

## Situating and relating children's experiences to existing literature

## 5.1 Introduction

In the previous chapter, I outlined the results of this study by presenting the themes, subthemes and categories that emerged through a process of inductive thematic analysis within a constructivist grounded theory approach.

In Chapter 5, I reflect on the emerged themes in terms of my conceptual framework to present a series of findings aligned with my research purpose. In this meaning making process, I expound congruent as well as conflicting findings between my study and the existing literature. In the next chapter, I reflect on and answer my research questions leading to my final thoughts, recommendations and conclusion.

#### 5.2 Findings of the study

In this section, I relate my results to the existing literature situated within my chosen conceptual framework. As explained in Chapter 2, the framework incorporates several key concepts from a broader literature base on risks, challenges and vulnerabilities associated with psychosocial issues relating to HIV&AIDS, including a conceptualisation of a positive psychology approach which affirms positive emotions, positive characteristics and positive and enabling systems, as well as aspects of resilience and coping.

I have structured this section according to the outline that I used in Chapter 4. I begin by discussing the findings of my study which related to the challenges and stressors that could increase the vulnerabilities and risk for children. Next, I present the findings of my study related to the pillars that offer strength and support. Thereafter, I discuss the findings related to the coping mechanisms that the children utilised. Finally, I discuss children's experiences of well-being while affected by HIV&AIDS.

# 5.2.1 Children affected by HIV&AIDS live within a context of challenges and stressors that could increase their vulnerabilities and risks.

In the context of my study, among the various challenges and stressors associated with being affected by HIV&AIDS, the stressors associated with the psychosocial consequences of HIV&AIDS, as well as unfulfilled psychosocial needs, emerged as significant for the children.



#### 5.2.1.1 The stressors associated with the psychosocial consequences of HIV&AIDS

It has been widely acknowledged that HIV&AIDS and the interrelated psychosocial issues, pose great challenges and place the child at immense risk for further vulnerabilities (Deacon & Stephney, 2007; Makame *et. al.*, 2002; Wild, 2001; Foster & Williamson, 2000; Pivnick & Villegas, 2000). Of the various psychosocial challenges that faced children in my study, I highlight and discuss the following:

- the children's perceptions and experiences of illness;
- internalisation and externalisation of behaviour associated with HIV&AIDS;
- o the silences, disclosure, stigma and discrimination;
- death and bereavement;
- o orphanhood and residential care.

These challenges emerged substantially in my study and were clustered as a sub-theme, namely the stressors associated with the psychosocial consequences of HIV&AIDS.

## a) Children's perceptions and experiences of illness

At the children's home where I conducted my study, the children seemed to have varied perceptions and information relating to the causes and spread of HIV&AIDS. One possible reason for the children's limited and often vague knowledge of aspects of HIV&AIDS could be their restricted access to information. Furthermore, it seemed that the children were discouraged from talking about HIV&AIDS and illness in the home. It emerged during the interviews that the children's present knowledge was based upon the information they received from their social worker, and as part of their curriculum at school. In addition, only a few of the children seemed to be aware that infection with HIV implied a long-term illness from which there was no known cure, whereas a common illness like the flu implied a complete recovery. The findings from my study seem to concur with those of Peltzer and Promtussananon (2003) who established that the understanding of AIDS among children followed the same developmental sequence reported for children's understanding of general illness. In contrast, while the results from my study showed that children had a limited knowledge base of HIV&AIDS, Slonim-Nevo and Mukuka (2005) found that adolescents in their study displayed a moderate to high AIDS-related knowledge.

## b) Internalising and externalising behaviour

It emerged from my study that being HIV-positive or related to someone with HIV or an AIDS-related illness construed anxiety and concerns for children which seemed to manifest in their internalising and externalising behaviour. Overall, most of the children demonstrated greater internalisation of their anxieties and concerns. Two children displayed both internalising and externalising behaviours.

Children's internalisation of their negative emotions was discernible through articulated as well as observed feelings of sadness, withdrawal, low self-esteem and despondency. For example, Dimple's words, *I think life is difficult and I am just an orphan child* (session 3:78-79) alluded to the despair and sadness that seemed to accompany the children experiencing adversities; it could possibly signal an expression of her negative emotions. Her self-isolation could infer a form of withdrawal and loneliness. While Dimple articulated her feelings, Michelle presented as shy, passive and reticent. She cried easily when she was reproached by other children and withdrew when faced with challenging situations (see Addendum 8:8.1.1).

External manifestations of trauma or negative emotions among the children in my study included crying, physical displays of anger and running away from the home as in the case of Dimple and Lizzy (see Addendum 6:6.2 p5). Similar to findings by Pivnick and Villegas (2000), I also established in my study that the children's altered behavior (internalising and externalising) might be interpreted as an expression not only of the need to be taken care of but also as a metaphor for the deeper fears they harboured about being HIV-infected themselves.

My findings corroborated with those of Wild (2001) in that external manifestations of trauma were rarely expressed amongst children as compared to the internalisation of feelings. Wild (2001) asserted that some children reacted to the stigma and the silence that accompanied HIV&AIDS by giving vent to their anger, confusion and anxiety through self-destructive, high-risk and antisocial behaviour. However, corresponding to my findings, these behaviours were relatively few as compared to acts of internalisation of behaviour.

It emerged from my study that the children mostly displayed a positive affect, and minimal signs of continued distress and fear and appeared to adapt positively to new situations and to new people. They engaged in age-appropriate forms of play and seemed to enjoy their peer group relationship as well as the relationship they shared across the age domains (see



Addendum 8:8.1.2). My findings seem to contradict those of Foster and Williamson (2000), who proposed that orphaned children exhibited greater sadness and worry, did not engage in activities such as play, were more solitary and showed signs of distress and fear in new situations. Pivnick and Villegas (2000) concurred with Foster and Williamson (2000) and added that a high rate of depressed moods along with chronic feelings of sadness and despair was observed. In contrast, children in my study did not present with recurrent depressed moods. Rather, episodes of negative affect seemed to be related specifically to certain incidents that occurred at the children's home (see Addendum 6:6.2 p6). However, ongoing depressed moods as well as feelings of sadness and despair could be attributed to a chain of chronic traumatic events, starting with parental illness and eventual death, the reorganisation of family life and a lack of clarity regarding their institutionalisation (Pivnick & Villegas, 2000). I conjecture that a possible explanation for differences between the findings from my study and those of Foster and Williamson (2000) and Pivnick and Villegas (2000) related to a lack of recurrent feelings of sadness and despair among the children in my study. These could be ascribed to the protective and buffering effects of living at the children's home (see Addendum 6:6.2).

Although most children in the study displayed positive emotions, I submit that I had observed negative emotions amongst the children on certain occasions (see Addendum 6:6.2 p2). In this regard, Aspinwall and Staudinger (2003) suggested that when examining human strengths, one should not ignore the negative aspects of human experience but rather consider how negative and positive emotionality are intrinsically linked and work in congruence to promote healthy outcomes in an individual. As observed amongst the children in my study, I assume that feelings of joy and happiness may co-exist alongside feelings of despair and sadness.

In some instances, internalisation of negative emotions may present concentration difficulties, which could adversely affect scholastic performance. A child in my study reported that she was unable to focus adequately on her academic work in her classroom (see Addendum 6:6.2). Based on my findings with regard to the children's concentration, I concur with the suggestion by Pivnick and Villegas (2000) that HIV&AIDS-affected children may be preoccupied with unanswered questions and anxieties and may find schooling challenging. I deduce that the anxieties that the children in my study presented with might predispose them to learning difficulties arising from a limited attention and concentration span. Furthermore, I submit that the efforts of the HIV-infected children in my study to maintain adequate attention and concentration in class might have been exacerbated due to the developmental and cognitive decline associated with the effect of the virus on the brain



function (Brown *et al.*, 2000), as well as the related and accompanying anxiety and trauma (Gosling *et al.*, 2004).

## c) Silences, disclosure, stigma and discrimination

#### o Silences

The children in my study observed and modelled the communication styles of adults with regard to the general silences and taboos that were usually associated with HIV&AIDS in their home. They articulated that they would not discuss HIV, were silent during discussions and portrayed their reluctance to talk, in their drawings. My assertion was elucidated during my numerous interactions with the children in the home as illustrated in Table 5.1 below.

Table 5.1: Silences with regard to HIV&AIDS

	What did I notice?	Child/Children	Activity/Session	Lines
1.	Intense emotions	Michelle	Session 5	26-27
2.	Silence/Stigma	Group 1	Session 7	105-106
3.	Silence/Stigma	Group1	Session 7	114-115
5.	Avoidance of HIV discussion	Meme	Session 8	214-224
6.	Silence about reasons for living at the home (non-verbal)	Kaemogetswe	Session 8	86-94
7.	Silence: "I don't know, but they don't talk about it"	Batman	Session 8	109-113
8.	Shared disclosure	Meme and Spiderman	Session 9	20-25
9.	Silence	Michelle	Session 11	42

HIV&AIDS have reshaped childhoods, compelling children to conceal secrets and to perpetuate the silences that are usually associated with the disease. Considering that the children in my study might have had limited personal maturity, I posit that emulating the coping styles of their caregivers by maintaining silences could have constrained their emotional expressions. This thought aligns with those of Cook *et al.* (2003) who suggested that children are influenced in their emotional expressions by the way in which their caregiver responds to situations. In addition, I contemplate the cultural aspects of communication styles in families and wonder about the role of the child within that system in maintaining secrecy (Kistner, Eberstein, Quadagno, Sly, Sittig, Foster, Balthazor, Castro & Osborne, 1997). I concur with Niederhoffer and Pennbaker (2002) that sharing one's story or open communication may alleviate the negative emotions that are usually associated with stress.

In my study, children seem to have coped with confusion and uncertainty arising from hushed whispers and maintaining secrecy from early childhood. Articulations by the children alluded to the possibility that discussions about sickness in general, and HIV&AIDS in particular are prohibited in their home (Group 1, session 7:97-98 and session 8:153). The findings from my study concurred with the views expressed by Gosling et al. (2004), which emphasised that although coping with a chronic illness is a risk factor for children's psychological adjustment, in the majority of families discussion about illnesses was still taboo, and that children's thoughts and feelings about their loss were not addressed. It is possible that in my study, limited discussions about death may have been influenced by the cultural affiliation of the families (more especially the caregiver's), as in some African cultures, children are kept away from an ill person and excluded from the rituals surrounding death and burial (Richter & Müller, 2005). Furthermore, death from an AIDS-related illness may add to the stigma and shame that families experience, thereby limiting a discussion of death (Gosling et al., 2004). While researchers recognise that open discussions in a public or private forum in many communities are still unthinkable, academic and investigative discourses around this critical issue persist (Kruger, 2006b; Kistner, 2005; Hutton & Oleske, 2005; Pivnick & Villegas, 2000; Siegel & Gorey, 1994).

#### o **Disclosure**

As illustrated in my study, a lack of communication and disclosure of HIV-related illness seemed closely related. Although the children knew their HIV status (they were previously informed by the social worker) they chose not to speak about it during this study. In most cases, the children acknowledged that their health status fluctuated and they needed to take medication in order to remain well. Nevertheless, they did not seem to link their illness to HIV infection (see Section 4.2.1.1:a). I surmise that withholding information from the children could possibly have contributed to their feelings of uncertainty and confusion. My view is based on my findings that children in the study overheard partial conversations amongst the caregivers that alluded to their HIV infection and illness. A lack of direct discussions and age-appropriate information possibly led to misconceptions and confusion amongst the children (see Section 4.2.1.1:c).

Although the children in my study were told about their HIV status and given age-appropriate information regarding HIV&AIDS by the social worker, they did not appear to have had further conversations and discussions with the caregivers. In fact the children were discouraged from talking about their illness (see Section 4.2.1.1:c). One possible reason could be that the caregivers were concerned that further discussion might cause the children to become distressed and anxious, which could lead to a decline in the children's health.



Another reason for discouraging the children from talking about their illness could be that the caregivers feared that the community's prejudice and hostility could upset their own well-being as well as that of the children (Kistner, 2005). This hesitancy to disclose illness seems to parallel and echo the sentiments among paediatric cancer patients where significant adults such as caregivers projected their own fears of disclosure and discussion about illness and death onto the children. With regard to my study, I support Hutton and Oleske's (2005) view that besides having to cope with the exposure of their illness to others, caregivers also had to answer difficult questions and have thereby been compelled to deal with their own emotional reactions regarding the children's HIV infection.

Allied to the findings from my study, I posit that the disclosure of developmentally appropriate facts about illness might improve the children's psychological adaptation. My view is supported by Siegel and Gorey (1994), who have stated that less secrecy about HIV helps children feel less shame and may lead to more intimate family relationships. Bachanas et al. (2001) corroborates this suggestion and emphasises that withholding information about HIV status or diagnosis of HIV from children was associated with more internalising behaviour problems. In addition, they add that withholding information leads to psychological distress amongst children's caregivers as well. Since my study did not examine caregiver responses to the children's HIV-related illness, I cannot substantiate the claims made by Bachanas *et al.* (2001) related to the psychological distress of caregivers.

#### o Stigma and discrimination

I gathered from my study that the silences surrounding HIV&AIDS were perpetuated by the stigma and discrimination that is associated with HIV infection. At school as well, the children were at risk for discrimination and rejection should their peers find out that they are HIV-infected or that they are associated with someone who is HIV-infected. Various studies (Epstein, 2003; Kelly, Ntlablati, Oyosi, Van der Riet & Parker, 2002; Strode & Barrett-Grant, 2001; Smart, 2000), confirm that children experience the fear of exclusion from a community of friends and peers should there be disclosure of HIV infection or an AIDS-related death in the family.

In many ways, the school, as a potential buffer, served as a place for learning and socialisation for the children in my study (see Section 4.2.2.1:b). However, my study also established that the school and the peer group in particular presented as a potential risk factor and aggravated the vulnerabilities of the children. I assume that the HIV status of the children in my study was not known to their peers. A result I posit that the discrimination against these children by their peers occurred at the level of association. Deacon and

Stephney (2007:6) called discrimination at the level of association courtesy stigma and it is usually attached to individuals because of their association with AIDS or HIV-positive people. Since acceptance by their peer group was essential to the children in my study (Mwamwenda, 2004), recurrent episodes of courtesy stigma and discrimination by peers at school could mean the end of their acceptance by their peer group. The children in my study were aged between 10 years and 15 years (pre-adolescence to adolescent phase), which is a critical phase for the establishment of peer identity within social relationships (Mwamwenda, 2004) and peer group rejection may possibly have a negative effect on the early adolescent's self-image and self-concept.

During a conversation with Kaemogetswe (session 8:112-155), it emerged that she was acutely aware of taking medication. It seemed that she experienced extreme distress because of the undisclosed reasons for her taking the medication. I suggest that a possible reason could be linked to a secondary level of stigma and discrimination. Deacon and Stephney (2007) have explained that children who take antiretroviral medication may experience the physical and cognitive side effects from the medication; they have also found that taking pills results in secondary disclosure to friends and peers. Despite the risk of secondary disclosure, Kaemogetswe asserted her right to information when she claimed that children should be told about their illnesses (session 8:212-213 and 318-320). I support West and Wedgwood's (2004) view that children have rights and opinions and where appropriate should participate in decisions concerning them.

In my study, as well as in the findings of Ebersöhn (2007), the school has been regarded as a potential risk factor in terms of the taunting by peers to which the stigma associated with HIV often leads; it may have made it difficult for children to communicate with their teachers about illness or death in the family. In contrast, a few children in my study related instances where they felt comfortable talking to their teachers and felt that their teachers understood them. I found that Batman and Lizzy reported positive experiences with their teachers. Lizzy also alluded to her positive emotions that seemed to be associated with the perceived empathy that she received from her teacher (see Section 4.2.2.1:b).

The findings from my study indicated that after the AIDS-related death of a primary caregiver, life became even more challenging for the newly orphaned child. Dimple in particular experienced many stressors and challenges associated with orphanhood. Dimple's challenges and stressors seem to be similar to those experienced by other newly orphaned children as outlined by Foster, Makufa, Drew, Mashumba & Kambeu (1997). These include:

o having to cope with the pain and trauma of caregiver death;



- o the possibility of having to drop out of school or to change schools;
- o an increased work load;
- o changed friends;
- o difficult relationships with new caregivers; and
- o social isolation, including a lack of visits and neglect of support responsibilities by relatives (Foster *et al.*, 1997).

In my study, Dimple alluded to the failure of her parents and other significant people to provide her with appropriate information regarding her parents' health, which seems to have perpetuated her fears and uncertainty of the future. According to Foster *et al.* (1997), while caregivers process their HIV status by means of pre- and post-test HIV&AIDS counselling and support groups, they often neglected to communicate information about their declining health and any possible adjustment it may have on the children's future lives.

Based on the evidence I obtained in my study about Batman's early life (see Addendum 2:2.1) I agree with the Department of Social Development (2002) that decisions made by caregivers impact on and may impede children's access to support and services. In the absence of effective treatments for children in their early years, developmental delays may lead to HIV-positive children becoming progressively less able than other children to develop coping strategies around the risks and challenges posed to them. Caregivers who do not disclose their HIV status may also jeopardise their own access to support as their deteriorating cognitive skills limit sound decision making regarding their own health and the future of the children in their care (Department of Social Development, 2002).

## d) Death and bereavement

#### o **Death**

The need to grieve (as identified in my study) is supported by the views of Cook *et al.* (2003) and Black (2005) that children need to say goodbye as part of the grieving process which is common to many cultures. While the children seemed to need the opportunity to grieve and have their losses acknowledged, some of the children in my study seemed to have embraced the opportunity to grieve orally or through writing and drawing. There is a portrayal of my assertion in sessions 9 and 11 (see Addendum 4:4.9 and 4.11) where the children role-played a funeral scene and then told a story about a picture they had drawn depicting their impressions about HIV&AIDS in a family. The children's scenes of death, funerals and burial in their role-play of illness in the family linked their association of illness with death, which appears relevant to their life experiences as orphaned children. Given their experiences of



illness and death in their daily lives, it seems understandable that the children have added the word *burial* to their repertoire of words during their play activities (Kruger, 2006b).

## o Caregiver and parental bereavement

Parental (particularly maternal) bereavement may be regarded as a key risk for emotional and behavioural difficulties among the children in my study. During the course of the study, the children articulated their sense of impending loss related to their caregiver's absence (Batman, session 2 and Superman, session 2). The findings from my study suggested that the children's confusion and distress seemed to emanate from the impeded communication related to health issues between the caregiver and the child, which constituted chronic stress for children. These findings corroborate those of the Cluver and Gardner (2007:320) study where respondents articulated a similar sense of impending loss when a mother went out to work and never came back, stating that happiness emanated from having a living caregiver to take care of them and that multiple bereavement resulted in distress.

The results from my study that placed emphasis on caregiver (maternal) bereavement as a risk factor may be attributed to the fact that caregivers are the first in line to provide their children with emotional needs such as love, affection and a sense of belonging (Berger, 2000; Pringle, 1975; USAID, 2000). However, when a caregiver (especially the mother) dies, the psychosocial needs stemming from loss and bereavement create a gap in the child's support structure, and when not filled by other significant adults, exacerbates the vulnerability of the orphaned child. According to Glasser (1965), everybody needs to love and be loved. In the absence of a nurturing caregiver to provide love, psychological symptoms such as depression, withdrawal, anxiety, discomfort and other forms of behaviour may arise. As children are born with the intrinsic need to love, to be loved and to belong (Glasser, 1965), the presence of a caring and compassionate caregiver seems crucial for curbing long-term mental health problems. Furthermore, as demonstrated in my study, children also need to gain self-worth and recognition from significant others.

Findings from my study suggested that the children's grieving processes might have been stunted by caregivers who tended to place more emphasis on the children's physical needs and less on their emotional and psychological concerns (Cook *et al.*, 2003; Brown *et al.*, 2000) and possibly dismissed their grief reactions. My finding allies with that of Cook *et al.* (2003:96) who suggested that children have been referred to as the *forgotten mourners* because adults at times do not realise children's capacity and need to be informed, to be included and to mourn. Consequently, it seems that many children in my study might be finding it difficult to complete their grief reactions. I offer this view in the light of the



underlying essence of grief that surfaced when the children enacted the role-play scene (see Section 4.3 and session 9). This dismissal of grief could be construed as an effect of the stigma, discrimination or the silence that surrounds an AIDS-related death. Siegel and Gorey (1994) explicated that grief which cannot be expressed due to fears of stigmatisation or ostracism may be termed disenfranchised grief and may worsen the symptoms of mourning. I support Siegel and Gorey's (1994) view in my understanding of the incomplete grieving processes of the children in my study. I assume that in perpetuating the silences that surrounded HIV&AIDS in the household and also fearing possible victimisation, children may not have been allowed the freedom to express their grief in an open manner. Although I concede that the children in my study have had regular counselling sessions with the social worker, I nevertheless suggest they needed continued compassion and empathy from a supportive caregiver as well.

#### Death of significant others

Children in my study demonstrated that they were also affected by the illness and death of other significant people in their lives such as friends and extended family members. The findings from my study supported the view that children may be affected by the loss or death of people who were close to them (Meintjes & Giese, 2006). For example, in my study, Meme had lost her sister J. and Harry Potter had lost his best friend E. The impact of these experiences was evident in their lives (session 4). Allied to the grief reactions for lost family members or close friends, Kistner (2005) found that children felt a degree of personal responsibility for their caregiver's health and welfare. In session 4, Lizzy displayed concern for her mother's health and wished that she could be there to take care of her. Dimple's concern for her uncle's health seemed to be related to her concern about herself and her future, should her uncle die (session 8).

In this section, I have demonstrated that in the absence of protective factors, the cumulative experiences of the death of family members or of significant other people in the lives of children may render them helpless and vulnerable to recurring emotional difficulties such as negative internalising behaviour and depressed mood. In the context of my study, I conjecture that the consequences of unresolved grief among the children in my study could be mitigated by the buffering effects of the support systems at the children's home.

## e) Orphanhood and institutional care

The traditional extended family system of caring for orphaned children is likely to collapse under the enormous weight of the growing numbers of children needing family care; it therefore implies limitations to this usually preferred care of orphaned and vulnerable children (Meintjes *et al.*, 2007; Freeman & Nkomo, 2006; Bray, 2003; Barolsky, 2003). Just like the children in my study, those who are slipping out of family safety nets are being absorbed into institutional care facilities (see Section 2.2.2.2:e).

In my study, a few children expressed negative views about their lives in residential care since their emotional needs were not always taken care of and they were being made to feel rejected and isolated (see Section 4.2.1.1:e). I posit that instead of discrimination and biased treatment within residential care, children need to be supported to foster a sense of belonging and identity to refute the history of negativity that is associated with residential care. Salole (1991) and Freeman (in Richter, 2004) have asserted that orphanages (residential care settings) and unstable foster care have been identified as high-risk environments for neglect and abuse, as children's responses to high levels of stress are usually determined to a large extent by the personality and temperament of caregivers. Findings from Cluver and Gardner's (2007) study support the findings from my study that the children were particularly unhappy when they felt discriminated against or different from other children in the home. In a similar vein, children in both studies alluded to equating unequal distribution of resources to discrimination.

In my study it emerged that the children were distressed when they were spoken about in a negative manner (see Section 4.2.1.1:e). While overt acts of hostility and rejection may hurt children, they actually experience greater personal pain and humiliation when they know that people gossip about them or their families (Kruger, 2006b). There are striking similarities between my findings and those of the Cluver and Gardner (2007) study wherein respondents described their negative experiences of stigma and gossip as potential sources of distress for children affected by HIV&AIDS. Similarly, results from a Zimbabwean study (UNICEF, 2004:17) have indicated that orphaned children are exposed to verbal abuse from their caregivers through repeated taunting and humiliation about their orphaned status. I surmise that gossiping about and humiliation and degradation of the children in my study may be considered a form of emotional abuse that further raises the risk for these children to acquire long-term emotional and psychological difficulties. Furthermore, I assert that it seems possible that the likelihood for negative adaptation is increased when stressful and



adverse conditions endure over time, when the stressors are cumulative and when the children are given few opportunities for support and hope.

In addition to the rejection and ostracisation that some children in my study perceived at the hands of their caregivers, a few of them might have regarded their admission into residential care as a form of rejection and abandonment from their families (Tolfree, 2003). According to my examination of the social worker's intake report on each child in my study (textual data, see Addendum 2 for examples), many children were admitted into residential care at an early age (see Addendum 8:8.2.1). Meme, Michelle, Dimple, Lizzy and Batman had relatives with whom they had lived when they were younger. In addition to being placed in residential care, Harry Potter had been separated from his siblings who lived in a childheaded household. Researchers agree that when orphaned children are separated from their siblings, their sense of loss, displacement and emotional distress is compounded (Atwine et al., 2005; UNICEF, 2004). Apart from the associated stigma, the loss of personal and family identity, of a sense of belonging to a community, and the consequent loss of support networks can have a powerful effect on the growing child's identity and self-esteem (see Section 5.2.2.2). This is because opportunities for attachment and for reasonably continuous relationships with caregiver figures are fundamental to child development, especially in the early years (Tolfree, 2003).

In the context of my study, the extended families could not financially afford to take care of extra children. The detrimental effects of poverty on maintaining intact families seem to be a worldwide phenomenon. UNICEF (2007) has claimed that worldwide, many children who live in institutional care do not need to be there as the majority of these children have a surviving caregiver or contactable relative. For example, 80 per cent of children in institutional care in Sri Lanka were placed there by caregivers or guardians who felt that they could not provide them with material necessities (Save the Children, 2005). As in the case of the children in my study, poverty was cited as the main reason for placing the children into residential care; as a mitigating factor, admission into this children's home has allowed their basic material needs to be adequately met.

Whilst the social worker's attempts to reunite the abandoned children with their extended families were successful, the extended family members nevertheless continued to be reluctant to assume the primary caregiver role for the children, perhaps due to poverty, stigma and fear of victimisation. Consequently, these children continued to live at the children's home. Tolfree (2003) has suggested that when children are abandoned, tracing the family of origin or members of the extended family is first choice for placement of the



child, enabling the child to live with familiar adults and to retain his or her sense of family belonging and identity.

Maintaining contact with extended family members emerged as important for the children in my study as it could possibly relate to the child's sense of identity and self-esteem as indicated in an earlier paragraph. Even though the children were not living with the extended family members, they looked forward to seeing them during holidays. For a few children with extended families, the sadness that was related to missing their family appeared to be mitigated in anticipation of school holidays when the social worker, in conjunction with the children, planned visits to their extended families (see Addendum 6:6.2 p6, 7). The results from Cluver and Gardner's (2007) study seem to align with my suggestion that the lack of family contact may be regarded as a risk factor for those children who do have an extended family, but have no contact with them. I tend to support Cook et al. (2003), who suggested that intervention programmes must recognise the emotional bonds that children have with significant other people. In this regard, siblings could be permitted to remain together as much as possible to maintain a sense of connection with the larger community. Despite limited contact, extended families that support the orphaned child may be regarded as a protective factor and afford the child a sense of belonging and identity. Based on my observations and the results obtained from my study, I suggest that the emotional needs of HIV&AIDS-affected children could be best met through family and community-based residential care settings rather than in large and impersonal institutions.

Many of the children in my study helped with household chores such as sweeping and cleaning (see Section 4.2.1.1:e). A number of the children seemed to resent these domestic tasks and consider them additional burdens. Cook *et al.* (2003) commented that children in AIDS-impacted communities commonly assume much of the families responsibilities and these were consired as additional stressors in the children's lives. Then again, I posit that sharing household responsibilities may be regarded as a characteristic of a cohesive and adaptive family environment and it may heighten feelings of self-efficacy. Thus, a protective factor for children could be required helpfulness or being assigned chores in the home (Werner, 2000: 119).

Furthermore, since institutionalization of children have been linked to encouraging dependence and discouraging children from thinking and solving problems themselves, there could be a tendency for children to be left ill equipped to live independently (Tolfree, 2003) upon their transition from residential care to independent living. I therefore submit that children should learn vital life-skills and that sharing household responsibilities such as



cooking may be viewed as valuable assets. Consequently, a variety of peer-group relationships and exposure to normal family life are important for children's development (Tolfree, 2003). I assert that a part of childhood experiences could be aimed at equipping the child with the knowledge and skills required for a transition to adulthood.

#### 5.2.1.2 The challenges implied by unfulfilled psychosocial needs

Children in my study indicated a need and desire for nurturance, socialisation, and communication. In the context of my study, particular attention was given to listening to the children while they communicated their needs as, according to Salovey (in Ebersöhn, 2008: vii), "the needs of children are often given insufficient priority as children do not represent an influential constituency in the political arena. They neither vote nor pay taxes (at least not directly), and so they are easily ignored".

The children in my study expressed their need to be listened to and to receive information. As stated in Section 4.2.1.2:c, it is likely that in the light of impeded communication within the family, children need to have someone else to be able to talk to, especially the presence and attention of someone who is capable of displaying empathy. This thought is in line with the United Nations Convention on the Rights of the Child, where it is stated that children have the right to say what they think about anything that affects them, and that what they say must be listened to and given due consideration (Save the Children, 2001:12).

Children in my study expressed a need for open communication. In this study, open communication appeared to be on different levels: Firstly, children expressed the need to talk to others, to give information about themselves and to be listened to and heard. This finding is supported by West and Wedgwood's (2004) opinion that in the context of the uncertainty associated with death, loss and reorganisation of a family life, children are growing up without a close adult with whom they can share feelings, experiences, worries, concerns, plans for the future and who can provide advice and guidance. Secondly, the children in my study expressed a need to receive information about themselves, about people around them and about pertinent matters concerning their illnesses and their families. Frustration, anger, sadness and withdrawal were among the emotions that manifested when the children perceived themselves as not being heard and not being given information. Pivnick and Villegas (2000) uphold that although the maintenance of silence is understandable, given the stigma that still surrounds HIV&AIDS, it can leave orphaned children without anyone with whom to share their feelings and fears. Furthermore,



helplessness and frustration about not being acknowledged can be manifested in anger and a low self-esteem where the child perceives herself as not being important.

Children's need for communication may actually imply their need to express their grief, ask questions, and receive answers where there seems to be a silence. As HIV&AIDS are still shrouded in secrecy and silence in many communities, there is an absence of open discussions where children could ask questions about illness and death (see Section 5.2.1.1:a). As a result, children may have very disturbing and frightening thoughts on these subjects. Impeded communication resulting in distorted perceptions may be described as problematic for children as it may lead to further psychological disturbances based on these undue perceptions or altered cognitions (Daniel, 2005).

As indicated earlier in this chapter (section 5.2.1.1:d), children's needs include the need to express grief (Cook *et al.*, 2003; Black, 2005). The communication and information-giving process could contribute to helping orphaned children to stay emotionally connected to their deceased family member/s by remembering past interactions or by keeping an item that belonged to the person. Memory boxes serve an important role in this regard (Swanepoel, 2008; Denis, 2000). Cook *et al.* (2003) called this connection an attempt to mentally locate the deceased. Other needs identified by a few children in the study included the need for a continuing bond and stability in their existing relationships with a caregiver and the need for hope for the future. When such support is lacking, children might withdraw, resign and isolate themselves. Furthermore, they could develop a sense of insecurity and instability, a sense that life is empty and that adults are not to be trusted (Kelly, 2000).

In Ogina's (2007) study, the need for acceptance, support, sharing and socialising with peers appeared crucial for the orphaned learner. My study supports Ogina's (2007) findings as I established that although the children in my study had their basic physiological needs met, they still had other unfulfilled psychosocial needs, including the need for social and emotional support and understanding. In situations where psychosocial needs are met and social stability achieved, the positive outcomes for children coping with the crisis of parental or significant others' death may include closeness and understanding, empathy for others, improved problem solving skills, greater maturity and a sense of competence (Cook *et al.*, 2003). I assume that children are capable of coping with grief and loss if they are given adequate social and emotional support, which could lead to enhanced positive emotions and relationships.



In the Ogina (2007) study, orphaned children expressed an emotional longing for their deceased caregiver. Some of the emotions that emerged when orphaned children spoke of their deceased caregiver were feelings of alienation, anger, frustration, helplessness and emotional pain. The SCOPE-OVC/Zambia study (2003) also established that orphaned children missing their deceased caregiver and guardians expressed anger and frustration. Similarly, Sengendo and Nambi (1997) revealed that most orphans were still angry about their caregiver s' deaths, especially when there was nobody else to fulfill their needs.

In contrast to the above studies, in my study the emotional longing that some children expressed seemed to stem from a need for nurturance. Helplessness manifested as arising from a lack of knowledge or a lack of communication about important matters that pertained directly to their everyday lives. Furthermore, in contrast to Sengendo and Nambi's (1997) findings, it was not evident whether the children experienced anger about their parent's death. Instead, I found that they experienced confusion and possibly fear arising from perpetuated silences and impeded communication in the microsystem.

Research has documented that HIV-affected children presented with needs relating to education, shelter, medical, housing and psychosocial services (Cluver & Gardner, 2007; Singhal & Howard, 2003; Makame et al., 2002). Of these needs, the basic need for survival appears to manifest the most among non-institutionalised orphaned children. Maslow (in Mwamwenda, 2004) refers to a theory of human needs wherein basic physiological needs such as hunger, thirst and sleep are regarded as urgent and requiring immediate fulfillment. Accordingly, the environment is important for the fulfillment of basic needs for survival. Other needs that follow in Maslow's hierarchy include needs for safety (stability, security, structure, law and order, limits and freedom from fear); affiliation and love needs (belonging somewhere, belonging to someone, and giving and receiving love); self-esteem needs (based on achievements and the esteem of others) and self-actualisation or self-realisation needs (such as truth, justice, meaningfulness and aesthetic needs). The significance of this theory relates to the findings of various studies that looked into the needs of children who are affected by HIV&AIDS. In a study of HIV-affected Tanzanian orphaned and nonorphaned adolescents, Makame et al. (2002) discovered that basic needs were allied with the provision of food. A second important need was related to the lack of money in the home to pay for school fees, books and uniforms. In Cluver and Gardner's (2007) study of orphaned children in Cape Town, almost all the participants described poverty as a risk for emotional and behavioural distress. Primarily, the lack of food and starvation were identified as a risk by children in the study. Concerns around food (primarily limited access to food and



food of a poor quality) were the concerns of orphaned and institutionalised adolescents in Zimbabwe (UNICEF, 2003) as well.

In contrast to the findings of Makame *et al.* (2002), Cluver and Gardner (2007) and UNICEF (2003), the children in my study did not identify basic needs such as food and clothing as a priority. In terms of Maslow's hierarchy of needs, essential basic needs were adequately fulfilled. I attribute the differences in the findings of the studies mentioned and my own study to the fact that the children in my study lived in a residential care setting (see Addendum 8) as opposed to extended family and foster care placements in the Makame *et*, *al.* (2002) and Cluver and Gardner's (2007) studies. Consequently, I regard residential care which is embedded in the community as a buffer for the children, because basic needs such as food, clothing, education and medical needs are being adequately addressed by an extensive network of caregivers, social workers and community initiatives.

## 5.2.2 Pillars that offer strength and support

In this section I outline the pillars that support a positive psychological approach to resilient coping amidst adversity which is considered an integration between positive systems and positive intrapersonal characteristics that subsumes positive emotional states. At a group or societal level, a positive psychology approach focuses on the development, creation and maintenance of positive systems. At an individual and subjective level, positive emotional states include having hope, feeling optimistic and experiencing subjective well-being. Positive emotional states also encompass a positive affect and a possible future perspective. In my study, I delineated positive subjective states as including positive thoughts about the self and the future. In this section, I shall discuss my findings related to positive and enabling systems and positive intrapersonal characteristics, including positive emotional states.

## 5.2.2.1 Positive and enabling systems

It is generally accepted that a wide social network with ongoing supportive and caring relationships acts as a strong support system for children who are orphaned by AIDS (Battles & Wiener, 2002; Lemay & Ghazal, 2001; Lightfoot & Healy, 2001). Participants in my study perceived that they were receiving support from the caregivers at the children's home, teachers and peers at school and members of the wider community. In this section, I discuss my findings related to the children's home, the school and the community as positive



and enabling systems that buffer and protect these children, who were experiencing challenges and stressors in their lives.

#### a) The children's home

Within the context of my study, the children's home presented with various buffers and protective mechanisms for the children living there. Apart from the essential material resources such as clothing and nutritious food, the children had access to computers and computer-based games and learning programmes that seemed to enhance their interest in learning. Because of a keen interest in and desire for learning, the children looked forward to and rarely missed school. In this case, I regard the caregivers at the children's home as supportive and encouraging, thereby increasing the possibility of a brighter future for the children thanks to higher levels of education.

In certain instances, the children's home could be regarded as a secure base from which the children may venture. A structured family life, established by the primary caregiver in the form of rules and boundaries in the home, seems to have created a semblance of stability and security in the lives of the children. Researchers such as Gilligan (2000) and Lemay and Ghazal (2001) concur with my findings that order and organisation in a home buffer or protect children from additional vulnerabilities. Furthermore, Gilligan's (2000:40) view is that resilience stems (in part) from having a sense of a secure base. Gilligan (2000) argued for the importance of daily activities at home, together with familiar routines around meals, bedtime stories, getting up and family outings, as they can be important sources of a sense of order and structure. The findings of my study correlate with the thoughts expressed by Gilligan (2000) in terms of specific mealtime, playtime, study time and bedtime routines. The children's positive adaptation to a daily routine that also included leisure time possibly indicated that structure and discipline in the home afforded the children a sense of stability, comfort and security in knowing what to expect. Based on my findings and on my observations during my study, I posit that the children's perception of a stable family life was cultivated by a sense of belonging within supportive social networks, by attachmenttype relationships to reliable, responsive people, and by routines and structures (including household chores as discussed earlier) in their day to day lives.

Findings from my study indicated that generally, the children were able to communicate with certain adults at the children's home. Based on my findings, I regard the positive and caring relationship with at least one stable caregiver as a protective factor for the children in my study. Furthermore, I suggest that strength and resilience among children is especially

enhanced when they are taken seriously, treated with respect, and when adults and children work together according to certain principles and values. This finding is supported by the work of researchers such as Kruger (2006b), Richter (2004), Lemay and Ghazal (2001) and Garmezy (1993), who agree that the basis of children's resilience may largely be found in family cohesion and warmth, and children's ongoing relationships with caring others. Their findings are based on studies that show that children exposed to extremely disadvantaging situations thrive, achieve high intellectual standards, are well adjusted and are less affected in negative ways when they are supported by sustained and caring relationships.

The relationship between the caregiver and the child plays a crucial role in buffering the child from further psychological and emotional hardship. In addition, children's personal well-being has been found to hinge closely on the emotionality of the primary caregiver (Kruger, 2006b). Elaborating on the caregiver and child relationship, children in my study alluded to their experiences of positive care-giving. The primary caregiver and the social worker took care of the children's medical, physical and nutritional needs (see Chapter 4). Most of the children (seven children from a group of nine) were taking anti-retroviral medication, and their medical needs were taken care of in terms of adherence to medication. In addition, the children consulted with their medical practitioner at the clinic on a monthly basis. Although these physical and medical needs were being fulfilled, some children hinted that they were not receiving the type and quality of emotional support that they would have liked to (see Section 5.2.1.2).

In Cluver and Gardner's (2007) study, all participants emphasised the importance (risk and protective) of the primary caregiver. Caregivers as participants in the study perceived care as a crucial protective factor. This type of care included support, honesty, praise and closeness, help with homework, reading and stories, advice on education and attending school meetings. Professionals as participants in the study identified the caregivers' mental health, social support and access to antiretroviral medication as affecting children's well-being. It emerged that harmful caregiving, translated as multiple moves, caregiver changes and caregiver illness, also put children at risk.

In addition to the many ways by which the children's home acted as a buffer, I put forth that the support offered by the caregivers could be enhanced by offering the children a life skills support group aimed to educate and inform the children in an age-appropriate manner of their illness and thereby encourage adherence to their medical regimes and to advocate a responsible lifestyle. I make this suggestion in the light of concerns that children in my study raised over the lack of or limited information that they received over their own health. A



similar concern about the lack of life-skills facilitation and preparation for when adolescents leave an institution, was raised in a study of institutions in Zimbabwe (UNICEF, 2003). Included in the concerns was the fact that there was a lack of a transitional programme, as children were not being adequately prepared and supported for their eventual discharge from the institution. While the older children in my study did not speak openly about their eventual move from the children's home, they alluded to their future prospects in terms of possible careers and eventually marriage (see Section 5.2.4.4).

## b) The school as a positive and enabling system

In my study, the school emerged as another positive system that supported and offered strength to the children. The children in my study ascribed positive feelings to the perceived compassion and empathy that they received from their teachers (see Section 4.2.2.1:b). I noticed that children presented with increased self-esteem and self-worth related to academic and sporting achievements at school (session 4). Therefore, as a system that creates opportunities for children to enhance their self-concept, the school functions as a buffer to protect children from further vulnerabilities implied by their orphaned and HIV-positive status. Furthermore, considering the age range of the children in the home the school provided the basis for these children to develop and practice their socialisation skills in an age-appropriate manner with their peers and teachers. Therefore, maintaining children's schooling is an integral component in retaining children's connectedness to peers and familiar adults and helping them to find stability in an institutional identity.

The children in my study regarded schooling as affirmative based on their experiences of compassion, encouragement and understanding from their teachers. At school, the teachers operated as potential buffers from their home environment, often perceived as stressful. It might seem that though a child experiences great loss with the death of a caregiver, sibling or other close relative, the presence of a caring adult at school can buffer that child as he or she faces that loss and other related losses (Kruger, 2006a; Cook *et al.*, 2003).

Positive relationships and sustained support from individuals outside their own family enhance resilience in children and they tend to rely on friends, neighbours and teachers for counsel and comfort (Werner in Shonkoff & Meisels, 2000:125). However, for orphaned children who live in institutions, their teachers may be the only adults that the orphaned child can look up to for the fulfillment of the needs normally provided by a caregiver (Zapulla, 1997). Usually, the presence of caring and supportive teachers is indicative of a protective



environment for children who are experiencing adversities and increases the likelihood that these children will regard schooling as a positive experience.

Likewise, the influence of positive relationships with friends and peers plays a crucial role in children's development. As many of the children in my study were in their early adolescent years, they were greatly influenced by their peer relationships. West and Wedgwood (2004) noted that children have already identified that other children are their confidantes and that the persons they would approach to share difficulties (apart from caregivers, should they be alive) would be their friends. Cook *et al.* (2003), suggest that while such peer interactions are important to their development, further interactions with friends who have experienced similar losses may also be therapeutic as time spent together could have a mood-enhancing effect on a child who is grieving.

## c) Positive and enabling communities

In my study, other protective systems that possibly mitigate anxiety and tension in the children's lives are volunteer workers who offer their support to the children (see Section 4.2.2.1:d). These individuals are usually embedded in the community and they often provide outings and field trips for the children, engaging them at community level. In this way, they thus foster a sense of identity and belonging. Besides the adults, these volunteer workers include adolescents from the community who provide stimulation to the children with computer lessons on a weekly basis.

My findings are substantiated by others (Kruger, 2006b; Black, 2005; Battles & Wiener, 2002; Lightfoot & Healy, 2001) who claim that among the protective factors for children experiencing adversity is the availability and use of external support systems by caregiver and children, in the neighbourhood or elsewhere in the community. The implication is that familiar institutions allow children to socialise, thereby generating resiliency through positive emotions which could possibly stem depression and isolation (Kruger, 2006b; Battles & Wiener, 2002; Lightfoot & Healy, 2001). Furthermore, according to Bernard (2004), community-based resources function as safety nets; consequently, less than a third of the children who are exposed to general adverse conditions are affected negatively in the long term. Richter (2004) included HIV-affected children in this category. From the discussion it seems that the more children can turn to trusted others in their supportive networks within and beyond the family, the more they can be helped to cope with stressful problems and life situations (Donald *et al.*, 2006).

I gathered from my study that the existing social networks of children, their peers and supportive volunteer workers, together with their skills, resources and assets, needed to be recognised and mobilised to develop strategies and activities to boost their positive emotions, resilience and well-being. Provision of mutual support among these social networks could be developed using centres, activities and perhaps training in peer counselling and support (West & Wedgwood, 2004). Regular recreational activities for children, as indicated by the findings of the Ebersöhn (2007) UNICEF study, should include life-skills, peer support and the identification of particular vulnerabilities and needs. In addition, West and Wedgwood (2004) have proposed that activities to involve children should include the provision of useful life skills and information such as raising awareness of the importance of good nutrition, sleep and finding, providing and sharing mechanisms of support.

The recreational activities that the children in my study engaged in included camping trips, visits to the zoo and regular outings to the movies. These outings were organised by the volunteer workers as well as a larger corporate initiative, the Reach for a Dream Foundation, which supports all levels of vulnerable children. While I concede that these organised initiatives enhance optimism and an expectancy of good and positive emotions, there is a need for an enduring and sustained support aimed at the adolescent in preparation for life.

#### 5.2.2.2 Positive intrapersonal characteristics that buffer children

Related to the findings of my study and inherent in the pillar of positive individual characteristics that support and buffer children, are the notions of positive self-esteem, positive self-image, positive self-concept, self-worth and self-efficacy.

In my study, some children showed evidence of a positive self-image and self-concept as evident in their articulations (see Section 4.2.2.2:a). Some of my findings related to the positive self-worth and self-esteem of the children in my study concur with those of Ogina's (2007) study. However, while in Ogina's (2007) study a number of the orphaned children had displayed a positive self-image, indicated by their seemingly having accepted their orphanhood and talking of moving on, in my study positive self-image and a positive self-concept seemed to arise from, amongst others, positive relationships. I posit that the essential difference between Ogina's (2007) findings and the findings from my study as related to self-concept and self-image lies in my view that a few children in my study may

179

<sup>&</sup>lt;sup>1</sup> Reach for a Dream Foundation: An organisation that supports children with terminal illnesses by providing opportunities for the children to live or experience their dreams.



not have adequately dealt with their orphanhood and therefore possibly have not have accepted their stay at the children's home.

Cluver and Gardner (2007) described situations in their study that seem to have promoted the self-esteem of children and thereby generated positive emotions. Activities that improved children's well-being and provided comfort included sport, playing, TV, and outings, singing, music, dancing and reading. The children also mentioned that they gained comfort from homework, diary writing, library visits, TV, reading, spending time alone, and prayer/church. These findings corroborate with the findings from my study where the children indicated that in their leisure time they enjoyed sport, music, TV shows, singing, dancing and playing with each other. Thus it seems that positive interpersonal social relationships could generate and elevate levels of self-esteem and self-concept as positive intrapersonal characteristics.

The children's positive individual attributes may be considered protective in the face of adversity. The personal qualities of the children as well as the experiences that the children encountered and how they processed those experiences were important in understanding their resilience processes (Gilligan, 2000:39). The important components of resilience include having a sense of a secure base, self-worth and self-esteem and the sense of self-efficacy (Williams, 2001; Gilligan, 2000:39). As a dispositional factor, a component of resilience is self-worth and self-esteem (Gilligan, 2000). According to Rutter (2000), self-esteem comprised of two important experiences: secure and harmonious love relationships and success in accomplishing tasks that are identified by individuals that are central to their interests.

Independence and task accomplishment are considered elements of self-efficacy and may be viewed as a form of resilience that has implications for self-control, responsiveness and decision making capacity within one's own life (Gilligan, 2000:41). Hence, self-efficacy should be viewed developmentally and nurtured through consistency, warmth, praise, support and encouragement for children to engage in their environment. Makame *et al.* (2002) support Gilligan's (2000) view of self-efficacy and have further conjectured that receiving a reward or praise for good behaviour reduces internalising problems, reinforces desired behaviour and also promotes good self-esteem. Based on my informal observations of the children and their caregiver relationship in the children's home, I put forth that caregivers who praise and affirm desirable behaviour and achievements are more likely to have a warm reciprocal relationship with a child that could possibly lead to positive self-esteem and self-concept. This is especially important for the children in my study who are



facing a multitude of risks and stressors arising from HIV&AIDS. Bearing in mind that a person's self-concept is not innate, but learned (Mwamwenda, 2004), self-concept should be enhanced by giving a child opportunities to contribute to discussions and to express and logically substantiate his or her views and to be treated equally. These views bear relevance to my study, in which the children described their need to be treated equally and not be discriminated against (see Section 4.2.1.1:e).

## 5.2.3 Children coping with HIV&AIDS

The children in my study employed different mechanisms to cope with the adversities that they were experiencing. I refer to these coping mechanisms as a form of resilient psychosocial coping. The sub-themes that emerged under the umbrella term resilient psychosocial coping were a sense of spiritual connectedness and disengagement and detachment as coping styles. I have integrated my results with the relevant literature in order to understand and make sense of the experiences of the children in my study.

Luthar et al. (2000:543) described resilience as "a dynamic process encompassing positive adaptation within the context of significant adversity". Implicit in the description are the critical conditions of exposure to significant threat or adversity and the achievement of positive adaptation despite the risks and challenges. Thus, a key requirement of resilience appears to be the presence of both risks and protective factors that either encourage a positive outcome or moderate the risks associated with negative effects.

The resilience of children facing adversity has been ascribed to the internal (personal and individual) attributes of children such as autonomy or high self-esteem (Masten & Garmezy, 1985) and an internal locus of control as well as an achievement orientation, within and external to the school (Barnard, 1994), together with factors that are external to the child. In addition to the internal and personal characteristics of the child, researchers delineate other factors that they regard as implicated in the development of resilience in children, viz. aspects of their families and characteristics of their wider social environments (Bolig & Weddle, 1988; Masten & Garmezy, 1985; Werner & Smith, 1982). The suggested resilience-enhancing systems align with the pillars of strength that a positive psychology approach encourages, in order to support and buffer individuals and families (Seligman & Csiksentzmihalyi, 2000). While resilience most likely differs from one person to the next, it seems to be made up of different mixtures of dispositional and situational characteristics that may enhance resilience and coping or further adversities (Lemay & Ghazal, 2001; Bolig & Weddle, 1988).



## 5.2.3.1 Religious and spiritual coping

A few children in my study (Meme, Kaemogetswe and Dimple) seemed to have embraced a religious or spiritual style of coping with challenges in their daily lives. Findings from other studies (Folkman & Moskowitz, 2004:759; Hill & Pargament, 2003), also claim that some people use religion to help cope with the immediate demands of stressful events, especially to help them find the strength to endure and to find purpose and meaning in circumstances.

It seems that religion and spirituality can be expressed differently in the process of coping. These include private forms of spiritual coping (faith, prayer) and social forms (getting more involved in church activities, discussing problems with one's minister). I found that the children in my study utilised both private and social forms of coping at different times. While they engaged in personal prayer on a daily basis, the children also went to church and attended Sunday school as regularly as the caregiver could take them. The children also looked forward to their weekly Bible-reading classes, which were conducted at their home by a volunteer worker who lived in the neighbourhood.

While some children referred to the importance of their daily prayer, other children alluded to the importance of prayer especially when someone was sick. The familiar and daily routine of prayer appeared to provide structure, consistency and discipline for the children (see Section 4.2.3.1). I regard the spiritual connectedness demonstrated by the children in this study as a form of spiritual coping to enhance resilience.

In addition to enhancing resilience, embracing religion has been linked to improved physical and mental health (Hill & Pargament, 2003). One possible suggestion is the ability of religious beliefs, faith and religious activities to buffer the impact of stress; it might be the primary reason that religiosity or spirituality is often associated with improved health (George *et al.* in Compton, 2005). A religious form of coping for adults seems to have had specific physical health benefits, perceived as follows:

- o evoking comforting emotions and feelings;
- o offering strength, empowerment and control;
- o easing the emotional burden of the illness;
- o offering social support and a sense of belonging;
- o facilitating meaning and acceptance of the illness;
- o helping to preserve health;
- relieving the fear and uncertainty of death;
- o facilitating self-acceptance and



# o reducing self-blame (Siegel & Schrimshaw, 2002).

While spiritual coping emerged as a form of coping amongst the children in my study, it was not researched in depth and I am not able to conclude whether the findings from my study support or contradict those of Siegel and Schrimshaw (2002) with regard to the perceived health benefits of religious coping.

In addition to the potential of physical health benefits for adults, the mental health benefits stemming from spiritual coping has also been documented in situations of poverty among children. In a study by Werner (2000:125) with children from a variety of socioeconomic and ethnic backgrounds, it was noted that resilient children generally descended from families that held religious beliefs, which provided stability and meaning to their lives, especially in times of hardship and adversity. Werner (2000) referred to Antonovsky (1987) in explaining that such faith gave resilient children a sense of rootedness and coherence, a conviction that their lives would have meaning. Furthermore, people who are committed to religious beliefs and practices experience higher levels of well-being, since religious or spiritual coping could also include a sense of optimism or hope that is fostered by religious beliefs (Compton, 2005). I agree with Compton (2005) that particularly when life is difficult, religion provides solace through explanations for unexpected events and by providing hope at a personal and community level. In this regard, participants in a study by Ferreira (2006) identified personal religion, faith and prayer as important coping strategies when supporting relatives or community members living with HIV&AIDS, thereby implying enhancing resilience at community level by utilising religious coping mechanisms.

Conversely, religious forms of coping may also be divided into positive and negative forms: there are positive forms that depend on positive emotions such as support, compassion or hope, while negative forms of coping involve negative emotions such as guilt, or fear of retribution from God (Compton, 2005). The latter view of religious coping is supported by Ferreira, Keikelame and Mosaval (2001), who claim that by instilling fear and a moral discourse, the church is implicated in providing both support and stigma.

Understandably, only positive forms of coping have been found to have a beneficial impact on mental and physical health status. Pargament, Koenig, Tarakeshwar and Hahn (2004) have described the role of positive and negative religious coping in their study of medically ill, elderly and hospitalised patients. In this study, positive methods of religious coping such as seeking religious support and benevolent religious reappraisals were generally associated with improvements in health. Negative methods of religious coping such as punishment, God



reappraisal and interpersonal religious discontent, were predictive of declines in health. Pargament *et al.* (2004) thereby construed that patients who continued to struggle with religious issues over time may be particularly at risk for health-related problems. Among the children of my study, reference was made to only positive forms of coping such as daily prayer, finding comfort in religion and seeking spiritual support and guidance.

Examination of the role of religion and spirituality in adjustment to HIV&AIDS illness has only recently begun among HIV&AIDS adult patients. Boeving (2006) has identified a lack of research into spiritual and religious coping in children and adolescent populations, thereby implying a need for research into an aspect that appears to be increasingly significant in understanding and supporting children and adolescents through adversities.

## 5.2.3.2 Disengagement and denial as coping responses

Some children in my study appeared to disengage from stressful situations. Disengagement emerged in different forms: physical removal of themselves from a difficult situation (Kaemogetswe isolating herself in the bedroom and Dimple climbing into a tree) and engaging in fantasy and make-believe (see Section 4.2.3.2). I regard disengagement to be a form of defence mechanism that may be subconsciously utilised in order to safeguard the self from further emotional trauma. According to Mwamwenda (2004:293), defence mechanisms are special strategies that are used as safeguards against anything that poses as a threat or danger to the personality. Therefore, I suggest that in the context of my study, the use of defence mechanisms may be viewed as an alternative form of coping for children in distress.

Pivnick and Villegas (2000) have found that denial and repression were defence mechanisms utilised by non-orphaned children. These researchers explained that the defence mechanisms of denial and repression were adopted in order for children to function normally in the context of a caregiver's HIV-related illness and impending death. In the context of my study, I submit that in the face of cumulative stressors and adversities the possibility of children utilising denial, repression and other defence mechanisms to cope with the trauma may be increased. Fantasising seems to be another way by which the children seemed to disengage from reality. This finding was illustrated in another study exploring disease awareness in HIV-affected children. In this case, Willemson and Ascombe (2001) found that HIV-positive children utilised more fantasy figures in their play.

## 5.2.4 Children's experiences of well-being while affected by HIV&AIDS

In this section, I discuss children's experiences of well-being in this study from a broad positive psychological perspective. I base my discussion on the children's direct and indirect expressions of hope, optimism and happiness; positive emotions; positive relationships and future orientation as indicators of well-being.

## 5.2.4.1 Experiences of hope, optimism and happiness as indicators of well-being

The children in my study expressed their feelings about hope, optimism and happiness as possible indicators for well-being. Elements of hope and optimism and happiness were portrayed by Lizzy and Dimple in their paintings (session 1) and in the metaphoric stories based on their paintings that they articulated<sup>2</sup> Meme and Spiderman reflected hope and optimism for the future in their role-play scene (session 9) and in the story that they related.

As a positive individual characteristic, hope, synonymous with optimism, has been regarded as assuming a protective role (Seligman & Peterson, 2003). Generally, hope may be explained as the perceived capacity to derive pathways to desired goals and to motivate oneself via agency thinking to use those pathways. In this light hope may be implied as a desire or a wish for something. Inherently hope is filled with an expectation of fulfillment. Optimism is used to denote a positive attitude or disposition that *good things* will take place, independent of one's ability. In this study, optimism denotes states of happiness, perseverance, achievement and positive thoughts and feelings about the present and the future (Seligman & Peterson, 2003). I regard optimism as manifesting in positive thoughts relating to future orientation and future-perspectiveness as well as anticipation for the future. Therefore, related to my study, optimistic children may be regarded as those children who expected to have positive outcomes in their lives even when faced with challenges.

Optimism and pessimism are considered basic attributes of personality and they possibly influence how people orient to events in their lives; moreover, they influence people's subjective experiences when confronting problems. They also influence people's actions in trying to deal with these problems. Tiger (in Peterson, 2000) described optimism as a mood or attitude associated with an expectation about the social or material future – one which the evaluator regards as socially desirable, to his advantage and for his pleasure. Intrinsic in this view is that optimism is an inherent aspect of human nature. In my study I conjecture that although hope and optimism may be regarded as inherently trait-related, they would

-

<sup>&</sup>lt;sup>2</sup> Refer to section 4.2.4.1



require potential triggers or catalysts to manifest. Examples of such catalysts could be the buffering effects of the interaction between the protective systems and positive relationships that seem to envelop the child.

#### 5.2.4.2 Positive emotions as indicators of well-being

Considering that the children in my study presented with behaviour denoting positive emotions such as laughter, smiles, joy and playfulness (see Section 4.2.2.1:c) it would seem that these are a few of the intrapersonal characteristics that could contribute to the children's resilient adaptation. My view is based on Seligman's (1992) explanation that optimism, a sense of adventure, courage, self-understanding, humour, a capacity for hard work, and an ability to endure and find outlets for emotions may be considered enhancers or building blocks for resilience. As illustrated in my study, I concur with the views expressed by Bonanno *et al.* (2003) and Keltner and Bonanno (1997) that one of the ways by which resilient children appear to cope with adversity is to infuse positive emotions generated by laughter, enjoyment and pleasure in their lives (see Section 4.2.2.1:c). In addition, Bonanno and Keltner (1997) have claimed that resilience to loss may be associated with the experience and expression of positive emotions.

Related to my study, children who experienced positive emotional states were also aware of and interested in knowing more about their illness and their current state of health. I posit that children's need to know might be allied with the need for power and implied control over their illness. My view is based on the children's accounts of wanting to know more about their illness and their emphatic articulations that they took their medication daily in order to feel well (see Section 4.2.1.1:a). Ferreira (2006) suggests that the need to obtain basic knowledge about HIV&AIDS might be related to the extensive media coverage of HIV& AIDS-related issues.

In this regard, I consider knowledge to be a form of empowerment for the children, which could result in the generation of positive emotions. My view is supported by Salovey *et al.* (2000), who claim that positive emotional states such as humour and optimism may also facilitate healthy behavioural practices such as information-seeking and the ability to cope with illness-related stressors, thereby increasing the resilience that such children need.

An added advantage of encouraging positive emotions in children experiencing stressors and challenges is that they may act as antidotes to the effects of negative emotions (Fredrickson, 2001). Thus, negative and positive emotional states may influence a person's physical health



and have an impact on their motivation to acquire medical assistance and to encourage their own health promotion (see Section 4.2.1.1:a). Balancing positive and negative emotions while living under adverse circumstances might seem idealistic and unsustainable. In the case of the children in my study, who could be regarded as living in a state of chronic and multiple adversities, it seems critical to incorporate and build on their existing positive emotional states. Fredrickson's (2001) broaden-and-build approach underscores the ways in which positive emotions are essential elements of optimal functioning. Fredrickson's (2001:1375) theory has suggested that positive emotions broaden people's attention and thinking, undo negative emotional arousal, fuel psychological resilience, build consequential personal resources, trigger upward spirals towards greater well-being in the future and seed human flourishing. While Fredrickson's (2001) theory related mainly to adults in crisis situations, my findings suggest that the key elements could be relevant and transferable to children, thereby encouraging the growth and development of positive emotions to encourage the long-term consequences for well-being.

## 5.2.4.3 Positive relationships

In my study, positive interpersonal relationships were described as being nurturing, caring, reciprocal and supportive in nature. Children in my study illustrated various examples of encouraging relationships that they shared with their caregivers, other children in their home, peers, teachers and volunteer workers (see Section 4.2.4.2). I put forth that positive relationships are another factor that could have enhanced the well-being of the children in the study. My suggestion is based on the implied positive emotions generated by such supportive associations with significant others. The interpersonal relationship context, in which the children were embedded in a web of relationships with other individuals on a daily basis, both influenced their behaviour and influenced others' behaviour towards them (Berscheid, 2003:38). My findings are corroborated by Williams (2001), who established that positive interpersonal relationships based on reality were a resilience factor amongst children impacted by HIV&AIDS.

#### 5.2.4.4 Future orientation as an indicator of well-being

Children in my study were mainly optimistic about their futures (see Section 4.2.4.3). Optimism, hope and positive emotions regarding the future were inferred when children spoke about possible careers, marriage and family. It could be surmised that the children in this study had high expectations for their future lives. There seems to be a similarity between my findings and those of Pivnick and Villegas (2000), who indicated that in their



study, children affected by HIV&AIDS expected to own homes, attend college and have stable families.

Based on my findings related to future-directedness, I regard the children in my study as manifesting resilience characteristics. I make this assumption in the light of evidence in this study relating to the children's positive adaptation, indicated by their focused future orientation in spite of enduring extremely difficult psychosocial and emotional challenges (see Section 4.2.4). On the other hand, Pivnick and Villegas (2000) posit that despite children's high levels of optimism for their future, the reality of life might defer their dreams – whilst these children construct their futures to include higher education, well paying jobs, and loving relationships, their projections might seem out of touch with the opportunities available to them. I submit that to sustain children's hope and optimism within a context of adversity resilience building should include skills training especially for adolescents who are on the verge of leaving the protection of residential care (see Chapter 6).

#### 5.3 An overview

In Chapter 4 I presented the results of my study. In Chapter 5, I presented my findings that were based on my discussion of the emerged themes, sub-themes and categories that I presented in Chapter 4. I related my findings to the relevant literature and highlighted similarities, contradictions and the understandings at which I arrived.

In Chapter 6, I answer the research questions that guided my inquiry and consider the potential contributions of the study. I also offer recommendations for future research.