual may choose when faced with challenging situations. The central processes involved in building resilience are training in and development of adaptive coping skills. The transactional model of stress and coping explains that when a stressful encounter occurs (or a potential source of stress is anticipated), cognitive appraisal takes place (deciding whether the stressor represents something that can be readily dealt with or is a source of stress because it may be beyond one's coping resources). Based on the cognitive appraisal, if a stressor is considered a danger, coping responses are triggered. In this instance, coping strategies may be outwardly focused on the problem (problem-focused) or inwardly on emotions (emotion-focused).

Problem-focused coping includes attempts to define a problem, generate and weigh alternate solutions and follow a plan of action to change the problematic situation. On the other hand, a person adopting an emotion-focused coping approach makes no attempt to change the actual problem situation but appraises it more benignly and in a positive manner (Lazarus, 2003). Therefore, emotion-focused coping includes processes such as avoidance, denial, seeking emotional support, and positive reappraisal (Stanton, Parsa & Austenfeld, 2005). The emotion-focused coping strategies favoured by adolescents may at times increase the distress associated with their own or parental illness, reducing adolescents' ability to cope with the associated stigma. As children mature their repertoire of coping strategies increases and they can hence activate self-regulation mechanisms to avoid or address challenging situations. While younger children are found to be utilising more physical and material strategies of coping, adolescents engage more in cognitive coping

strategies such as positive thinking and distraction (Deacon & Stephney, 2007). In most attempts, coping processes are thought to subsume both direct efforts to cope as well as efforts to regulate emotions arising from the stressful situation (Stanton *et al.*, 2005).

At a societal level, successful coping behaviours are those that contribute to the survival and well-being of others as well as to the self. In a study by Ferreira (2006), the informal settlement community was found to be coping with HIV&AIDS by relying on their own abilities and the resources available in the immediate local community. This form of coping aligns with the tenets of the asset-based approach (Ebersöhn & Eloff, 2003, 2006) and is referred to by Ferreira (2006:301) as *asset-based coping*. According to Ferreira (2006), asset-based coping refers to the ability of a community (or an individual) to deal with one or more life challenges (such as HIV&AIDS) by identifying and mobilising existing assets within the community and amongst other community members as well as external resources available to the community.

2.2.1.3 Pillars of support from a positive psychological perspective

As outlined in the preceding discussion, a key area in providing support to families and children affected by HIV&AIDS is to identify and mobilise human strengths and assets, and in the process, to create opportunities for personal growth, happiness and well-being.

Fostering well-being by identifying and building human strength appears to be the underlying theme of what Seligman and Csikszentmihalyi (2000) refer to as the essential components of a move towards positive psychology that consists of three pillars: the first being the study of positive emotions; the second pillar is the study of positive characteristics, skills and capabilities; and the third pillar is the study of positive systems¹. Seligman, Steen, Park and Peterson (2005) describe positive psychology as an umbrella term for the study of enabling institutions, positive character traits and positive emotions. In my study, I base my discussions on the pillars of support that positive psychology suggests, to explore the strengths, resources and capacities of children as they relate to their coping and well-being.

a) Positive (enabling) systems

From an ecosystemic standpoint, enabling systems refer to the nested arrangement of families, schools, neighbourhood, communities, societies, and the caring professions that

¹ Although Seligman, Steen, Park and Peterson (2005), Keyes and Haidt (2003) utilise the term “institution” in their descriptions, I use the word “system” instead as in other parts of this study the term “institution” implies “residential care”.

work interactively to facilitate the well-being of individuals and families (Donald, Lazarus & Lolwana, 2006). Enabling systems facilitate the development and display of positive individual characteristics, which in turn facilitate positive subjective experiences. Seligman (2003) emphasised the notion of facilitation and integration rather than just a casual relationship between society, institutions and organisations.

In the case of HIV&AIDS, the potential exists for affected adolescents who live in residential care (implied family and home) to mature into adulthood with enhanced skills, abilities and capacities, considering the generally protective system within which they develop. Within this system, positive development indicates a potential for resilient outcomes. In contrast to these suggestions, findings that emerged from the Ebersöhn (2007) study indicated that most of the risk factors for children affected by HIV&AIDS appear to be located in the school and family, and most of the protective factors in the community.

Foster (2002) asserts that the greatest asset Africa has in providing psychosocial support is its extended family. Increasingly, children that slip through the safety nets are being supported by the community, which adopts the role of the extended family (see Section 2.2.2.2:e). As community initiatives to support vulnerable children are proliferating in many parts of Africa and moving beyond the material concerns of orphaned children into psychosocial support, community-based approaches encourage self-help and build on local resources, culture, realities and perceptions of child development (Foster, 2002; Amon, 2002). Community members also need bolstering in order to sustain their levels of enthusiasm for supportive initiatives. Ferreira (2006) argues that community members' sense of well-being is enhanced when their levels of confidence and self-worth improve; this may have a positive outcome as a ripple effect on the children's well-being.

From an ecological-transactional perspective (Bronfenbrenner, 1986, 1989; Sameroff, 1987), it is pertinent to consider that the complexity and interrelatedness of the various overlapping contexts impinging on a child's growth and development imply that not all systems may be positive and enabling. Instead, the outcomes on a child are the result of the interplay between the child and the context across time, in which the state of the one affects the state of the other in a continuous and dynamic process. This transformation of a child from infant to child to adult takes place via a complex system of multidirectional levels of influence within a broad range of biological, physical and sociocultural settings on development (Bronfenbrenner, 1989). The positive development of a child who is living within a context of multiple adversities may depend to a large extent on the continuous and dynamic interaction between the child and the experiences provided by his family and his social context, with an

emphasis on the effect of the child on the environment within which he develops (Dutra *et al.*, 2000; Sameroff, 1987).

Within a microsystem, the child influences and is influenced by the physical and material properties of his environment (resources and provisions at home and school), the personal qualities of those with whom he interacts (caregivers, peers, teachers, community workers), and the activities, roles and interpersonal relations experienced by the child in his daily life, together with the interrelationship of these various settings (Bukatko & Daehler, 1995; Bronfenbrenner, 1989). Hence, the type of relationships to which the child is exposed at home and amongst significant other people may influence the development of his self-esteem and self-concept as well as his resilient adaptive outcomes. The child's microsystem, usually considered a protective factor and a pillar of support, is stunted and becomes a source of developmental risk when it is socially impoverished, for instance when there are too few reciprocal interactions or when patterns of interaction are psychologically destructive. In some cases it can be a combination. Bronfenbrenner (1989) considers the microsystem to be a gateway to the world and not a locked room.

Children and their families who are affected by HIV&AIDS are also directly affected by the political, social, cultural and economic climate of the country. Here the child's exosystem, comprising the wider society, has exerted a powerful influence on socio-cultural belief systems, resulting in widespread stigma, discrimination and ostracisation of its members. The psychosocial challenges that place children and families at risk have been compounded by the government's initial hesitation and later delay in providing antiretroviral medication to mothers and children, resulting in a proliferation of HIV infection. However, the current antiretroviral medication has been shown to improve the health status of HIV-infected children, indicating that positive and enabling decisions taken at national level have a ripple effect and extend outward to touch and improve the lives of these most vulnerable people.

b) Positive emotions

A second supporting pillar arising from the realm of positive psychology is that of positive emotions. Emotions are regarded as positive when they feel good subjectively, when they are brought about by favourable life conditions and when they result in desirable life outcomes (Lazarus, 2003:98). In the light of limited knowledge of the way in which positive emotions promote health, Salovey, Rothman, Detweiler and Steward (2000) suggest that since positive and negative emotions are generally inversely correlated, substituting the former for the latter may have therapeutic effects. However, Held (2004) argues for an integrative approach towards conceptualising positive and negative emotions. Indeed, I do consider Lazarus's (2003) stance, which suggests that it might appear simplistic to polarise negative and positive emotions and to assume that they exist as separate entities. Therefore, I concur with Lazarus (2003) that positive and negative emotions have the potential of being either one or the other or both in different contexts and even in the same context when the emotion is experienced by different persons.

My thoughts resonate with the views of Aspinwall and Staudinger (2003:16), who emphasise contextual dependencies and maintain that examining the positive aspects of negative states and the negative aspects of positive states would be an essential part of a psychology of human strengths. However, Eloff (2007:174) warns against creating "*binaries*" in the process and thereby losing sight of the inherent complexities within each side. The complexities rising from the interrelatedness of positive and negative emotions are evident when one considers the functional and dysfunctional aspects of both these emotions. Thus, depending on the social context one person's happiness could be the source of another's unhappiness and the reverse could also be true (Lazarus, 2003).

In some instances, positive emotions have been shown to be functional when it helped people overcome negative emotions and were related to coping styles that are considered important for resource building (Tugade, Fredrickson & Barrett, 2004). In addition, many health benefits are associated with positive emotions, as illustrated by the following studies:

- o Salovey *et al.* (2000) consider the direct effects of affect on physiology and the immune system;
- o Bachorowski and Owren (2001) link laughter and humour to increased positive emotion;
- o Middleton and Byrd (1996) describe that elderly patients with cardiovascular disease who reported greater happiness for 90 days after hospital release had lower readmission rates to the hospital;

- o Emmons and McCullough (2003) indicate that when positive emotional content is evident in the disclosure of any form, health benefits are observable and
- o Moskowitz (2003) relates longevity as a benefit of positive emotions. Moskowitz (2003) also demonstrated in research that positive affect in HIV-positive men predicted a lower risk of HIV mortality.

In addition, Folkman and Moskowitz (2000) expound the benefits of positive emotions not just to physical health but to psychological health as well. For instance, Fredrickson (2000) claims that coping strategies related to the occurrence and maintenance of positive emotions such as positive reappraisal, problem-focused coping and infusing ordinary events with positive meaning, help to buffer individuals against stress and depressed moods. These strategies help individuals emerge from crises with new coping skills, closer relationships and a richer appreciation for life, all of which, it is thought, increases psychological well-being (Tugade *et al.*, 2004).

I conclude this section by speculating that in the context of my study, the capacity to experience positive emotions may largely be an untapped individual strength in children facing significant adversities in their daily lives. It thus seems from the studies reviewed that effective positive approaches may optimise children's health and well-being and promote their resilience in psychosocial contexts.

c) Positive (intrapersonal) characteristics

Drawing from a positive psychology perspective, intrapersonal characteristics of individuals that may contribute to resilient efforts include subjective well-being (Diener, 2000), optimism (Peterson, 2000), happiness (Myers, 2000) and self-determinism (Ryan & Deci, 2000). Well-being, optimism and happiness are constructs that are explored in the framework of my study.

Subjective well-being may refer to what we think and how we feel about our lives (Diener, 2000). This description implies the cognitive and affective conclusions we reach when we evaluate our lives. Later in this chapter (see Section 2.2.3.2:a), I will review the literature and provide an in-depth exploration in this regard. Another positive personality trait that seems to mediate between external events and a person's interpretation of them is optimism. Peterson (2000) considers optimism as involving cognitive, emotional and motivational components. Generally, individuals who display high levels of optimism have better moods, are thought to be more persevering and successful and experience better

physical health (Peterson, 2000). Adopting a critical stance, Peterson (2000) claims that complex psychological issues cannot be understood in isolation from the social and cultural context in which they are embedded.

Resilient children² are associated with other common positive intrapersonal characteristics, including positive self-esteem, self-awareness, internal locus of control, motivation and curiosity (Mandleco & Peery, 2000). Positive self-esteem, confidence, self-reliance and self-efficacy are important components of resilient adaptation in the face of difficult life circumstances. Closely related to the concept of self-esteem are the constructs of self-awareness and self-understanding. Children with a positive self-esteem are often aware of their own strengths and weaknesses. They are thought to realistically accept responsibility for their own actions and function independently (Mandleco & Peery, 2000; Beardslee & Podorefsky, 1988).

Self-determination, as a positive personality trait, describes an emphasis on and a need for competence, belonging and a sense of autonomy. Ryan and Deci (2000) assert that only when these needs are satisfied, is an individual's claim to well-being and social development optimised. This implies that individuals who show self-determination are usually intrinsically motivated and able to fulfill their potential. As a criticism against Ryan and Deci (2000), Schwartz (2000) argues for an emphasis on cultural norms and values in effecting self-determinism, as cultural constraints are sometimes necessary for leading a meaningful and satisfying life.

As some African worldviews place less emphasis on the individual and greater emphasis on extended families and communities (Foster, 2002), the psychological and psychosocial health of individual African children may be described as being intrinsically linked to the health and perceptions of the community at large in the first instance and then to their own individual positive characteristics as they perceive themselves through the eyes of their families and community. Strengthening the community as an enabling institution might be one of the most important goals in providing psychosocial support to orphaned and vulnerable children.

Although childhood is marked by different interpretations, common to all is the period in the early life of an individual that is indicated by rapid growth and development. During the

² In this study, I accept the thinking of Luthar, Cicchetti and Becker (2000) and propose that the term "resilient children" does not imply reference to a discrete personal attribute, akin to intelligence or empathy. Rather it is used to refer to the two coexisting conditions of resilience – the presence of a threat to a given child's well-being and the evidence of positive adaptation in this child despite the threat.

years of physical growth in which a child matures towards adulthood, the child is also developing psychologically and in ways that define intellectual, social, spiritual and emotional characteristics. The circumstances or conditions in which this growth takes place (deprivation, illness and the uncertainty that marks the field of HIV&AIDS) can limit or enhance development. Physical and emotional well-being and social and intellectual development can be permanently limited for a person deprived of the opportunities and time to grow and develop successfully in their childhood.

Related to the broader landscape of HIV&AIDS and specifically to the concept of the childhood in my study, children affected by HIV&AIDS are regarded as at risk, vulnerable and susceptible to exploitation and discrimination. Despite attempts at local, national and international levels, the magnitude and scope of the pandemic renders support unattainable and children helpless. The extensive literature on the multidimensional adverse consequences of HIV&AIDS has prompted this enquiry for an alternate means of addressing children's psychosocial and emotional challenges in the hope of building resilience amongst millions of children.

I propose that children who are cared for and supported by positive and enabling systems in their proximal settings will manifest resilient outcomes as portrayed in their sense of well-being. For social influences to impact positively on these anticipated outcomes, interpersonal relationships ought to be immediate and ongoing, thus creating stability for children who are being supported. Moreover, I posit an integration between children's intrapersonal characteristics such as feelings of hope, optimism and happiness, and their positive and negative emotions (joy, contentment, sadness, distress, despondency) with the buffering and protective effects of significant others in enhancing resilient outcomes that are manifested in feelings of well-being. Within the proliferation of HIV&AIDS, a challenge would be to ensure the sustainability of well-being.

2.2.2 The context of HIV&AIDS

In this section, I review the literature related to the magnitude of the HIV&AIDS pandemic, the challenges and stressors that increase the risks and vulnerabilities of children and studies focusing on well-being in adversity.

A perusal of the extensive literature on HIV&AIDS has indicated that research on the medical concerns of HIV&AIDS in adolescents and children (Tinsley, Lees & Sumartojo, 2004; Patsalides, Wood, Atac, Sandifer, Butman & Patronas, 2002; Mialky, Vagnoni & Rutstein,

2001) is substantial. In addition, empirically substantiated studies regarding the psychosocial concerns of HIV&AIDS with children and adolescents are emerging (Cluver, Gardner & Operario, 2007; Cluver & Gardner, 2007; Ebersöhn, 2007; Eloff, Ebersöhn & Viljoen, 2007; Ebersöhn & Maree, 2006; Cluver & Gardner, 2006; Abadia, Cesar & Larusso, 2006; Kruger, 2006a & b; Bhargava, 2005; Bray, 2003; Makame, Ani & Grantham-McGregor, 2002; Ebersöhn & Eloff, 2002; Booyesen & Arntz, 2002; Mialky *et al.*, 2001; Pivnick & Villegas, 2000).

The difficulties that I encountered while reviewing the literature mainly pertained to a lack of consensus on conceptual and methodological issues and the dynamic nature of HIV&AIDS research. While the deluge of HIV&AIDS research seems to be dominated by conceptual, opinion, statistical and demographic perspectives (according to Richter *et al.*, 2006; Dunn, 2005; Wild, 2001; Lwin & Melvin, 2001; Folkman & Greer, 2000; Lyons, 2000), many of the studies reviewed indicated that results were specific to regions and contexts, thereby limiting generalisability (Abadia, Cesar & Larusso, 2006; Abadia, Cesar & Castro, 2006; Cree, Kay, Tisdall & Wallace, 2006; Bhargava, 2005; Evans, 2005; Ansell & Van Blerk, 2004; Mialky *et al.*, 2001; Williams, 2001). Considering these limitations, I have restricted my review to the psychosocial impact of stressors and challenges of HIV&AIDS on children as it relates specifically to the scope of my research questions.

As I developed a central line of argument in this review, I contemplated the following questions: What empirical research has been conducted with children who are affected by HIV&AIDS? What is known about children's experiences of well-being while living within the context of HIV&AIDS? What are the gaps in the existing literature? What contribution could this present study make to the existing literature base on well-being in adversity and positive psychology? What new knowledge can be constructed from understanding children's experiences?

The present worldwide impact of the HIV&AIDS pandemic cannot be overemphasised. As a biopsychosocial disease, HIV&AIDS have touched lives on all continents of the world. Vast numbers of children across the globe become infected with HIV every year. Children in Africa in particular, who are already facing extraordinary challenges related to rampant poverty and post-war conditions, are having to deal with the consequences of the HIV&AIDS pandemic. Thousands of children without treatment die annually because of AIDS. In addition, millions more who are not infected with HIV are directly affected by the epidemic as a result of the death and the suffering that AIDS and its related diseases trigger and proliferate in their families and in their communities. It is prudent to assume that children

may be most severely affected by HIV&AIDS in their social, emotional, educational and psychological contexts due to parental illness and death as well as to their own infection (Richter *et al.*, 2006; Brookes, Shisana & Richter, 2004; Smart, 2003a & b; Bray, 2003; Hepburn, 2002; Booyesen & Arntz, 2002; Hunter & Williamson, 2000).

In developed and developing countries with access to antiretroviral (ARV) treatment, the focus seems to have shifted from HIV&AIDS being synonymous with death to HIV&AIDS being regarded as a manageable terminal illness (UNAIDS/WHO, 2006; Joslin & Harrison, 2002; DeMatteo, Wells, Goldie, & King, 2002). In the global context, we face a challenging dilemma as infected children live longer life spans and manifest fewer symptoms in the early stages of infection. Brown, Lourie and Pao (2000) assert that even without medical treatment, a small number of HIV-infected children may remain asymptomatic of the virus for as long as a decade. This assertion implies that infected children have at least a decade in which to lead healthy lives from the time of infection with the HI virus to the eventual progression to AIDS.

Unfortunately, ARVs have been available predominantly in well-resourced parts of the world since 1996 while underresourced communities are still not benefiting. By 2005, just one in ten people in Africa requiring anti-retroviral therapy received it; the majority of developing countries are struggling to cope with the increasing numbers of people requiring treatment. The reality is that approximately 90% of HIV-infected children are being denied their right to treatment and thereby their right to good health (UNAIDS/WHO, 2006).

Given the fact that children affected by HIV&AIDS face a multitude of risks (see Section 2.2.2.2), considerable effort has been invested in research which examines maladaptive behaviours resulting from high exposure to risk situations. It is equally valuable to explore the approaches by which some children come through high-risk situations exhibiting adaptive behaviours. I therefore argue that the exploration of positive constructs, more especially the construct of well-being, offers a significant opportunity to guide prevention and intervention programming aimed at improving children's lives. While the construct of resilience in children has been widely investigated in general population groups and among children facing a myriad of adversities (McCubbin, Balling, Possin, Frierdich & Byrne, 2002; Luthar, 1999; Enthoven, 2007), empirically based resilience studies with children in an HIV&AIDS context are emerging (Ebersöhn & Maree, 2006). Increasingly, the impact of HIV&AIDS on children's mental health and psychosocial needs is being documented (Cluver & Gardner, 2007; Richter & Müller, 2005; Foster, 2002; Earls & Carlson, 2001; Wild, 2001; Pivnick & Villegas, 2000).

2.2.2.1 The magnitude of the HIV&AIDS pandemic

At this stage, I wish to explore the literature that highlights the enormity of the HIV&AIDS pandemic by providing the alarming statistics that have become synonymous with HIV&AIDS. While statistics should be interpreted with caution, as they are estimates, the impact suggested by the numbers is nevertheless alarming. At the end of 2007, an estimated 33.2 million people worldwide were living with HIV&AIDS. Of these people, 30.8 million were adults, and 2.5 million children. Despite improvements in access to antiretroviral treatment, adult AIDS deaths reached 1.7 million at the end of 2007 while child AIDS deaths were estimated at 0.33 million in the same period (UNAIDS/WHO, 2007).

In Sub-Saharan Africa, which is regarded as the worst affected by the pandemic, 24.5 million adults and children were living with HIV at the end of 2005. During that year an estimated 2 million people died from AIDS. The epidemic has left behind an estimated 12 million orphaned children needing care in this region. Closer to home, in South Africa, an estimated 5.4 million people (about 11% of the total population) including 257 000 children, were living with HIV in mid-2006. The prediction is that the number will exceed 6 million by 2015, by which time around 5.4 million South Africans will have died of AIDS (Centre for Actuarial Research, 2006; UNAIDS/WHO, 2007).

In South Africa, an estimated 830 000 children were orphaned by AIDS in 2005. This figure is predicted to rise to 2.3 million by 2020 (Actuarial Society of South Africa, 2005). Millions more children are living with infected and sick parents. According to statistics provided by UNAIDS (2004), in 2004, between 13 and 18 million children worldwide were orphaned by AIDS. Presently Africa alone has an estimated number of 12 million AIDS-orphaned children. Survey results presented by Alcorn (2004) in Cape Town, South Africa, showed that nearly 7% of South African children between the ages of 2 and 9 are HIV-infected. Nearly 10% of the 2-9 age groups had already lost at least one parent. HIV prevalence in the general population of South Africa was 11.4% (12.8% in females and 9.5% in males) (Connolly, Colvin, Shisana & Stoker, 2004).

The implications of such statistics are profound. It is significant and necessary information that enables researchers to take full cognisance of the extent of the psychosocial effects of the pandemic and to justify and intensify research and support for children who are infected with and affected by HIV&AIDS. Such estimates are also vital to put into perspective the enormity of the multilayered challenges that face countries, regions and communities.

While HIV and its AIDS-related illnesses have ravaged countries and communities alike, in this study the concern lies with the children who are left behind when their parents and families die. Many such children are themselves HIV-positive and often have to cope with their fears and anxieties relating to a long period of parental illness and eventual death. Together with fear and uncertainty over their own illness, orphanhood and extreme poverty, a breeding ground for many emotional difficulties is created. Furthermore, in many cultures, children who are either HIV-positive themselves or who are associated with an adult who is HIV-positive or who has died of an AIDS-related illness, routinely face discrimination from their peers, guardians, teachers and from their communities in general. They may be barred from school, harassed and teased by peers and barred from participating in community-based activities, thereby exacerbating the risks, challenges and vulnerabilities facing these children, families and communities (Cluver *et al.*, 2007; Bhargava, 2005; Booysen, & Arntz, 2002; Grainger, Webb & Elliott, 2001; Sengendo & Nambi, 1997).

2.2.2.2 The stressors and challenges that could increase the risks and vulnerabilities facing children

There is a common agreement amongst researchers that being affected by HIV&AIDS encompasses a range of cumulative stressors and challenges for children and adolescents, many of them usually beginning even before a child becomes orphaned and placing them at increased risk for further vulnerabilities (Kvalsig, Taylor, Jinabhai & Coovadia, 2004, Brookes *et al.*, 2004; Smart, 2003a & b). In this section, I shall discuss the effects of HIV&AIDS on children and families; disclosure of HIV infection and AIDS-related illnesses; stigma and discrimination; death, loss, separation and bereavement; and orphanhood and residential care as related to the stressors and challenges that increase the risks and vulnerabilities facing children.

a) The effects of HIV&AIDS on children

In this section, I shall discuss the literature pertaining to the emotional, psychological and behavioural effects together with the psychosocial and cognitive effects of HIV&AIDS on children and families.

o Emotional, psychological and behavioural effects

The emotional and psychological impact of HIV&AIDS on children and families usually manifests well before the eventual death of parents from an AIDS-related illness. In many cases, children start to experience physical and emotional neglect when their parents' health

begins to deteriorate. Fear and uncertainty surrounding parental illness may result in psychological manifestations such as anxiety and depression. These stressors, which may be internalised or externalised, include the effects of poverty, limited shelter, sadness and distress related to death, loss and bereavement, social stigma and discrimination as well as limited learning opportunities (Kvalsig, *et al.*, 2004; Brookes *et al.*, 2004; Smart, 2003a).

Several studies have suggested that, children orphaned by AIDS experience depression (Bhargava, 2005; Atwine, Cantor-Graae & Banjunirwe, 2005; Pivnick & Villegas, 2000; Luthar, 1993), anxiety (Atwine *et al.*, 2005; Pelton & Forehand, 2005) and anger (Atwine *et al.*, 2005). These manifestations are described as internalising behaviour; researchers concur that orphaned children's circumstances predispose them to more internalising problems (Cluver & Gardner, 2007; Bhargava, 2005; Atwine *et al.*, 2005; Makame *et al.*, 2002) and a less positive affect (Pivnick & Villegas, 2000). In particular, Cluver and Gardner (2007) have surmised from their study that AIDS-related parental bereavement subsumes heightened levels of internalising and some externalising distress.

In their therapeutic work with HIV&AIDS-affected children and their parents, Willemsen and Anscombe (2001) have pointed out that children have lively imaginations which results in their internalising and distorting fears and anxieties. Among the psychological and emotional issues that emerged from their study were parents' feelings of guilt, constant anxiety over their own and their children's health, and the impact of the social stigma surrounding HIV&AIDS on their lives. The intermittent loss that the children had to endure when parents were hospitalised, exacerbated their anxiety and promoted fears of desertion and abandonment. Furthermore, children who were HIV-infected themselves could have endured recurrent hospitalisations, thereby multiplying their stresses and anxiety levels. Mendelsohn (1997:399) attributes chronic trauma in the lives of children and parents to the pervasive threat of impending death. In Willemsen and Anscombe's study (2001), it was suggested that children tended to displace their anxiety onto other caregivers or children around them, mainly resulting in aggression and acting-out behaviour. Displacement of anxieties and acting-out behaviour may be considered forms of coping for children experiencing distress (Wild, 2001).

A lack of support from families and communities and unmet psychosocial needs may more often than not lead to risk-taking behaviours or depression amongst young people. Pivnick and Villegas (2000:105) investigated this hypothesis to bring the voices and experiences of HIV-affected children and adolescents into sharper focus and found that orphaned and HIV-affected children experience depressed moods and clinical depression. In addition, high

degrees of somatisation and sleep disorders (including recurrent nightmares) were noted. As a unique contribution of this study, it was found that adolescents did not engage in high-risk behaviour. Positive and adaptive behaviour, considered a protective factor, was attributed to community-based social and emotional HIV support. The Pivnick and Villegas (2000) study highlighted the value of community or social support structures to alleviate risk behaviours and enhance the coping strategies in young people. Similarly, Huebner and Brassard (1999) assert that higher levels of support from multiple sources are related to greater numbers of coping strategies employed by adolescents and adults.

A wide social network offering multiple sources and different levels of support acts as a strong base from which children can venture. Furthermore, the association with a network of caring, compassionate and understanding people fosters positive experiences and alleviates feelings of depression and isolation (Battles & Wiener, 2002; Lightfoot & Healy, 2001). Intervention may occur at different levels: support of people (caregiver training); places (making schools a safer and protective environment); practices (daily engagement with children) and programmes (investment by external support organisations) (Rochat & Hough, 2007).

o **Psychosocial effects**

Orphaned children are usually predisposed to psychological distress arising from their psychosocial situation during parental illness and following the death of their parents. Some of these children may have had to care for their ill parents for some time, and the death of their parent(s) often produces major life changes that exacerbate their psychosocial situation. Often such children and families have been living in the throes of poverty and vulnerability anyway. HIV&AIDS serve to exacerbate their life situation. Children may have to move to a new area, leaving behind friends and school or even worse, becoming separated from a sibling or losing a sibling to AIDS. They become dependent upon the abilities and attitudes of adults who are given ownership or control over their property and decisions about their future life. Frequent changes in caregivers add to the uncertainty and chaos. Basic needs for food, shelter and education may be unmet. Perhaps one of the greatest stressors for a young child to live with would be the stigma that is still attached to HIV&AIDS. In addition, the illness and AIDS-related death of parents or caregivers can rob a child of the emotional and physical support that defines and sustains childhood. It leaves a void where parents and caregivers once provided protection, love, care and support (Strydom & Raath, 2005; Woodring, Cancelli, Ponterotto & Keitel, 2005; Ansell & Young, 2004; Ansell & Van Blerk, 2004; Richter, 2003; Bauman, Camacho, Silver, Hudis & Draimin, 2002; Pivnick & Villegas, 2000; Lyons, 2000).

In a South African study, Strydom and Raath (2005) found that the common emotions expressed by HIV-infected adolescents were anxiousness, fear, sadness and hopelessness. Among the highest psychosocial needs of these adolescents was the need to make peace with the illness and the need to be accepted by their families and communities. It also emerged that regular social visits and physical and emotional support by family, friends, and social workers were high on the list of priorities for the HIV-positive adolescents in this study, as it contributed to their well-being. Disclosure was also an issue for participants in the Strydom and Raath (2005) study.

A further investigation by Woodring *et al.* (2005) was an attempt to understand how parental HIV&AIDS affect adolescents' psychosocial functioning, particularly in the home and school environment. The major themes that were elicited from this study included loss, transitions, school implications, paradoxical situations, support networks and coping. Confirming Strydom and Raath's (2005) findings, disclosure was an issue for the adolescents in this study as well.

Coping with the multiple and ongoing psychosocial stressors related to HIV infection and AIDS-related deaths impacts on relationships as well. The effects of children's losses on parent-child relationships are foregrounded in the Willemsen and Anscombe (2001) study. Their study also offers an insight into the varied roles that children are often forced to embrace following the death of a parent. These findings resonate with those of Chabilall (2004), who found that adolescent females took on the role of a parent in the household following the parental death.

o **Cognitive effects**

While all children with chronic life-threatening illness are at risk for emotional, behavioural and educational difficulties, children infected by HIV are at a particular risk for psychological disturbance. This is due to the direct effects of HIV infection on brain structures involved in the regulation of emotion, behaviour and cognition, as well as the indirect effects related to coping with the range of medical, psychological and social stressors associated with the disease (Bonanno, Noll, Putnam, O'Neill & Trickett, 2003; Bachanas, Kullgren, Schwartz, Lanier, McDaniel, Smith & Nesheim, 2001; Carson & Swanson, 1992).

Furthermore, children infected with HIV manifest a high prevalence of behavioural and attentional difficulties together with deteriorating cognitive functioning and poor adaptive functioning (Gosling *et al.*, 2004). Kullgren, Morris, Bachanas and Jones (2004) assessed the cognitive, adaptive and behavioural functioning of a group of HIV-infected children aged

between 3 and 16 years in the United States and found stronger adaptive functioning in comparison with the children's cognitive potential as measured on an IQ test. Another study by Smith (2005) examined the effect of HIV in combination with other important health and social factors on the development of cognitive abilities of children who were perinatally exposed to HIV. Children with HIV infection scored lower in all domains of cognitive development than those who were infected without an AIDS-defining illness, thereby confirming the findings of Kullgren *et al.* (2004) and Gosling *et al.* (2004) that a cognitive decline in HIV-infected children places them at increased risk for behavioural problems stemming from limited coping skills and underdeveloped resilience traits (Smith, 2005, Gosling *et al.*, 2004; Kullgren *et al.*, 2004).

o **Educational effects**

Children's education has been severely affected by the HIV&AIDS crisis in various ways. Many children are forced to drop out of school during parental illness, either to stay home to care for ill parents or because of limited financial means to support schooling. Studies with adolescents have shown that the main reasons for discontinued schooling arose from dire poverty when parents are unable to earn an income (thereby being unable to pay for school fees and to buy uniforms) (Mishra, Arnold, Otieno, Cross & Hong, 2005; Boller & Carroll, 2003; Makame *et al.*, 2002).

Moreover, upon parental death, many children are forced to relocate to new living arrangements resulting in forced migrations (Evans, 2005; Ansell & Young, 2003), which generally take them away from their community school to another area. In other cases, children have no option but to stay home to take care of younger siblings and manage a household (child-headed household); as a result, they forfeit their educational opportunities (Chabilall, 2004; Giese, Meintjes, Croke & Chamberlain, 2003; Makame *et al.*, 2002; Sengendo & Nambi, 1997).

For the children who do manage to attend school, the situation is bleak as they are often faced with teacher absenteeism resulting from the teachers' suffering from AIDS-related illnesses (Machawira, 2008; De Witt & Lessing, 2005; Mbugua, 2004; Zapulla, 1997). Furthermore, a perception of a lack of support (conceived as care, compassion and empathy) from teachers is reflected in children's feelings of rejection, despondency and stigmatisation in the Ogina (2007) study. This also alluded to the fact that teachers differed in their pastoral roles, thereby exacerbating the mixed messages that children seem to be receiving from their teachers regarding their importance as children. While schools serve as a place of socialisation for many children whose homes are disrupted, the prevailing risk factors such

as stigma and discrimination from peers and teachers in many instances increase the vulnerabilities of children.

b) Stigma and discrimination

HIV&AIDS have disrupted the lives of millions of individuals, families and communities across the world. Guest (2003:159) has posed the question of what will happen "*to the minds of a generation that grows up alone, poor and ashamed by the stigma that killed their parents*". Smart (2003a) described the stigma and discrimination associated with the disease as being pervasive, as it can exacerbate the material and psychological problems children already face in the context of the HIV&AIDS pandemic. Stigma can prevent proper access to education, well-being, treatment and care both directly (through abuse, denial of care, forced child labour and loss of inheritance) and indirectly (by avoiding potentially stigmatising situations such as social interactions, healthcare and educational opportunities because stigma is expected or internalised) (Letteney & Laporte, 2004; Strode & Barrett-Grant, 2001).

According to UNAIDS (2000), stigma may manifest itself externally or internally and may have different effects. Internal stigma is the shame associated with HIV&AIDS. People living with HIV&AIDS fear being discriminated against. Internal stigma is characterised by self-exclusion from services, low self-esteem, social withdrawal and fear of disclosure. External stigma as defined by UNAIDS (2000) is the actual experience of discrimination, which may include domination, harassment, categorising, accusation, blame, ridicule and resentment.

Children are likely to experience stigma and discrimination in different ways from those of adults. Furthermore, there appears to be a variation in the extent, effects and nature of stigma and discrimination across regional, cultural, socio-economic and gender contexts (Deacon & Stephney, 2007). In Scotland children from affected households bear the brunt of parental HIV stigma on many levels and in all aspects of their lives as they experience this stigma and discrimination (Cree, Kay, Tisdall & Wallace, 2004). Thus, as children are particularly vulnerable to courtesy stigma (associated with parental HIV status) they might experience stigma more intensely than adults do (Cree *et al.*, 2004). It seems likely that the stigmatised nature of HIV separates it from other chronic illnesses. Children orphaned by AIDS are often expected to work harder and are the last in line to receive food and even school fees from extended family members who support them (Raufu, 2002). In Sao Paulo, Brazil, AIDS-related stigma occurs within complex discrimination processes that changes as children reach adolescence: access to highly active antiretroviral therapy (HAART) changes

the lived experiences of these children and helps to reduce the accompanying stigma (Abadia, Cesar & Castro, 2006).

The complex discrimination processes are partly caused by the larger social community of adults and children alike who marginalise and isolate affected and infected children (Smart, 2003a and b), which further decreases their access to quality health care and education (Hepburn, 2002). However, research conducted in rural Malawi has suggested that in terms of physical well-being, the extended family in this society had not discriminated against surviving children whose parent have been ill or have died because of HIV&AIDS (Crampin, Floyd, Glynn, Madise, Nyondo, Khondowe, Njoka, Kanyongoloka, Ngwira, Zaba & Fine, 2003). Related to the research questions that guide this review, I contemplate the emotional and psychological impact of discrimination and stigma on the well-being of children and adolescents and wonder to what extent children cope when faced with stigma and discrimination.

Arising from the stigma associated with HIV&AIDS, silences are perpetuated. According to Wild (2001:12), this conspiracy of silence surrounding AIDS also increases the likelihood that children will not be given sufficient opportunity to share their feelings of confusion, anxiety and anger and will instead act them out in disruptive, antisocial and high-risk ways. Breaking the silence that surrounds HIV infection and promoting open discussions are ways of addressing stigma and discrimination and helping children gain access to basic protection, services and financial opportunities, especially after the death of their parents (Hamra, Ross, Karuri, Orrs, D'Agostino, 2005).

c) Disclosure of HIV infection and related illnesses

Many concerns around the disclosure, non-disclosure and early disclosure of HIV infection and children's understandings thereof have been raised in the literature base (Nostlinger, Jonckheer, De Belder, Van Wijngaerden, Wylock, Pelgrom & Colebunders, 2004; Lester, Chesney, Cooke, Weiss, Whalley, Perez, Glidden, Petru, Dorenbaum & Wara, 2002; Shaffer, Jones, Kotchick, Forehand & Family Health Project Research Group, 2001; Sherman, Bonanno, Wiener & Battles, 2000).

Children's cognitive and emotional understanding of illness and death may be determined by their developmental stage and their exposure to illness and death. Furthermore, their knowledge and understanding also precipitate the manner and extent of their coping (Lester *et al.*, 2002). Factors such as a higher child intelligence and greater family expressiveness

seem to determine the timing and probability of non-disclosure or of earlier disclosure of HIV status to infected children. While diagnostic disclosure may not necessarily minimise the emotional distress of children (Lester *et al.*, 2002), self-disclosure by infected children themselves to their friends resulted in a slower rate of disease progression as measured by the CD4 count of infected children (Sherman *et al.*, 2000). In addition, self-disclosure to friends did not affect the HIV-infected child's behaviour or self-concept (Sherman *et al.*, 2000; Instone, 2000).

With regard to disclosure and behaviour, a significant increase in child behaviour problems and a decrease in the quality of mother-child relationship from pre- to post-disclosure were described by Shaffer *et al.* (2001). In the same study, though, the children reported a significant increase in their understanding of HIV&AIDS post disclosure; and they also did not notice a significant behavioural change in themselves (Shaffer *et al.*, 2001). These results are consistent with previous studies showing the positive health consequences of self-disclosure in adults (Paxton, 2002) and suggest potentially important implications for professional and familial caregivers of HIV&AIDS-infected and affected individuals.

From a psychological perspective, self-disclosure of traumatic or secretive information may produce observable health benefits and be linked to improved psychological health (Paxton, 2002). To understand the impact on HIV-infected people of publicly disclosing their status, in-dept interviews were conducted with 75 HIV-positive people from 20 countries in Africa and the Asia-Pacific region. Findings indicated that public disclosure led to a diminution of discrimination. Respondents found that speaking out was extremely rewarding for them as it led to a less stressful, more productive life and to improved well-being. It was suggested that the paradox of coming out openly as an HIV-positive person is that by facing the AIDS-related stigma, one finds psychological release or liberation from the burden of secrecy and shame (Paxton, 2002).

Disclosure as well as bereavement may be expressed in different ways. Swanepoel (2008) suggests the use of a memory box as a culturally-friendly intervention designed to help individuals cope with death or dying and to have a safe way of expressing their grief. It also provides the infected individual with the opportunity to disclose his or her HIV status in the making of the memory box, therefore making it a cathartic process and freeing individuals with HIV&AIDS of the shame and fear that is usually associated with the disease (Smetherham, 2002; Denis, 2000). Thus, parental disclosure to their children via a memory box may result in parents feeling unburdened and liberated after harbouring a secret. Stein (2003) argues that disclosure prior to parental death allows children to come to terms with

impending bereavement, to say goodbye to their parent, and to preserve and foster a relationship of trust and openness between parent and child. On the other hand, Lee and Rotheram-Borus (2002) refute this claim, stating that parental disclosure of HIV status can be associated with long-lasting negative consequences for both parents and children, including more problem behaviours in adolescents and greater stigma and discrimination.

d) Death, loss, separation and bereavement

In the case of HIV-orphaned and affected children, the stigmas associated with HIV&AIDS heighten the likelihood of persistent and unresolved grief. These children would require unique treatment interventions to address the effects of these stigmas and the consequences of often prolonged and unpredictable parental illness and eventual death (Kukard, 2003; Griffiths, 2003; Willemsen & Anscombe, 2001; Siegel & Gorey, 1994). The stigma and secrecy associated with HIV&AIDS are known to lead many families and children into emotional seclusion, resulting in abnormal grief reactions (Gossart-Walker & Moss, 1998). Aspects of grief include fantasies of reunion, the absence of overt expressions of grief and persistent feelings of anger and reproach (Villegas & Pivnick, 2000). Unresolved feelings of loss and grief in the absence of adequate treatment can lead to severely diminished personal opportunities for orphaned and HIV-affected children. The silence that surrounds the disease leaves these children without anyone with whom to share their feelings and fears, heightens their feelings of being “different” from other children, and associates their losses with a sense of shame (Villegas & Pivnick, 2000). Such grief reactions would also include low tolerance frustration, acts of rage, fighting in school, class clowning and truancy (Pivnick & Villegas, 2000).

However, Willemsen and Anscombe (2001) found in their study of play therapy as part of a treatment intervention that it addressed the anxieties that surround young children’s perceptions of loss and separation as they related to bereavement in their lives. However, the anxieties that usually started out due to separation from caregivers following hospitalisation, often resulted in feelings of bereavement and disruption to family life. Very young children who experience long periods of anxiety and stress associated with witnessing the trauma of their parents’ illness and death will be affected psychosocially as well as psychologically (Dunn, 2005). In addition, see the discussion in Section 2.2.2.2.

e) **Orphanhood and residential care**

The relentless growth in the size of the population of orphans and vulnerable children has precipitated a multifaceted care burden that will also grow for the next 20 years (UNICEF, 2007). HIV&AIDS present themselves as a family disease; the devastating impact of the pandemic leaves behind an entire generation of orphaned and vulnerable children, thus forcing societies to be re-shaped (Hunter & Williamson, 2000).

Researchers concur that the life situation of orphaned and vulnerable children as a result of HIV&AIDS-related deaths is long-term and of a large scale (Germann, Madörin & Ncube, 2001; Hunter & Williamson, 2000). Foster and Williamson (2000) also predict that the proportion of orphaned children will remain high throughout the first half of the twenty-first century. The enormous pressure placed on communities in response to the crises of homeless orphaned children has resulted in different coping approaches. These responses to coping with orphaned and vulnerable children differ according to countries, regions and communities. Thus far, the responses for providing a home for orphaned children and youth have included incorporation within extended families; orphanages; shelters, institutions; foster care and adoption (Nyambedha, Wandibba & Aagaard-Hansen, 2003; Foster, 2000). Increasing numbers of adolescents are presently heading households, a fraction of these with community and governmental support. Increasingly, these children are deprived from learning opportunities as the chore of caregiving falls on them (Chabilall, 2004; Townsend & Dawes, 2004; Foster, 1997, 2000).

The traditional practice in Africa has been for substitute parents from within the extended family system (usually an elderly and widowed female relative) to absorb and include children. This then becomes a permanent living arrangement. It has been estimated that more than 90% of orphaned children in Africa have been cared for in this way, in most cases by families already overburdened and impoverished (UNICEF, 2007). Grandparents are increasingly raising grandchildren at a time in their lives when they could have expected support from their own adult children (McKerrow, 1994).

Kodero's (2001) study in Kenya challenged the common belief in Africa that the extended families would be there to meet the needs of the orphaned children when a parent dies. Kodero (2001) maintains that educational, psychological and psychosocial needs of the orphans were best met by orphanages (by implication, institutions), followed by guardians' homes, and were least met by extended families. The attitude of caregivers towards orphans and peer support were identified as two factors that could have affected the psychological

well-being of orphans. This study further alludes to the fact that extended families can no longer adequately care for the orphan children. Furthermore, as children whose parents die and who live with extended families work more, attend school less, and fall sick more often, they are subject to a greater tendency toward social pathology. Caring for these orphans increases the vulnerability of the families and communities that take them in as it reduces household income and food security, stretches social services and undermines community cohesion (Atwine *et al.*, 2005; Alcorn, 2004; Bray, 2003; Booyesen & Arntz, 2002).

Based on the above descriptions it has been suggested that there should be a move away from the normative assumption that childcare should take place in family settings and to an objective position that focus on the childcare practiced in institutional settings (Gilborn, Nyonyintono, Kabumbuli, Jagwe-Wadda, 2001; Ntozi, 1997). The Russian Federation presents an example of a community which promotes institutional forms of care; where HIV-positive parents are often already marginalised, parents may be implicitly or explicitly encouraged to place their children in institutional care, especially when the children are also living with HIV or AIDS (UNICEF, 2007).

Experiencing a life-threatening extended illness does not necessarily imply that parents would plan for their children's future and the transition to an alternate caregiver. Generally, parents were reluctant to discuss parental illness, death and custody planning with minor children for fear of stigmatisation and discrimination should such personal information be inadvertently disclosed by the minor children (Giese *et al.*, 2003; Siegel & Gorey, 1994). The fear of discussing death and the stigmatised nature of HIV&AIDS may make parents less likely to do custody planning for children in advance of their death. Kodero (2001) agrees that AIDS patients do not make placement and custody arrangements for their children before dying.

As the projections of the number of AIDS orphans rise, there has been a call from some sectors for an increase in institutionalised care for children. Gilborn *et al.* (2001) and Ntozi (1997) proclaim that placing orphaned children in the care of institutions is not entirely new in most African settings and some of these institutions are highly desired because they provide the children with important facilities such as boarding schools and medical facilities (hospitals and clinics).

However, others (Zimmerman, 2005; Tolfree, 2003; Dunn, Jareg & Webb, 2003; McCreery, 2003) argue that institutional care is not only expensive but also detrimental to the children. Those who are against this form of care insist that institutional care stores up problems for a

society which is ill equipped to cope with an influx of young adults who have not been socialised in the community in which they have to live. Amongst others, children in institutions present with a range of emotional and psychological difficulties related to the self-concept development, maternal deprivation, attachment disturbances and mother-child interaction (Tolfree, 2003; Dunn *et al.*, 2003).

Besides negatively affecting children's development, institutional forms of care have been linked to a serious and negative effect on children's rights. Tolfree (2003:9) outlines typical negative features of institutional care that impact on children's development and rights:

- o the segregation, discrimination and isolation that institutionalised children often experience;
- o the fact that admission is often based on the needs of the parent and not on the interests of the child;
- o the lack of personal care and stimulation;
- o the lack of opportunities to learn about the roles of adults;
- o the high risk of institutional abuse;
- o the lack of attention to specific psychological needs and the fact that institutionalised *children often experience problems in adjusting to life outside of the institution.*

Once institutionalised, children affected by HIV&AIDS (especially HIV-infected children) are often separated from other children, leading to further stigmatisation.

While institutions for orphan and vulnerable children might be perceived as the most recent symbol of modernisation , researchers and aid organisations generally consider institutions as the 'last resort' for the placement of children (Christian Aid & UNICEF, 2006; Dunn *et al.*, 2003; Hunter & Williamson, 2000). The explanations centre on the cost of running an institution in comparison to assisting orphans living in households, the psychosocial state of the children who are separated from the family setting, and the increased risk that especially male orphans do not inherit land from their fathers. The broad range of institutions, children's villages, and highly advanced boarding schools for orphans will probably prove a continuum ranging between associations of modernisation to symbols of poverty, marginalisation and tradition.

Partly in response to this, recent years have seen an increasing emphasis on the development of community-based approaches, both to prevent separation and to ensure that children who lose, or become separated from their own families can have the benefits of normal family life within the community (Tolfree, 2003; Foster, 2000). I call this form of

institutional care community-embedded residential care. I shall describe my choice of terminology by providing an in-depth description of my research site in Chapter 3 of this study. Although this approach to institutional care appears to be the ideal form, Tolfree (2003) says this type of residential care is the exception rather than the rule in Africa. Social scientific research could explore the extensive issues related to the influence of institutionalising orphaned children, in order to provide the care that is most appropriate for the children, their families, and the social context at large.

2.2.3 Well-being and adversity

In this section, I shall discuss the literature relating to resilience, coping, well-being, hope and positive emotions that arise from a positive psychology domain and that bear relevance to the focus of my study.

2.2.3.1 Resilience and coping

It is well known that HIV&AIDS constitute one of the most serious present-day health hazards. Today, South Africa is the site of one of the fastest growing HIV epidemics in the world with far-reaching effects (Marais, 2000). According to Dunn (2005), HIV&AIDS will affect 1.5 million children worldwide under 5 years of age by 2010. The social context for many children affected by HIV&AIDS includes poverty, a lack of resources, multiple family losses and orphanhood. Although children and families experience significant stressors arising from multiple and cumulative risk factors, features of resilience may be utilized in the guidance, prevention and intervention programming for vulnerable children and families.

The phenomenon of resilience has been the focus of considerable research, particularly in the study of children who appear to rise above severe environmental challenges (Eloff, 2008; Ebersöhn, 2007; Ebersöhn & Maree, 2006; Masten, 2001). Linked to resilience research, the focus of my study pertains to an individual child's capacity to maintain well-being in the face of substantial, multiple and cumulative adversities. I locate my work within the field of emotional resilience.

Resilience presents as multidimensional in nature. However, the consensus among scholars and researchers is that one should not generalise and assume that resilience means positive adaptation across all domains in life. Instead, findings on resilience are increasingly being described in terms of specific adaptations. As a result, resilience is being described in specific terms, such as educational resilience, emotional resilience and behavioural resilience

(Cicchetti & Garmezy 1993; Luthar, 1993). Kaufman, Cook, Arny, Jones and Pittinsky (1994) claimed that while two thirds of maltreated children are academically resilient, only twenty-one percent of maltreated children manifested resilience in the domain of social competence. Earlier findings by Luthar (1991) indicated that among adolescents who experienced significant adversities, those who overtly reflected successful adaptation often struggled with covert psychological difficulties such as problems of depression and posttraumatic stress disorder. Related to my study, I explored emotional resilience as a well-being indicator among children experiencing severe stress (Cicchetti & Garmezy, 1993; Luthar, 1993).

While much of the psychological research surrounding HIV&AIDS investigated adults or adolescents coping with stress and psychosocial difficulties (Evans, 2005; Ansell & Van Blerk, 2004), South African research into the psychological needs of young children is emerging (Ebersöhn, 2007; Sekokotla & Mturi, 2004; Ansell & Young, 2003; Bray, 2003). Ebersöhn (2007) focused on the ways in which vulnerable children in South African communities cope with the impact of HIV&AIDS. Dimensions of resilience were investigated to extract evidence of vulnerable children's resilient coping. The author's findings indicate that children's resilient coping is affected by protective factors as well as the individual's pragmatism and motivation. This investigation also evidenced children struggling to cope with the many stressors due to their vulnerability. Vulnerable children's resilient coping was portrayed as emotional giftedness (Ebersöhn, 2007).

Resilient coping includes a sense of self-worth, hope and optimism, and a sense of security, comfort and belonging; it may be described as a form of emotional giftedness that demonstrates resilience (Ebersöhn, 2007). Similarly, Rutter (2000) describes qualities such as potential protective factors which include rational appraisal, self-esteem, social support, positive life events, a sense of control and the types of coping strategies typically needed to deal with stressors. Arising from these studies there seems to be the impression that stress reactions and coping abilities may be directly related to children's social development, their adjustment and their well-being.

Protective factors that enhance or encourage family resilience and resilience in children appear to highlight different elements. McCubbin *et al.* (2002) researched family resiliency and childhood cancer. Factors that appeared to contribute to family resiliency included internal family strengths, support from the health care team, extended family, community and workplace. Coscia, Christensen, Henry, Wallston, Radcliffe and Rutstein (2001) concur and add that stability in a home environment and the socioeconomic status of the parents

seem crucial for resilient outcomes. In addition, family confidence and family coping are assumed to predict positive cognitive development (Carson & Swanson, 1992).

While the above promotive factors contributed to family resiliency in the midst of adversity, childhood resiliency appears to derive from factors such as the willingness to accept a surrogate caregiver, an open definition of family, a developmental age consistent with or greater than their chronological age, good interpersonal relationships as well as a positive perception of home life and family relations that included perceptions of warmth, nurturance and stability (Williams, 2001; Friedland, Renwick & McColl, 1996). Moreover, Coscia *et al.* (2001) suggested that the health status of children is an important consideration which both protects and hinders development. HIV infection is known to affect the cognitive functioning of children, especially during the advanced stages of the disease, and thus impinges on their resilient emotional adaptation. In such cases, children's health status could be regarded as a risk factor.

As discussed in Section 2.2.2.2, communities and families affected by HIV&AIDS are daily challenged to eke out a living. Individual families' passive coping and spiritual support seems to be coping techniques used most often by families affected by HIV&AIDS. The Ferreira (2006) study also found that individual members of communities ascribed to a spiritual form of coping. Interestingly though, despite the efforts by community organisations to offer support to such families, the fear of stigma and discrimination prevented those families from accessing such social support (Martin, Wolters, Klaas, Perez & Wood, 2004).

Other resources used by individuals and families to ensure their coping or as part of their survival strategy was that of migration (Ansell & Young, 2004; Ansell & van Blerk, 2004; Evans, 2005). It is suggested that migrating to urban areas to seek a living in the informal sector represented a survival strategy adopted by some children and adolescents orphaned by AIDS when their families and communities were unable or unwilling to support them.

However, despite their predispositions to psychological problems, few studies have examined the predictors of psychological well-being of children orphaned by AIDS (Cluver & Gardner, 2006; Bhargava, 2005; Makame *et al.*, 2002; Foster, 2000). Bhargava (2005) noted during a study of Ethiopian AIDS orphans, that the predictors of children's psychological well-being included the presence of the father, household income, feeding and clothing conditions, and the attitude of a fostering family. Brown *et al.*, (2000), add that the context of the family and cultural beliefs influence how children and adolescents cope with their illness and their losses. Bachanas *et al.* (2001) attributed psychological adjustment to

the age of the child and the coping styles that were utilised. These findings exemplify the view that coping with HIV infection is a complex phenomenon for all concerned, which involves multiple interacting variables. Young HIV-infected children appear to be more at risk for developing subjective distress because of deteriorating developmental skills and the many stressors associated with HIV infection (Brown *et al.*, 2000).

I conjecture that since resiliency and vulnerability appear to exist on a continuum in the lives of children and since children are vulnerable to different life events at different stages of their lives, key protective factors could be enhanced throughout a child's growth and development to buffer against risk and further vulnerabilities.

2.2.3.2 Well-being

The psychosocial characteristics of the impact of HIV&AIDS with its accompanying orphanhood have a profound influence on the emotional development and well-being of children. This influence is compounded when children are also infected with the HI virus. In this section, I shall contemplate on the different dimensions of well-being and how it relates to the focus of my study. I shall discuss the following domains:

- o psychological well-being
- o coping and well-being
- o hope as an indicator of well-being
- o positive emotions and well-being
- o happiness and well-being
- o human strength and well-being and
- o health and well-being.

I understand wellness³ or well-being as possessing positive indicators such as "*having a sense of control over one's fate, a sense of purpose and belongingness and a basic satisfaction with oneself and one's existence*" (Cowen, 1991:404). Children's well-being seems to stem from a multidimensionality of constructs: one's sense of dignity, security and mastery of particular settings (Earls & Carlson, 2001); positive self-esteem and satisfaction with life (Cowen, 1991); positive evaluation of one's life, indicating positive emotion, engagement, satisfaction and meaning (Seligman, 2003). In addition, Ryff and Singer (2003:277-279) have outlined six dimensions of psychological well-being in adults:

- o self-acceptance – the capacity to see and accept one's strengths and weaknesses;
- o purpose in life – having goals and objectives that give life meaning and direction;

³ In this study I shall refer to the terms "well-being" and wellness" interchangeably to mean the same concept.

- personal growth – the feeling that personal talents and potential are being realised over time;
- positive relations with others – having close, valued connections with significant others;
- environmental mastery – being able to manage the demands of everyday life; and
- autonomy – having the strength to follow personal convictions.

Research in positive psychology has explored constructs such as individual characteristics, positive experiences, positive emotions and positive institutions and communities that enhance and promote well-being (Seligman & Csikszentmihalyi, 2000). Although positive psychology has long been a part of psychology's history, the present emphasis on well-being as a construct that emphasises the strengths, resources and assets of individuals and institutions is an emerging field (Seligman, 2003; Snyder & Lopez, 2002) that is foregrounded in my study.

As one of the core components of positive psychology, subjective well-being subsumes constructs such as a positive outlook, setting meaningful goals, engaging in close social relationships, and a moderate temperament, which appear to be indicators for high subjective well-being (Diener *et al.*, 2005). In addition to nurturing subjective well-being indicators, efforts to improve children's lives must also focus on developing strengths, facilitating positive responses to adversity and strengthening the important institutions in children's lives (Huebner, Suldo, Smith, McKnight, 2004; Diener, 2000; Seligman & Csikszentmihalyi, 2000). These important institutions refer to the contexts of family, school and community. I put forth that resilience encourages well-being in children who face adversity, especially when they are supported and buffered by resources and protective factors within the contexts of the home, school and community.

(a) Subjective well-being

To facilitate optimal well-being, an individual should possess high levels of subjective well-being and psychological well-being (Keyes *et al.*, 2002). For understanding these constructs, a distinction needs to be made between subjective well-being and psychological well-being. Subjective well-being may be described as an evaluation of life in terms of life satisfaction and the balance between positive and negative affect. Psychological well-being, on the other hand, refers to the perceptions of engaging with the existential challenges of life (Keyes *et al.*, 2002), embodied in the dimensions of environmental mastery, positive relationships, autonomy, personal growth, self-acceptance, and purpose in life (Ryff & Singer, 2003). A closer examination of the traits associated with subjective well-being and psychological well-being indicates that they appear to tap into both intrapersonal characteristics and social interaction. High self-esteem, perceived control, optimism, sense of meaning and the means to cope with conflicts suggest that a person has achieved a sense of emotional balance in their lives.

The interrelationship between the subjective well-being of children and their various environmental contexts (Heubner & Gilman, 2003) offers an understanding of children's behaviour and functioning (Henry, 2003). Therefore, although individual factors such as individual personality traits and positive emotions mediate in a person achieving a state of well-being, the transactional nature of the individual and the social environment should not be ignored. In fact, individuals who maintain significant social support are more likely to sustain health under stressful situations than those who have minimal psychosocial resources (Salovey *et al.*, 2000). I suggest that a supportive network of family, friends and community resources may increase the positive outlook of people infected with HIV or living with an HIV-related illness.

As the number of children affected by HIV&AIDS continues to increase, their psychological needs are being recognised as equal in importance to needs relating to subsistence, health and education (Cook, Fritz & Mwonya, 2003). Certainly more guidance is needed to better understand and address the psychological and emotional needs of children orphaned and made vulnerable by HIV&AIDS. This view is shared by Pillay (2003), who maintains that the psychological challenges faced by these young children are usually internalised and are thereby often overshadowed by more tangible manifestations of the pandemic such as health, shelter, nutrition and social service issues.

In many community-based support programmes for orphaned children, volunteer workers often assess children's needs in terms of material goods and neglect the children's psychosocial needs (Grainger, Webb & Elliott, 2001). The implication, namely that the psychosocial needs of HIV-affected children are less well understood than their material needs, may be attributed to the caregivers' failure to identify psychological and emotional difficulties as the cause of more visible problems such as truancy or anti-social behaviour. It is suggested that concerted efforts to identify and support the psychosocial needs of children might lead to the facilitation of improved coping skills amongst children, thereby minimising the development of psychological and emotional difficulties.

b) Coping and well-being

While it might seem contradictory to assume that people can achieve or experience well-being in spite of having a chronic illness or living with someone who has a chronic life-threatening illness, some studies have shown that people do experience well-being under the most difficult of circumstances, viz. the work of Chesney, Folkman and Chambers (1996) (men living with HIV) and Folkman (1997) (people coping with severe stress). In this line of thinking, Moskowitz (2003) studied the coping responses of homosexual men while caring for their HIV-infected partners during illness and after their death. Moskowitz's findings bear relevance to my study-it was found that high levels of positive emotions co-existed with periods of depression throughout caregiving and bereavement. The findings of this study were replicated by the same researchers in an ethnically diverse sample of maternal caregivers (biological and non-biological mothers) of children with HIV and other chronic illnesses (Moskowitz, 2003). The findings of the Moskowitz (2003) study substantiate my suggestion that maintaining well-being within a context of adversity is a possibility.

However, what about the young child affected by HIV&AIDS? According to Dunn (2005), there were gaps in the policies and programmes to mobilise resources to address the needs and experiences of very young children (aged 0-8) in HIV&AIDS-affected communities at local, national and international levels. Just as researchers and clinicians should give as much attention to the development and maintenance of psychological well-being in the face of serious illness as they do to the etiology and treatment of symptoms, so too should young children experiencing HIV&AIDS in their homes and communities be afforded a sense of well-being by appropriate intervention (Folkman & Greer, 2000).

c) Hope as an indicator of well-being

In early readings, hope was depicted as a motivating force and an inner readiness to reach goals (Herth, 1990) and might have been described as instrumental in the coping responses of people facing an array of adversities, more especially in the case of terminally ill people. While Snyder *et al.* (in Snyder & Lopez, 2005) advocate using their hope theory to see the strengths in people, Diener, Suh, Lucas, Smith (1999) assume that people who are more optimistic (in essence, more hopeful) about the future are generally happier and more satisfied with life.

Rump (2004) examined parent hope and child hope as resilient factors related to parenting stress and negative mood states. How parents perceived their child's adjustment was examined as it related to the child's hope and the parents' perceived quality of life for the child. The sample in Rump's (2004) study included those children who were diagnosed with sickle cell disease, juvenile rheumatoid arthritis and diabetes, and their families. They were compared to a sample of children without chronic illness and their families. Findings indicated that hope (whether it was the chronically ill child's or the parents'), played a pivotal role in the parents' psychological adjustment. An advantage of this study is that it contributed to a literature base (Suldo & Huebner, 2004; Park, Peterson & Seligman, 2004; Street, Nathan, Durkin, Morling, Dzahari, Carson & Durkin, 2003; Seligman & Csikszentmihalyi, 2000) that aimed to identify the positive psychology constructs and character strengths that buffer children and families and assist health care providers in meeting the needs of children and families who are living in the context of chronic illness.

In an earlier study, the focus was on determining a common understanding of what constituted hope-fostering and hope-hindering strategies in a sample of terminally ill patients in hospice care (Herth, 1990). It emerged from this study that hope-fostering measures employed by terminally ill patients included interpersonal connectedness, attainable aims, a spiritual base, positive personal attributes such as courage and serenity, lightheartedness, uplifting memories and affirmations of worth. Hope-hindering strategies were regarded as feelings of abandonment and isolation, uncontrollable pain and discomfort and the devaluation of personhood. From this study, hope was conceptualised as complex and dynamic in nature, involving many thoughts, feelings and actions (Herth, 1990).

Hope, synonymous with optimism, is one example of various positive intrapersonal characteristics (Seligman & Peterson, 2003) that is thought to assume a protective role. Other examples of such human strengths include traits like the capacity for love and

vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future-mindedness, spirituality, high talent and wisdom (Seligman & Csikszentmihalyi, 2000:5).

An effective social support network would also serve to enhance a person's well-being by encouraging a sense of hope, motivation and optimism. By encouraging and nurturing hopeful thoughts, one is also required to reflect on the belief that one can find pathways to desired goals and become motivated to use those pathways. Hope may thus be seen as one of the resilience factors that enhances a person's adjustment to stressors.

d) Positive emotions as an indicator of well-being

Positive emotions⁴, generated by a sense of well-being, are known to co-occur alongside negative emotions during stressful circumstances (Folkman & Moskowitz, 2000). A growing number of theorists (Folkman & Moskowitz, 2000, 2003; Fredrickson, 2001; Ryff & Singer, 1998; Keltner & Bonanno, 1997; Bonanno & Keltner, 1997; Folkman, 1997) see positive emotions as active ingredients in coping and thriving despite adversity.

Fredrickson (2001), the proponent of the broaden-and-build theory, underscores the ways in which positive emotions are essential elements of optimal functioning and therefore essential in any discussion on well-being. Furthermore, resilience is built by finding positive meaning and experiencing positive emotions (Fredrickson, Brown, Cohn, Conway, Crosby, McGivern Mikels, 2004). Fredrickson's (2001:220) research on positive emotions (joy, interest, contentment, love), asserted that positive emotions not only produce a pleasant momentary state, but also contribute to psychological growth and improved well-being over time. This notion is in line with the broaden-and-build theory. This theory proposes that positive emotions broaden the scopes of attention, cognition and action and build physical, intellectual and social resources. The theory positively affects interpersonal relationships, correct the effects of negative emotions, improve psychological resilience and enhance emotional well-being (Fredrickson, 2001). Similarly, Khosla (2006) suggested that a positive affect not only broadens one's thinking and builds resources, but also increases the likelihood that people will feel good in future. Although it might seem idealistic, it is nonetheless important to cultivate positive emotions in our lives and those around us to feel good and achieve psychological growth for others and ourselves.

⁴ I concur with Isen (2003) and use the words "emotion", "affect" and "feeling" interchangeably in this study

Extrapolating from Fredrickson's (2001) broaden-and-build theory of positive emotions, Fredrickson, Tugade, Waugh and Larkin (2003) hypothesised that positive emotions co-exist alongside adverse conditions, and are active ingredients within trait resilience. In this study, US college students (18 men and 28 women) were tested early in 2001 and again in the weeks following the September 11 terrorist attacks. Mediation analyses showed that the positive emotions that were experienced in the wake of the attacks – such as gratitude, interest, love – accounted for the relationships between pre-crisis resilience and the later development of depressive symptoms, and also pre-crisis resilience and post-crisis growth in psychological resources. Findings suggested that positive emotions in the aftermath of a crisis buffer resilient people against depression that was consistent with the broaden-and-build theory. These findings exemplify the goals of my present study to explore the presence of positive emotional states within children who are affected by HIV&AIDS.

Positive emotional states are also more often associated with healthier outcomes in functioning and adaptability, while a person's negative emotional state is more often than not associated with maladjusted patterns of physiological functioning (Salovey *et al.*, 2000). Negative and positive emotional states thus influence a person's physical health and have an impact on their motivation to obtain medical assistance and to encourage their own health promotion. Positive emotional states such as humour and optimism may facilitate healthy behavioural practices and information seeking, as well as the ability to cope with illness-related stressors, thereby increasing the resilience people may need to face such events (Salovey *et al.*, 2000).

In a study that exemplified this view, positive emotions were related to a rapid recovery from cardiovascular reactivity generated by negative emotions for resilient individuals. Tugade and Fredrickson (2004) collected continuous measures from 57 participants in their study. Using physiological data and self-report measures, they confirmed their hypothesis that faster cardiovascular recovery from negative emotional arousal would be partly attributable to experiences of positive emotions, and added that resilience predicted positive emotionality.

In another study of Italian adolescents, the aim was to identify the personal characteristics and the developmental pathways that were conducive to successful adaptation from childhood to adulthood. This study, conducted by Italian researchers Caprara, Steca, Gerbino, Paciello and Vecchio (2006), examined the impact of self-efficacy beliefs on subjective well-being in adolescents, namely positive thinking and happiness. Positive thinking was operationalised as the latent dimension underlying life satisfaction, self-esteem

and optimism. Happiness was operationalised as the difference between positive and negative effects, as they are experienced in a variety of daily situations. The conclusions drawn here were that adolescents' self-efficacy beliefs to manage positive and negative emotions and interpersonal relationships contributed to promoting positive expectations about the future, maintaining a high self-concept, perceiving a sense of satisfaction for life and experiencing more positive emotions.

To conclude this section, I advocate that positive coping is facilitated by the availability of supportive, nurturing caregivers, and by positive social and physical environments that facilitate perceptions of control. Humour and laughter, optimism and gratitude are contributors to positive emotions. Fredrickson (2001) describes positive emotions as a transitory and brief reaction to some happening that is personally meaningful. It is about feeling happy in the moment, an enjoyment of the present.

e) Happiness as an indicator of well-being

As a construct of positive psychology, happiness as relating to well-being is possibly the most fundamental pursuit of humanity for every generation and is placed as the most central motivator of human goals (Street *et al.*, 2003). Even in its highest form, happiness may reflect an underlying contentment and a sense of harmony, even in the face of adversity. However, what is children's understanding of well-being and happiness and how does this relate to their life goals?

Children's conceptions of happiness were an area explored by Street *et al.* (2003). A combined interpretive and quantitative methodology was used with thirty-six children aged 10-12 years who participated in six focus groups discussing their understandings of happiness, important goals and beliefs concerning conditional goal setting. The majority of the children conceptualised happiness as goal-dependent upon something extrinsic to themselves (such as an achievement or event). Since a significant relationship existed between goal-setting styles, conceptualisations of happiness and depression, the findings suggested that some children conceptualised happiness as an outcome that is dependent on their important achievements and acquisitions. Arising from their findings, Street *et al.* (2003) also hypothesised the idea that depressed children were more likely than non-depressed children to be conditional goal-setters. From this study, I conjecture that non-depressed children who conceptualise happiness as a process which is independent of goal achievement or failure, display traits of subjective well-being.

f) Human strengths as indicators of well-being

A study of human strengths is invariably associated with personality characteristics such as optimism, self-efficacy and ego-resilience, aspects usually allied with positive life outcomes (Aspinwall & Staudinger, 2003). However, in trying to understand the role of human strengths as a protective mechanism, one needs to acknowledge contextual dependencies and the interplay between these dimensions (Aspinwall & Staudinger, 2003; Stokols, 2003). The identification and mobilising of particular developmental, material and social contexts that promote or enhance human strengths, resulting in well-being outcomes for individuals experiencing conditions of adversity, should be encouraged at all levels of society.

Psychologists within a positive psychology framework have proposed the existence of a set of psychological strengths that buffer against the development of psychopathology and the promotion of well-being (Suldo & Huebner, 2004; Park *et al.*, 2004; Aspinwall & Staudinger, 2003). A strong relationship seems to exist between character strengths and life satisfaction, which is an aspect of well-being, where well-being constructs such as hope, zest, gratitude, curiosity and love are most highly associated with life satisfaction (Park *et al.*, 2004). In the Suldo and Huebner (2004) study to test the assumption that adolescents' judgements of life satisfaction moderated the influence of stressful life events on the subsequent development of psychopathological behaviour, adolescents who reported positive life satisfaction were less likely to develop externalising behaviour problems in the face of stressful life events. The authors concluded that increasing an adolescent's subjective well-being, especially life satisfaction, could provide a protective effect against delinquent behaviour (Suldo & Huebner, 2004; Park *et al.* 2004).

g) Health and well-being

The conceptualisation of HIV&AIDS extends beyond a medical description to include psychosocial aspects that promote health and positive living. Researchers such as Antonovsky (1987) and Hill Rice (2000) argued that it was necessary to move beyond the focus on disease and examine those factors that enhanced an individual's capacity to cope. The salutogenesis model describes the process of maintaining well-being despite being exposed to a life stressor. The recognition that psychological well-being can be experienced regardless of the improvement or deterioration of a chronic life-threatening illness made an important contribution to both psychology and medicine, and provides an alternative to the biomedical model, which focuses on pathogenesis and not salutogenesis (Hill Rice, 2000). My study slants towards a salutogenic approach to health which focuses on the positive

aspects of environments that promote and sustain healthy outcomes (Antonovsky, 1987), rather than the traditional pathogenic or bio-medical model that emphasises risks and primarily sets out to correct deficits through intervention targeted at vulnerable individuals. The salutogenic aim when addressing children affected by HIV&AIDS is to enhance happiness by fostering wellness rather than by purely treating existing pathological disorders.

2.3 Towards a positive psychological approach

In conceptualising this study, I considered that the greatest challenge to families in the current millennium is embedded in the psychosocial vulnerabilities and risks to which children worldwide are subjected, none more so than the devastating effects of HIV&AIDS. As suggested by Salovey (in Ebersöhn, 2008:ix): *"as ARVs finally make their way to Africa, providing some hope that HIV&AIDS will no longer be a death sentence, possessing the social and psychological tools to manage this disease and its consequences will be all the more consequential"*. More than ever before, children and families impacted by the psychosocial challenges imposed by HIV&AIDS require both subjective and community-based care, understanding and support to bolster their well-being experiences.

The dire need for emotional, psychological and social support comes at a time when there is a worldwide resurgence and move towards positive psychology and a strengths-based perspective with a focus on supporting, encouraging and uplifting people at risk and experiencing distress. In this study I concur with and adopt the stance of Ebersöhn (2007:2) that although children affected by HIV&AIDS live in disadvantaged circumstances, they are not disadvantaged in order to be pitied and viewed as inferior. Instead, children ought to be recognised as possessing innate strengths, resources and abilities, thereby discharging the charity discourse that is often associated with children living in adverse conditions. I posit that if children affected by HIV&AIDS are considered active members of their community rather than victims, their lives can be given purpose and dignity. At a community level, many children already function as heads of households and as caregivers. Children should be supported in their efforts to lessen the impact of HIV&AIDS on their families and communities. On a subjective level, children could be supported in identifying and understanding their innate strengths, thereby creating opportunities for hope and well-being.

2.4 Conclusion

My aim in this chapter was twofold: firstly, I constructed and suggested a conceptual framework and secondly, I reviewed the relevant literature, which led to my understanding of the key concepts and constructs that formed the basis of my conceptual framework. I began this chapter by suggesting a conceptual framework that was anchored in the context of children facing a myriad of risks, challenges and adversities, which are supported by three fundamental support structures, namely positive and enabling systems, positive intrapersonal characteristics and positive emotions, and resulting in resilient psychosocial coping as manifested in experiences of well-being.

My subsequent literature review provided an overview of the critical psychological and psychosocial challenges in the field of HIV&AIDS research with children and families. I went on to explore well-being and its relatedness to resilient psychosocial coping efforts. By integrating aspects of well-being studies from a positive psychology domain, I attempted to explore the assumption that wellness in adversity might exist.

In Chapter 3, I shall provide a detailed discussion of the research design and methodology that steered this study.

