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Abstract

Against a burgeoning worldwide discourse on the psychological and emotional impact of HIV&AIDS on children's development, I conducted an empirical inquiry to explore how a group of nine orphaned and vulnerable children who were residing in a children's home negotiated pathways to well-being while they were affected by HIV&AIDS. The study aimed to explore, understand and describe the phenomenon of well-being within the specific context of the child participants' perspectives of their life-worlds. The study was informed by a qualitative and instrumental case study design within an interpretivist paradigm. In addition, it was guided by a conceptual framework derived from key concepts within the fields of HIV&AIDS, positive psychology, coping and resilience theories.

The study employed both inductive and deductive methods for knowledge development. I utilised task-based participatory activities to guide the informal and conversational interviews with the children in the study as the main data generation strategy. I incorporated the use of informal observations and an examination of documentation as additional data generation methods. By means of a thematic analysis approach incorporating principles of the constructivist grounded theory analysis of the children's expressions, I gained insights that informed my understanding of the children's perceptions and experiences of well-being, risks, challenges and stressors.

Findings indicate that the children in the study experienced risks, challenges and stressors arising from personal illness, stigma, discrimination, orphanhood, residential care, death and bereavement. The study has further revealed that those children who portrayed characteristics of well-being and resilient adaptation utilised psychosocial coping mechanisms. In addition, they were supported and strengthened by their positive intrapersonal characteristics and affirmative relationships that offered emotional and psychosocial support within their environments. The findings of the study suggest that feelings of well-being, hope and optimism might have co-existed with feelings of despair and hopelessness in the daily lives of the children in the study who were affected by HIV&AIDS. I concluded this study by suggesting that the well-being experiences of the children in this study may exist on a continuum and may depend on specific events, occasions or incidents on a day-to-day basis.

Key concepts:

- HIV&AIDS
- Orphaned and vulnerable children
- Residential care
- Risks, challenges and stressors
- Positive psychology
- Well-being
- Intrapersonal characteristics
- Positive and enabling systems
- Coping
- Resilient adaptation

CHAPTER 1

Introducing the study

1.1 Introduction

The primary purpose of Chapter 1 is to provide an introduction to and a framework for this study. In this regard, I have outlined the purpose and the rationale as well as the critical research questions that guided this enquiry. Thereafter, I provide an overview of the research methodology and design that informed the research process. The core concepts and terminologies that framed an understanding of this inquiry are then clarified. Furthermore, I have indicated my ethical considerations and taken care of the quality criteria that informed this study. Towards the end, I reflect on the potential limitations of my inquiry and then present a summary of my findings. I conclude this chapter by outlining the chapters that follow. Figure 1.1 provides an overview of the study.

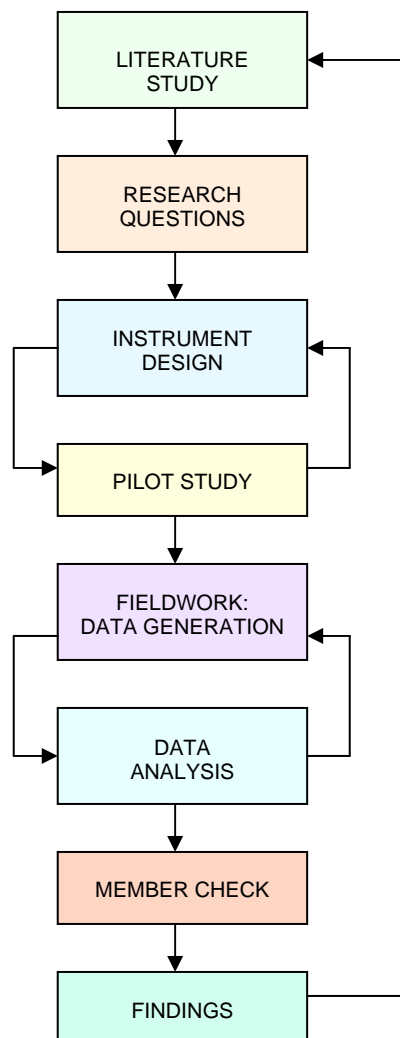


Figure 1.1: An overview

1.2 The focus of the inquiry

The HIV&AIDS pandemic has touched lives on all continents of the world, in some cases obliterating entire communities. Its devastating consequences have permeated and reshaped the social, cultural and economic fabric of family lives, rendering children destitute and vulnerable. My study focused on gaining a deep understanding of the lived experiences of a group of children who are affected by HIV&AIDS¹ and have constructed their well-being in a context of challenges and stressors.

From a positive psychology perspective, I contemplated the following broad questions (not research questions) as they related to children who were affected by HIV&AIDS: How do children who live with a life-threatening illness, experience the possibility of feeling hopeful and optimistic with a sense of well-being? What is known about well-being in adversity? What are the indicators of well-being? To what extent can children be taught to generate positive emotions while they are also dealing with distress? What is known about young children's experiences of positive emotions while living within a context of HIV&AIDS?

The main purpose of this inquiry was to explore, understand and describe how institutionalised children negotiated (navigated, got around, coped with, got past) obstacles to create pathways to well-being while affected by HIV&AIDS and experiencing the accompanying social, psychological, emotional and physical challenges. I located my study in the silences I encountered in the empirically based literature relating to children's experiences and perceptions of well-being while affected by HIV&AIDS.

I was guided in my inquiry by the following primary research question:

How do children who are affected by HIV&AIDS negotiate obstacles to create pathways to well-being in their daily lives?

In order to explore this primary research question, I addressed the following secondary questions as they related to the children in my study who are affected by HIV&AIDS:

- How do the children in my study express a sense of well-being?
- What are the challenges and stressors that place the children in my study at risk?
- How do the children experience distress and despair?
- What are the children's psychosocial needs?
- How are the children supported?
- What are the children's coping responses?

¹ Refer to Section 1.7 for a clarification of concepts and terminologies.

The underlying assumption of this inquiry was that within the context of my research setting, there might be children who maintained a sense of well-being. I entered the research situation assuming that the children would be willing to communicate with me regarding HIV&AIDS, that the children would be coping with HIV&AIDS and that the children in this study were experiencing well-being.

1.3 The rationale for this study

While a life-threatening illness disrupts the physical, cognitive, social and emotional development of a child, it has been the trend in the past for research to focus on finding a medical cure for the physical symptoms of illness, with insufficient attention to the psychosocial and emotional concerns of the ill person. Thus, based on a biomedical model the focus has been on the medical diagnosis and treatment of long term illnesses both in psychology and in medicine (Ross & Devereil, 2004; Stroebe, 2000). While the biomedical model emphasises the role of medicine in the elimination of disease and is a crucial aspect of treatment for children with a terminal illness, I subscribe to a biopsychosocial model that advocates the promotion and maintenance of health and well-being through socio-environmental and behavioural changes (Ross & Devereil, 2004). Consistent with this view is a move towards the paradigm that a person who is supported holistically while living in a context of a chronic life-threatening illness (in this case, HIV&AIDS) may also experience a sense of well-being (Lyons, 2000).

With the latest advances in medical research and the rollout of ARVs² in Africa, there is hope that like in countries such as the UK and the USA, HIV will no longer mean a death sentence but rather that infected children will be able to live longer and healthier lives (Salovey, 2008; UNAIDS/WHO, 2006; Gibbs, Duong & Tookey, 2003; Foster, 2002). Consequently, the challenge lies in the need for sustained emotional support (Domek, 2006) by providing the social and psychological tools (Salovey in Ebersöhn, 2008) to manage the psychosocial effects of the disease and its consequences, as children undergo their course of treatment.

In this regard, I posit a shift from viewing children from a needs-based and deficit stance to adopting a positive psychological approach which incorporates a strengths-based perspective in addressing the emotional and psychosocial challenges of children affected by HIV&AIDS. I regard children and communities that support children as possessing strengths and capacities that bolster and add buoyancy to their lives. In the next section, I shall link

² ARV: Antiretroviral medication

the core concepts that emerged from my review of literature from the field of HIV&AIDS and positive psychology to a conceptual framework.

The meaning that I assign to this study is framed by two sources that comprise my identity as a researcher: the academic and the personal. Firstly, on an academic and professional level, I wish to contribute to the emerging body of empirically based literature regarding the emotional and psychosocial consequences of HIV&AIDS among children by locating and foregrounding the voices of the children within the discourse of adversity. Specifically in this study, I wish to adopt a positive psychology approach with regard to the children in my study who are affected by HIV&AIDS. To this end, I embraced a strengths-based view of children, thereby possibly contributing to a growing discourse on children as social agents. Perhaps due to a general tendency to research children from an adult perspective, children's own experiences tend to be underrepresented in the literature on children and HIV&AIDS (Deacon & Stephney, 2007).

On a personal level, as an educational psychologist working therapeutically with young children, my interests lie in the socio-emotional aspects of children's development, especially children who are experiencing adversities in their lives that affect their psychological well-being. Furthermore, my personal experience of witnessing a young pre-school boy's courage, bravery and pain while living with HIV and eventually dying of AIDS has prompted and fuelled this journey towards an understanding of children's emotional and psychological responses to the HIV&AIDS devastation. It makes sense to teach children to identify and cope with problems and to find the resources within themselves and from others, which could lead to an improved quality of life. The challenge for caregivers in all sectors is to find, discover or invent ways in which to help children to regulate their emotions positively as a buffer against the negative psychological effects of living in adverse circumstances.

In this study, it was not my intention to simplistically separate or polarise the negative and positive emotions and experiences of children. Neither did I wish to document what was going wrong with children and suggest ways of putting it right. Rather, it was my intention to explore and understand how a child's positive and negative experiences depend on each other and work together to produce well-being outcomes. In the words of Lyubomirsky and Abbe (2003:132), "*in this study I would focus my research energy on studying the positive side of life alongside the negative side of life.*" My stance in this inquiry was to look for multi-layered and nuanced understandings of a complex and dynamic phenomenon.

The results of this study could possibly contribute to the knowledge base of children's psychosocial coping with HIV&AIDS and also provide empirically grounded knowledge of well-being in the lives of HIV&AIDS affected children in the emerging field of positive psychology (refer to Chapter 2 for a detailed review of the relevant literature). I assert that the knowledge gained about children's construction of well-being in the face of HIV&AIDS could be applicable to other groups of children who are living within the context of chronic adversity such as other terminal illnesses, abuse, war, poverty and neglect.

1.4 Research design and methodology

1.4.1 Paradigmatic choices

Researching a complex and dynamic phenomenon such as the lived experiences of children presented methodological challenges and dilemmas. In this regard, I chose a qualitative case study design within an epistemological perspective of an interpretivist paradigm to explore the diversified and underlying perceptions, understandings, feelings and experiences of the children in this study.

In choosing an instrumental case study design, I took into consideration that this design is regarded as one of the most appropriate means to explore a social issue in a real life context. Its strength lies in its attention to the subtlety and complexity of the case in its own right and the embeddedness of social truths (Stake, 2005:444). I submit that by means of an instrumental case study design, I was able to address my research questions by obtaining thick, rich and vivid accounts of children's well-being experiences. I utilized the instrumental case study as a process and as the product of the inquiry (Stake, 2005: 444).

I conducted my study from a qualitative-interpretivist paradigm within the children's natural setting (their home) as I wanted to explore and gain insights at a much deeper level (Denzin & Lincoln, 2003). In addition, I sought to understand the children's own experiences and their perceptions of well-being (Denzin & Lincoln, 2000:2). I considered that the meanings the children attached to their lived experiences and the process of interpreting these meanings were essential to what they were experiencing. Thus, from an interpretivist stance, I assumed that since children's experiences are real and should be taken seriously, I could understand by interacting and listening to them (Denzin & Lincoln, 2000:3; Terre Blanche & Durrheim, 1999:123).

The point of departure in my study is that as no single social reality and therefore no single truth exists (Stake, 2000), the understandings and interpretations of the experiences of children in this study are regarded as complex, nuanced and multilayered. Denzin and Lincoln (2000) view the researcher as a bricoleur, who would use any method, strategy or empirical materials available in the context to produce the bricolage that is the solution to the puzzle or provides an understanding of the case. Within my chosen paradigm, I, the researcher, became the primary instrument for data collection, analysis and interpretation (Miles & Huberman, 1994). In section 3.2, I provide an in-depth discussion regarding my paradigmatic choices.

1.4.2 My research setting

My research was conducted at a children's home which is a residential care setting³ for children affected by HIV&AIDS. As a unit of analysis, all nine children who live at this children's home were partners⁴ in this study. The children's home is situated in a residential suburb, Queenswood which is to the north-east of the city of Pretoria (see Addendum 8).

As it was my intention to collate in-depth information concerning the construction of the well-being experiences of children who are living in a HIV&AIDS context, I employed a purposive sampling strategy (Patton, 2002; Babbie & Mouton, 2001) to select the particular case (the children's home). I believed that there was a likelihood of this case offering a rich and rewarding exploration of experiences and perceptions from a small cohort of children whom I got to know well. Importantly, the element of trust that was established between me as researcher and the selected group of children seemed to facilitate relevant discussion about feelings, experiences, thoughts and concerns. In so doing I understood that I would not be able to generalise the results or the findings of my study. This stance rested comfortably with me as that was not my intention. My intention was to describe or highlight the in-depth experiences of a particular group of children at a particular point in time. However, I do concede that by providing thick and detailed descriptions of my research processes, I offer the possibility of this study being transferable (Seale, 1999) to the reader.

³ Henceforth, I shall refer to my research setting which is the institution, as "the children's home"

⁴ In future, the partners in my study are referred to as "the children in my study" or "the children"

1.4.3 Getting to know the children in the study

As critical inclusion criteria, the children in my study were either infected with the HI virus, affected by having lost a family member (mother, father or sibling) to an alleged AIDS-related illness or living amongst other children who were infected by HIV or affected by loss. Of the nine children who lived at this children's home, eight were orphaned children. One child (non-orphaned) lived at the children's home because of parental neglect. I regard her as being affected by HIV&AIDS as she lived in a context where other children are HIV positive (see Addendum 8:8.2.1). In my attempt to protect the identities of the children in the study I offered them an opportunity to choose pseudonyms for themselves for the duration of the study. This section provides thumbnail sketches of the children in my study (see Addendum 8:8.2.1). I refer to the children by their preferred pseudonym. I gathered the background information on the children mainly from my examination of the social worker's case report for each child (see Addendum 2 for examples). The information that I gathered from examining the reports is included in this study as textual data.

Dimple is 13 years old and is in Grade 5. She is HIV negative and she has lost both her parents. Dimple has a half-brother and an uncle with whom she has limited contact. Dimple loves fashionable clothing, dressing up and going to parties. She and Lizzy are best friends. **Lizzy** is 15 years old and in 2007 was in Grade 8 at a special school. She is also HIV negative. Lizzy was admitted into residential care when her mother was in prison and she was left vulnerable to alleged abuse. Upon her mother's release from prison in January 2008, Lizzy and her mother have been reconciled and Lizzy has chosen to discontinue her schooling.

The four boys, **Batman**, **Superman** and **Harry Potter** and **Spiderman** share a room at the children's home and spend much of their leisure time playing or watching television together. **Batman** is 12 years old and is in Grade 6. He is HIV positive and is receiving antiretroviral treatment. He has been at the children's home since he was three years old. His mother is deceased and his father, unknown. Batman has four siblings who live with their grandmother and with whom he has no contact. He has a weekend parent whom he visits during the school holidays. Batman has a love for cars and would someday love to design his own car. **Superman** is 12 years old and is in Grade 5. He is HIV positive and is also receiving antiretroviral treatment. Both of his parents are deceased and he has no other family members. Superman spends most of his time at the children's home over the school holidays. **Harry Potter** is 11 years old and in Grade 5. He is HIV positive and is receiving antiretroviral treatment. Harry Potter has four brothers who live independently in a child-headed household. However, the family lived in dire poverty and had limited resources to care for Harry Potter's medical needs. He was admitted to the

children's home upon the death of his mother from an alleged AIDS-related illness. He has contact with his brothers who call him telephonically and visit him occasionally. *Spiderman* is 11 years old and is in Grade 5. He is HIV positive and is receiving antiretroviral treatment. He was abandoned by his mother when he was six years old. Presently, *Spiderman* has limited contact with his father.

Meme is 13 years old and is in Grade 6. She is HIV positive and is receiving antiretroviral treatment. She has been living at the home since she was 4 years old. It is believed that her mother and older sister died of AIDS-related illnesses. *Meme* has contact with her grandmother and she looks forward to spending time with her family over the school holidays. *Michelle* is 12 years old and is in Grade 5. She is HIV positive and is receiving antiretroviral treatment. Both of her parents are deceased. Like *Meme*, *Michelle* also has family (grandfather and an aunt) with whom she shares a good relationship and visits during school holidays. *Kaemogetswe* is 12 years old and is in Grade 5. She is HIV positive and is receiving antiretroviral treatment. Her mother is deceased and her father unknown. She has been living at the children's home since she was 3 years old. She has a weekend family whom she loves to visit over weekends and in school holidays. *Kaemogetswe's* wish is to be fostered and eventually adopted by her weekend family.

1.4.4 Data generation: strategies, documentation and analysis

In my attempt to gather thick, rich and detailed descriptions of the experiences of children negotiating well-being in the face of HIV&AIDS, I employed informal and conversational interviews (Patton, 2002) as the primary data generating method. I furthermore incorporated the use of research instruments to aid the interview process. In addition, I employed informal observation strategies (observation-as-context-of-analysis) (Angrosino & Mays de Pèrez, 2000) throughout the research process which were recorded as field notes in my research journal.

The purpose of interviewing in qualitative research is to derive interpretations and to understand the meanings of respondents' experiences and life worlds (Gubrium & Holstein, 2002). The purpose of the informal and conversational interviews was not to get answers to questions or to test hypotheses, but rather to explore the experiences of the children and to seek an understanding of the experience and the meaning they made of that experience (De Vos, Strydom, Fouche & Delport, 2005). At times, I resorted to using an unstructured form of interviewing (Mouton, 2001) with the children in the study as a means of extending my discussions and conversations with them.

Considering the sensitive nature of the phenomenon that I wished to explore, I decided to incorporate the use of task-based instruments and activities to assist the interview process by facilitating the self-expression of children in this study (Mouton, 2001). Furthermore, I took into consideration that the varying competency levels of the children in my study might not be compatible with structured and formal interviews. I therefore aimed to communicate with the children and explore their experiences in this study using multimodal media such as visual (drawings, pictures, written texts), auditory (stories, conversation) and tactile/kinesthetic (role-play and clay modeling) as data generation instruments. These modalities were incorporated in task-based activities as a means to stimulate conversation, keep the children motivated and provide them with a range of mediums of expression. Terre Blanche and Durrheim (1999:128) explained that in an attempt to understand a phenomenon it must be approached from several different angles. I incorporated the use of multiple methods of data generation in order to minimise and possibly avoid the risk of misinterpretation or distortion of material.

I also applied informal observations (Angrosino & Mays de Pèrez, 2000) and recorded field notes in my research journal (Terre Blanche & Kelly, 2002) with a view to deriving additional data. Informal observational methods, applied throughout the research process, were used to note nuances in body language, and facial and gestural cues that lent meaning to the words of the children being interviewed, together with their actions during their task-based activities (Angrosino, 2005:729).

Another source of data in my study was derived from the social worker's case report (textual data) (see Addendum 2). The information that I gathered from these reports was valuable for understanding the contextual background of the children in the study and in the process for situating my meaning-making in context. An ethical issue when conducting research with children is to ensure that children are not asked to provide information that may be gathered elsewhere (Schenk & Williamson, 2005). Table 1.1 provides a summary of the data generation methods and the instruments that were utilized.

Table 1.1: Summary of data generation methods and instruments

Data generating methods	Instruments that guided data generation	Trail of evidence
Informal and conversational interviews	Drawings	Addendum 4: 4.2; 4.3; 4.10; 4.11
	Incomplete sentence schedule	Addendum 4: 4.4
	Collage	Addendum 4: 4.5
	Draw and write activity	Addendum 4: 4.6

Data generating methods	Instruments that guided data generation	Trail of evidence
	Board game	Addendum 4: 4.7
	Clay modeling	Addendum 4: 4.8
	Role-play	Addendum 4: 4.9
Textual data	Social worker's case report	Addendum 2
Observation	Observation-as-context-of-interaction	Addendum 6

The data generation process continued until there was a saturation of themes or categories from the expressions of the children (Merriam, 1998). From an iterative process of data generation and analysis, I generated open-ended and emerging codes from the data with the primary intent of developing themes from the codes and as such, utilized an inductive thematic analysis process from a constructivist grounded theory approach (Charmaz, 2000; Merriam, 1998). I noticed an intricately webbed process of research questions being addressed via multiple data generation methods, and multi-layered meaning-making through data analysis and interpretation in the exploration and construction of an understanding of children's experiences. Thus, a distinctive characteristic of a qualitative-interpretivist approach to research is the interactive nature of data generation, analysis and reporting. Using an interpretive analytic approach provided a thorough description of the characteristics, processes, transactions and contexts that formed the basis of this study (Terre Blanche & Durrheim, 1999).

1.5 Ethical considerations

Ethics may be described as the study of fundamental principles that define values and determine moral duties and obligations (Schenk & Williamson, 2005:ii). Ethical considerations formed an integral part of my study: firstly, my study was situated in the life-world of vulnerable children that commanded my respect at all times. Secondly, my research was also about HIV&AIDS which is highly stigmatised in certain population groups and very sensitive, and required the utmost confidentiality on the part of the researcher who was privy to confidential information regarding the children in the study. As a fully qualified and registered educational psychologist, I am at all times bound to abide by the ethical guidelines as stipulated by the Health Professions Council of South Africa (HPCSA). My study was also guided by the ethical principles outlined by the University of Pretoria Research Ethics Committee.

In my interactions with the children, I acted in such a way as to preserve their dignity, respect and privacy as human beings (Cohen, Manion & Morrison, 2000). I obtained

informed consent from the social worker (as primary caregiver) as well as the children's informed assent to participate in this study. To further enhance the ethicality of this study, I engaged the cooperation of the social worker at the children's home to act as child advocate and witness to the assent process and to ensure that adequate protection was provided to the children (Schenk & Williamson, 2005).

I had an obligation not to intentionally harm the children or any other person in this study and this obligation required that I consider the potential risks that I might inflict such as physical, emotional, social, or other forms of harm. Where some risk was identified, I carefully examined whether the potential benefits of the research outweighed the risk of harm. In such deliberations I sought the advice of my supervisors (experts in the field of educational psychology) to advise on the management of ethical or practical risks. In such an instance, considerations led to a change in order to minimise the risk. In cases where participants needed emotional support, I directed them to resources where they could receive such support (see Addendum 6:6.2.1, p6).

During the study as well as in the dissemination of the findings, the children had a right to anonymity and confidentiality. To this end, children chose pseudonyms and I had visual images edited to ensure anonymity. I consulted with the children to ensure that the interpretations that were generated reflected their voices and their experiences (Cohen *et al.*, 2000). All raw data were stored in a secure environment. I offer a detailed description of the ethical considerations that guided this study in Chapter 3.

1.6 Ensuring the quality

Considering that the aim of my study was to understand the participants' construction of well-being, ensuring the quality of this study could not be established separately but was an integral component of the overall design and implementation of the various processes throughout the study.

Various terms in qualitative research allude to the establishment of believable results. When a qualitative researcher speaks of credibility, transferability, dependability and authenticity, it is accepted that the validity (Creswell, 2003) of the study is being referred to. Validity may be regarded as the strength of qualitative research and may be used to determine whether findings are accurate from the standpoint of the researcher, the participant, and the readers (Creswell, 2003).

To fulfil my aim of ensuring believable results, the following procedures were undertaken⁵:

- a) I strived for transferability by providing in-depth and detailed descriptions.
- b) My prolonged engagement in the field enhanced the credibility of my findings.
- d) I conducted member checks by discussing the emergent themes and my tentative understandings and interpretations with the children in my study.
- e) As my results emerged, I engaged my professional colleagues in peer review to confirm my interpretations.
- f) My critical presence in the field enhanced my understandings and interpretations.
- g) I reflected on and clarified my bias and subjectivity in the study.
- h) I crystallised the sources of information in this study and used them to build a coherent justification for the emergent themes.

1.7 Clarification of core concepts and terminologies

To avoid misconceptions and to ensure a clear and common understanding of the relevant concepts, I would like to describe the following core concepts and terminologies and clarify their meanings in the context of my study.

1.7.1 HIV&AIDS

HIV is the abbreviation of Human Immunodeficiency Virus. The virus is transmitted through blood, semen, and vaginal fluids including from pregnant mother to foetus as well as through breast milk. Once in the body, the virus uses the CD4 cells of the body's immune system to replicate itself, and in the process destroys these cells. These CD4 cells are vital as they co-ordinate the body's immune system, protecting the person from illness. As the HIV infection in the body increases, the number of CD4 cells decreases, weakening the efficacy of the body's immune system even further. AIDS (Acquired Immunodeficiency Syndrome) is a syndrome of the immune system characterized by opportunistic diseases such as tuberculosis, cancer and pneumonia. The syndrome is caused by the human immunodeficiency virus (HIV-1, HIV-2). A diagnosis of AIDS is usually based on clinical criteria and/or the results of blood tests (Donald, Lazarus & Lolwana, 2006; Stedman's Medical Dictionary, 2005; Ross & Deverell, 2004).

In the literature, the term HIV&AIDS has been used jointly to refer to the virus and the syndrome to show the interrelatedness and that one impacts on the other. In this study I

⁵ Refer to Chapter 2 for a detailed discussion.

shall use the term HIV&AIDS to refer to the Human Immunodeficiency Virus (HIV) and to the Acquired Immunodeficiency Syndrome (AIDS) collectively.

1.7.2 Children

Variations exist in terms of the age at which individuals may be considered children. In most international and national literature, children are defined as boys and girls up to the age of 18 years. However according to UNAIDS (2002) (in Smart, 2003a), a child orphaned by HIV&AIDS is defined as being under 15 years of age and having lost at least one parent to AIDS. In line with the United Nations Convention on the Rights of the Child (CRC), (1989), UNAIDS (2004) and Skinner, Tsheko, Mtero-Munyati, Segwabe, Chibatamoto, Mfecane, Chandiwana, Tlou and Chitiyo (2004), children in my study may be defined as individuals 18 years and younger.

In this study, I subscribe to the following broad view of childhood adopted by sociologists of childhood, the CRC and other rights-based approaches to development, namely that childhood is not a homogenous state and differs cross-culturally; that children are significantly differentiated through factors such as age, gender or ethnicity; that children are social actors who engage in and have different effects on the social world around them and that children have rights and opinions and should therefore participate in determining what happens to them (West & Wedgwood, 2004).

1.7.3 Children affected by HIV&AIDS

As the number of children affected by HIV&AIDS is growing, so is the sense of the complexity of how children are affected. This makes it difficult to define the concept of *affected*. I adopt the framework outlined by Sherr (2005) in understanding the different levels by which children are impacted by HIV&AIDS. The following levels can be described, and they are not necessarily mutually exclusive:

Level 1: The child is HIV positive

Level 2: The child is HIV negative, but has been indirectly affected by one or more of the following situations: exposed to HIV in utero (often described in the literature as seroreverting); the child has one HIV positive immediate family member (parent, sibling); the child has multiple HIV positive immediate family members (parents, siblings).

Level 3: The child is HIV negative, their immediate family members (parents and siblings) are HIV negative, but other family members are HIV positive (grandparents, aunts, uncles, cousins, half-brothers, sisters, step-parents).

Level 4: The child is HIV negative but lives in a social system where HIV has affected many people. The social system is burdened by bereavement, illness, and other orphaned children, and the outcome is a vulnerability experienced by the child living in this social ecosystem.

Within these levels, there is an additional consideration of the health status of both the child and the infected family member(s) or member of his social ecosystem, which has a bearing on the psychological issues. Is the child and/or others who are HIV positive well, ill, dying or deceased? With HIV, there may be multiple categorisations with various members of a family network in different stages of illness (Sherr, 2005: 1-3).

In the context of my study, seven of the children in my study are at level 1 while two children are affected by HIV&AIDS at level 2 as indicated by Sherr (2005). Furthermore, although I acknowledge the international use of the term people living with HIV&AIDS (PLWHA) (Richter, Foster & Sherr, 2006), in the context of my study I prefer to use the term children affected by HIV&AIDS because of its subjective and personal connotations.

1.7.4 Orphaned child

In this study, the term *orphaned child* refers to a child younger than 18 years who has lost one or both parents. According to Deacon and Stephney (2007), the term orphan and vulnerable children (OVC) was coined to extend the discussion of disadvantage beyond orphans to other categories of children such as the children of sick parents. However, West and Wedgwood (2004) regard the current shorthand term OVC in itself stigmatising, by not referring to these children as children, or as individuals but as a set of initials. In the context of my study, I adhere to West and Wedgwood's (2004) stance and refer to children who have lost one or both parents as orphaned children and if their parents are alive, I refer to these children as children affected by HIV&AIDS.

1.7.5 Residential care and children's home (institution)

Unlike many other developing world governments (Tolfree in Meintjes, Moses, Berry & Mampane, 2007), the South African government has a clear regulatory framework for the residential care of orphaned and vulnerable children as has been outlined in the Child Care Act of 1983. Alternate forms of childcare have been incorporated in the amended Child Care Act of 2007 (Republic of South Africa, 2008).

According to the Child Care Act of 1983 (in Meintjes *et al.*, 2007:12) a children's home may comprise any residence or home maintained for the reception, protection, care and bringing up of more than six children apart from their parents. Residential care has also been referred to as institutional care and includes a children's home.

For the purposes of my study, I shall refer to my research setting as the children's home as I prefer the connotation of a secure, stable and compassionate environment. However, when I refer to the literature I shall use the terms residential care or institutional care.

1.7.6 Well-being

The literature on well-being recognises the different streams of inquiry guiding this broad domain. According to the Webster Comprehensive Dictionary (1992:1429) well-being refers to a condition or state of happiness or prosperity; with regard to welfare. From a psychological perspective, subjective well-being refers to an evaluation of life in terms of satisfaction and a balance between positive and negative emotions, while psychological well-being entails the perception of engagement with the existential challenges of life (Keyes, Shmotkin & Ryff, 2002:1007). Furthermore, Ryan and Deci (2001) delineate the field of well-being into broad traditions dealing with happiness (hedonic well-being) and human potential (eudaimonic well-being).

In the context of my study, and derived from different readings of indicators of well-being (Diener, Lucas & Oishi, 2005; Seligman, 2005; Keyes *et al.*, 2002; Ryan & Deci, 2001; Diener, 2000), I refer to well-being as a state of contentment and happiness derived from life satisfaction which may be manifested in hope, optimism and the interplay between positive and negative emotions. In Chapter 2, I shall discuss these aspects in detail.

1.7.7 *To negotiate obstacles to create pathways*

In the context of my study, to *negotiate obstacles to create pathways* is intended to imply: *to get past, to overcome, to get around, to deal with and to cope with obstacles, impediments, barriers, risks, challenges and stressors [related to HIV&AIDS], to invent, discover, find, routes, tracks or ways to reach one's goals [well-being]* (Merriam-Webster, 2008)

1.7.8 Psychosocial

In the context of my study, a number of descriptions of the term *psychosocial* applies (Richter *et al.*, 2006):

- Psychosocial generally refers to the social and emotional aspects of life.
- Psychosocial needs refer to the needs that all people have, namely to be happy, creative, to belong in social groups and to have hope for the future. When children face difficulties and deprivation, particularly when these are chronic or repetitive, they are especially in need of stability, affection and reassurance.
- Psychosocial well-being refers to the positive age and stage appropriate outcome of children's physical, social and psychological development. It is determined by a combination of children's capacities and their social and material environment. Psychosocial well-being is essential for children's survival and development, especially in chronically difficult circumstances.
- Psychosocial care and support is provided through interpersonal interactions that occur in caring relationships in everyday life at home, school and in the community. This includes the love and protection that children experience in family environments, together with the interventions that assist children and their families in coping. Care and support enable children to have a sense of self-worth and belonging and are essential for children to learn, to develop life skills, to participate in society and to have faith in the future.
- Psychosocial support would encompass all the means of supporting the psychosocial needs and well-being of children and adolescents. I adopt an understanding in this study that psychosocial care and support refer to everyday family systems of care which support children's psychosocial well-being, thereby fostering/enhancing resilient coping.

1.7.9 Positive psychology

According to Gable and Haidt, (2005:103), "*positive psychology is the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups and institutions*". In striving to understand this conceptualisation, one is faced with a myriad of constructs that is subsumed under the umbrella term positive psychology and is not limited to the following: subjective well-being (Diener *et al.*, 2005; Diener, 2000); psychological well-being (Ryff & Singer, 2003; Wissing & Van Eeden, 2002); positive emotions (Fredrickson, 2005); optimism (Carver & Scheier, 2005; Seligman, 1992); hope (Snyder, Rand & Sigmon, 2005; Snyder, 2000); flourishing (Keyes, 2004; Keyes & Haidt,

2003); human strengths (Aspinwall & Staudinger, 2003); salutogenesis (Antonovsky, 1987); fortigenesis and salutogenesis (Strümpfer, 1990); emotional intelligence (Salovey, Mayer & Caruso, 2005) and flow (Nakamura & Csikszentmihalyi, 2005). Basic to these constructs are certain core themes and consistencies contained in the explanation by Seligman and Csikszentmihalyi (2000:5) that *“the field of positive psychology at the subjective level is about valued subjective experiences: well-being, contentment, and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present).”* Within the realm of positive psychology, the focus of this study extends beyond the identification of well-being constructs to include the nature, dynamics and the possible enhancement of individual as well as collective human strengths and well-being.

1.8 Summary of findings

In order to complete the overview of my study I provide a summary of the key findings in Table 1.2 which is based on the research questions that I posed earlier in this chapter. Chapter 6 provides a detailed discussion of the findings of my study.

Table 1.2: Summary of the main findings of my study

Research questions	Findings
Primary question: How do children who are affected by HIV&AIDS negotiate obstacles to create pathways to well-being?	Children portrayed features of resilience and well-being by utilising psychosocial coping mechanisms which were supported and strengthened by their intrapersonal characteristics and affirmative relationships within positive and enabling systems.
Secondary questions: 1. How do children in my study express a sense of well-being?	<ul style="list-style-type: none"> o hope o optimism o future perspectives o positive relationships o positive emotions
2. What are the challenges and stressors that place children at risk?	<ul style="list-style-type: none"> o illness o orphanhood and residential care o stigma, discrimination and rejection o death and bereavement
3. How do children experience despair and distress?	<ul style="list-style-type: none"> o internalising and externalising behaviour
4. What are the children's psychosocial needs?	<ul style="list-style-type: none"> o nurturance o communication o socialisation
5. How are children supported?	<ul style="list-style-type: none"> o positive and enabling systems o positive intrapersonal characteristics
6. What are children's coping responses?	<ul style="list-style-type: none"> o spiritual or religious form of coping o disengagement, denial and detachment

1.9 Potential limitations of the study

In this section, I would like to introduce the potential limitations of this study. Due to the research design of this study (instrumental case study), the generalization possibilities of these findings are limited. Data were gathered from a specific group of children who were bounded by situational factors such as their environment, culture and society. Rather than generalisability, the research findings promote complex and multilayered conceptions of well-being, risks, challenges and stressors. As I regard the children's home as protective and a safeguard of the children's welfare, the well-being experiences of the children may be attributed to the buffering effect of their home and may be particular to this group of children living in this particular context. As such, the possibility exists that other groups of children who are affected by HIV&AIDS and who live in different children's homes may express numerous other experiences. In addition, considering that the children live together at the children's home, there is the possibility that their familiarity with each other may have influenced the findings.

From the early stages of my interaction with the children in this study, I sensed reluctance from the children to talk about HIV&AIDS (see Chapter 5). I felt challenged to conduct research in the field of HIV&AIDS when the research participants were not keen to engage in an open discussion. I believe that I was able to overcome this limitation to a certain degree by spending time to establish rapport and trust with the children. Once the children appeared comfortable with my presence in their home, I continued to engage with them in potentially non-threatening and non-intrusive informal and conversational interviews that were based on participatory activities that the children seemed to enjoy. Towards the end of the data generation process, I initiated direct engagement with the children on sensitive themes such as HIV&AIDS and parental loss (see Addendum 4: 4.8, 4.9, 4.11). I ensured that all interviews with the children were conducted individually and in privacy. Despite these safe measures, a few children persisted in maintaining the silence that is usually associated with HIV&AIDS. Related to the children's apprehension to talk about HIV&AIDS, I also sensed unwillingness on the part of the primary caregiver to provide support to this study in the beginning stages. Concurrent with my data generation sessions with the children, I spent time with the primary caregiver, expounding the potential benefits of this study to the children and to caregivers in general. Thereafter I became aware that she seemed to have accepted the study with the children and offered her cooperation (see Addendum 6:6.2 p3).

Due to the sensitivity of my research focus and the fact that I was engaging with orphaned children, I constantly faced the dilemma of distinguishing between my role as researcher and that of potential therapist (see Section 3.7). From an ethical standpoint, I constantly afforded the children the opportunity to debrief after emotionally burdened sessions. I also referred one child for counselling. I found that by striving for self-awareness and self-reflection on an ongoing basis I was able to confront my challenges in this regard. However, I do concede that there is a possibility that in certain instances my interpretations of the children's expressions could have been formed from my biased and subjective standpoint.

In addition, I realise that adopting a Westernised conceptualisation of well-being and despair might be considered a cultural bias and a potential limitation of my study. While conceding this potential limitation, my reasons for adopting a generally Western approach are twofold: firstly, as the children in my study were schooled and socialised within a contemporary and Westernised schooling system, I considered it reasonable to conduct the study in the manner that I did. Secondly, I wished to explore the experiences of a particular group of children and constructing their experiences as knowledge to add to the growing literature base in the field of positive psychology. As such, variables such as culture, gender and age were not considered.

I also found it challenging to maintain the children's attention and concentration during the data generation stages, as one of the side effects of antiretroviral medication is decreased attention and concentration as well as fatigue. I also took into consideration that the effects of the neurological decline in the children who are infected with the HI virus might have had an impact on the quality of the stories the children produced. Another potential limitation is that I conducted just one pilot study (see Chapter 3 for a discussion). In Chapter 6, I consider the potential strengths of this study.

1.10 Outline of chapters

I have situated the focus and the rationale of my study within the broader field of HIV&AIDS research in Chapter 1. I went on to outline my choice of research design and my research methodology. I have also considered the ethical issues and quality criteria as related to the trustworthiness of my study. In Chapter 1, I also clarified the key concepts and terminologies, the understanding of which is crucial to an understanding of the study in its entirety. Furthermore, I provided a summary of the findings of my study and a brief overview of the potential limitations of my inquiry.

I utilised Chapter 2 to provide a conceptual framework for my study derived from an exploration of empirical literature in the domain of HIV&AIDS especially the psychosocial effects on children as well as related aspects of positive psychology.

In Chapter 3, I explain and justify my choice of research design and outline the methodology that I chose to explore the research questions. In this chapter, I also expound the ethical aspects of this study and outline the challenges and dilemmas that I encountered.

In Chapter 4, I highlight the voices of the children in my study by presenting the results in the form of direct quotations, child-generated metaphors and vignettes, as well as images and written text.

Chapter 5 presents the findings of my study which are integrated with the literature and interspersed with my interpretations of the well-being experiences of children in my study.

I conclude this study in Chapter 6 by answering my research questions, reflecting on the strengths of the study and offering recommendations for future research and practice.



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.

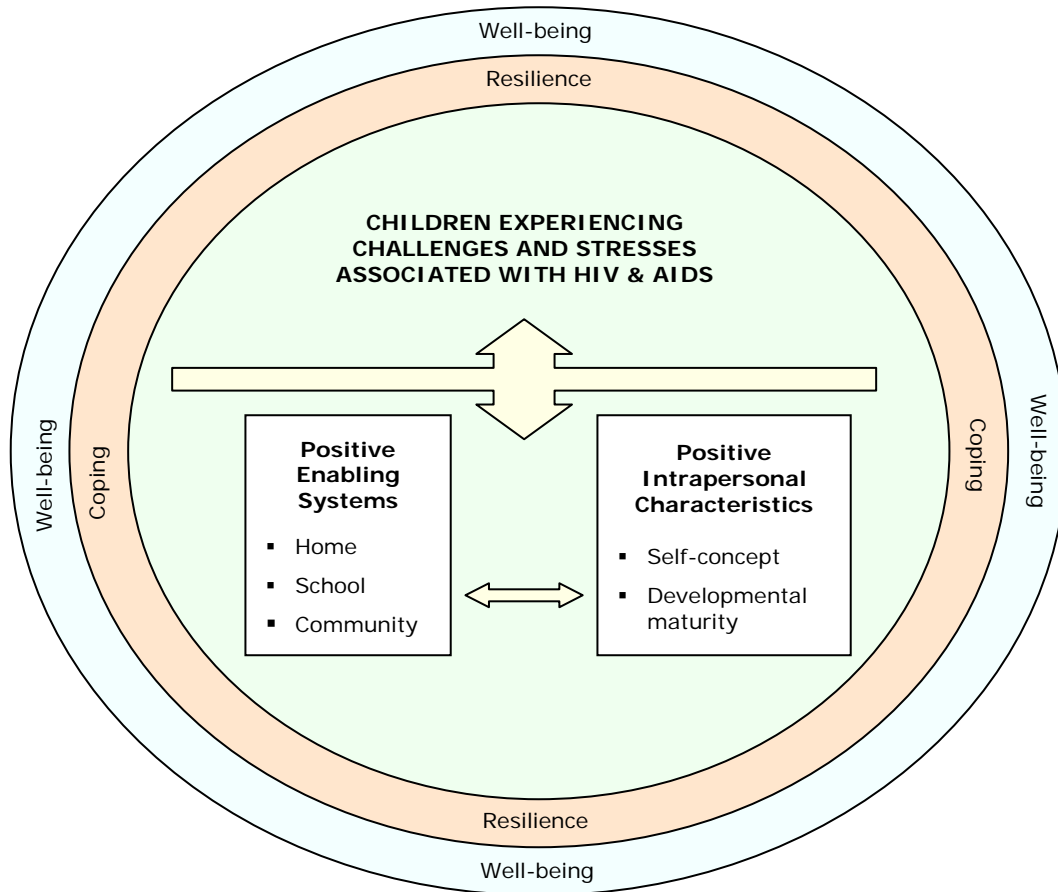


Figure 2.1: Conceptual framework

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; Booysen & 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.



CHAPTER 3

Research Design and Methodology

3.1 Introduction

The aim of this study was to explore and describe how children negotiated pathways to well-being while affected by HIV&AIDS. In Chapter 2, I provided a conceptual lens to this study that was derived from an exploration of the literature that was relevant to the focus of my study.

In Chapter 3, I explain and elaborate on my methodological choices as they informed the study. I justify my choice of research design and the primary data generation methods and instruments that were used to aid in the children's self-expression in order to answer critical questions in this study. I also explain the role of the secondary data generation methods that guided me. Furthermore, I set out the ethical issues that I considered significant to this study, expound the challenges, dilemmas and limitations that accompanied me throughout this study and explore my role as a researcher. I conclude the chapter with a discussion of the steps that I took to ensure the quality of the study. Figure 3.1 illustrates this process.

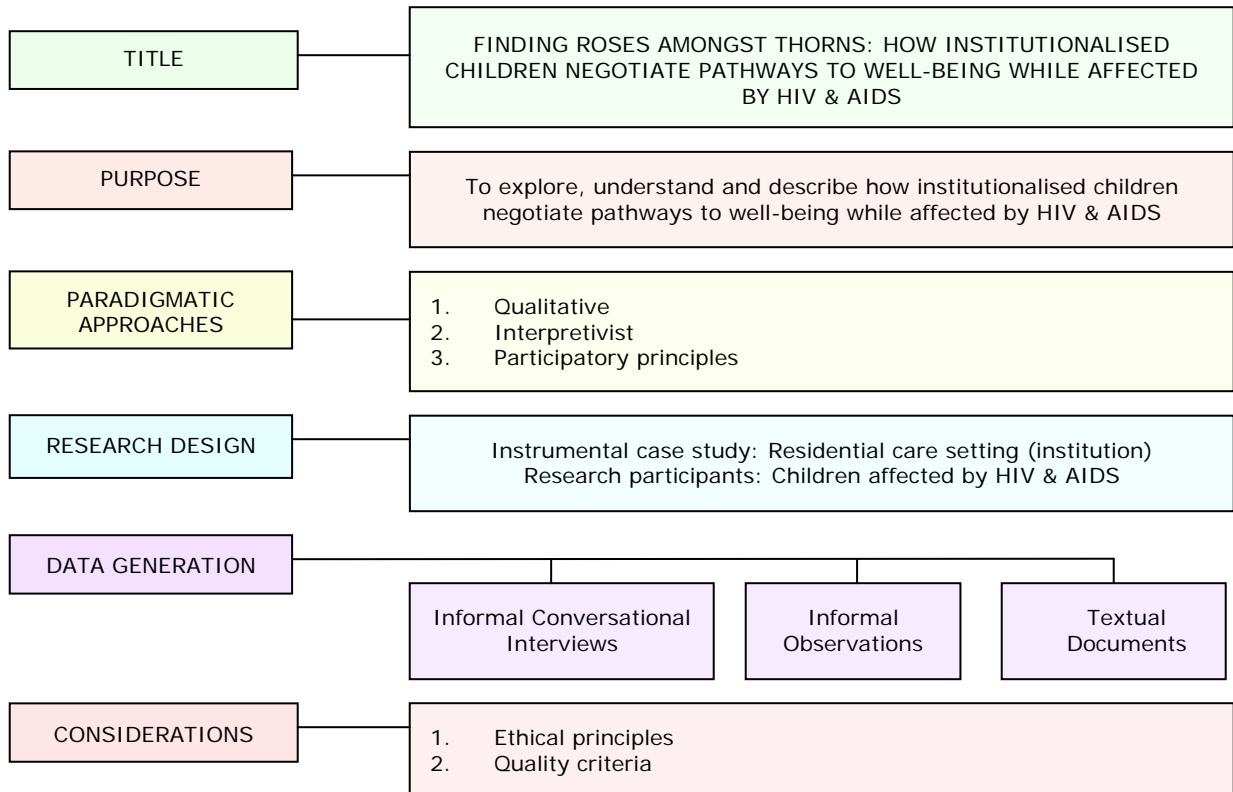


Figure 3.1: An illustration of the research process

3.2 My research paradigms

3.2.1 Methodological paradigm

When I initially conceptualised this study, I understood that my decision to explore the experiences of a vulnerable group of children would require a multifaceted approach to establishing relationships, interactions, data generation, data analysis, understandings and interpretations in a complex and dynamic setting. Initially, I considered adopting a quantitative approach to this study. I could have designed a questionnaire and administered it to the child participants to elicit their views about their life experiences. Thereafter I could then have quantified these experiences. I could also have employed a mixed method approach where I would have incorporated both qualitative and quantitative approaches (Onwuegbuzie, 2006; Creswell, 2003). However, I felt uncomfortable about these approaches as I questioned the trustworthiness of adopting a positivist approach to conduct a study in an intensely emotive field (Power, 1998).

I chose a qualitative approach for various reasons. Firstly, it related to the focus of the study, which aimed to explore and understand at a deep level the lived experiences of a group of children who are affected by HIV&AIDS. Next, I believed that the inductive and descriptive nature of a qualitative approach (Power, 1998) could be a suitable way to explore different views, experiences, feelings, perceptions and understandings of individual children in this study. I posit that such an approach could allow me access to inductive nuances that could possibly be missed in a questionnaire approach. In choosing a qualitative paradigm, I ascribed to the words of Denzin and Lincoln (2005:3), who claim: *“qualitative researchers study things in their natural settings, attempting to make sense, or interpret phenomena in terms of meanings people bring to them.”*

Furthermore, I was influenced by Merriam’s (1998) view that the data that emerge from a qualitative study are reported in words (primarily the participant’s words) or pictures, rather than in numbers. These qualities resonated with my stance as a qualitative researcher who recognises the unique contributions that children can make to research processes and outcomes. I was therefore comfortable in choosing a qualitative research paradigm that reflected my way of thinking about the phenomenon that I was researching. At all times, I took cognisance that it was impossible to separate the phenomenon being researched from other variables in the context (Merriam, 1998). As HIV&AIDS is highly stigmatised in many communities, research conducted with children within this field necessitates sensitivity to the social constraints that could affect the child.

In my qualitative approach, I entered the field carefully and with much respect for my partners. I spent time during the initial sessions on establishing rapport and trust with the children in the study. My prolonged engagement with the children (approximately 7 months) (see Addendum 6:6.1) meant that I was afforded in-depth insights that could have been overlooked had my engagement with the children been limited or brief (Charmaz, 2000). This intense qualitative engagement also meant that I became fully immersed and involved (Patton, 2002). As such, I as researcher became the primary research instrument (Patton, 2002; Miles & Huberman, 1994; Lincoln & Guba, 1985). I abided by Power's (1998:698) view that "*the non-intrusive and subtle nature of qualitative research has been particularly appropriate in examining HIV-related issues.*" Thus, my decision to employ a qualitative approach to my study rested in the reasons that I have discussed.

3.2.2 Meta-theoretical paradigm

As the focus of my study related to understanding, interpreting and describing the lived experiences of a particular group of highly vulnerable children, an interpretivist paradigm guided my inquiry into this process. I grounded my study in a qualitative-interpretive paradigm, as my concern was to understand the perceptions of the children regarding their well-being (Denzin & Lincoln, 2000:2).

The interpretivist paradigm reflects my personal view of the *world*, namely that people socially construct meanings *via* their interaction with the world around them. Considering that the main aim of my study was to understand and make sense of children's experiences, I regarded the children as being the experts in their lives and as such co-creators of knowledge. Knowledge is created through a process of personal interactions based on the understanding and interpretation of experiences within the particular context (Terre Blanche & Durrheim, 2002). Schwandt (2000) refers to the process of understanding as empathic identification, where understanding the meaning of human action and interaction requires of the researcher to understand or grasp the subjective intent of the participant.

Throughout this study, I defined the nature of the social context as being multiple, personal and internal (my ontological assumptions). In my writings, I consistently aimed to portray the subjective experiences of children in their reality by including various direct quotations and extracts of my reflections from my research journal. At various stages of the process, I reflected on the role of values in this study (my axiological assumptions) and acknowledged that in my attempts to authenticate my understandings of children's experiences of well-being from an interpretivist stance, my findings might be regarded as subjective and biased.

I also understand that this study was an interactive process shaped by my own personal history, gender, social class, race and ethnicity, and by the children in my research setting (Terre Blanche & Kelly, 2002; Denzin & Lincoln, 2000:6; Cohen *et al.*, 2000).

I adopted an insider perspective (Denzin & Lincoln, 2000) while I listened to the children for an understanding of how they construed their life world. Imbued in my writings are my perceptions derived from a mutual process of knowledge creation and interpretation. All interpretations would therefore be their interpretations and all understandings generated would be that which the children wanted or needed me to understand. However, how could I represent these voices in my writing without subsuming my personal values and judgements? To do this effectively, I needed to be one with the children: to interact, listen and understand (Terre Blanche & Durrheim, 1999:123). Denzin and Lincoln (2000:16) call this dilemma a crisis of representation and concede that in the final product there was no distinction between the writing and the fieldwork.

3.2.3 Adopting participatory principles

Children's place in society may be viewed through the lenses adults use to conceive childhood. In line with the sociology of childhood, I sought to view children in my study not as *objects of concern* but to engage with them as *active participants* (James & Prout, 1990). According to article 12 of the United Nations Convention on the Rights of the Child, (1989) children and young people have a right to be involved in decisions which affect them; this includes acknowledging them as social actors in their own lives. Increasingly, children are being recognised not as adults in waiting but as a diverse group of valuable contributors to society and competent in voicing their experiences (Noble-Carr, 2006).

In the particular context of my study, which required the exploration of sensitive subjects with children, I adopted participatory techniques for their power of communication and their suitability to the study. Their advantages seemed to lie in the active representation of ideas and thoughts based on the power of visual impressions (O'Kane, 2000) that did not depend heavily on reading or writing skills. By incorporating participatory techniques in this study, I posit that spaces had been created for children in this study to be listened to and heard. According to Clarke (2005), listening is understood to be an active process of communication, involving hearing, interpreting and constructing meanings, and is not limited to the spoken word.



3.3 Research design

In this section I discuss the case study design that I utilized. I also describe my research setting and the children who participated in the study.

3.3.1 A case study design

I intentionally chose an instrumental case study design within the qualitative approach to explore and provide a detailed description of the life world of a group of children who are affected by HIV&AIDS. My choice was informed by the highly emotional and sensitive nature of the study, together with the critical questions that guided the inquiry. I found that my case, a residential care setting for orphaned and vulnerable children, was bounded by time and activity, and was an appropriate system within which I could gather detailed information using a variety of data collection strategies over a sustained period of time (Creswell, 2003:14; Creswell, 1998:61).

While a case study is both a process of inquiry about the case and the product of that inquiry (Stake, 2005:444), a case study design is one of the most appropriate designs when one is examining a social issue in a real life context, as its particular strength lies in its attention to the subtlety and complexity of the case in its own right and the embeddedness of social truths. Although the nature of my study lent itself to an instrumental case study as its purpose was mainly to provide insight into a phenomenon (Denzin & Lincoln, 2000:437), I lean towards Stake's view (2005: 445), that there is no hard-and-fast line dividing instrumental case studies from intrinsic case studies; rather, there seems to be a zone of combined purpose. Furthermore, as I discovered and reported on a complex, dynamic and unfolding interaction of events, relationships and contexts in this unique instance, I found a resonance between my research design (case study) and my interpretivist epistemology (Cohen *et al.*, 2000).

Within this design, I could have selected only specific children with whom to conduct my investigation. However, from an ethical stance, I chose to include all nine children who lived at the children's home as they met my inclusion criteria. By employing an instrumental case study design, I was able to focus on the aim of gaining a better understanding of the children in this unit of analysis, which was a unique and dynamic children's home (Creswell, 1998:61). The purpose was therefore not to obtain a broad understanding of HIV&AIDS in this home, but to explore, understand and describe in depth the phenomenon of the well-being experiences of children who were affected by HIV&AIDS. I sought to uncover the

case's own issues, contexts and interpretations by means of thick, detailed and intense descriptions (Stake, 2005:445; Stake, 1995) (see Addendum 6).

From the outset the trust and rapport between the children and myself (as researcher) seemed to facilitate comprehensive interactions leading to profound insights (Mouton, 2001:150). The emphatic researcher-child relationship that ensued gave the impression that the children were encouraged in their expression of experiences and perceptions of negotiating well-being. I suggest that in the process, theory (such as coping, resilience, well-being related to children affected by HIV&AIDS) might be refined or created. In this manner, children's experiences may be constructed as knowledge.

As a researcher, I was obliged to take personal decisions during the course of the research activities, which might have influenced my results and findings in this study and which, in this light, might be regarded as one of the limitations of using a case study design in this study (Denzin & Lincoln, 2000:439). Further, when one considers Mouton's (2001:149-150) views, case studies are low in control and lack generalisability of results. Within the context of my study, I did not intend to generalise my findings. As with other qualitative research designs, the main sources of error may lie in researcher bias and lack of rigour in the analysis of data¹. I engaged with my peers to reflect critically on my research practices throughout the process (see Addendum 6). Although it was not my intention to generalise the findings of this study, I do submit that by providing detailed descriptions of the processes and the setting (see Addenda 6 & 8) a possibility exists of certain characteristics of this study being transferable (Stake, 2005; Seale, 1999).

3.3.1.1 My research setting

My research was conducted at a residential care² facility for orphaned and vulnerable children (see Addendum 8:8.1). This particular home is regarded as a family unit where the children are in the care and protection of a primary caregiver and a domestic helper. The overall guardianship of the children rests with the social worker under the auspices of the main hospital. Nine children, aged between 10 and 15 years, live at this children's home.

I chose to interact with the children at their home as I regard the setting in which the research is being carried out as crucial in establishing a perception of power equalisation. In addition, as children may perhaps behave and interact with adults differently in different settings I took into consideration that the location where the interviews were carried out was

¹ I will address my approach to ensuring rigour in Section 3.8

² As explained in Chapter 1, I use the terms **residential care** and **institutional care** interchangeably. For the purpose of my study, I shall refer to my research setting as **the children's home**.

quite likely to influence the way the children would respond (Noble-Carr, 2006). As such, Mahon, Glendinning, Clarke and Craig (1996:152) are of the opinion that *"it is frequently desirable to interview people (children) in their own homes and this often provides important observational data"* for the researcher. I concur with Punch (2002b:328) that interviewing children in their own setting can also make children feel more comfortable and less anxious. Despite these precautions I observed in my study that a few children were not comfortable with talking about sensitive issues in their own home while other children were around and within hearing distance (see Addendum 6:6.2). Furthermore, the presence of others in the interview space felt disruptive and perhaps intrusive to the children being interviewed. Especially for purposes of confidentiality, I conducted individual sessions either in a private room in the house, in the study or in the garden.

In their research with children with disabilities, Save the Children (2001) also found that children could often be interrupted by siblings or parents at home and that privacy was often a lot harder to negotiate in a home setting. Therefore, *"the implications of the research setting need to be considered with particular care, awareness and sensitivity in research with children"* (Punch, 2002b:328). I adhere to my position that interviews should be conducted in a setting where the child feels comfortable, both physically and emotionally. Figure 3.2 is a visual image of the children's home.



Figure 3.2: Harry Potter in front of his home

3.3.1.2 Selecting my research partners

At this stage of my writing, I wish to share my struggle to access research participants. Despite the campaigning at different social, political and educational levels to reduce the stigma and discrimination surrounding HIV&AIDS, stigma persists in all strata of society. When I conceptualised this project, my interest resided in exploring the experiences of a

diverse group of children affected by HIV&AIDS, across different cultures, racial divides and economic barriers. My attempt to find inter-racial, urban and middle income group HIV&AIDS-affected families who were willing to be participants in this study was futile (see Addendum 6).

Therefore, bearing in mind the sensitivity, stigma, confidentiality and ethical issues surrounding HIV&AIDS, I was constantly aware of the need for a careful choice of participants. As I had intended to collate extensive information concerning the well-being experiences of children who are living in a HIV&AIDS context, I utilised a purposive sampling procedure (Patton, 2002) that allowed me to choose the research setting (and the children who lived there) that best described the characteristics of the population I was interested in. My intention was to understand, describe and highlight the lived experiences of this particular group of young children at a particular point in time.

The children in my study were aged between 10 years and 15 years (see Section 1.4.3 and Addendum 8:8.2). They may be regarded as being in the preadolescent and adolescent phases of their lives (Mwamwenda, 2004). According to Piaget (in Thomas, 2005:191), individuals in this phase of cognitive development would probably be able to recognise (construct) symbolisation through means of imitation, of gestures, play, drawing and oral echoing. While Mwamwenda (1995:115) considers Piaget's cognitive development theory to have relevance in a dynamic and urban African context, I do surmise that the children in my study could possibly be functioning at a cognitive level lower than Piaget's expectations due to environmental and emotional deprivation together with the cognitive developmental implications of being infected by the HI virus (Smith, 2005; Gosling *et al.* 2004; Kullgren *et al.*, 2004). Children who are in my predefined age group may also be starting to act internally on objects (manipulate them mentally) while observing and working with them (Thomas, 2005:191). The competence of being able to engage in acts of internalisation would have important implications for the study as it enabled the participants to generate intense, vivid and rich descriptions of their experiences (see Chapter 4). In my data generation approach, I considered Mwamwenda's (1995:115) explanation: *"dialogue is disadvantageous to African subjects whose cultures do not facilitate or encourage intensive discussion between an adult and a child."*

The purpose of this study required that the child participants be willing to communicate with me about HIV&AIDS and be willing to share their personal experiences, feelings and emotions. In addition, the nature of the data generation required that participants should be motivated, have the time and be committed to being part of this study. I assume that the

level of commitment to the study that I required was achieved as I spent time in the initial sessions with the children on gaining and sustaining a mutual relationship of sincerity and trust (see Addendum 6). I surmise that the use of child-friendly data generation instruments had added to the sustained interest and enthusiasm that the children displayed at being part of this study.

When I selected this case, I carefully considered accessibility as another important criterion as I intended a prolonged engagement with the children. In collaboration with the children and their caregivers at our initial contact, I conducted my sessions with the children between 2 pm and 6 pm on a Friday afternoon. Although I had planned to use a research assistant to assist me with translating the children's mother tongue language (a combination of Sesotho, Tshi-Venda and Sepedi) to me and my English to the children in their mother tongue. However, I realised at my first introductory session that a translator might not be necessary as the children attended an English-medium school and spoke English fluently. Furthermore, they communicated with their caregivers in English. Nevertheless, I offered the children the opportunity to speak in their mother tongue whenever they needed to and to have my conversations translated to them in their mother tongue. I knew that I was audio-recording their conversations and so the information would be translated should I need it to be. However, none of the children opted to speak in their mother tongue nor did they require my conversations to be translated to them. For the purposes of this study, I did not explore the reasons for their choice in speaking English in this study, but I believe that it probably relates to the language of teaching and learning they are used to in school.

At the outset my decision was to exclude the voices of caregivers, teachers and other significant adults in the children's lives. I preferred to listen just to the voices of the children and to explore *their* experiences. I made this choice after reading the following comment from Eder and Fingerston (2002:181), "... *one clear reason for interviewing respondents is to allow them to give voice to their own interpretations and thoughts rather than rely solely on our adult interpretations of their lives.*"

3.3.2 The research process

It has been highlighted in the literature that to fully engage children in a study, the process of data generation should consist of more than a one-off encounter with the children (Noble-Carr, 2006). I found it helpful to conduct a series of interviews especially as we were engaging in conversations that could be emotional and sensitive (see Addendum 6). The series of interviews and activities assisted with maintaining a trusting relationship by

providing opportunities to follow-up on conversations and further explore or confirm children's ideas and thoughts (Punch, 2002a & b; Mason & Urquhart, 2001). Milne, Munford and Saunders (in Noble-Carr, 2006) emphasised that research of high quality usually arises from relationships that are carefully constructed.

From the outset my dilemma revolved around these questions: How does a researcher gather data from a group of children orphaned and made vulnerable by HIV&AIDS? How does a researcher safeguard these children from further vulnerabilities to which the research process may expose them? I took my cue from Power (1998:690), who suggested that *"...researching the knowledge and attitudes of children regarding a matter such as HIV disease requires skill and sensitivity."* While deliberating on suitable data generation choices with my supervisor and colleagues, I was clear that the emotional safety of the children was the priority in this study. Therefore, I could not choose to use data generation methods that would be intrusive and insensitive to the children. I acknowledge that throughout the research process I was acutely aware of my position (see Addendum 6) and that methodological choices were made in the best interests of the children (see Addendum 6). During the course of my study, I also took the children's expressions of their experiences seriously and recognised that they had their own distinctive abilities in the way which they understood and explained their world (Noble-Carr, 2006; Banks, 2001; Christensen & James, 2000). I posit that recognition and encouragement of the children's potentials could have possibly contributed to the rich and valuable data that were generated in this study.

3.3.2.1 Piloting the study

I conducted a pilot study in order to orientate myself to the study, to determine the exact formulation of my research problem (De Vos *et al.*, 2005) and to ascertain the effectiveness of my data generation methods. In particular, I conducted a pilot study in August 2007 in order to explore the feasibility and usefulness of certain instruments that I required to aid the interview process (see Addendum 3). To do this, I approached a friend whom I knew was taking care of her 11-year-old orphaned nephew, as his mother (my friend's sister), had died two years earlier. The child and I are familiar to each other.

According to information given to me by my friend, the child's father had also died in January 2007 and she then took responsibility for raising the child. The causes of the parental deaths are unknown. I clearly explained the purpose of the study to the caregiver and then again, in a developmentally appropriate manner, to the child. I thereby gained informed consent and informed assent to engage the child in an informal and conversational

interview regarding his experience of well-being after the death of his parents. I do concede that I did not probe the child's HIV status as I regarded it as an intensely private and confidential matter, however pertinent it might have been to this pilot study. In this respect, my participant for the pilot study differed in two characteristics from most other children in my primary study: unclear information about his HIV status and the fact that he was not in institutional care.

I conducted two interview sessions with him to explore his thoughts on what made him happy. The instruments that I used to guide these interviews were based on sand trays³ and drawings. Based on these sessions, I decided to exclude the use of sand trays as an instrument to support the informal interviews. I found that I could not control the cultural and contextual variables that the child ascribed to the Westernised versions of the miniature toys that were utilised in this activity. However, I found that the drawings formed the basis for rich and detailed informal interviews that contributed to my meaning-making processes.

Subsequent to this pilot study, I realised that having conducted just one pilot study was a potential limitation. In retrospect, I believe that I would have gained greater insight into the feasibility of using the other instruments, had I conducted an additional pilot study. However, I attempted to overcome this challenge by executing this study in a flexible and non-prescriptive manner. I constantly revised, reviewed and reflected on the approaches and the instruments that guided the approaches in this study (see Addendum 6).

3.4 Research methodology: data generation and documentation

Considering that this study was conducted with children facing multiple adversities in their lives, I chose my methods carefully and sensitively and I executed them skillfully. I am fortunate to have had extensive experience of working with children. I began my career as an educator and worked in foundational phase schooling for 12 years. Thereafter I qualified and worked as a practicing educational psychologist. My experience of working with children in a classroom context and in an educational psychology practice has prepared me to understand that children may not readily speak about emotional concerns that affect them most. Rather, there appears a greater possibility of children playing out their emotionality. According to Landreth (1991:7), "*...unlike adults, whose natural medium of communication is verbalisation, the natural medium of communication for children is play and activity.*"

³ Sand play is a therapeutic technique for children and adults with psychological and emotional challenges. In this pilot exercise, it was used as a data generation tool (see Addendum 3:3.2).

I accepted Noble-Carr's (2006) insight and adopted her multi-modal approach for engaging children in research on sensitive issues. A multi-modal technique may include utilising a combination of informal observation, open-ended interviews (to gain personal stories and experiences) and discussion groups based on activities (to build on individual narratives and to discuss broader issues and ideas). Offering options to children is thought to be particularly helpful in data generation, especially when the ages of children in a study varies, as some older children may not want to talk about sensitive subjects in front of younger children (Edwards in Noble-Carr, 2006). I incorporated participatory task-based activities in my study as I was encouraged by Power (1998), who maintained that although there is an emerging paradigm of complementary methods and approaches in qualitative research, it should not limit the scope of qualitative work.

Whatever particular structures are chosen for the generation of data, the literature placed the greatest emphasis on using creative and innovative techniques, such as visual and task-based activities or a *toolkit* of different activities, to prompt discussion and debate within the interview or discussion group setting (Noble-Carr, 2006). In particular, Sorin (2003) suggested that by including children's voices in the data generation strategies, richer and more meaningful data would be produced.

Although I adhered to the stance of Landreth (1991) and Oaklander (1988) that children can express their thoughts and feelings better through playing and acting out than through talking about them, I also considered Punch's (2002a & b) assertion that we as researchers should not undermine children by assuming that they do not have the competence to articulate their thoughts and feelings. From an African cultural perspective, Mwamwenda (1995:115) comments, *"...when subjects are provided with familiar materials and are encouraged to reflect on their answers, results are likely to be more positive."* By juxtaposing these scholarly views, I embraced what I considered the most appropriate manner to engage with the children in this study: informal and conversational interviews, which would be aided by task-based activities to stimulate, elicit and maintain conversation.

3.4.1 Data generation strategies

I began data generation with the children at my first visit to the children's home on 7 September 2007. During this initial contact, I casually observed the children as we interacted inside the home. I was able to sense their willingness or reluctance to be a part of the study. After this initial visit, I followed a planned schedule and I always informed the children about the dates when I would be visiting. I endeavoured to be consistent and

predictable in my weekly visits. However, during times when I could not visit the home I telephonically informed the housemother. My telephonic contact implied that I respected the children and therefore needed to ensure that they would be informed in time of my intended absence. If I had not informed them, they would have been anticipating my visit.

Although the initial conceptualisation and operationalising of this study began in 2006, the actual time that I spent in the field was between September 2007 and March 2008. Each session with the children ranged from one to four hours. The shortest session was on 22 November 2007 (see Addendum 6). A distinct advantage of conducting this study in a qualitative manner was related to the flexibility of the design. On many occasions I scheduled meetings with the children for an activity but had to cancel either because the children had to go someplace or I had work commitments that came up unexpectedly. Furthermore, although I had planned each session, I often had to alter my plan and then engage in another activity as the children were not keen on that particular planned activity but rather wanted to do something else. The following excerpt from my research journal illustrates my point.

Today's activity ought to have been-Draw a picture of yourself. Then we will talk about it. However, when I got there I realised that the children had something else on their minds. I think that their discussion had occurred earlier in the day because when I got there, they playfully coerced me to "ditch" the drawing because they wanted to play the board game once more. They apparently enjoyed it "so much" the last time and wanted to play again. So I postponed my planned activity for that day and enjoyed the board game with the children. (2008:03:07).

Table 3.1 provides a summary of the data generation and documentation processes that were utilized. I also provide a reference to the addenda where examples of the data may be viewed.

Table 3.1: Summary of data generation and documentation methods

Method	Type	Instrument	Documentation	Addendum
Interviews	Informal, conversational	<ul style="list-style-type: none"> o Spontaneous painting o Drawings o Incomplete sentence schedule o Collage o Draw and write activity o Board game o Clay modelling o Role-play 	<ul style="list-style-type: none"> o Voice recorded and transcribed into texts o Visual data-photographs 	4
Observations	Observation-as-context-of-interaction		<ul style="list-style-type: none"> o Research journal o Visual data-photographs 	6 8
Textual data: Document	Case reports		<ul style="list-style-type: none"> o Copied from social worker's file 	2

3.4.1.1 Informal conversational interviews

According to Punch (2002b:338), the choice of research methods *“not only depends on the age, competence, experience, preference and social status of the research subjects but also on the cultural environment and the physical setting, as well as the research questions and the competencies of the researcher.”* I considered the above variables when I decided to engage in qualitative research techniques for data generation that afforded a flexibility of design.

For the primary data generation strategy, I had the choice of different types of interviews (Patton in Cohen *et al.*, 2000) informal conversational interviews; interview guide approaches; standardised open-ended interviews and closed quantitative interviews. I chose to engage in informal and conversational interviews with the children, as this approach concurred with my research questions, and the context and the profile of the children. Cohen *et al.* (2000) refers to this type of interviewing as informal and non-directive interviews. This interviewing strategy resonated with my research approach as, germane to its flexible and fluid nature, I regarded myself open at all times to incorporate new areas of interest and concern as they were identified by the children in the study (Ridge, 2003).

I adhered to the following guidelines suggested by Noble-Carr (2006) as being necessary for conducting successful interviews with children:

- o I chose an appropriate setting;
- o I then established rapport with my participants;
- o I conducted informal and (at times semi-structured) interviews;
- o I enabled the children to provide a open account of their lived experiences;
- o I used open-ended questions; and
- o I employed the aid of various visual and task-based activities.

I used the medium of the informal interviews to talk about important issues in a conversational style and based on some activity that the child has performed (Cohen *et al.*, 2000:268-269). As I was careful to conduct interviews in a private space where each child was afforded confidentiality, I therefore took each child to a quiet spot in the garden (weather permitting) or to the corner of the room so we could talk in privacy.

The advantages of using informal and conversational interviewing for my study varied. Questions that emerged from the immediate context of the child were asked in the natural course of things and in a natural setting; and this approach to interviewing avoided the rigid question and answer method. The child's unique perspectives on many issues were thereby brought to the fore (Patton in Cohen *et al.*, 2000).

However, there were also limitations that were noted with this approach. The children were sometimes bored with the verbal conversations, were reluctant to talk and gave partial responses, as they seemed keen to get on with task-based activities. Other potential challenges related to (the researcher's) appropriate conversational skills (Patton, 2002). In this regard, I noticed that informal and conversational interviewing had the potential of becoming long-winded and required adept interviewing skills to bring the conversation into focus. Oppenheimer (in Cohen *et al.*, 2000:270) believes that facilitating interviews require skill on the part of the interviewer to handle the interview situation, thus enabling the participants to talk freely and emotionally. My interviewing skills as an experienced counsellor appeared valuable, as I was able to add to the richness, depth, authenticity and honesty of each participant's experiences. I also utilised my interviewing skills to draw the children's focus back to the conversation on hand where needed. I recognised that if my attempt to be child-centered was to be well grounded, then I had to negotiate around matters that were seen as important by the children (Kay *et al.*, 2003).

I adopted a flexible approach to foreground the children's subjective experiences during the interviews. Mauthner (1997) described three forms in which this process of flexibility can take place. Firstly, the researcher can let the children have a greater say in setting the terms of the conversations. A second way would be for the researcher to encourage the children to describe events from their daily lives through story telling and anecdotes, as children's stories would provide a background to their lives and act as a cue for the researcher to ask specific questions and give children their own voices in the interview. Thirdly, the researcher could also consider children's experiences of the research process itself. In my study, I chose to allow children to describe events from their daily lives, their personal likes and dislikes and information about themselves and their families, through story telling by means of anecdotes, role-play and drawings. I also allowed the children a sense of control in the study by allowing them to switch the voice recorder on and off at the start and at the end of a session and to listen to their voices whenever they asked to. They were aware of the voice recorder and often spoke in a deliberately loud and clear voice. This interweaving of the children's relationship to the research process, the researcher and each other was ongoing. I posit that this reciprocal and integrated process added to the depth and the quality of the data gathered for this study.

a) An introduction to the instruments that aided the interviews

During the exploration phase of this study, I was challenged by Power (1998:692) to engage in qualitative HIV&AIDS research that was imaginative and creative, "*...as unique data may be generated by insight, chance, serendipity, happenstance and the imaginative application of flexible methods.*" For instance, the use of a variety of task-based techniques to put children at ease and elicit discussion has been the most prominent distinguishing feature of the research conducted with children in recent times (Noble-Carr, 2006). However, there were drawbacks inherent in these choices. Kay *et al.* (2003) were confronted with the challenges of incorporating tasks for the in-between years (11 to 14 year age range), as these children regarded games as too childish, but found formal talk sessions intimidating. In a South African study, Strode and Grant (2001) presented children with pictures and vignettes, which allowed them to make up a story based on their experiences or to talk explicitly about the similarities between the scenario in the pictures and their own experience.

I stated earlier that I wanted to maintain their levels of interest and motivation for the duration of the research process. Therefore, I incorporated task-based activities in order to stimulate and encourage conversation with the children. My choice was also based on the

possibility of the presence of varying levels of competencies, articulateness and attention span among the children (Punch, 2002a & b). I attempted to strike a balance between not patronising the children and recognising their competencies, while keeping the study interesting and relevant to them (Punch, 2002b:54) in the chance of generating unique data (Power, 1998).

In Table 3.2 that follows, I provide a summary of the task-based instruments that I employed to guide the informal conversational interviews. Many of the instruments required drawings or writings. In the table, I comment on the format of the activities, the estimated duration of each task and the documentation process. I also provide a reference to the addenda where completed examples of the instruments may be viewed.

Table 3.2: Data generation instruments

Primary data generation method: Informal interviews Instruments that guided the interviews: Child-focused task-based activities			
What did we do?	How long did we spend?	How did I record?	Addendum 4
1. Spontaneous painting activity o group activity o individual interviews	45 minutes	o Completed picture was photographed o Interview was audio-taped and transcribed	4.1
2. Drawing: Drawing a person o individual activity and interview	30 minutes	o Completed drawing was photographed o Interview was audio-taped and transcribed	4.2
3. Drawing: A child in the rain o individual activity and interview	30 minutes	o Completed drawing was photographed o Interview was audio-taped and transcribed	4.3
4. Incomplete sentence schedule o small group activity	2-hour session	o Completed worksheet	4.4
5. Picture collage: All about me o group activity o individual interview	o 2-hour session – group activity to construct the collage o Individual 30-minute interviews with each child	o Completed collage was photographed o Interview was audio-taped and transcribed	4.5
6. Draw and write activity: I think, I feel, I need o individual activity	30 minutes individual activity	o Drawing and written text	4.6



Primary data generation method: Informal interviews Instruments that guided the interviews: Child-focused task-based activities			
What did we do?	How long did we spend?	How did I record?	Addendum 4
7. Board game: o small group activity and group discussion	45 minutes per group	o Field notes o Photograph of activity	4.7
8. Clay modelling o individual activity and interview	60 minutes per individual interview	o Photograph of modelled forms o Interview was audio-taped and transcribed	4.8
9. Role-play: A family experiencing illness o children worked in pairs	60 minutes per pair of children	o Photograph of children engaged in role-play o Audio-taped and transcribed	4.9
10. Drawing: How I see myself – self portrait o individual activity o small group interview	30 minutes	o Completed drawing was photographed o Interview was audio-taped and transcribed	4.10
11. Drawing: HIV in the family	o 30 minutes to draw the picture o 60 minutes per individual interview	o Completed drawing was photographed o Interview was audio-taped and transcribed	4.11

During the process of engaging the children, I endeavoured to tap into their interests when I incorporated the use of paintwork, cutting and pasting pictures about themselves, playing a group board game and engaging in role-play. I considered that school-going children usually find visual and written techniques familiar and non-threatening (Punch, 2002a). In addition, I was also aware that in qualitative research, the design is flexible and unique and evolves throughout the research process (De Vos *et al.*, 2005). In my study it meant that I had to adapt and change some of my initial ideas in order to suit the interests and competencies of the children in the study (see Addendum 6). My intention with these activities was not to impose my researcher’s perceptions and interpretations on the tasks. Rather, I preferred to listen to the children’s descriptions and interpretations of their activities (Punch, 2002a & b). I ascribe to the thinking of Cohen *et al.* (2000:267) that *“the interview is not simply concerned with collecting data about life: it is part of life itself and that its human embeddedness is inescapable.”*

I also incorporated task-based activities to facilitate the informal interviews on a sensitive subject with the children. I did not attempt to use psychological analysis or personal interpretations on any of the activities (Noble-Carr, 2006), as I am influenced by current debate, that raises concerns with the process and interpretations of children's drawings as the vehicles for establishing meanings and views (Backett-Milburn & McKie, 1999). These discourses have raised concerns that children are usually influenced to draw what they see in their environment, implying that they may reproduce images from their surroundings (Backett-Milburn & McKie, 1999). I therefore used the completed tasks as a means to communicate with the children and to gain their insights. My understanding of their pictures was based on their explanations. Therefore, it was the children's stories that conveyed relevance; their pictures were secondary to the process of data generation.

o **Drawings and picture making activities**

I utilised drawings and pictures as the primary instrument during interviews as it is recognised as one of the key means to encourage self-expression in children (Sampson, Rasinski & Sampson, 2003), and helps to reveal their inner mind (Greig & Taylor, 1999). Noble-Carr (2006) recognises drawing as one of the most popular and effective techniques employed in research with children. For example, Thomas & O'Kane (1998:342) used prepared sheets of paper for drawings with headings such as, *My favourite place* or *What I would change with my magic wand*. Hill, Laybourn and Borland (1996) used a similar technique and asked children to draw on a sheet of paper with the title: *This is a child who is feeling ___ because ___*.

I used my initial painting session as a helpful warm-up and relationship building activity in a group session to help alleviate possible anxiety and to put the children at ease (Kortesuoma, Hentinen & Nikkonen, 2003). Beazley, Bessell, Ennew and Waterson (in Noble-Carr, 2006) also used drawings in their study with children. Specifically, children were asked to draw *protection tools* such as umbrellas, shields or a jacket and to write something in each section of the drawing to represent things such as happiest memory, person you love most, and what makes you feel safe. In my study I adapted this approach and asked children to *draw a picture of a person walking in the rain and then to tell me a story about this person*. I assumed that in the process of relating a story of the child walking in the rain, I could gain possible insights into the children's self-image, confidence and potential sources of their anxieties.

In my study, the drawings that the children executed were: a picture of what makes you happy, a person, and a child walking in the rain, a self-portrait and depicting HIV in the

family. My rationale for using these activities was twofold. Firstly, the children perceived these activities as enjoyable and fun. I also offered them a barrier or a safe space from which to talk about their creations. Secondly, I was able to use the drawings as a stimulus for conversation. I noticed a significant aspect, namely that some of the instruments generated metaphoric responses from the children. These were in the form of stories and in the images that they created. See Addendum 4 for examples of the visual data that were generated by the children in this study.

In whatever format, drawing is effective because it gives children time to think about what they wish to portray. An added advantage is that the images can be changed or added to (Punch, 2002b: 331) if so desired. During the process, I was able to observe verbal and non-verbal interactions between the children. As I stated earlier, I chose to allow the children to engage in this activity as children may not always realise that their artwork expresses thoughts and feelings and are therefore not usually defensive about their drawings (Lyon, 1993).

In retrospect, I concede that drawing, or other artwork may not be a suitable technique to use with all children as some older children may be inhibited by a perceived lack of artistic competence and may not consider drawing to be a fun method (Punch, 2002a). For many children, drawing does not come naturally. I chose not to analyse the drawings, as I did not want to misinterpret the children's drawings by imposing my (adult) interpretations on the analysis (Punch, 2002b: 322). Therefore, I chose to talk to the children about the meanings they themselves attributed to their pictures (Morrow & Richards, 1996: 100). Throughout the data generation process, I adhered to asking the children in an open way to explain what their drawing meant to them and why they decided to draw those images (Punch, 2002b: 322).

- o **Collage**

This activity was useful in my study relating to sensitive and often emotional content as it allowed the children to step back from their own experience and discuss broader issues first, until they felt safe enough to relate to their own experiences. Nobel-Carr (2006) cited Aubrey and Dahl's (2006) study where children chose photographs of other children and were questioned about their perceptions of these photographs.

I used this activity to explore what children considered important in their lives and to talk about their hopes, dreams and plans for the future. It also helped spark the discussion and trigger memories of the children's personal experiences. My prompt to the children was:

Collect pictures and make a collage about yourselves and your lives. Remember, we will talk about each picture that you chose, later on (see Addendum 4:4.5).

○ **Draw and write activity: I think, I feel, I need**

The children drew a picture of a person and then indicated what they thought that this person is thinking, what he/she is feeling and what he/she needs. The rationale for using this activity was to allow the children to distance themselves from their responses, thereby creating a safe medium to express themselves. Furthermore, as explained elsewhere, it is assumed that children sometimes refer to themselves in the third person, so it was hoped that this approach would allow the researcher to get a glimpse into the thoughts of the children in the study. My prompt to the children was: *Make a picture of a person. Then write down what this person is thinking, what he/she is feeling and what he /she needs in his /her life.* The drawings and written answers were discussed with the children to ascertain their meanings. Rather than being used in a diagnostic sense, the use of children's drawing and writing offers one way of exploring their beliefs (see Addendum 4:4.6).

The draw and write technique presents advantages and possible challenges. Firstly, this technique is described as an innovative method to provide an empirical demonstration of the high quality of data that may be gathered from children (Pridmore & Bendelow, 1995). It offers many opportunities to explore meanings, especially related to health and illness (Piko & Bak, 2006; Backett-Milburn & McKie, 1999). Because images may be reproduced from other familiar images, an understanding of the child's social context would be needed before interpretations could be justified (Backett-Milburn & McKie, 1999). However, in my study I did not intend to interpret the drawings, but rather used them as a basis to elicit information about the child's thoughts, feelings and needs.

Other participatory techniques

Cook *et al.* (2003) suggest that children who rarely express their feelings through words may spontaneously share them through art and music. The creative process may not only provide an emotional outlet for the child but could possibly allow one to see what the child is thinking and feeling. I included other multi-modal instruments to aid the interview process.

○ **Board game**

The purpose of this board game was to explore the children's understandings and perceptions about different carefully chosen concepts related to the theme of my study. Board games have often been used in therapeutic processes. Byles (2007) used a board game to study its impact as a parent guidance strategy to reinforce Cognitive Control

Therapy in the home environment. In my study, I adapted the word cards of a board game used in psychotherapy with children, (Seedat, 2006) to make it relevant to my study (see Addendum 4:4.7). Word cards are usually borrowed in research practices from therapeutic work with children and are regarded as non-threatening and may be useful for children of all ages (Noble-Carr, 2006).

I also explored the dynamics between the children and the manifestations of confidence, self-esteem and self-worth that emerged. I recorded my observations in my research journal. A possible limitation that arose was that my voice recorder was not working on the day we played the board game. As a result, I had to depend on writing field notes and on photographing the process. I illustrate with an extract from my field notes.

The children were so excited about the idea of playing the board game today. During a previous session, I introduced the idea of a board game with them and then realised that they had not played a board game previously. So today, before we began, I explained the aim of the game and outlined ground rules. At the first roll of the dice, I turned on my voice recorder and noticed with dismay that it had no power. I tried to conceal my disappointment from the children and surreptitiously scribbled notes on a notepad regarding the content of the children's conversations and group dynamics. 2008:02:01.

Bellinson (in Byles, 2007) regards board games as structured activities that have specific rules of interaction. Arising from this view, the limitation of its use in my study was that the children were not familiar with the rules of board games and I had to adapt the rules to suit the needs of the children (see Addendum 4:4.7).

○ **Clay modelling**

At a later stage in the data generation process, I used clay to provide a medium through which I could base an informal conversational interview to explore deeper issues regarding family, HIV&AIDS and other relevant and emotional issues (see Addendum 4:4.8). This informal conversational interview and the clay modelling activity were conducted in an individual and private manner. My prompt to the children: *Use this clay and make a family with it. As you do that, we will talk about many things in your life.*

○ **Role-play**

Another instrument that seemed to appeal to the creativity of the children in my study was role-playing (see Addendum 4:4.9). Role-play can be an important tool for young children to express their feelings and can be an alternate way for listening to and observing young children involve their bodies and their senses (Clarke, 2005).

Children were grouped in pairs during this activity. I chose this activity to offer the children another modality in which to express themselves. Firstly, I wanted the children to engage in an unrestricted and spontaneous activity where I did not ask questions. Secondly, by using this approach I considered the possibility of the children subconsciously acting out pertinent aspects of their lives. My prompt to the children was: *Using these toys, I would like the two of you to plan and then to role-play a scene or act out a scene where a family is affected by HIV or where someone in the family is sick.*

Role-play methods can be developed by children or young people to portray events, life stories or issues that concern them (NSW Commission for Children and Young People, cited in Noble-Carr, 2006). This technique helped me to understand how the children perceived important events, and the role of significant others in their lives. In most cases, it is likely that the children in this study drew on their direct experiences when they role-played. Therapy was not an aim in my study. However, from a therapeutic standpoint, play may be regarded as beneficial for children who find it difficult to articulate their grief, because the process of play allows children to confront emotionally painful situations using a repetitive process of acting out their feelings and the situations that evoke them (Cook *et al.*, 2003).

I found the role-play sessions challenging for the following reasons: they were time consuming; they required clear guidelines; there were issues of control within the dyads of children – some children may have wanted to take control of the process. In addition, I found that a few children felt uncomfortable performing which could perhaps be attributed to their limited self-confidence or their introverted personality type. Noble-Carr (2006) also thought that some older children might be shy and would not want to participate in role-play. However, I did not find age to be a factor in role-play in my study. I acknowledge that children can be given more power over the research process if they are allowed to choose and/or direct the role-plays (Noble-Carr, 2006). However, I was focused on exploring a particular aspect of the study and did not allow the children to direct the theme of the role-play, but they were allowed to control the content by selecting the miniature toys they wished to use in their role-play.

o **Worksheet (Incomplete sentence schedule)**

In her research, Punch (2002a) utilised prepared closed and open-ended questions for children to complete. Noble-Carr (2006) cites other studies (Harden *et al.*, 2000; Beazley *et al.*, 2005 in: Noble-Carr, 2006) where written texts such as sentence completion exercises were used. I used this activity to explore the children’s subconscious responses to partially completed sentences (see Addendum 4:4.4). My prompt to the children was: *Complete these sentences with the first thought that comes to your mind.*

b) Potential benefits and limitations of instruments utilised

At this point, I would like to posit **benefits and challenges** of the task-based activities as a means to explore the children’s experiences of well-being while affected by HIV&AIDS. Table 3.3 provides a summary of the potential benefits and challenges that I encountered.

Table 3.3: Potential benefits and limitations of the task-based activities

Task-based activity	Potential benefits	Limitations
Spontaneous painting activity	<ul style="list-style-type: none"> o Useful in establishing rapport o Enhanced participation o Achievable, therefore boosted self-esteem o Non-threatening o Fun, engaging and enjoyable for all 	<ul style="list-style-type: none"> o Children tended to copy one another o Limited number of colours of paint that was made available limited their responses
Drawings: <ul style="list-style-type: none"> o a person o child walking in the rain o HIV in the family o self portrait 	<ul style="list-style-type: none"> o Drawings allowed the children to be creative o Provided rich visual images of what children considered important in their lives and how they viewed the world o Drawings were used in an exploratory manner in conversations with the children to avoid adult-imposed interpretations o Third drawing was a powerful tool upon which to base our conversation about HIV in the family 	<ul style="list-style-type: none"> o In the first 2 drawings children either tended to copy each other or draw in a similar manner
Incomplete sentence schedule	<ul style="list-style-type: none"> o The children chose the order in which they answered questions, which gave them time to think about their responses o They had the opportunity of afterthought where they were allowed to go back and add on or delete responses they were not comfortable about sharing o Not dependent on spoken language 	<ul style="list-style-type: none"> o Difficulty in expressing thoughts in writing
Paper collage	<ul style="list-style-type: none"> o Detailed information was gathered o Provided rich visual images of what the children considered important in their lives 	<ul style="list-style-type: none"> o Time-consuming o Restricted to the pictures contained in the magazines provided to the children



Task-based activity	Potential benefits	Limitations
Draw and write activity: I think, I feel, I need	<ul style="list-style-type: none"> o A combination of writing and drawing provided in-depth information o Not dependent on spoken language 	<ul style="list-style-type: none"> o Difficulty in expressing thoughts in writing o Too abstract for some of the children
Board game	<ul style="list-style-type: none"> o Small group activity that allowed observations of nonverbal behaviour and reaction and understanding of keywords in the game 	<ul style="list-style-type: none"> o My voice recorder did not work and so I covertly wrote field notes
Clay modelling	<ul style="list-style-type: none"> o Physical manipulation of clay possibly served as an outlet for emotions o Seemed to have allowed the children distance from the topic in which they were engaging 	
Role-play	<ul style="list-style-type: none"> o An attempt to make the study fun, to maintain levels of enthusiasm for the study o An alternate mode that took different interests into consideration as not all children might have found paper-based activities fun and enjoyable 	<ul style="list-style-type: none"> o Time-consuming o Children bickered about who should pair with whom in this activity

I found that one of the main advantages of using multimodal task-based activities as a means of data generation was the sustained level of enthusiasm it offered the children in the study. By utilising participatory techniques, I was able to cater for the varying interests and competencies amongst the children. As the study progressed, I was able to engage with the data that was emerging by constantly moving back and forth between the analysis and the data generation to ensure that my understandings were in fact the interpretations that the children provided. Thus, my presence ensured that I did not miss important phenomena and the use of multiple task-based activities proved to be a useful validation mechanism. In this way I was also able to implement an informal procedure for member checking. Member checking (Lincoln & Guba, 1985) is one of the ways in which a qualitative researcher may enhance the validity of the study.

Overall, I found the drawings and picture making activities as well as the role-play activity to be the most successful in terms of the quality of data they generated during the informal interview. I found the incomplete sentence activity to be the least successful as the children were least motivated to complete this task. I believe that a possible reason for the lack of interest in this activity was because of their limited spelling and writing skills as illustrated in their school reports. Furthermore, the incomplete sentence activity was perceived as less fun and inspired little creativity from the children. Although conducting the board game proved extremely challenging due to the group dynamics, the children’s responses to the cue words offered me a glimpse into their perceptions of key concepts (see Addendum 6).

3.4.1.2 Observation

My role as a qualitative researcher meant that I was interested in observing the children as participants in my study. Hence observations formed an essential part of my research on both the individual and group levels. Although I relied mainly on informal conversational interviews as the in Cohen *et al.*, (2000) primary data generation strategy, I also utilised observational methods to note body language and other gestural cues that lent meaning to the words of the children being interviewed (Angrosino, 2005:729) and to observe interactions amongst the children and between the children and myself. I adopted a participatory role in this study so I could observe from an insider perspective. For these reasons, my chosen observation method may be described as observation-as-context-of-interaction (Angrosino & Mays de Pèrez, 2000).

I took into account that observation of human actions and interaction can only be interpreted in the situational context in which it occurs and not by means of pre-determined codes (Angrosino & Mays de Pèrez, 2000). Therefore, my observational methods did not entail structured or predetermined categories of responses but rather was broad and descriptive. I relied on casual and unobtrusive observations to gain insight into the environment of the children in the study, their relationships with each other, their caregivers and community volunteers. Moreover, considering the health status of the children in my study, an advantage of observational methods was that it guided me in structuring my interviews with the children. From my insider stance, I was able to ascertain when the children were not feeling well enough to engage in interviews or whether they needed to rest (see Addendum 6).

The challenge that I experienced in utilising observation related to my experience that observations might be directed at external behaviours; as a result I had to infer the thoughts and feelings of the children in the study. As I utilised interviews in conjunction with observations, I was able to verify my meaning-making processes. Another challenging aspect of observation is that the researcher has the potential to influence the situation being observed, thereby resulting in data that is not reliable (Patton, 2002). I continually reflected on my positionality and the possibility that my presence might have influenced my observations (see Addendum 6:6.2).

My weekly visits to the children's home were ideal for recording my observations as unobtrusively as possible. Perhaps due to my background as a psychologist, I am not comfortable about writing or recording notes in the presence of the children with whom I am

engaging. I found that this approach served as an obstacle and limited my engagement. Therefore, in this study, I would often simply scribble key words in between the children's activities. I waited to get home in the afternoons and then wrote my detailed descriptions in my research journal. In the early stages, this recall was difficult for me and I later realised that I had forgotten to record important observations. However, as I delved further into the study and became more familiar with each child and their home situation, it became easier for me to write key words and phrases at the site and then the detailed descriptions when I got home.

I recorded my observations of the physical descriptions of each child, their mood for the day, their interactions with others or perhaps a particular interaction that I observed as important. I also recorded their interactions with significant adults in the home. During our conversations, I recorded non-verbal behaviour as well as body language and facial expressions. Often, I also recorded my feelings and perceptions. I found it to be an advantage of the observations that I was able to view the children's actual behaviour in its particular context. However, I also found that when I relied too heavily on observations, I risked losing the voices of the children.

I used a research journal to record my informal observations, my field notes and my reflexive thoughts (Patton, 2002; Terre Blanche & Kelly, 2002). However, some parts were captured electronically while at other times, I wrote in my journal. Early in the study, I found that using a research journal would prove especially valuable in documenting the processes, time lines, logistics and decisions made in the early stages of proposal writing and gaining access to the research site. However, further on, I realised that my research journal had become an even more valuable companion to me as I began to document my thoughts, feelings, perceptions and observations during and between sessions with the children (Patton, 2002; Terre Blanche & Kelly 2002). I depended heavily on my field notes for recording emotions and non-verbal behaviour as well as key words during conversations. This was especially so when my voice recorder would not work and or the child requested that the voice recorder be switched off (see Addendum 6:6.2, p6).

My research journal allowed me space to reflect and to express my emotions in a safe and constructive manner. In addition, my research journal became a tool for ensuring the quality of the study, to provide the messy evidence and to record how processes and decisions were reached. Rowling (1999) kept a research journal as distinct from her field notes. Corresponding to Rowling's (1999:178) views, the research journal allowed me to trust the process.

I provide an example of the potential value of recoding my observations and conversations in my research journal. Although I had indicated that in this study, the voices of the children would be foregrounded, I must add that I also spoke to the social worker at particular points as the information she provided helped me to direct the research process. During a particular session with the children, I had the opportunity of having an unplanned and unscheduled conversation with the social worker who arrived at the research site. After our conversation, I recorded the important points in my research journal. In this informal and spontaneous manner, I was able to gather valuable information pertaining to the children in the study that informed my data generation process (see Addendum 6:6.2).

3.4.1.3 Textual Data: Social worker's report

The social worker, who has been appointed as the guardian of the children, allowed me access to each child's medical file and the case report that she compiled when the children were initially admitted to the children's home. I utilised the information from the case report as a means to understand the children's life context. Furthermore, only information that was essential to this study was utilised. All information that was provided has been kept strictly confidential: children's identities have been protected as much as possible in the information that I report on (see Addendum 2).

3.5 Data analysis and interpretation

A key characteristic during data analysis in interpretative studies is to produce high quality, meaningful and relevant data that make it possible for valuable insights to emerge within a social context. In my quest to maintain my research partner's presence throughout the research process, I utilised the principles of the constructivist grounded theory approach in the thematic analysis and interpretation of my data (Charmaz, 2000). Gathering and analysing data concurrently formed a mutual interaction between what was known and what I needed to know. This pacing and the iterative interaction between data and analysis formed the core of attaining reliability, validity and rigour in my study (Morse, Barret, Mayan, Olson & Spiers, 2002; Lincoln & Guba, 1985).

3.5.1 Constructivist grounded theory

The principles of the constructivist grounded theory (Charmaz, 2000:509-535) that informed my approach to data generation and analysis included a collaborative relationship between myself (the researcher) and the children in my study; keeping myself (the researcher) close

to the children in the study by keeping their words intact in the process of analysis and by writing in a manner that demonstrated the potential to communicate how the children constructed their worlds (Mills, Bonner & Francis, 2006).

In my approach, I considered the multiple social realities in which my study is embedded. In light of this, I ascribed to eliciting multiple meanings from a process of mutual (myself and my participants') knowledge creation (Mills *et al.*, 2006). In addition, I was guided by the following data analysis and interpretation strategies suggested by Charmaz (2000) (see Addendum 5):

- o I coded the data I gathered from the multiple data generation methods.
- o I applied selective or focused coding to highlight the specific concepts that shaped my understanding.
- o I defined and categorised data.
- o I wrote memos (notes) throughout the process.
- o I employed theoretical sampling (purposive sampling).
- o I integrated these suggestions in my approach to data analysis and interpretation.

3.5.2 Thematic analysis

The experiences of the children are embedded in the data that has been generated across a spectrum of sources. Considering the diverse, complex and nuanced underpinnings of qualitative research in general, thematic analysis in this instance offered a foundational method for analysing the data (Braun & Clarke, 2006). I utilised this approach for identifying, analysing and reporting patterns or themes within the data. In the process, I discovered that often, the analysis went deeper than a single level to interpret various aspects of a research topic.

One of the benefits of a thematic analysis is its flexibility (Braun & Clarke, 2006) and the fact that it may be applied across a range of theoretical and epistemological approaches while not anchored in a particular theory or epistemology. According to Braun & Clarke (2006:78), *"through its theoretical freedom, thematic analysis provides a flexible and useful research tool which can potentially provide a rich and detailed, yet complex account of data."* I adapted and integrated the approaches suggested by Charmaz (2000) and Braun & Clarke (2006) to inform my data analysis and understanding process. I followed the suggested steps quite broadly, as I found that the stages and processes tended to overlap.

3.5.3 Process of data analysis and interpretation

After my initial session with the children, I immediately and independently transcribed the interview (see Addendum 5) making sure that my typed transcriptions reflected as much of the exact voice recording as was possible. For an accurate reflection of the taped interviews, I also compared my field notes to my transcription (Cohen *et al.*, 2000). During the initial stages of reading, I started to look for and notice patterns of meaning and issues of potential interest. I read and reread my transcriptions (to become immersed in the material) while writing memos in the margin and in the field notes (Creswell, 1998) (see Addendum 5). Considering that I conducted the entire research process independently in the field (data generation, transcriptions of voice recording, photography of visual images, analysis of textual evidence), it was an advantage to me as I was familiar with the material. The concept of familiarisation distinguishes interpretive research from its positivist counterpart in that there is no attempt to define variables (Mills *et al.*, 2006). I found that the suggestion by Terre Blanche and Durrheim (1999), to stay close to the data and to interpret it from the position of emphatic understanding, was of tremendous benefit to me as I was fully immersed in the data and was able to conduct the open coding process fairly rapidly.

Since I regard writing as an integral part of the analysis process, my writing began with the jotting down of ideas, potential codes and possible themes. When I advanced into the second and third phases of data analysis and interpretation, I worked closely with my research supervisor on a weekly basis. We coded and re-coded the interviews, line by line (Charmaz, 2000) which helped me to discover recurring ideas, patterns or and concepts.

Concurrently, we made notes regarding emerging patterns and possible the broad themes that could be used (see Addendum 5). This phase, which involved the production of initial codes from the data, is referred to as open coding (Ezzy, 2002; Charmaz, 2000). I used a bottom-up approach (inductive approach) to work out naturally occurring commonalities in words, phrases, and themes. We began sorting and organising the elicited codes into categories that seemed to share or reflect similar thoughts, feelings or behaviours. In this process, I also had in mind the conceptual framework of this study and thereby attempted to generate categories that could possibly align with key concepts in the conceptual framework while adding new or different insights to generate a theory on how the children in this study experienced well-being.

Allied to the process, at one stage of data generation and data analysis, I found that I required further expressions about aspects related to a particular research question. Going

back to the field is characteristic of constructivist grounded theory. However, the theoretical sampling process that I undertook was purely to refine and focus my ideas and to add depth on specific information (Charmaz, 2000). The intention was not to contribute more data. I constantly took cognisance of suggestions by Braun and Clarke (2006), to code for as many potential categories and themes as possible and to code extracts of data inclusively so that I did not lose the context of the data (Terre Blanche & Kelly 2002; Patton, 2002; Miles & Huberman, 1994) (see Addendum 5).

Based on the initial analysis sessions with my supervisor, I was able to engage personally and at a deeper level with the material and to go back to the raw data to alter, adjust or modify the codes that I had generated, to align them with my conceptual framework. I found that the analysis and interpretation process was not simply linear, but rather more recursive in nature (Braun & Clarke, 2006). I moved back and forth as needed throughout the process to elaborate, clarify and rephrase initial ideas as they related to the critical questions in my study. I aligned the raw data with the actual codes that were used, and then the codes were grouped into categories and possible themes. I employed a visual strategy of recording all codes on individual cards, which were then pasted onto a wall (see Addendum 5:5.4). They served as reminder to me and I was able to constantly engage in the process of analysis, interpretation, synthesis and theory construction. Along these lines, I discovered relationships between and across categories and themes, which encouraged me to make linkages and offer plausible explanations for these.

When it seemed that I had saturated (Morse *et al.*, 2002) the coding process, I formalised the emergent themes by cross-checking and validating with the raw data and the list of codes. This reviewing and refining process alerted me to the occurrence of possible sub-themes, which I then incorporated in the final analysis.

I employed member checks (Lincoln & Guba, 1985) to verify my findings. I presented a summary of my findings to a few children in my study to review for accuracy in my understandings and interpretations in the emergent themes. This member validation process afforded me the opportunity to re-engage with my partners in order to encourage further elaboration, clarification or correction (see Addendum 7).

In Chapter 4, I shall present the results of my thematic analysis. In Chapter 5 I shall then engage in a critical discussion of the findings constructed from a qualitative inductive thematic analysis approach.



3.6 Ethical considerations

Researching children's lives raises a number of methodological issues. Along with issues of consent, access, privacy and confidentiality there was also the question of unequal power relationships between vulnerable children and myself as an adult researcher. Mauthner (1997) described several ways of minimising unequal power relations between the researcher and the child participants. The ideas that I incorporated into my study included researcher responsiveness, reflexivity (see Section 3.7.2) and open-ended research goals and methods, which allowed the children to set their own agendas and talk about their views and their daily lives.

I learnt early on in the research process that by adopting a reflexive approach to the study, I would be able to engage with many of the following ethical considerations that arise in research in general, and in particular when conducting research with vulnerable children. I considered the following issues: informed consent and children's assent, protection, privacy, confidentiality, being accountable and addressing power imbalances.

I shall now describe the various ethical principles that underlined this study and how I engaged with them. As my research participants were minors, I obtained written informed consent from the primary caregiver of the children, the social worker who was appointed by the Children's Court to act as guardian to the children (see Addendum 1:1.3).

I obtained written informed assent from the child participants. Schenk and Williamson (2005) describe informed assent as an active agreement from the child while recognising the child's age and level of maturity. My research participants voluntarily agreed to be a part of this research after I explained the research in detail to them, on an age-appropriate level and in language with which they are familiar. To enhance the ethicality of this study, I engaged the cooperation of the social worker to act as child advocate and witness to the informed assent process, and to ensure that adequate protection was provided to the child participants (Schenk & Williamson, 2005).

Throughout the research process I was acutely aware of the potential for harm and took all precautions to ensure that the participants were protected at all times. I continuously strived to act in such a way as to preserve their dignity, respect and privacy as human beings (Cohen *et al.*, 2000). I constantly reflected on my role and my presence in the children's lives and ultimately decided that I was accountable to the children in different ways. Firstly, I was accountable for representing the stories of their lives as accurately as possible. Then I

was accountable for the children's well-being for the duration that they were in my care for this research.

For these reasons, I took the following measures during the research process:

- o I clarified my role as a researcher to the children in the study and to their caregivers at the first session.
- o I engaged in activities that were aimed to put the children at ease and to reduce anxiety as much as possible.
- o I referred children to the social worker for counselling after an intense and emotional session. I followed up with the social worker the following week to ensure that the child had indeed received counselling.
- o I discontinued sessions when I realised that the children were tired or were not really in the mood to engage in activities.

I ensured privacy and confidentiality in the following manner: I switched off the voice recorder at certain points; I did not probe or ask intrusive questions when I saw that children were visibly upset, either by their words spoken or by gestures and other body language; moreover, the children chose pseudonyms at the start of the study in order to protect their identities (see Addendum 6). Furthermore, I obscured the children's images in my presentation of my results to further ensure anonymity.

3.7 What challenged me and how I worked through the issues

3.7.1 My role as researcher

My greatest dilemma prior to beginning this study involved a clash between my ontological beliefs about how I believed this research with the children ought to be conducted and how to execute it in a scholarly, scientific, accountable and responsible manner. It is a commonly held perception among academics and researchers that in order to elicit reliable and valid data that is untainted by researcher bias, one has to maintain an emotional and empathic distance from the research participants (Schwandt, 2000).

I decided that if I needed to connect with the children on a deep level in order to understand their experiences, then I would firstly have to work on building a mutual relationship of trust and sincerity between my research participants and myself. I worked intensely at establishing a firm foundation of trust and respect as, according to Power (1998), the

qualitative researcher is responsible for forging trusting and sensitive links with the respondents in AIDS research.

I provide an excerpt from my research journal that highlights the dilemmas I faced.

In my initial planning I decided to make my engagement with the children fun and exciting. Since HIV&AIDS is highly stigmatised and still very much taboo in many societies, I was sure that I definitely could not broach the subject very early on in my relationship building with the children. When I drew up my research proposal and defended it in January 2007, my plan was to spend 2 months in the field with the children. I had planned a session each of drawings, clay modelling, completing an incomplete sentence schedule and sand tray images. I had also planned to conduct interviews with the caregivers and the teachers. However, after my first 2 visits with the children, it dawned on me, that there was really no way in which I could gather deep and relevant data from children who had experienced severe trauma and who appeared to be distrusting and emotionally "closed." I struggled with the dilemma of my ethical obligations to the children after I have established a relationship of trust. I was once asked, "What is the ethics around doing research with someone who is dying?" The implication with this question was, "what's the point of conducting research as he is going to die anyway." These comments struck a deep chord within me and I felt an overwhelming sense of relief when I came to the realisation that it was the voices of the children that was the most important component in this study. Children in this study were not children who were dying, but children who are living and they deserved to be heard. (February 2008).

I constantly reflected on my role in this study (see Section 3.6.2 and Addendum 6:6.2) and after reading Burgess (1994), I realised that I was accountable to the children in this study who placed their trust in me. Burgess (1994) stressed that researchers needed to be balanced in their quest for moral accountability and responsibility to participants in the research. Furthermore, I took cognisance of Mason's (2002:67) warning that one should not try to turn an interview into a therapeutic encounter because this may not be the *best* moral choice. When I understood and personalised the study as such, I became unstuck and found it easier to distance myself as a researcher, albeit in a very empathic manner. I was able to define my role as the researcher clearly and to work within the confines of that distinction.

I was advised by my family and colleagues not to get *too close* to the children in the study. Rowling (1999) grappled with a similar dilemma many years earlier. She pointed out that maintaining distance from your research participants actually implies detachment. This detachment relates to indifference and coldness to the emotional responses of participants. To me this indifference actually implied a paradoxical situation, as my participants' emotional responses to their experiences were the empirical data of this study. Therefore, I

concur with Rowling (1999) that being detached would not yield the quality of data that would answer the critical questions of the study. I therefore engaged in a process of empathic interviewing as a means to reduce the emotional distance between the children and myself as researcher. Rowling (1999) refers to empathic distance as part of her researcher's role. I concur with Rowling (1999:174) in her view that "*researching sensitive issues needs an empathic involvement because of the nature of the research topics and consequent subjective experiences in the research process.*" In essence, these views represented the qualities underpinning my interpretivist inquiry.

This means that interpretations may be influenced by language, gender, social class, race and ethnicity. Therefore, I consistently reflected on my personal involvement in the research situation. Furthermore, by keeping a research journal, I documented my thoughts, feelings and my reflections on how my personal circumstances might have influenced the findings of this study.

I acknowledge that throughout the data generation and writing up processes, emotions (those of my child-participants and my own) played an important part. I found that my research journal proved to be an extremely useful space within which I could reflect on my emotions as well as my personal bias and subjectivity, which could have influenced the findings of this study (Terre Blanche & Durrheim, 1999). I acknowledged the children's emotions in a respectful and sincere manner, a skill I have developed in my training and practice as a therapist. In writing up, I found that I had to exercise control over emotions in order to theorise the findings. I found that writing and then re-writing helped me to de-emotionalise the text. I often replaced evocative or emotional language with scholarly language. This helped me to remain focused on writing this thesis in a scholarly and academic voice. Another strategy that I employed in my writing was to write in a very structured way. I discovered that this tool helped create a distance between me, the researcher and writer of this text, and me, the person who engaged with the children on a personal and emotional level for a prolonged period of time (see Addendum 6).

3.7.2 Reflexivity

According to Richardson and St. Pierre (2005), reflexivity describes the author's subjectivity as a producer and as a product of the written text. Significant questions asked by Richardson and St. Pierre (2005:964) include, *"Is there adequate self-awareness and self-exposure for the reader to make judgements about points of view? Does the author hold himself or herself accountable to the standards of knowing and telling of the people he or she has studied?"* Guillemin and Gillam (2004:275) explain that *"adopting a reflexive research process means adopting a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data but also to the researcher, participants and the research context."*

In this study, I achieved a reflexive practice through internal dialogue and constant (and intensive) scrutiny of the process through which I constructed and questioned my interpretations of field experiences (Noble-Carr, 2006). In other words, reflexivity requires that researchers step back from their own adult perspectives to constantly question their role, assumptions, choice of methods and application of these methods throughout the whole research process (Punch, 2002b). Flexibility and openness to new ideas and ways of conducting research are crucial to a reflexive practice.

In my reflexive approach, I made careful observations and assessments on what was and what was not working. I then adapted or changed my techniques according to the children's competence and whether or not the key research questions were being answered (see Addendum 6). Furthermore, to address power imbalances, I utilised non-confrontational participatory techniques, which were in some instances chosen by the children themselves (Morrow & Richards, 1996). In my study, a reflexive stance was also useful when I analysed and attempted to make sense of my data. As a researcher I was constantly aware of the potential of my own bias that might encourage me to interpret children's behaviours or views through my own frame of reference of a graduate, middle-class woman. I therefore abided by Noble-Carr's (2006) suggestion to meet with other members of the research team (my supervisor and co-supervisor) who assisted me in addressing these issues (see Addendum 6:6.2 p16, 19).

Throughout the research process, I adopted a critical approach and constantly reflected individually in my research journal as well as with colleagues in my field and with my research supervisor upon choices and decisions that I made, my role in the field and the unplanned for ethical challenges along the way. I believe that by adopting this reflective

attitude, I was able to improve on the quality and validity of each stage of the process thereby leading to research that was more rigorous. This view is made explicit by Guillemin and Gillam (2004), who deem reflexivity in qualitative research as a perceived way of ensuring rigour. In my reflexive practice I therefore engaged in a process of critical self-reflection pertaining to how I (as the researcher) constructed knowledge from the research process, what factors influenced my construction of knowledge and how these influences were revealed in the planning, conduct and writing up of the research.

3.8 Ensuring the rigour and quality of the study

“Without rigour, research is worthless, becomes fiction and loses its utility” (Morse et al., 2002:2). I strived to ensure rigour in my study by addressing aspects of reliability, validity and trustworthiness. As the aim of my study was to understand participants’ construction of well-being, the credibility of the research could not be established separately as an outcome but was constructed into and was integral to the entire research process (Morse et al., 2002).

Various terms in qualitative research allude to the establishment of believable results. When a qualitative researcher speaks of credibility, trustworthiness and authenticity (Creswell, 2003), it is accepted that the validity of the study is being referred to. I adopted these terminologies when I referred to the validity of this study. Validity may be regarded as the strength of qualitative research and maybe used to determine whether findings are accurate from the standpoint of the researcher, the participant, and the readers (Creswell, 2003; Kvale, 1989). Throughout the processes involved in this study, I strived to ensure that the research was conducted in a trustworthy manner. Techniques to improve the internal validity (the match between findings and reality) such as using member checks, triangulation (crystallisation) and peer reviewing were all a part of my research plan (Creswell, 1998; Merriam, 1998).

The aim of this study was to establish believable results and to demonstrate that the research had proceeded in a manner that was consistent with accurate identification and description of the participants’ experiences. I will now outline the procedures that I followed to enhance the credibility of my study.

Because of my lengthy interaction with the children (Lincoln & Guba, 1985) in the field, I was able to develop an in-depth understanding of the experiences of the children in this study. In addition, I believe that my patience and acceptance of the children added value

and rigour as I was able to slow down the field work and not push the children because of researcher time constraints. I allowed the children to conduct activities and to respond in a manner that suited them. The children in my study were not pressurised to conclude an activity or respond quickly. Instead, at each session, if an activity was not concluded, I arranged for completion at the next session. I also made a deliberate attempt at more conscious use of language as I was aware that I should not appear patronising to the children (Punch, 2002a & b). I have provided a schedule detailing the time that I spent with the children at each session in Table 3.1 (also see Addendum 6:6.1).

While some writers use the term triangulation (Patton, 2002; Creswell, 1998) to refer to the deployment of different methods to validate findings, I adhered to the term crystallisation (Richardson & St. Pierre, 2005:963). Unlike triangulation which involves a rigid, fixed, two-dimensional object, crystallisation is described by Richardson & St. Pierre (2005:963) as *combining symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities and angles of approach*. Therefore, I utilized a crystallised approach for a deepened and multifaceted understanding of the phenomenon under investigation.

While the primary data source was from the informal conversational interviews, I also gathered data by observations, field notes, and engaging in ad hoc conversations with other caregivers involved in the daily care of the children. This process of crystallisation unfolded when I engaged the children in a variety of participatory task-based activities that formed the basis for the informal and conversational interviews. These activities were discussed in detail earlier in this chapter. I conducted member checks (Lincoln & Guba, 1985) as an integral and integrated part of my conversations with the children. I integrated member checks as part of my interviewing style. This means that during the interviews, I constantly reflected, repeated and summarised the children's words to ensure that I did not misunderstand the children's words or their interpretations (see Addendum 5). Furthermore, whenever I read the transcripts and realised that I was not quite sure about what the child said or was referring to in a conversation, I followed up with the child on this point on a subsequent visit. In this way member checks were recurrent during the data generation and analysis phase. At the conclusion of my study I collaborated with the children in the study to confirm my findings (see Addendum 7).

From the outset, it was vital for me as a novice researcher to collaborate with senior and experienced researchers in my field to offer objective and valuable peer review and debriefing (see Addendum 6:6.2 p16). I approached PhD qualified colleagues in the

department of Educational Psychology who acted as critical readers (see Addendum 6:6.2 p19). Furthermore, I sought the professional opinion of another colleague to analyse a transcript of my conversation with the children. I then compared her coding to mine and my supervisor's and incorporated her suggestions. I also collaborated with my colleagues and more especially with my supervisor to debrief after emotionally laden sessions with the children. I realised that since emotions were a key component of this research, I needed to address mine in a constructive manner to be able to contain those of the children when I met with them (Rowling, 1999). Creswell (1998) refers to this strategy as peer debriefing to enhance the accuracy of the account. These debriefing sessions provided me with immense emotional support and in this mode, I believe, the trustworthiness of the data was enhanced.

In addition, I provided an in-depth description of the setting of the study, the participants, social groups and interaction patterns as a means of enhancing the trustworthiness of the study (see Addendum 8). I was critically present in the case study by engaging my participants and listening to their reflections about their experiences of their negotiating constructs of well-being while living in the adversity of HIV&AIDS. Such presence ensured that I did not miss the occurrence of phenomena.

I incorporated a chain of evidence (Miles & Huberman, 1994) as proof the processes and engagements (see Addenda 1 to 8). My notes my research journal with regard to logistical arrangements, requests for appointments to meet with the children and my personal and reflexive thoughts and research schedule were included in the chain of evidence. In my writing of this thesis, I incorporated low-inference descriptors such as participants' verbatim accounts of their experiences and descriptions of their stories to ensure the internal reliability and dependability of this study (Seale, 1999:148). Furthermore, the mechanical recording of data was an important element that I considered. I documented my data generation using audio (voice recordings) and visual documentations (photographs as end products of activities) to ensure that data would be stored in its original form.

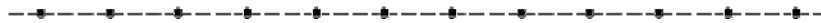
3.9 Summary of the chapter

In this chapter, I focused on a comprehensive account of the methodological processes that I employed in my exploration of children's experiences of well-being. I explained the choices that I made at each stage of the research process while also offering glimpses into my reflexive notes and research journal. I integrated dialogue pertaining to my primary and secondary data generating methods with a critical discussion of the research instruments



that guided the data generation methods. I also expounded my data analysis strategy while outlining the key principles that guided this process. I documented my ethical decisions and reflected on the challenges that I encountered. I concluded this chapter by explaining the ways in which I enhanced the trustworthiness of this study.

In the next chapter, Chapter 4, I report on the results of this study. I structure the chapter by addressing the themes, sub-themes and categories as they addressed my research questions.



CHAPTER 4

Reporting the results of the study

4.1 Introduction

In Chapter 3, I presented the empirical basis of my study by describing and justifying my choice of research design, data generation methods and my approach to data analysis and interpretation. My choices were based on the purpose of my study and the critical research questions that guided my inquiry.

In this chapter, I report on the results of my study by presenting the themes that emerged during the thematic analysis of the raw data. The discussion of themes, sub-themes and categories is enhanced and enriched by direct quotations, vignettes and visual images. In most cases, I present the unedited versions of the children's actual words. This chapter presents examples of rich descriptive data that represent the children's voices.

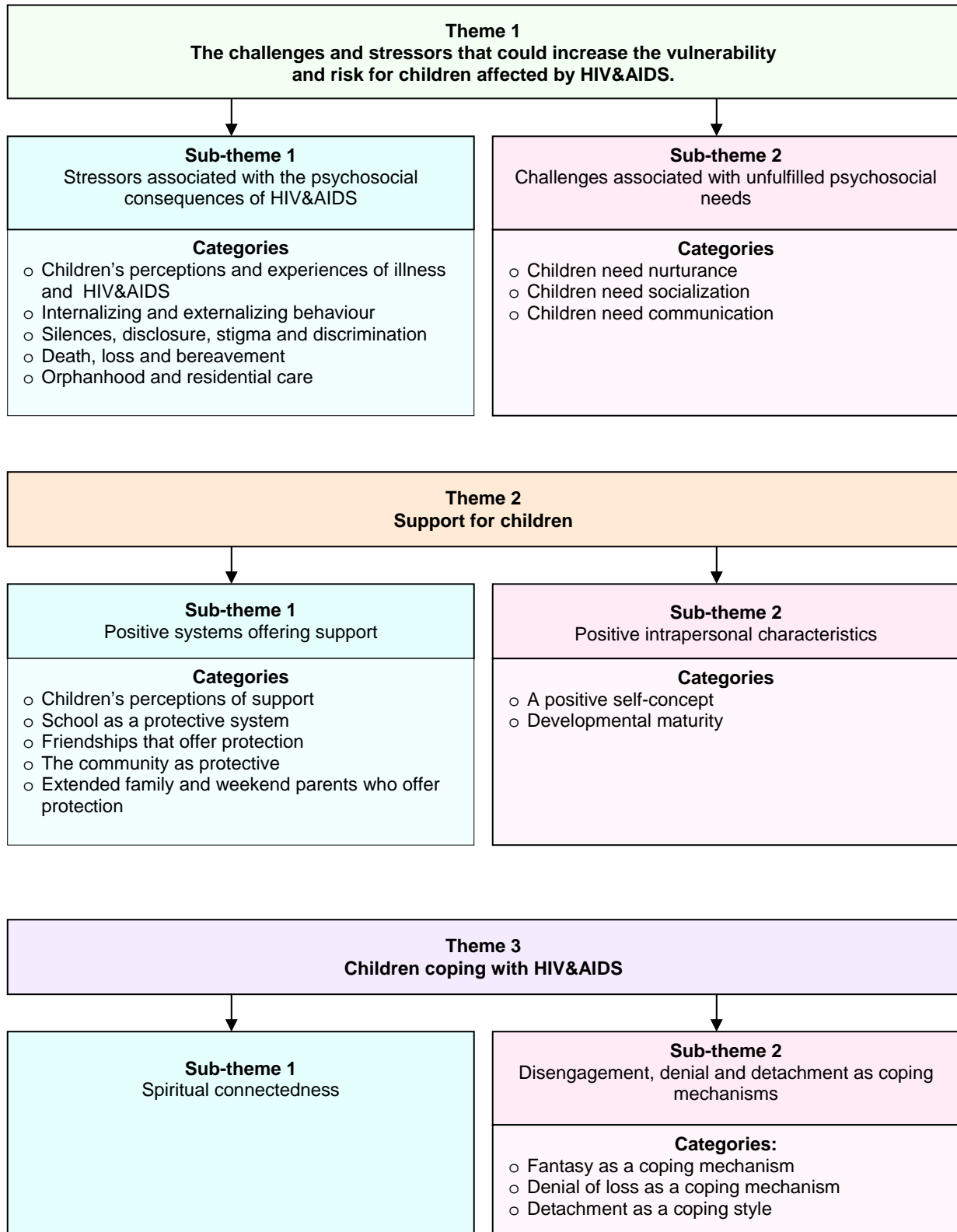
4.2 Presenting the results of this study

I structure this chapter according to the following themes that emerged:

- The challenges and stressors that could increase the vulnerability and risk for children affected by HIV&AIDS.
- Support for children.
- Children coping with HIV&AIDS.
- What are the well-being experiences of children affected by HIV&AIDS?

In this section, I provide the inclusion and where relevant, the exclusion criteria for presenting the results which emerged from the data. This study focused on exploring, understanding and describing how a group of children (aged between 10 years and 15 years) who were affected by HIV&AIDS constructed well-being in their daily lives. To do this, I excluded the voices of other important people in the children's lives, namely their caregivers and teachers. In certain instances and where relevant for background information and understanding, I incorporated extracts from my field notes in which I described my conversations with the social worker who is the children's guardian. Furthermore, in my exploration and analysis of the data, I included the children's direct and indirect references to the psychological, social and emotional aspects of their lives. I also included children's responses that may be regarded as negative cases. In this study, I did not differentiate the children's experiences by age, gender or HIV status. I excluded references that were made

to the financial or economic implications of the impact of HIV&AIDS. Figure 4.1 provides a visual representation of the emerged themes, sub-themes and categories.



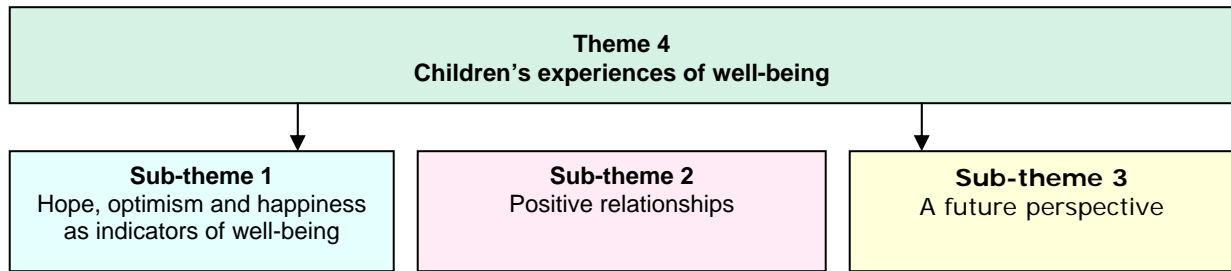


Figure 4.1: A visual representation of the emerged themes, sub-themes and categories

4.2.1 Theme 1: The challenges and stressors that could increase the vulnerability and risk for children affected by HIV&AIDS

In this section I report on the results which related to the challenges and stressors that could increase the vulnerability and risk for children affected by HIV&AIDS. The sub-themes that support the main theme are: *Stressors associated with the psychosocial consequences of HIV&AIDS*, and *the challenges of unfulfilled psychosocial needs*.

4.2.1.1 *HIV is a big word* (Meme, session 8:6) The stressors associated with the psychosocial consequences of HIV&AIDS

I begin this section by presenting the children's perceptions and experiences of illness and HIV&AIDS. Thereafter, I describe the risks implied by the silences, stigma, discrimination and disclosure of HIV&AIDS as reported by the children. Next, I present supporting evidence as illustrated in verbatim quotations and extracts from my research journal, of the grief and despair arising from the death, loss and bereavement that surrounded the children and that could exacerbate their potential for further risk and vulnerabilities. Lastly, I report on the children's experiences of orphanhood and residential care as potential risk factors.

a) Children's perceptions and experiences of illness and HIV&AIDS

The children in this study attributed the causes of HIV and illness to reasons ranging from touching someone else's blood and coughing to the lack of nutritious food and adequate medication. The children's words implied different understandings relating to their experience and perceptions about illness and HIV&AIDS. In specific instances, their knowledge was accurate but at other times, they seemed to be misinformed. I therefore assert that children's perceptions about HIV&AIDS might be linked to their potentially

impeded knowledge regarding HIV&AIDS, which could have originated from their limited access to information.

I touch somebody's blood

A common but restricted perception among the children was that HIV is spread when you touch another person's blood and if that person has HIV, then you would get it too. During a board game (session 7:101-104) Kaemogetswe picked up a word card that said, *HIV*. Her reaction was: *Ha! Look at this word. It said HIV. OK, my friend has HIV. It is a [sic] illness when I touch somebody's blood and [if] that boy has HIV I will also get it. And it makes you very sick.*

Batman's understanding seemed to echo that of Kaemogetswe when he explained the cause of another child's illness: *because another child, he was having HIV and he touch the blood* (session 11:10-11).

This one was coughing

While some of the children understood that HIV was contracted by direct contact with infected blood, another child, Michelle, had the view that one contracted HIV via germs that were transmitted during an infected person's coughing: *This one was coughing in front of them and the mother got sick* (session 11:24). She clarified her statement by saying that the boy who had HIV, coughed in front of his mother who then also contracted the disease. Furthermore, she claimed that the young boy in the picture that she drew contracted HIV, *by not eating vegetables* (session 11:35). When asked: "*what is HIV?*" she replied, "*HIV is when you are sick*" (session 11:39). Figure 4.2 is an image of Michelle's drawing of *HIV in the family*.

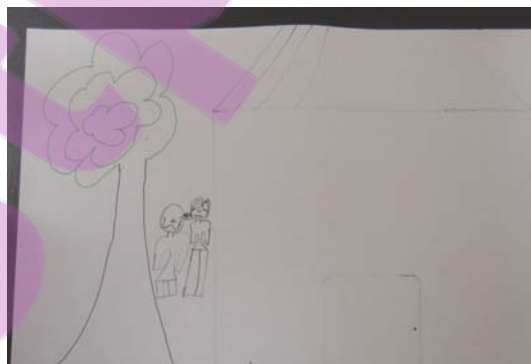


Figure 4.2: HIV in the family – Michelle

Give him medicine

Superman understood that when a person is sick or has HIV, they needed medical treatment. He drew a picture of a person with HIV smiling, because, *it means that the doctor is going to give him medicine* (session 11:17) and *he is going to drink it everyday* (session 11:19) and *get better*. The implication is that there seems to be some hope of recovery from illness when a person seeks and adheres to medical treatment.

They must eat veggies

In addition to medication, Meme described her understanding of illness as arising from the lack of nutritious food and that consuming vegetables will help an ill person to recover (session 7, group 1:32-36):

Meme: *When a person is sick they cough and sneeze and lie down forever and they vomit and they can't eat. They must eat veggies. That's all.*

Interviewer: *Have you been sick?* (Other children laugh).

During this conversation, Batman felt a need to clarify their laughter: *She's sick lots of times. She takes medication and the medicines make her better* (session 7, group 1:37-38).

They'll feel very very sick

In Batman's expression of his experiences of illness, he demonstrated his belief that when someone is infected with HIV: *They'll feel very very sick* (session 8:70) and *when they are very sick, their heart will stop and they will die* (session 8:72-73). He recognised that *it is not nice having HIV* (session 8:77) because *you won't feel nice in your heart and you will feel lonely* (session 8:79). He described feeling *sad* when he is ill and that his *stomach, head and body* (session 8:135) ached. He took *one tablet* every morning that helped him to feel better. He seemed to comprehend the importance of the adherence to medication: *so I can feel better* (session 8:170). Portrayed in Batman's words is the underlying perception that illness arising from HIV infection makes him vulnerable to loneliness and at risk for death.

Another understanding of HIV is illuminated by Kaemogetswe: *HIV is the germ* (session 8:330) and that when they are with friends, *they should play with her but don't touch, they must not touch her blood* (session 8:346-347). Furthermore, she understood that: *HIV I know when you touch someone's blood and you don't know but that person has HIV then you might get it* (session 8:104-105). Her knowledge and perception of HIV extended to the fact that it meant you are *100%, I mean 90%* (session 8:117) sick and that the medication that she consumed was *D4T and 3CM* (session 8:121) as well as *multivitamins* (session 8:127). She visited the doctor at the clinic every second month and although she would have liked to know what the doctor's views on her health were, he only informed the

caregivers: *I don't know but they don't tell us* (session 8:148). Along with other children, she described her need to have information about herself. Batman also echoed the need for children to know more about HIV: *just about HIV. I want to know more about it* (session 8:231), *like when they have HIV and they don't want to tell someone, I want to know it* (session 8:233-234). He stressed the importance to know about HIV because *you must always know about it* (session 8:248).

She was naughty

Dimple's comprehension of the spread of HIV seems to be based on her understanding of morally right and wrong behaviour. This view is suggested in her story (session 11:1-6):

There once was a woman called Maria. Maria was 18 years old and then she went to another boy and then she was naughty and then she had a baby. That baby was called Nkosinathi. And that boy who was called Nkosinathi, the mother had HIV and so now the HIV went to the child and now the child has also HIV.

The children's perceptions about the spread of HIV&AIDS appeared to depend on their developmental maturity and experience as well as the information they were given access to.

I am afraid

HIV and its associated implication of extreme illness and impending death has instilled *fear* into the children in the study to the extent that they express: *I am afraid of dying* [dying] *in my bad* [bed] *slepen* [sleeping] (Dimple, session 4:26) which probably implied fear related to an AIDS-related death, seen in the possible context of her parent's death. Lizzy (session 4:14) said, *I worry about when my mother is sick and I don't see him* which might be linked to HIV&AIDS, thereby exemplifying fear. Harry Potter had a fear of hospitals which carries a connotation of illness and impending death in a context of HIV&AIDS to many people: *my greatest fear is of the hospitals* (session 4:17). His fear of hospitals arose from his repeated hospitalisations due to the illnesses and the painful medical procedures that he has had to endure. It is possible that he might have witnessed a death during one of these visits to the hospitals. I illustrate my view with an excerpt from my discussion with him taken from field notes in my research journal:

During my conversation with HP today, he mentioned that he disliked hospitals. I began to question him about his fear, but then I refrained, thinking that perhaps he wouldn't want to talk about it. However, later in the session, he came up to me and said: Kesh, do you know why I don't like hospitals? Because I was there too much-in K*** and in some other hospitals, they just poke you and it is paining. So I don't like it. Also some people died. 2007:11:02.

The fear of the gravity of HIV&AIDS is magnified in Meme's articulations (session 8:64-67):

Meme: *Flu you can get better but HIV it stays for the rest of your life.*

Interviewer: *For the rest of your life?*

Meme: *Yes, until you die.*

b) Internalising and externalising behaviour

The challenges and stressors that the children experience seemed to manifest themselves in different forms of negative internalising and externalising behaviour amongst the children. Negative internalising behaviour was depicted in reported and manifested feelings of *sadness, worry, withdrawal, fear and loneliness* (sessions 4; session 11) amongst the children.

Dimple portrayed her despair and distress by: *my heart was sore* (Dimple, session 3:92) and by removing herself from potentially threatening situations and retreating to the *tree* or to her *room* (session 5:202-210). Dimple externalised her distress by: *I squash the pillow on my face and then I shout* (Dimple, session 2:98).

The following lines related to Superman's manifestations of sadness (Superman, Session 11:33-38):

Interviewer: *What do you do when you are worried or sad?*

Superman: *Cry.*

Interviewer: *So you cry when you are worried or sad. And what makes it better?*

Superman: *By eating makes it better.*

Interviewer: *So if you are worried and sad and you get something to eat, what happens?*

Superman: *I get happy.*

c) Silences, stigma, discrimination and disclosure

At different levels of the HIV&AIDS pandemic, people are continually being ostracised, marginalised and rejected. Similarly, the children in this study had been subjected to different forms of discrimination arising from the stigma and implied disclosure of HIV&AIDS. Many of the children (Dimple, Batman, Kaemogetswe, Meme and Harry Potter) felt the impact of stigma and discrimination at some stage in their lives as depicted in their utterances, drawings and in the metaphors that they used to express themselves.

Other children don't want to play with you

Loneliness often accompanied discrimination and ostracisation: *and if other children don't want to play with you and then you want to cry and you don't feel happy and you feel sad and you are just not going to talk to anyone* (Batman, session 8:84-86). Furthermore, the stigma that is attached to HIV&AIDS results in widespread rejection: *Everyday when she sits down next to someone they run away, they run away. It's not nice when you have HIV and someone just runs away from you. All of them just throw apples and peaches and tomatoes at the girl. And when she cried the teacher did also chase her away. She had nowhere to go. Also at the children's home they did chase her away. So she was there at the bin and she couldn't have anything to eat. Her illness was worse and she just passed away there. No-one cared about her* (Dimple, session 11:14-23).

School is difficult

Many children in this study related to their schooling experiences in a positive manner and for them, school served as a buffer against risk and further threats. On the other hand, this positive experience did not appear to be the case for all the children. Two children in this study, Dimple and Batman, shared their negative experiences of schooling. The likely reasons for these unfavourable schooling experiences could be linked to possible learning difficulties (HIV-related) and social exclusion in the school environment.

Dimple declared: *school is difficult to me becaros [because] I don't now [know] the wire [work]* (session 4:18). She attributed her likely learning difficulties to confusion: *like when the teachers are explaining something just a minute then they go to something else also when she gets confused she don't know where to start and where to end* (session 2:52-54). However, confusion about challenging schoolwork did not appear to be the only negative factors hindering her positive association with schooling. Social factors such as teasing also contributed to the stressors that Dimple experienced at school: *sometimes people at school swear her and tease her and like when people do bad things to her she does not like it* (session 2:39-41).

Batman was also subjected to teasing at school and he portrayed the sadness and loneliness that may associated with the social isolation that teasing instigated: *because the other big children came to him and pulled him by his hair and hit him and tear off his clothes and steal his takkies* (session 2:103-105); and: *if [ntwe] other children don't want to play with you and then you want to cry and you don't feel happy and you feel sad and you are just not going to talk to anyone, you just going to talk to the teacher* (session 8:84-87).



They put his things outside

Kaemogetswe, Meme and Harry Potter chose to depict their interpretation of discrimination and rejection visually in the form of a drawing and an accompanying story that illustrated and gave meaning to their drawing: *Ok this is people who have HIV. This house doesn't have HIV. This one every day they go and say they don't have food and this one lie to them and say they don't have food. Now they these are poor and these are rich. Now this child goes and plays with this child. And this child runs away to his mother. Then the mother beats this child* (Kaemogetswe: session 11:1-6); *then this man, the father, he came in the church and he took the boy and he wanted to throw him in the water because of HIV* (Meme, session 11:11-13); *its just that Brenda's mother died of HIV and now other children don't want to play with her,* (Kaemogetswe, session 8:336-337).

For Harry Potter, discrimination and rejection meant the physical removal of a person from a household as well as the refusal to associate with this person in any way (Harry Potter, session 11:1-12):

Harry Potter: *This boy as very sick and he got HIV and he start, they did not like him. They took him outside and they put his things outside for him.*

Interviewer: *So they took him out and they put his bed out?*

Harry Potter: *(nods) And his food because they didn't like him and they didn't want to have HIV and these boys here were playing together but they did not want to play with him and they were eating alone inside here and they were not eating with him and it was raining outside and he was very cold and then he cried and then they just not look at him and they just ignore him and then they ate alone and ignoring him while he was crying and then he died.*



Figure 4.3: HIV in the family – Harry Potter

We don't have to discuss our HIV, it's for ourselves (Meme, session 7:105-106)

In many instances, when the subject of HIV&AIDS was broached in this study, the children remained silent, chose to avoid that discussion or talked around it. I relied on documenting the non-verbal expressions in my field notes each time I sensed avoidance (see Addendum 6). Possible reasons for the silence that surrounded illness and HIV in this home could be the pain that it evoked for the children or the fact that the children were discouraged from discussing their illness.

When we talked about her mother (session 5:26-27), Michelle kept her head lowered and could not respond verbally to my questions about how it made her feel. It was possible that the memories of her deceased mother brought back intense emotions for this child. Some children chose to tell others that HIV was not something that they should talk about. For instance, Meme said: *It means that we don't have to discuss our HIV, it's for ourselves* (session 7:105-106). Batman emphasised that when someone was sick, the family must take care of him: *we must support them and play with them. And we must check that he drinks his medicines and tell mama when he is not feeling too well. Also we must not tell others about it. It is only for us* (session 7:112-115). The implication might be that due to fear of stigma and discrimination, it would be best to keep the illness a secret and within the family. Ironically, according to the social worker's report on this child, he was brought to the home as the aunt feared the community's reaction when they learned that she took care of a child who was HIV-positive (see Addendum 2:2.1).

Meme followed through on her statement: *we don't have to discuss our HIV* (session 7:105) and skillfully avoided a discussion on HIV and illness during the clay modeling session. I depict her avoidance in the following extract (session 8:210-224):

Interviewer: *Do you talk about it here in the house?*

Meme: *No.*

Interviewer: *Why not?*

Meme: *Because.*

Interviewer: *Because?*

Meme: *We play.*

Interviewer: *What do you mean you play?*

Meme: *We go out and play.*

Interviewer: *What do you play?*

Meme: (silence).

Meme: *I'm finished.*

In the following excerpt, Batman was resolute that HIV is something they did not talk about (session 8:109-122):

Interviewer: *Do people around you talk about HIV? Do you talk about it?*

Batman: *No.*

Interviewer: *Why not?*

Batman: *I don't know but they don't talk about it.*

Interviewer: *So they keep quiet?*

Batman: *Yes.*

Interviewer: *Mmm*

Interviewer: *So how did you feel when I spoke about HIV?*

Batman: *Sad.*

Interviewer: *You felt sad. Did I make you feel sad?*

Batman: *Yes.*

Interviewer: *Why?*

Batman: *Because I don't like it when someone has HIV.*

You tell them

A lack of disclosure to children about important issues relating to their parents' health resulted in feelings of distrust and aggravated the confusion that a lack of information instilled in the children: *They told me she had flu* (Dimple, session 8:153), and, *I'm unsure about my parents* (Kaemogetswe, session 4:22).

Children's confusion arising out of matters pertaining to their parents is illustrated in the following group discussion (session 7: group 2, Dimple, Harry Potter and Superman: 39-44):

Dimple: *My father and my mother did not stay together. I don't know now, maybe they were divorced.*

Harry Potter: *I don't know my father.*

Superman: *Me too.*

Dimple: *They told me that my father died and my mother that is why I came to live here.*

Uncertainty and vulnerability, arising from a lack of knowledge or information, placed children at risk: *When you are sitting at school we get confused and when your friend is sick you get confused, because I don't know what to do and I don't know why she is sick so I get confused*, (Meme, session 7: group 1:42-45). Therefore, Batman needed to know more about HIV&AIDS (session 8:231). In this section, through their utterances, drawings and stories, the children implied that they would like to gain more knowledge and information about the HIV&AIDS pandemic.

In contrast, not all the children believed that it was okay to be quiet about HIV. Kaemogetswe described her reasons why she thought that it was important for people to know about their HIV status (session 8:318-320): *Because sometimes people if they don't know they have HIV they just give them medicine they don't know what for and they don't take them and then they die.* Therefore, a doctor has the important job to *help people and if you don't know you have HIV you tell them* (Kaemogetswe, session 8:312-313), implying that disclosure is necessary when people's lives are threatened and could be saved.

The significance of disclosure and specifically shared disclosure permeated the role-play by Meme and Spiderman and by Kaemogetswe and Batman. Both their role-plays contained elements of disclosure: *And the social worker told Matilda that her mother had HIV positive then the mother came from there and took her child Matilda and they went home and they had some food* (Kaemogetswe and Batman, session 9:22-25).

In many households, disclosure occurred in a hierarchical system: *Then this nurse phoned the grandmother and the big sister answered and said who do you want then they said can I speak to the grandmother. Then she gave the grandmother the phone then the grandmother answered the phone they said your child has HIV. Then they said did you know for the first time, they didn't know they just saw for the first time and then they said its ok. And then the grandmother told the grandfather that the child has HIV. Then the grandfather phoned the parents. The parents said they will be back tomorrow and then the grandfather said they must come back today because the child is in the hospital and we need to take him to church* (Meme and Spiderman, session 9:16-29).

d) Death, loss, separation and bereavement

Grief related to death, loss and separation, appeared to be commonly experienced by the children in this study as part of their daily lives, as expressed in their stories, drawings and in their play. Batman, Superman, Harry Potter, Meme, Dimple and Kaemogetswe alluded to their pining and sorrow related to the death of significant people in their lives.

I want to cry

Batman and Superman described their sadness and distress arising from death. Batman articulated that he was *sad* when *he sees his people dying and his mother* and when he is sad, he showed his sadness by *walks [walking] alone and he puts his eyes down and not look [does not look] at the people and he is crying* (session 2:35 and 42-43). Superman's sadness seemed to stem from the unexplained failure of his mum to return home: *Because*

his mother did not come home (session 2:83) and he *thought that his mum is at the hospital* (session 2:87) and *he was thinking that his mum was sick* (session 2:91), because *she did get flu* (session 2:93).

Harry Potter talked about his friend who died because of an AIDS-related illness: *I want to cry when I miss E* (session 4:11). *I worry about E, because I miss him* (session 4:14). Meme also related her experience of grief to sadness which is implied: *I want to cry when my mum want to die* (session 4:11). Batman expressed a strong negative emotion about death: *I hate it yan [when] samwan [someone] die* (session 4:8). Kaemogetswe described the depth of her grief as physical: *I want to cry when I fall down when my mother died* (session 4:11).

When Meme attempted to describe her sister J's death, all she said was, *She was just sick* and that now, she was *in heaven* (session 8:258 and 253), perhaps indicating that it was too painful and she would rather not talk about it. However, she did mention that when she thought about her, she thought about *all things good* (session 8:266), possibly indicating the buoyancy that is linked to positive relationships with significant others whether they are dead or alive. In her clay modeling activity, Meme placed her sister J at the top of the page, (as if in heaven) looking down on her. Meme's reluctance to speak about her mother and father was noticed when she averted her eyes, pounded the clay and gave monosyllabic responses to questions. I respected her reluctance to speak about these highly sensitive areas in her life and did not pursue this line of discussion (session 8:255-284). Figure 4.4 is an image of Meme's completed clay modelling activity.



Figure 4.4: Clay modelling – Meme

I am scared

I provide self-explanatory direct quotations from the children demonstrating their vulnerability related to fear:

Lizzy: *I want to cry when they tell me that I well [will] never go home anymore* (session 4:11).

Lizzy: *My mother is so sick and riet [right] noa [now] she need me to help* (session 4:16).

Lizzy: *I am afraid of dying [dying] in my bad slepen [bed sleeping]* (session 4:26).

Kaemogetswe: *When I am sad I cry for more than three minutes* (session 4:12).

I wished my father never died

Kaemogetswe and Batman portrayed their interpretation of death, a funeral scene and grief in their role-play activity (session 9:40-43):

And the ambulance took him to the doctors tried to help him to stay alive and there was no time and he died and they phoned them and said he passed away. They were crying. There is also a sense that *it is not the end* (session 9:54) as the grief and the longing for loved ones remained for a long time, *and this child came over quickly and wished that his father never died* (session 9:58-59).

Another example that depicted death and the accompanying grief, sorrow and despair is vividly illustrated in the following vignette from a role-play scene with Dimple and Harry Potter (session 9:36-52):

Dimple: *And so they took they out to the ambulance. She wasn't breathing imagine. They took her (siren sound) quickly there and called the...*

Harry Potter: *The nurse...*

Dimple: *The news...*

Harry Potter: *The nurse...*

Dimple: *...and they quickly called the nurse and asked him to check up her heart she wasn't breathing and so they took the hot iron and (sound of the shock treatment) and then she breathed a little bit. They gave her some medicine. They gave her some medicine quickly so she breathe again. Hey, put the breathing pipe. And then after that there came a doctor. It was so sad because they tried and tried and tried. She lived. She lived for many days in that clinic. She wasn't well and her doctor asked, her first daughter was crying, was crying so much that she even goes every time to the wishing ... star and then she wish every time that her mother could live.*

Dimple: *Oh no and suddenly she went to heaven* (session 9:60). *It was so sad that even the sky went grey. They could do anything [nothing]* (session 9:61-62). *I've wished a thousand times and nothing happened. Oh no, I've lost my dear mother* (session 9:65-67). *It was so sad, very sad* (session 9:90).

Harry Potter: *Good bye, we all miss you.*

Dimple: *Yes and everyone cried it wasn't good* (session 9:93-94). The vignette seemed to portray grief and anguish made visible in the expressions of pain and sorrow of losing someone you love.

Dimple remembered her father's death: *My father is dad [dead] from 1995. It is bad to me (session 4:9). She went on to reminisce, in session 8, about what really happened to her father: He took me to a holidays that time it was December almost Christmas and then he enjoyed it but he didn't sleep for 36 hours because he was doing the work for the family and then the next morning, we didn't find him (session 8:241-244). We didn't know where he is and then the next morning we found him in Mamelodi (session 8:246-247). We didn't know when he went. We just found him in Mamelodi. They said my father passed away because he was sleeping and he couldn't wake up anymore (session 8:250-251).*

The depth of Dimple's anguish over her parents' death is further depicted in the following supportive extract where she talked about her mother's death: *Then they took her to the clinic, they said she had a heart problem. Then she couldn't breathe and then she passed away.* Furthermore, her distress seems to be caused by the possibility of her being provided with inaccurate information about her mother's death (Dimple, session 8:153).

Michelle's experience of illness and death is portrayed in an extract from her story (session 11:5-11):

Then the girl said you have HIV and then the boy cried then the girl went inside the house. Then she found his mother and his father getting sick and she also cried and then they phoned the ambulance and then the ambulance came and then the ambulance took the mother and the father to the clinic and then the girl went to the clinic and asked the doctor how is his mother and the doctor said your mother is coming to die.

No words

The loss of loved ones through death or separation renders one helpless. This impression of helplessness is imbued in the role-play scene depicting a sick child in hospital (presumably with an AIDS-related illness) (Meme and Spiderman, session 9:72-74). *They kept him in the hospital. The next morning they took her, she was sleeping then they checked her. The next morning she could die.* She died. *Then she went ...* (and she could not continue talking as if she did not know what more to say). Spiderman then took over the conversation and said: *they took her to the...* (session 9:74-75). He also found it difficult to find the words and could not continue as if the reality of death made you so helpless that no words could express the depth of your loss. It seems as if one could say death, and then what? Therefore, I put forth that death renders children powerless and vulnerable to risk for psychological and emotional setbacks. Meme described her uncertainty and sadness arising from the loss of her friend (Meme, session 7:119-123):

Meme: *I feel sad when my friend dies or somebody don't play with me also when the teacher at school hits me.*

Interviewer: *did you lose a friend of yours, Meme?*

M: *Yes, at M**** but I only know she got sick and I never saw her again and when I asked mama she said she is with Jesus.*

No-one else to take care of me

Presently, Dimple's distress and fear of impending loss and worry for the future is linked to her uncle: *Because he might pass away and then there will be no-one else to take care of me* (session, 8:206-207):

Dimple: *I'm afraid the most important person is going to pass away when I am not there.*

Interviewer: *Who is this important person?*

Dimple: *My uncle, he signed the form that he is going to take care of me and that is why I always want to phone him and ask him if he is okay* (Dimple, session 8:192-197). Arising from the discussions in this section, I posit that in the absence of protective factors, the cumulative and chronic challenges and stressors that the children in this study experience may place them in a position for aggravated and sustained psychological and emotional risk and thereby restrict their individual positive adaptation to their life events.

e) Orphanhood and residential care

Living in a residential care setting may be associated with various challenges and stressors that have the potential to increase the vulnerability and risk for children. This was the general view of the children in the study. While some children talked openly about the challenges they experienced (Lizzy, Dimple, Batman and Kaemogetswe), others were more reluctant to express themselves (Michelle and Meme). Children alluded to feelings of restrictedness and confinement as well as degradation, humiliation and being unappreciated.

We feel like we are locked up

Dimple mentioned that she is not happy living in the home, *because I don't feel comfortable because sometimes I just feel like going away* (session 5:159-160). Dimple believes, *I never do something right*, (session 5:185), *because every time when I do something it never works out* (session 5:187) and *every time they shout at me* (session 5:189), *like when I clean I miss out something and they tell me stuff* (session 5:192-193). Her belief that she is being discriminated against by her caregivers is implied in: *She doesn't like coloureds, like I'm always doing something wrong. Like when I forgot something at school she also shouts*

at me (session 5:195-196). She declared her resentment to living at the children's home: *as soon as I come here I don't want to stay here also* (session 8:185).

Dimple related other challenges in her life which imply a lack of respect and insensitivity from her caregivers (session 3:80-83 and 85-92):

Dimple: *I had this thing. Mama G told me, I also know it but I didn't want her to tell it in front of all the children. I was in an Afrikaans school, a Sotho school and now an English school. So I am getting disturbed. When it's English I am writing Afrikaans.*

Interviewer: *I see. You are getting confused?*

Dimple: *Yes. Now mama just said because I was calling M to come and help me with other work that I don't understand. I said M. and then mum said I mustn't talk. I said I'm sorry mum. She told me that you fail every time at the school. You tell us you are getting disturbed and that's why you lie and you are always just sitting there doing nothing. M is passing and you are just lazy – a big girl, like a granny sitting there. So my heart was sore so I just went up the tree.*

It appears from the extract that living in residential care may sometimes imply humiliating, degrading and demeaning experiences for certain children. During this session, Dimple wept, signifying that the encounter that she had described was immensely disturbing for her. Furthermore, she requested that the voice recorder be turned off as she did not want anyone to hear her. I provide a brief extract from my field notes that describe my conversation with Dimple thereafter and the consequences thereof.

My conversation with Dimple

After I turned off the voice recorder, Dimple said to me that she was very upset because the "people" disliked her. I asked her if she needed to talk to someone who understood and could possibly help her to understand her feelings: she agreed.

Immediately after my session, I called the social worker and informed her that Dimple was feeling sad and distressed. I asked her to schedule counselling sessions with her to help her to understand her feelings.

She agreed and counselling sessions began the next day. 2007:10:12.

Another conversation with Dimple alluded to images of confinement. I drew this conclusion from: *It's not great when you are locked up in jail here. But I wont say more* (session 7, group 2:22-23). In this study another child, Lizzy, also suggested the idea that they were in jail: *because we always stay here like we feel we are locked up. Sometimes when we go out we feel free you know* (session 3:25-27). Presently she displayed ambivalent thoughts about her future stay at the home: *I am unsure about stay [staying] at B* (session 4:22). I conjecture that Dimple used a metaphoric image to imply that she would like to escape from

the confines of the home as it is regarded as a source of stress, which emanates from humiliating experiences and restrictedness in the home. Furthermore, her perception of negative experiences at the children's home reinforced her feelings: *I think that life is difficult and I am just an orphan child and I just think of my life* (Dimple, session 3:70-71).

They want us to clean the house

Kaemogetswe elaborated on other challenges that confronted the children in the home (session 8:262-273):

Kaemogetswe: *Here it is so boring, the way that they treat us. They want us to clean the whole house.*

Interviewer: *Where?*

Kaemogetswe: *Here, and they make us tired. When we are hungry they force us to clean the house.*

Interviewer: *Mmm, and you don't really want to do that when you are tired?*

Kaemogetswe: *No. And they did that to me when I was hungry. When the other children are eating, me, they wanted me to clean the stove and mop the kitchen, when I was hungry.*

From these comments it seems that children in this study experienced stress as related to unfair and unjust caregiving experiences.

4.2.1.2 The challenges associated with unfulfilled psychosocial needs

In this section, I provide data that related to the challenges that were associated with unfulfilled psychosocial needs. The needs (sub-themes) that emerged as possible protective factors were: nurturance, acceptance and belonging, socialisation, communication and affirmation.

a) Children need nurturance

While all the children in the study indicated a need for nurturance, it was expressed in different ways. Whereas some expressed a need for nurturance in the form of a mother-child relationship, another child spoke of a need for a show of physical affection. Although a yearning for home and the associated love, care and kindness from a compassionate adult are strongly articulated, there is also the notion that self-nurturance or self-reliance and that of nurturing others is also deemed important. Other children in this study expressed their basic survival needs that appear to be age-appropriate in nature.

The mother is combing my hair

In a conversation based on her collage (session 5). Michelle alluded to a yearning for a mother-child relationship. Figure 4.5 is an image of Michelle's collage.



Figure 4.5: Collage: All about me – Michelle

This picture of a mother combing her child's hair seemed to evoke a longing in Michelle for the physical nurturance from a loving caregiver, preferably her own mother. Here, in the home, Michelle reflected that she combed her hair herself, pointing to, amongst others, the lack of a nurturing figure in her life. Furthermore, she might have projected her feelings as being the child in the picture when she said that she chose that picture as it made her happy, *because the mother is combing my hair* (session 5:74). Meme also referred to a mother-child relationship: *It's like a mummy taking care of the baby* (session 5:149).

Despite her longing for home and the associated connotation of love, warmth and care, Meme also acknowledged the need to nurture herself. I infer that that in the absence of nurturance from others, she needed to depend on herself. Developmentally, I view this line of thinking as cognitive maturity and as a form of emotional intelligence. Meme recognised that she needed to feel pampered, cared for and looked after. She identified that her bath is her source of comfort and is important to her and for that reason she would need *towel, facecloth and some shampoo* (session 5:7). This recognition possibly implied a desire to nurture and protect her body and physically taking care of herself. It is important to note that the cue for this activity was to use pictures to tell me about herself. Reflecting on her choice of pictures for her collage, Meme demonstrated the high importance that she placed on her hygiene and health. Figure 4.6 is an image of Meme's collage.



Figure 4.6: Collage: All about me – Meme

Batman also nurtured himself. He said: *I wash my body when I am dirty and I must look after my body by exercising and by washing so you smell fresh and clean morning and evening* (session 7, group 1:83-85). Although Meme and Batman had identified a need to nurture themselves, a few other children expressed their willingness to take care of children in the home: *We must support them and play with them and we must check that he drinks his medicines and tell mama when he is not feeling too well* (Batman, session 7, group 1:112-114); *some of them who can't bath, I bath them* (Dimple, session 8:68-69).

Kaemogetswe believed that nurturance is demonstrated through physical affection. She maintained that: *Some children need caring. I need hugs [hugs]* (session 6). She reaffirmed this need for physical attention in another instance when she said: *I need a huge [hug], care, loving kiss when I cry* (session 4:15).

At my home it is nice

Children in this study expressed their longing for their own homes. In sessions 2 and 5 Dimple spoke about wanting a *new life*. She described her new life as:

She wanted a life where she did not stay in a children's home because sometimes the children do not want to play with you and sometimes you feel sad and like just going and having a family at home would feel much better (session 2:140-143). Her yearning and longing for her family is further signified in: *There's no place like home* (session 2:145).

Dimple demonstrated her sadness by anger and tears:

I don't think I have cried but sometimes I do because then I will be missing my mum or my day may be bad and I will feel like going away and I will be angry (session 2:91-94). In session 6, Dimple indicated that she needed a *caring home* and *parints* [parents] *to love hair* [her]. She longed for a new life in which she *feels colourful* (session 5:35). She explained

further that what made her happy was when *people are kind, presents that they give her and also love* (session 2:33-34).

Unlike Dimple who spoke with her eyes averted and with sadness etched on her face, Lizzy showed a positive affect and laughed readily when speaking about her mother. Unlike Dimple, perhaps Lizzy's hope emerged from her knowledge that her mother was still alive and she knew that she would be reunited with her soon. She said: *At my home it is nice and I love being with my mum 'cos every time when I'm with my mum she tells jokes and everything that makes me happy* (Lizzy, session 5:49-51). In addition, she portrayed positive thoughts about her relationship with her mother: *I like to go home to see my ma and my mum, she's so, she's so nice to me and she can tell me stories and that's why I like my mum because she tells me stories, nice stories* (session 1:10-13). Her longing and desire for her home and her mother are succinctly expressed in: *Eish, I wish I could go home now* (session 5:139).

Her acute desire for her home, especially during vulnerable moments, was implied when Meme said: *When I am sad I want to go home* (session 4:12). She further said: *I need to go home for ueuer [ever]* (session 4:15) and this thought was reinforced by: *She is want to go home* (Meme, session 9).

The best thing I can remember

Lizzy's reflection on her past life included fond memories and a yearning for her life to remain as it was when she was growing up with her family and friends. The following lines from my conversations with her, represented my understanding: *The best thing I can remember is the time when I was staying at home I used to have lots of friends and we used to play house dolls like we used to come to my home with all my friend with dolls and we used to play outside (session 5:57-60) and we used to play different games. We used to take stones and play diketo. We used to take ropes and play kite and we used to play lots of things like hopscotch, and lots of things* (session 5:64-66). Happy memories may be akin to beacons of hope that boost well-being with the anticipation of a brighter future.

Love

The desire for love featured high on the children's list of needs. Batman needed *love* while Dimple needed *to be alife [alive]; a home caring [a caring home]; parints [parents] to love hair [her] and God to love hair [her]* (session 6). Figure 4.7 is an image of Kaemogetswe's draw and write activity.

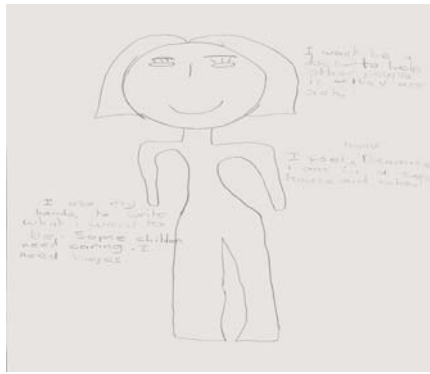


Figure 4.7: Draw and write activity: I think, I feel, I need – Kaemogetswe

b) Children need to socialise

Lizzy and Dimple articulated that they had limited opportunities for socialisation. Socialisation could also imply emancipation and independence for the children in my study.

At the party she danced

Lizzy explained: *Sometimes like when we go out because we always stay here like we feel like we are locked up. Sometimes when we go out we feel free, you know. Saturdays and Sundays, I think when we go to the shops with mama G or E or maybe A arranges something for us to go to Queenswood¹ for the day or somewhere. When we go to the movies, maybe someone arranges. When no one arranges anything we just stay here at B. And sometimes it gets boring* (session 3:25-33).

This desire for an active social life also included wanting to dress up to go to parties: *she was so ready to go to the party and she dressed so good, a nice jeans and a tee-shirt. She pushed herself and she was looking nice. So then she went* (Dimple, session 3:1-3). *At the party she danced, she clapped hands, she talked, she ate. She did only fun things* (Dimple, session 3:16-17).

I don't like staying indoors

Furthermore, Lizzy's boredom at the home might be related in part to the limited resources for the children to occupy themselves. While she prefers to be outdoors, *I don't like staying indoors at B* (session 4:5) she was forced to do so as the other children did not understand the games that she wanted to play. This observation is echoed in: *Because there's no ropes, things you know. And the other children can't understand how to play these* (session 5:73-74). Instead, she and Dimple occupied themselves by listening to music, riding their bicycles

¹ Queenswood: A residential suburb to the north-east of Pretoria

(when the tyre was fixed) swimming (depending on whether the pool was clean) (session 5:103-106).

c) Children need to communicate

For reporting results, I categorise communication as: *The need to give information and to be listened to* and *the need to receive information*

Listen, I'm talking to you

I assert that in order to feel wanted, accepted and acknowledged, it is important to be listened to. This thought is illustrated in:

I like my teacher because she's very kind to me. She understands our situation and you can talk to my teacher and you can talk to her anytime (Lizzy, session 1:23-24). Being listened to was an important need for Lizzy as she explained that when she talked to someone and they *ignore* her then she got very *angry*. She would then: *Go to the person and say, Listen I'm talking to you and you are not listening to me* (session 2:38-42). Her frustration and anger appeared to be associated with her perception that she was not being listened to.

Whilst Lizzy emphasised the importance of communication with people around her, Dimple seemed to have embraced other living creatures as a source of comfort and to curb loneliness. It seems likely that Dimple needed to communicate her feelings and emotional challenges with people who cared about her. However, in the absence of people to talk to, she tended to communicate with animals. I provide an extract from an interview with her, which was based on her drawing of a butterfly:

Interviewer: *Does she come here to talk to you?*

Dimple: *No, she just comes and talks to mama and she goes away. When I want to tell her then she is in a hurry and then the next day there is a meeting* (session 5:229-230). As a result, she believed that the *butterfly can also talk if you do understand it* (session 1:9-10). Elsewhere in the study, Dimple described her bond with animals: *Sometimes when I look at a cat for very long its like it can talk and its real like it's a person* (session 2:71-72). To my mind, Dimple sought solace and comfort externally rather than with the people around her. Further evidence for this view is reflected in her affinity for climbing trees to find peace when she is feeling especially stressed (see Section 4.2.3.2:c).

Lizzy demonstrated her frustration about having insufficient opportunities *for* communicating with her caregiver in the home. In my field notes, I recorded excerpts of my conversation with Lizzy when she was particularly upset and asked for the voice recorder to be switched off. The following extract is taken from field notes:



Lizzy appeared very upset and subdued today. She said to me that she was very unhappy living at the home. She thought that she was being treated unfairly. Although she was the eldest child there, she claimed that she was being treated as being the youngest simply because she was in a special school. She gave the following examples: When she brought home a letter or notification from school that needed to be read and signed, it was left for last. After all the other children have had their letters attended to, then Lizzy's was read and signed. Sometimes it was not even signed and she took it back to school unsigned. She was then detained by the teacher for not having had the letter signed. Her complaint was that nobody had time for her and nobody listened to her at the home. (2007:10:12).

I don't know

The children in the home seemed to resent the limited information that was provided to them by their caregivers. Their statements allude to the suggestion that limited information made them feel confused, helpless and sad. I thus conjecture that a lack of information or limited transference of information causes confusion among the children. Meme explained (session 7, group 1:35-39):

Meme: *When we are sitting at school we get confused and when your friend is sick you get confused.*

Interviewer: *Why do you get confused when your friend is sick?*

Meme: *Because I don't know what to do and I don't know why she is sick so I get confused.*

The implication in this conversation is that if Meme knew what was wrong with her friend, then she would know what to do and how to help her. However, a lack of knowledge about what was going on around her seemed to render her helpless. Harry Potter felt sad when he thought about his friend Eric. He said: *I worry about e (E) because miss him* (session 4:14) and *I want to cry when I miss e (E)* (session 4:11).

His worry and sadness arose from a lack of knowledge about his friend's death and that he was not informed about his friend's illness in the first place. He understood that his friend was sick and was taken away to the hospital but he had not returned from the hospital. (Research journal extract-2007:11:02).

4.2.2 Theme 2: Support for children

In this section, I present the results that demonstrate how children in this study were supported with their challenges and stressors by possible buffers and factors that could protect them from further risk. I present data pertaining to the following sub-themes that

emerged from an analysis of the main theme in this section: positive systems offering support and positive intrapersonal characteristics that buffer and protect the child.

4.2.2.1 Positive systems offering support

In this study, one potential protective force is that of systemic buffers. I provide data on: Children's perceptions of support; friendship that offers support; schools as protective systems; the extended family and weekend parents as systems that offer support and protection and the community as a source of support.

a) Children's perceptions of support

In the context of this study, children used the word support extensively. In the context of HIV&AIDS, support may be interpreted in different ways and have varying connotations for the children. I report on how the children interpreted receiving support and giving support.

We must support them

For Kaemogetswe, support has a practical implication as illustrated in her drawing depicting HIV in the family. She suggested possible ways in which neighbours in a community could support each other, especially when one family is encumbered by the financial implications of HIV&AIDS and another is not: *This one should give some money to this one to buy something or groceries* (session 11:21-22); and *also buy uniform for the child* (session 11:25); *a car to take them to school* (session 11:28); and *when the lights are off, when they don't have lights you have to give them some light* (session 11:31-32). Kaemogetswe's descriptions suggested that communities had the responsibility to take care of their less fortunate members. In particular, Kaemogetswe's drawing depicted the less fortunate family to be inflicted with HIV&AIDS-related stressors. Figure 4.8 is an image of Kaemogetswe's drawing of *HIV in the family*.



Figure 4.8: HIV in the family – Kaemogetswe

When Dimple showed support to those around her, she did so by: *Giving them healthy food and medicines. And some of them can't bath, I bath them* (session 8:lines 68-69). Meme believed that you could also show support by: *Giving him or her energy food* (session 8:91) and some *medicines* (session 8:102).

Batman articulated the word support many times during the session with the board game to demonstrate his interpretation of showing or giving support: *We must support them and play with them and we must check that he drinks his medicines and tell mama when he is not feeling too well* (session 7:112-115). He also suggested ways on how one could support another person who is infected with HIV (session 8:45-56):

Batman: *Yes and you mustn't [ntwe] say [ntwe] they have HIV you don't want to play with them, you must help each other.*

Interviewer: *How can you help each other?*

Batman: *By supporting each other.*

Interviewer: *Yes, by supporting each other. In what way do you support somebody? How do you show it?*

Batman: *like [ntwe] helping him when he doesn't know something.*

Interviewer: *Yes, helping him when he doesn't know something?*

Batman: *And share with him and show him all the good stuff.*

Interviewer: *Right.*

Batman: *So that he will not feel sad and so he will be happy when you play together.*

Batman's description of support seems to imply an underlying rejection of discriminatory practices. He seems to support the acceptance of people with illnesses and maintaining the silences associated with HIV&AIDS in the form of non-disclosure.

I clarified Batman's understanding of the word support (session 8:203-207):

Interviewer: *I notice that you know the word support. You say they must support him. How, what do you mean by the word support?*

Batman: *Like when helping or something.*

Interviewer: *Right. So support means helping?*

Batman: *Yes.*

Someone must help you

Although giving support is deemed essential in their relationships, the act of receiving support also featured as important. During her conversation in session 8 Meme described her understanding and interpretation of the act of receiving support as: *someone must help you* (line 12), when you *need someone to pray for you*, (line 20), and you *need other children at school to take care of you and not laugh at you* (lines 23-24).

When confronted with illness, the children tended to depend on their friends to uplift their moods by play, interaction and socialisation. Batman described the benefits he perceived of receiving support from his friends, especially when he felt sick (session 8: 138-144):

Interviewer: *So your body hurts?*

Batman: *Yes.*

Interviewer: *And what makes it better?*

Batman: *When I'm playing with my friends.*

Interviewer: *So when you play with your friends when you are sick, you feel a little better?*

Batman: *Yes and when my friends support me.*

Batman depended on the support of his friends when he was feeling sick and also when he was sad (session 2: 47-50):

Interviewer: *And when he is feeling that way, when he is feeling really sad, how does he become happy again?*

Batman: *Like when his friends cheer him up, ntwe, and they give him some coffee.*

In the climate of HIV&AIDS the word support, as demonstrated by the children, conjured images of compassion, kindness and protection that extended beyond a practical level to ameliorate the effects of psychosocial stressors.

b) School as a protective system

Children expressed positive emotions about their experiences of schooling and of their interaction with their teachers.

School is fyn [fine]

Whilst Meme and Superman agreed that *school is very good* (session 4:18), Batman thought that *school is fyn [fine]* (session 4:18) and *school is nice. There are clever children* (session 4:18). In particular, the following extract from my conversation with Lizzy about her schooling illustrates that the *kindness of teachers* can act as a protective factor for vulnerable children (session 1:23-29):

Lizzy: *I also like my teacher because she's very kind to me. She understands our situation and you can talk to my teacher and you can talk to her anytime.*

Interviewer: *And that's important to you?*

Lizzy: *Yes, and she don't be angry like that. When she's angry she just shouts at us and in one minute she's happy again and she laughs.*

By implication, the idea in this conversation is that teachers have the potential to protect the children from the stressors that might arise from their homes. Especially when caregivers lacked the time, the patience or the inclination to communicate with the children, the teacher possibly fulfilled this role.

We learn

Schooling also provided children with essential life skills: *I'm in a special school and in that school we can cook we work it's a school where you work with your hands but we cook and we do computers. We learn to cook, we bake and we cook pasta and things like that* (Lizzy, session 1:13-17). Lizzy added: *I like the school very much and I want to finish at the school* (Lizzy, session 1:19-20). In her account, Lizzy possibly alludes to her self-worth linked to her knowledge of a variety of life skills that could hold her in good stead in her future.

Harry Potter is another child in the study who experienced schooling as a positive experience as it related to his acquired knowledge of skills: *They teach us about flowers at school and I did write it nicely and I did paint it nicely* (session 1:4-6). Michelle's positive experience is linked to her favourite subject where she is possibly recognised for her achievement: *My favourite is Arts and Culture* (session 1:7). A positive schooling experience seemed to lead to a better self-concept and possibly increased levels of self-worth and self-acceptance in this group of children.

c) Friendships that offer protection

The essence of friendship and the need for socialisation amongst early adolescents is juxtaposed with images of showing support by caring, sharing and being available for your friend. In this section Harry Potter, Batman, Meme and Spiderman sketched images of their friendships.

The happiest time is when I play with my friends

In expounding his friendship with Harry Potter, Spiderman commented: *he is sharing with me* (session 10:38), and *he likes to borrow me something* (session 10:40) implying that *he liked to lend me his things*. According to Superman, Harry Potter is good friend because: *he gives me his food and when I am crying he comes to me and he said who hit you?* (session 10:49). Then he: *goes and tells mum that somebody hit me* (session 10:53). Batman also regarded Harry Potter as a good friend who showed him support by offering him friendship: *like when I have no friends he comes and plays with me* (session 10:64). He reinforced the

buffering effect of friendship in: *the happiest time is wan* [when] *I play with my friends* (session 4:2).

The importance of friendship as a protective factor is further signified in the following extract taken from a conversation with Kaemogetswe, when she described her friendship (session 3:2-14):

Kaemogetswe: *This is Lesego the girl. She is Ntagu's daughter. She is nice. She goes to school with me and we always like to play school and when we visit the other classes I go with her and we visit the other friends. And she is always happy, she is not sad, she laughs and she shares with other children.*

Interviewer: *Is she like you?*

Kaemogetswe: *Yes.*

Kaemogetswe: *And when it is raining when she sees someone don't have a jacket, she gives them and she said they must return it back when the rain stops. And if another girl or boy does not have food to eat she gives them and when her mother always like to send her to buy bread she does not complain she always obeys her mother and father. She respects them because they teach her manners.*

It was noticeable that Kaemogetswe highlighted the qualities that she admired in her friend while also claiming that she too possessed similar qualities. In this instance, I put forth that children learn from each other during socialisation and in their friendships and that their knowledge gained during these interactions may consequently be construed as protective and shielding.

They make me laugh

Lizzy spoke positively about the children's friendship in the home. For example, when she is feeling *dejected or sad: then the children make me laugh. They do things, like funny things and they make me laugh* (session 5:146-147), *Like when we watched Harry Potter and when we switch it off, A. act like the other person (laughs) and it really looks funny when he does that* (session 5:151-153). Engaging in positive relationships and friendships that nurture happiness and joy emerges as another protective factor for the children in this study. Figure 4.9 is an image of friendship.



Figure 4.9: Friendship

d) **The community as protective**

There seemed to be awareness amongst the children in the study that the community had the potential to play an important role in supporting families who are affected by HIV&AIDS. The following excerpts support the idea that a community's sense of *collective responsibility* may mitigate the *effects of poverty* which is often associated with an HIV&AIDS milieu. It is likely that *community support*, in this instance, depicted by the provision of food to a family in time of distress, offers *nurturance, comfort* and solace.

We support by giving

Earlier in this chapter (see Section 4.2.2.1a), I indicated that Kaemogetswe suggested ways by which neighbours could support each other. In a similar manner, Batman depicted his understanding of *community support* (session 9:59-65):

And in this family, the grandfather went to this family and told them that he is sorry about that the father passed away and then the grandfather went back to his house and this mother made some nice dessert for them and gave them and then he gave the mother a hug and then they went to bed. It was over.

The lady who brings us stuff

Embedded in the community are the volunteer workers and the social workers (see Addendum 6) who seem to serve as beacons of hope for the children, especially when they are bored, unstimulated and lonely. I shall illustrate my view with an extract taken from my research journal in which I described my encounter with a volunteer worker at the children's home.

Well, as I was talking to a child, we heard a loud hoot at the front gate. The children immediately jumped up from their chairs and craned their necks to get a look at the person at the gate. Then, with shouts of glee, they sprang up and dashed out of the room without a word to me. Imagine my surprise. I had no idea what was going on. It was raining heavily, lightning flashed across the sky and thunder rolled. The children ran indoors, grabbed umbrellas and then ran out again to open the gate and get to the car that was waiting. Soon, they were returning, one at a time carrying huge packets and boxes of what, from where I stood, looked like vegetables and fruit. They streamed in carrying these parcels and at the end I saw the lady who brought all of this stuff. Let's call her Anne. So I went out into the kitchen and I introduced myself to her. She was so polite and gentle, giving hugs to the children and greeted me warmly.

She said that she collected contributions of fresh produce, cakes, bread, biscuits, juice, yoghurt and other foodstuff from various donors which she then delivered to the children's home every Friday. I now understand the children's excitement, as there are sufficient treats to sustain them through the weekend and the following school week. Anne said that she has been doing this for a number of years and absolutely loves the children. After my brief conversation with her, I felt my mood lift. It seems like my meeting with someone who puts the children's needs before her own, put my life into perspective for me. (2007:11:02)

Anne had also been responsible for initiating excursions and holidays for the children. Among others, the children enjoyed a seaside holiday and a camping trip to a farm. During the school holidays, the volunteer workers organise numerous day visits. One such visit was to the Pretoria Zoo, which the children seem to have enjoyed immensely. I have also met Lilly who is a member of a team of people who organised and transported the children on their different outings. She also had the task of delivering medication to the home on a weekly basis. Yet another volunteer baked a birthday cake for each child on his or her birthday. Furthermore, the children benefited from computer lessons, which were provided by a student in the community. In addition, the children attended religious classes in the form of Sunday school and Bible reading classes.

The social worker, E. visited the children regularly. The children looked forward to her visits as she was primarily in charge of their welfare and they respected her as their guardian. When she visited the children, she spent time talking to them. In my conversations with her, she seemed to show tremendous insight into each child's challenges, resources and personality. She seemed to understand each child's needs. When school holidays drew closer the children looked forward to her visits because they knew that she would discuss their holiday placements with them. I include an extract from my research journal of a conversation with her:

E. went on to tell me about the arrangements that she was making for the children's holiday placements. They are starting to feel the excitement in anticipation of the upcoming Christmas holidays and the time that they would spend in the company of their weekend and holiday parents. She had confirmed arrangements for all but Superman. She said that it is a problem to place him as he bed wets. Meme will be going to her grandmother and Michelle to her grandfather. Dimple will go to her aunt and uncle in Mamelodi. The other children will go to their usual weekend parents. (2007:11:27)

e) **Extended family and weekend parents who offer protection**

The children in this study depended on extended family members such as their grandparents and aunts as well as their weekend parents who seemed to play a buffering and protective role in the children's lives.

The grandmother answered the phone

Meme, Michelle, Dimple and Harry Potter have family members whom they visit or who visits them or telephones them at the children's home. Michelle visited her grandfather over the school holidays and looked forward to seeing him, playing with the children and being part of the community where he lived (session 5:32-55). She also had an aunt whom she visited occasionally and with whom she shared a good relationship: *My aunt makes me happy and nice* (Michelle, session 5:99).

Meme seems to have a secure relationship with her grandmother. In her interview based on her collage, she indicated that that her grandmother bought her the toiletries that she loves (session 5:19-45). She also had an aunt living at her granny's house. Consistent with the social worker E's discussion, they loved her dearly but did not have the financial means to take care of her medical needs (see Addendum 8:8.2.1).

In many communities, especially those affected by HIV&AIDS, receiving support from the extended family such as the grandparents was significant and highly valued. My view is depicted in a portion of the initial vignette in section 4.2.3 (session 9:20-29):

Then she gave the grandmother the phone then the grandmother answered the phone they said your child has HIV. Then they said did you know for the first time, they didn't know they just saw for the first time and then they said its ok. And then the grandmother told the grandfather that the child has HIV. Then the grandfather phoned the parents. The parents said they will be back tomorrow and then the grandfather said they must come back today because the child is in the hospital and we need to take him to church.

In the above illustration, the grandmother possibly regarded as the head of the family, was the first to be informed of the child's HIV-positive status. She then informed the grandfather who disclosed it to the child's parents. The hierarchical system of information sharing portrays the social context in which disclosure occurred and how the children interpreted these processes.

The role of the grandmother as the potential provider of resources, encouragement and strength is also portrayed by Meme: *The grandmother brought some medicines and stuff and the grandmother said I am so worried about this daughter. I wish you could be well and do not die. In the night they were praying all of them together sitting in the circle and the little baby was sleeping* (session 9:49-54).

The one who fetches me who is my mother here

Kaemogetswe had been visiting her weekend mother M and her daughters N and P for a number of years. She looked forward to these visits as she regarded them as her family. She, together with C, an orphaned child from another children's home, experienced family life as they cooked, played, watched TV and exercised when they stayed over at M's house. When she was with her weekend family, Kaemogetswe said: *it makes me feel happy* (session 8:260) as she regards M as her mother: *M, the one who fetches me who is my mother here* (session 8:36-37) and N and P as her sisters: *My sister's name is N and P* (session 7, group 1: 53), *they are like my sisters. They come to pick me up and I go to stay with them sometime* (session 7, group 1:57-58). For Kaemogetswe, her weekend family afforded her the opportunity of implied escape from the children's home and a life away where she is cared for and listened to: *she give me her phone number* (session 8:46) and *when she goes to work and I am bored then I phone her* (session 8:48-49). Her place at her weekend parent's home seems to fulfill her need to belong and her desire for communication with people who are external to the home. Superman's weekend parent is J who lives in Johannesburg. He looked forward to his time at J's home as he got to *play Playstation* (session 5:124) and *swim* (session 5:143) and play with other children.

4.2.2.2 Positive intrapersonal characteristics

In this section, I shall describe children's positive intrapersonal characteristics. The characteristics that I report on are: positive self-concept and developmental maturity.

a) A positive self-concept

As I discussed in Chapter 2, a positive self-concept and self-image may be depicted in children's reported feelings of self-worth, pride in their abilities, confidence, assertiveness, self-awareness independence, competence and having a sense of responsibility. A positive self-concept also seems to arise from perceptions of strength.



I am beautiful

Harry Potter's positive self-concept is illustrated in the following: *My greatest strength is because I am responsible* (session 4:29). Furthermore, during session 10, Harry Potter described what he thought he was good at: *I am nice* (line 7), *I am ...good at taking care of things* (line 9), *I'm good at writing my schoolwork* (line 15) and *I'm good at saving money* (line 23). In addition, he claimed that: *I love my flower because they teach us about flowers at school and I did write it nicely and I did paint it nicely* (session 1:4-6).

Meme and Kaemogetswe seemed to draw strength from their physical beauty: *My greatest strength is that I am beautiful* (Meme, session 4:29); *I think I am beautiful, nice, pretty* (Kaemogetswe, session 4:23). Batman takes care of his body, thereby possibly reflecting a positive self-image: *I picked up "body" I wash my body when I am dirty and I must look after my body by exercising and by washing so you smell fresh and clean morning and evening* (Batman, session 7:83-84).

Kaemogetswe demonstrated positive emotions such as happiness and pride in her abilities regarding her home and school:

I feel happy because I am in a safe house and school (session 6).

I am doing OK (session, 3:24).

I can depend on myself (session 4:19).

Lizzy's self-awareness and positive self-concept are suggested in the following quotations:

I can't play netball [netball] at school but I wan to play (session 4:6).

I think I am a very good girl and I am so helpful (session 4:23).

My greatest strength is my smell and when I help people (session 4:29).

Dimple illustrated her awareness of her emotions and positive characteristics in the following lines: *She's proud of herself she's proud of her because she knows what's good for her*, (session 2:24-25). Other positive intrapersonal characteristics that Dimple portrayed were patience and kindness (session 2:10-11).

She is thinking that she is proud of herself

In session 2, Dimple said: *She is thinking about that she is proud of herself and she is happy* (session 2:19-20). Her love for herself is reflected in: *She knows that she will always love herself and some other people* (session 2:21-22). Dimple indicated that her other positive quality is her pride. She displays her pride in her self-knowledge: *She's proud of herself. She's proud of her because she knows what is good for her* (session 2:24-25). Dimple also

demonstrated self-awareness and self-affirmation when she said: *I like her because sometimes she is kind and she's also patient with other things* (session 2:10-11).

Taking pride in your self-knowledge is further illustrated in Lizzy's declaration: *I know a lot about traditional life* (session 5:33) and she explains that although she is in a special school, *in that school we cook, we work. It's a school where you work with your hands but we cook and we do computers. We learn to cook, we bake and we cook pasta and things like that* (session 1:13-16). Such knowledge is important to her and allows her to identify positively with herself and her school thereby establishing her self-identity: *I like the school very much and I want to finish at the school* (session 1:18-19). Being proud of your abilities and skills is also illustrated in the following: *I did write it nicely and I did paint it nicely* (Harry Potter, session 1:4-5).

Pride in her scholastic achievement was expressed when Kaemogetswe said: *She always has whatever she needs for the exams and she passes them* (Kaemogetswe, session 3:17-18). She passes because she studies very hard, *she studies from half past nine till two o' clock* (session 3:20). Kaemogetswe is also proud and satisfied with her ability to *make tea for visitors and to play netball* (session 1:5-6). Lizzy's pride is in being self-sufficient on a practical and functional level as she thought about going *to work* (session 2:13), and *working with her hands*, (session 2:18) and *sewing and doing the dishes* (session 2:20).

Because it is our team

A sense of national pride and the pride of group identity is demonstrated by Kaemogetswe (session 5:2-14):

Kaemogetswe: *This one is Habana and the coach.*

Interviewer: *So that is Habana, OK.*

Kaemogetswe: *And his coach when they were playing against England and they won the cup.*

Interviewer: *Do you know his name?*

Kaemogetswe: *No.*

Interviewer: *He is Jake White.*

Kaemogetswe: *Yes, he is Jake White, and now he kissed Habana on his cheek.*

Interviewer: *Right, so why did you choose that picture?*

Kaemogetswe: *Because it is our team.*

Interviewer: *It is our team?*

Kaemogetswe: *Yes the South African team.* Figure 4.10 is an image of Kaemogetswe's collage.



Figure 4.10: Collage: All about me – Kaemogetswe

I can depend on myself

Another indicator of the presence of a positive self-image were the children's displays of self-confidence and independence. This view is supported by the following direct quotations:

I can depend on myself (Kaemogetswe, session 4:19); *I think life is easy, nice* (Kaemogetswe, session 4:28); *I am doing OK* (Kaemogetswe, session 4:28); *I can depend on myself* (Superman, session 4:19); *I think life is good* (Harry Potter, session 4:28).

I am good

Positive self-image was also visible in the way the children viewed their physical and personal attributes, and what they related about one another. Kaemogetswe asserted, *I think I am beautiful, nice, pretty* (session 4:23). Lizzy said: *I think I am a very good girl and I am so helpful* (session 4:23). Meme also confidently pointed out, *My greatest strength is I am beautiful* (session 4:29).

In a conversation about himself, Harry Potter said: *My greatest strength is because I am responsible* (session 4:29). He also believes, *I am nice*, (session 10:7) and *I am good at taking care of thing* (session 10:9) *like DVDs and videos* (session 10:11) and *I'm good at writing my schoolwork* (session 10:15), and *saving money* (session 10:23). His friends think that he is a *good boy* (line 42) who *shares* (line 38) and *lends his stuff* (line 40). His friend Superman is particularly impressed with Harry Potter because, *he gives me his food* (session 10 :45) and *when I am crying he comes to me and he said who hit you?* (session 10:49) and, *then he goes and tells mum that somebody hit me* (session 10:53). Batman describes why he thinks that Harry Potter is a good friend: *like when I am alone and I have no friends he comes and plays with me* (session 10:64).

b) **Developmental maturity**

In this study, a few children's sense of responsibility and appropriate cognitive and reasoning skills demonstrated their developmental maturity.

This time I did think a lot

Significantly, some children were able to engage with me on a *higher cognitive level* than the other children in the home. Dimple made the comment *not always* (session 5:62) in our discussion about birds and wings and whether they took you places, which is perhaps indicative of a higher order thinking capacity. In her collage, Lizzy demonstrated *sound cognitive reasoning skills* when she explained her choice of pictures and the process of getting where you want to be in life. Her words (session 5:4-14):

Lizzy: *Ok, I did cut this page, this picture for, you have to work hard to get to this point.*

Interviewer: *Ok so you have to work hard and this picture is of a girl writing exams?*

Lizzy: *Yes.*

Interviewer: *So she is working hard?*

Lizzy: *Yes.*

Interviewer: *To get to which point?*

Lizzy: *This one.*

Interviewer: *Is it these ladies in the dresses?*

Lizzy: *Yes.*

Figure 4.11 is an image of Lizzy's collage



Figure 4.11: Collage: All about me – Lizzy

In another discussion, Lizzy reflected on her thoughts (session 5:166-169):

This time I did think a lot and I think that the best thing that I have to do now is to stay here and go to school and I will see what is going on with my life and then, if I am ready to go home and then I will. I noticed a deep level of maturity in understanding the role of self-efficacy and the need to show responsibility towards themselves when Meme responded we

have to, so we don't get sick (session 7, group 1:99) to my comment: *"it's good to hear that you play some sport in order to keep fit"* (session 7, group 1:97).

I suggest that being affected by adversity could have made the children in the home sensitive to the needs of others and it may have nurtured a sense of social responsibility within them. Kaemogetswe described why she thought that doctors performed an important job, the most important one being to disclose the HIV status to infected people (session 8:321-329):

Kaemogetswe: *If you are sick and to help people and if you don't know you have HIV you tell them.*

Interviewer: *So you think that it is important to know whether you have HIV or not?*

Kaemogetswe: *Yes.*

Interviewer: *Why is it important?*

Kaemogetswe: *Because sometimes people if they don't know they have HIV they just give them medicine they don't know what for and they don't take them and then they die.*

He will help poor people

When coping with the challenges of HIV&AIDS on a daily basis, many of the children in the study displayed social and emotional maturity in terms of a sense of responsibility that was often beyond their chronological ages. In her conversation with me about her collage, Kaemogetswe displayed sensitivity on issues such as the appropriate treatment of others. She asserted that she admired people who helped others and treated them well (session 5:27-34):

Interviewer: *So why did you choose this picture?*

Kaemogetswe: *Because Zola 7 helps people. When people treat them then he said not to.*

Interviewer: *I don't understand, how do people treat them?*

Kaemogetswe: *Like clean their shoes*

Interviewer: *So you say that some people treat other people badly and make them clean their shoes and he said?*

Kaemogetswe: *He said they must not lick their shoes*

She admires Zola 7 and would like to be like him as *he helps people* (session 5:44).

Elsewhere, Kaemogetswe's altruistic qualities, which may be ascribed to social and emotional maturity, are further exemplified in the following extract from my conversation with her (session 3:9-14):

...and when it is raining when she sees someone don't have a jacket, she gives them and she said they must return it back when the rain stops. And if another girl or boy does not have

food to eat she gives them and when her mother always like to send her to buy bread she does not complain she always obeys her mother and father. She respects them because they teach her manners.

Another situation in which Kaemogetswe displayed a sense of social maturity and responsibility as a coping mechanism was when she desired *services in the country* (session 2:18) which would be evident when *the land is clean and there is no papers* (session 2:23). There is also a sense of social responsibility towards the less privileged children when Kaemogetswe describes a story about a queen who gets angry at the princess because the princess does not allow her children to play with *poor* and *ugly* children (session 2:70-72).

In other instances, Kaemogetswe described her aspirations to become a children's doctor, in order to make sick children better and to be available to visit sick children at other residential care centres. When she was asked to write in her responses to the incomplete sentences schedule, her response to one phrase was: *I feel quite bad about B hite* [hitting] *K* (session, 4:30).

Dimple displayed emotional maturity in her awareness of appropriate social cues and gestures. Her recognition of the need to take care of and show support of others is evident in, *it also makes me feel like to send flowers to someone* (session 5:42-43) *when it is the person's birthday or at Christmas or at mother's day or father's day* (session 5:48-49).

In a conversation about how he coped with bullying by other children (session 2:59-80), Batman said that he, *feels like hitting them but does not hit them* (line 76), *because we must forgive and forget* (line 80). There seems to be recognition of a strong moral character. Batman also stresses his desire to be socially responsible and his need to help others because, *when he grows up he will be a powerful man and he will help poor people* (Batman, session 294-94).

As mentioned earlier in this discussion, children in this study sometimes appeared to have taken a developmental leap especially with regard to their mature thinking in terms of social responsibilities. In session 2, Lizzy thought about *going to work*, suggesting earning an income to become self-sufficient. Her future aspiration to become a *social worker* (session 2:102) is also indicative of a sense of social responsibility. This thought is reiterated in: *One day I want to be a social worker becous [because] I whant [want] to help ather [other] children"* (session 4:25) and, *My greatest strength is when I help other people* (session 4:29). Although her mother is dead, Meme indicated her concern for significant others in, *I worry about my mother and my grandma* (session 4:14).

4.2.3 Theme 3: Children coping with HIV&AIDS

I introduce the theme, *children coping with HIV&AIDS* with a vignette as it embodies the essence of how children and families who are at risk are also coping with HIV&AIDS. Thereafter, I explore the following sub-themes that report on the coping styles that children use: spiritual connectedness and disengagement.

M: this one have HIV (*very soft, barely audible voice*)

M: **this child has HIV**

S: This child has HIV.

M: And his father and mother are trying to help and his big sister. Now his mother and father was going for a long time and then the child became sick. Then the **grandparents phoned the mother** and father and told them that the child has HIV, he's sick. When this little daughter, when they helped the giving the grandmother and father the phone numbers.

S: And the doctor came and they phone the doctor and the doctor came to help the child and the big sister.

M: And then they phoned the **people that work at the clinic** and then they took the child to the clinic then they surrounded the child and **they helped her**, and then this nurse phoned the grandmother and the big sister answered and said who do you want then they said can I speak to the grandmother.

Then she gave the grandmother the phone then the grandmother answered the phone **they said your child has HIV**. Then they said **did you know for the first time**, they didn't know they just saw for the first time and then they said its ok. And then the grandmother told the grandfather that the child has HIV. Then the **grandfather phoned the parents**. The parents said they will be back tomorrow and then the **grandfather said they must come back today** because the child is in the hospital and we need to **take him to church**. And then they said OK we will come back right now. Then they bathed and they changed and then they came back. Then they knocked and the little baby brother and the big sister came outside with the little baby. Then the family took the ...to the hospital where the child ... co..

To the ... so she wont get cold of the HIV then...

Then they take her out and said OK

S: The doctor in the clinic helped her and the **child was very sick**. **We could help her** and they could **take him to the hospital**.

M: And the mother went to the hospital to fetch the baby and then they told the baby in 5 days, **if she don't take care and give her and give her healthy things she will die**. You will have to **take her to church every Sunday and every Monday if you can**.

S: Then the child...they took him outside. Then they put him inside.

M: Then they took him in. **But the child wasn't dead yet**. **The child survived a little bit**. Then his parents took him home and took home, took care of him. **The grandmother brought some medicines and stuff** and the

grandmother said I am so worried about this daughter. **I wish you could be well and do not die.** In the night **they were praying all of them together** sitting in the circle and the little baby was sleeping and the big sister. They felt that they gave the child medicine. She could not breathe and they took him they phoned the doctor quick so that they can take the child...

S: And **the doctor came**, they came and **they took him out of the grandmother's arms.** They took him to the hospital.

M: They phoned the parents back, they said **your child is only going to die because you didn't take her to church** and they said OK. We forgot we will take her now. When they went back they took him to the church and then **the holy bird came** and the holy bird and the priest prayed for the child **the holy bird took the child on his back and he flew with her around so that the child can have some strength.** Then the mother said we were praying so hard and we thought you wasn't breathing properly. So they say OK you can go we will keep you in the hospital with the big sister.

S: **They kept him in the hospital.** The next morning they took her, she was sleeping then they checked her. **The next morning she could die. She died.** Then she went ...

M: They took her to the.....**They phoned the parents and told them that your child is dead.** Then the **parents cried and cried** and then they asked **how much is the cost of burying the daughter.** Then they say **you don't have to pay because the child was very sick and you tried your best** and they took the child's skin off and then they put her in the...

S: ...skeleton box.

M: No it's not the skeleton box.

M: And then they went to bury the child. Then that day **they couldn't eat, they couldn't do nothing.** Then the little child said, I'm missing my little sister and they said... and they gave it to the little son and then they carried on. Then they went to **see the graveyard of the little sister.** Then the little sister... then the whole family came and buried the child and gave them everything they took out everything, the bed and they throw it in this big dustbin. **Then the bird came and it took the child because the child is an angel then they took the baby to heaven.** Then in the night when they were sleeping this child heard his sister coming and holding his hands and he said its you my little sister, I'm going to tell my mother then he flew away again and said you are an angel then he went back and said mother **I saw my little sister in the night touching my hands.** Then she said you were dreaming. Then he said no, ma it's the truth. **God was talking and the little sister was answering** and so **God said to the whole family your child will be fine in heaven you don't need to worry anymore because in heaven it's a safe place. No one can die. And you must live safely now. And you must live in a safe house and be safe.**

That's the end of the story.

Meme (M) and Spiderman (S): session 9

4.2.3.1 Spiritual connectedness

Throughout this study, I found that the children made references to their spiritual and religious connection² at some point in their conversations. Children in this study incorporated religious rituals and routines in their daily lives. Consequently, these children may have been afforded a semblance of stability and a resource from which to draw their strengths.

a) I will go to heaven

In the vignette, Meme's detailed description exemplified her faith in God in a vivid and emotional manner. She believed that the power of prayer could help to heal anyone who is sick. Her faith in God is further illustrated in the following direct quotations:

This here, its all about HIV. The family, this boy's father heard that the boy has HIV .Then the family went to church. Then they prayed to [for] the boy (session 11:1-3). Then they prayed for this boy then they said he must stay a little bit in the church. Then he slept in the church (session 11:9-11). Figure 4.12 is an image of Meme's drawing of HIV in the family.

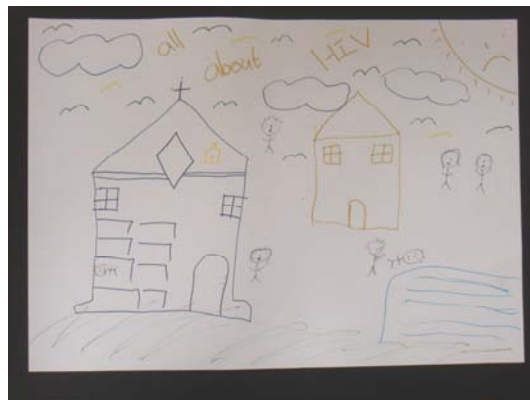


Figure 4.12: HIV in the family – Meme

Batman, Kaemogetswe and Meme referred to reading the Bible every day: *at night in my bed, I pray* (Batman, session 4:3); *at night in my bed, I read bible storys [stories] in the night* (Kaemogetswe: session 4:30); *She thinks of God* (Kaemogetswe: session 2:52); *She prays every night, she reads the bible* (Kaemogetswe: session 2:54); *Because God made her* (Kaemogetswe, session 2:56); *At night in my bed I read my bible and I do my praying* (Meme, session 4:3).

² I shall refer to the terms **religious** and **spiritual** connectedness interchangeably while acknowledging that an effort to find meaning and purpose in life may not be religious but spiritually based.

From the children's verbatim accounts, it seems reasonable to assume that the children have embraced religion as a safe haven and have found solace and comfort in their **faith** in God. As a result of his faith, Harry Potter does not fear death: *I'm not scared of dying because I will go to heaven* (Harry Potter, session 11). Further evidence of his faith is illustrated:

Interviewer: *When cowboy goes to bed, what does he think about?*

Harry Potter: *He thinks about he wants to go to heaven.*

Interviewer: *He thinks about wanting to go to heaven?*

Harry Potter: *Yes.*

Interviewer: *Why does he think that?*

Harry Potter: *He thinks heaven is a nice place and the other people did tell him that* (Harry Potter: session 2:44-49)

b) God blessed me

The children also expounded the view that if you turned to God or listened to God, then your life could be better. They explained that if you read your Bible daily, then God would protect you and bless you. In her clay modelling session, Dimple moulded *all the people who passed away* (session 8:295-296). *Her reasoning was: These are the ones who wanted nice lives but they didn't get it because they didn't turn to God, my mum, except my mum and dad* (Dimple, session 8:295-302). The children's implicit faith in God is further exemplified in: *she must trust God to protect her* (Meme, session 7: group 1:109-110); *Today I modelled but I didn't win but still God blessed me* (Dimple, session 1:20-21), implying that her faith in God would protect and buffer her from misfortune and adversity. Hence, she indicated her love of singing songs about God. She said that her favourite song was, *Stand up and shout if you love Jesus* (session 5:87-88). Results in this study suggest that many children are using spiritual connectedness as a means of coping. This might imply that spirituality, as a coping style, seems to give hope and keep children happy because: *The happiest time is wan [when] I am at the charch [church]* (Dimple, session 4:2).

To conclude this sub-theme I quote self-explanatory lines from the introductory vignette, which aptly reflect the spiritual connection that children in the study have assumed: *God said to the whole family your child will be fine in heaven you don't need to worry anymore because in heaven it's a safe place. No one can die* (Meme, session 9:102-105).

4.2.3.2 Disengagement, denial and detachment as coping mechanisms

In the context of this study, the term disengagement refers to the act of disconnection and detachment of oneself as opposed to becoming involved. Children in this study allowed themselves to disengage: to dream, fantasize and imagine, as a means of coping with the challenges allied with being affected by HIV&AIDS. The ways in which children in this study disengaged included fantasy, denial and detachment.

a) Fantasy as a coping mechanism

Living in a world of fantasy and make-belief, is one of the ways in which the children in this study coped with challenges in their lives.

Superheroes

The above point was illustrated at the outset of the study when four of the children choose pseudonyms of superheroes and action heroes (Harry Potter, Superman, Spiderman and Batman) (Harry Potter; session 4):

I like Harry Potter movies very much – line 1

The happiest time is when I see Harry Potter – line 2

At night in my bed, I think about Harry Potter – line 3

I badly want to be Harry Potter – line 4

I don't like it when I don't see Harry Potter – line 5

I can't stop thinking about Harry Potter – line 6

I think I am Harry Potter – line 23

The extent of Harry Potter's engagement in a world of fantasy seeps so deep that he would be prepared to change into Harry Potter (session 2: 71).

However, considering their ages, this seems to be developmentally appropriate behaviour. In particular, Batman (session 2:110-112): *he dream about flying in the sky and going to save people and telling the soldiers not to be bad and the soldiers became good people.* Earlier in the conversation he explained that he would like to be Hulk *because Hulk is big and strong* (session 2: 11), thereby implying that he would also like to be big and strong. He also thinks about *changing into green like the real Hulk and he will save his people from the soldiers because the soldiers want to change the city* (session 2: 16-18).



When I am a queen

While boys in the study fantasised about being superheroes and committing bravery, the girls' fantasies differed and revolved around royalty and the implied life of glamour, luxury and privilege. While Dimple claims: *Sometimes I imagine that I am a queen in the wild* [world] (session 4:10), Michelle, *is thinking about she is wishing she could be a queen* (session 2:52). Kaemogetswe talked about a princess called Arona who wanted to live in a clean land and provide services for her people. She would also see to it there was no discrimination against the *poor* and *ugly* children (session 2).

b) Denial of loss as a coping mechanism

In this study, the category of denial of loss is used to report on the affective and cognitive behaviour of children who speak of their dead parents as though they were still alive. To do this seems to deny the parent's absence or death.

My mother is at home

There were instances where children's utterances and written words in this study could have implied a denial of their parents' death. In this regard, denial could be regarded as a form of coping with the loss of a significant person. I provide evidence of the children's descriptions of their parents as though they were still living to exemplify my suggestion:

My father is a soldier (Batman, session 4:9)

I can depend on mom (Batman, session 4:19)

My father is so beautiful he is so special (Kaemogetswe, session 4:9)

My mother is at home (Superman, session 4:16)

My father is the best (Superman, session 4:9)

My father is a police and he catches robbers (Meme, session 4:9)

My mother is a lawyer she halp's [helps] people (Meme, session 4:16)

Dimple described her family as: *I think they are nice to me and they are the ones that make me feel nice and they protect me and I like them* (session 5:97-99). She also spoke of her mother as though she were alive: *My mum woke me up* (session 2:110).

c) Detachment as a coping style

The desire for escape and freedom from the context of HIV&AIDS was implied in a metaphorical sense as well as in physical detachment by the children in this study.

Wings take you places

Dimple, especially, used the metaphor of wings extensively in the study, perhaps symbolising a desire for flight, freedom and emancipation (session 5:54-62):

Interviewer: *Tell me about these.*

Dimple: *The wings. I pasted the wings because I would like to fly to see the world and I would like wings because they are the best.*

Interviewer: *Why are they the best?*

Dimple: *Because it take you in the air*

Interviewer: *...They take you places?*

Dimple: *Not always*

Figure 4.13 is an image of Dimple's collage.



Figure 4.13: Collage: All about me – Dimple

This desperation for escape and freedom is emphasised in, *I badly want to have wings to fly in the sky* (Dimple, session 4:4). Besides a metaphorical disengagement, Dimple also physically and consciously detached herself from her surroundings when she felt a need to. She removed herself from difficult situations by finding comfort being by herself in a tree. She maintained that since the other children disturbed her when she was studying she preferred to study in the tree (session 3, 59-71):

Interviewer: *You study in the tree? Why?*

Dimple: *I like the tree. I don't know why.*

Interviewer: *Do you go there often?*

Dimple: *Yes.*

Interviewer: *What do you go and do there?*

Dimple: *Sometimes when I'm bored, I just go up there and talk.*

Interviewer: *You just go and talk?*

Dimple: *Yes.*

Interviewer: *About what?*

Dimple: *About how life is.*

Interviewer: *And what do you think about it?*

Dimple: *I think that life is difficult and I am just an orphan child and I just think of my life.*

On a particular day, I arrived at the home and found Dimple sitting high up in the big tree. In the following extract from my field notes, I describe a particular incident where Dimple escaped to the tree, perhaps as a way of protecting herself from a challenging situation.

When I arrived there, I was again surrounded by the children. However, conspicuously, 2 faces were absent - Dimple and Lizzy. As I rounded the corner, I looked up and there on the large tree was Dimple, perched on the top. She looked down and gave me a wry smile. I knew immediately that something was amiss - I could not see her trademark dimples. Then I noticed Lizzy sauntering in from around the side of the house, not looking too pleased. No smiles here! What was going on? Visit 3 (2007:10:05).

On a subsequent visit to the home, Dimple explained the reason for her escape to the tree. This discussion was described earlier in this chapter (see Section 4.2.1.1). On another occasion, Dimple spoke overtly to me about her desire to leave the home especially when it seemed the conditions became too unbearable for her (Dimple, session 5:159-164). She indicated that she was not happy living at the home because: *I don't feel comfortable because sometimes I just feel like going away* (session 5:159-160). Although she had thought about leaving the home, she had not considered ... *I don't know, just to go out through the big gate and to walk* (session 5:162-163). Superman also incorporated a metaphorical analogy to describe his desire for freedom. He would like to be a bird: *because a bird flies free*, possibly implying escape and emancipation (session 2:67).

I want to be alone

Other children also engaged in physical detachment by isolating themselves in order to help them cope. Kaemogetswe explained that when the other children were fighting or when Superman was hitting Michelle: *me, I just sit somewhere else because I let the others tell him to stop. The big girls tell him to stop* (session 3:59-60). Harry Potter also preferred to be by himself (session 2:23-25 and 26-27):

Harry Potter: *He wants to be alone.*

Interviewer: *What makes him most happy?*

Harry Potter: *Like when he is alone.*

Interviewer: *What makes him sad?*

Harry Potter: *When other people are next to him.*

4.2.4 Theme 4: Children experiencing well-being

In this section, I present data related to how children in this study depicted a sense of well-being. I illustrated the sub-themes of hope, optimism, happiness and positive relationships as indicators of well-being. I conclude this section by describing data related to the children's future aspirations.

4.2.4.1 Hope, optimism and happiness as indicators of well-being

The children in this study manifested a sense of hope, happiness and well-being in various ways. While some expressed their emotions overtly, others (Lizzy, Dimple and Meme) perhaps felt safer to project their thoughts and feelings and used metaphors to relate their life circumstances.

a) These flowers, now they are happy because they are life again

In the following extract from a conversation with Lizzy and the accompanying picture, Lizzy used a metaphor to explain how she felt about her life:

And surely these roses, these roses are me. These flowers actually are me because these flowers were dead and someone came and watered these flowers and now they're grown up again. Now, so these flowers now they are happy because they are life again (session 1:3-7).

It seems imbued in this metaphor that despite the vulnerabilities and risk factors that impinge on her development, Lizzy had adopted a positive and optimistic approach to her life. Her descriptions allude to the possibility of hopefulness, zest and growth as indicators of her well-being experiences. Figure 4.14 is an image of Lizzy's spontaneous painting activity.



Figure 4.14: Spontaneous painting activity: Happiness –Lizzy

She still thinks about good things that is going to happen tomorrow

Lizzy's hopefulness for life is also encapsulated in the following extract (session 2: 66-68):

Lizzy: *Even if there's bad things that happened or she dreamed about bad things, she still think about good things that is going to happen tomorrow.*

Interviewer: *Such as what? What are the good things for her?*

Lizzy: *Eh... such as she's still alive.*

Interviewer: *Yes.*

Lizzy: *And tomorrow she is going to have a good time. She is going to work happily.*

Interviewer: *So she is going to work happily as she has a job?*

Lizzy: *And a lot of things that God gave her*

Interviewer: *An example, like?*

Lizzy: *Like a house and the fact that she eats and all the things that she has, other people don't have.*

It makes me feel colourful

In other interactions with the children in this study, hope and happiness were implied by the choice of the children's words, the bright colours of their drawings and the subjects they chose to paint. For example, Meme and Michelle chose to paint pictures that expressed growth and life (Meme, session 1: 1-4):

I have a picture of a spring day and me I'm picking some apples and put them in a basket and the most part I like is the flowers and the sky. Figure 4.15 is an image of Meme's spontaneous painting activity.



Figure 4.15: Spontaneous painting activity: Happiness – Meme

Michelle's picture depicted happiness in the form of bright colours: *I painted a picture. This picture, the picture tells me that it is (laughs) beautiful. I painted, I used colour yellow and green and blue and I love my picture and I want to paint it again* (session 1:1-4). Figure 4.16 is an image of Michelle's spontaneous painting activity.



Figure 4.16: Spontaneous painting activity: Happiness – Michelle

Other children portrayed hope, optimism and happiness in the following manner:

The sun is outside and the grass is green and there is beautiful roses (Superman, session 1:2-3).

Today I modelled but I didn't win but still God blessed me (Dimple, session 1:20-21).

It's when I grow up I want to marry and have a good life (Dimple, session 5:237-238).

It makes me feel colourful (Dimple, session 5:35).

4.2.4.2 Positive relationships

Children in this study demonstrated their well-being by engaging in positive and encouraging relationships with others. These affirmative relationships were portrayed by Kaemogetswe, Lizzy, Harry Potter and Superman.

Kaemogetswe affirms her relationship with her weekend family by describing her relationship with them (session 8:254-260):

Interviewer: *What do you do together when you go there?*

Kaemogetswe: *We cook.*

Interviewer: *Yes.*

Kaemogetswe: *We play together. We watch TV together.*

Interviewer: *How does it make you feel when you go there?*

Kaemogetswe: *It makes me feel happy.*

Besides her weekend family, Kaemogetswe has healthy friendships with other peers (session 8:169-175):

Kaemogetswe: *She's 100% my friend.*

Interviewer: *Yes, and for how long do you know her? Is it 1 year or 2 years?*

Kaemogetswe: *She's been my friend since 2000.*

Interviewer: *2000. That's a long time, which means that this year she will be your friend for about 8 years.*

Lizzy also seem to engage in friendships which seemed to generate happy and joyful moments for her (session 5:109-117):

Lizzy: (laughs) *The best part is that I am going to have a birthday and it is different from home. At home I don't celebrate it and I celebrate it here and I don't get presents and there's none to celebrate with but here I have lots of friends to celebrate with.*

Interviewer: *How do you celebrate your birthday here? Tell me about it.*

Lizzy: *They take you away, they lock you in the room and then they deck the table nicely and then they take you out, they switch off all the lights and then they shout "happy birthday".*

Lizzy seems to have enjoyed a warm and supportive relationship with her mother prior to her stay at the children's home (session 5:48-60):

Interviewer: *Tell me about your home.*

Lizzy: *At my home, it's nice.*

I'm and I love being with my mum 'cos every time when I'm with my mum she tells jokes and everything that makes he happy. She is fun.

The importance of warm and nurturing relationships with friends was illustrated elsewhere in our discussions as well (session 5:57-60): *the best thing I can remember is the time when I was staying at home I used to have lots of friends and we used to play house dolls like we used to come to my home with all my friend with dolls and we used to play outside.* There seemed to be moments when Lizzy enjoyed living at the children's home as she was surrounded by people who demonstrated their care and compassion for the children in different ways such as baking a birthday cake and giving her presents when it was her birthday (Lizzy, session 5:119-132).

Dimple's warm relationships extend to her caregivers as well (session 1:14-17): *And this weekend I want to have some fun with mama D. and bless her and bless everyone and I also want to have some fun and pray and also swim if the swimming pool gets right.*

Superman and Harry Potter share a friendship wherein they showed concern for each other (session 10:49-53):

Superman: *And when I am crying he comes to me and he says who hit you?*

Interviewer: *So he is concerned about you and he asks you who hit you?*

Superman: *Yes.*

Interviewer: *And what does he do?*

Superman: *Then he goes and tells mum that somebody hit me*

Dimple suggests that she would like to demonstrate her warm sentiments about others by sending them flowers (session 5:43-54):

Dimple: *It also makes me feel like to send flowers to someone.*

Interviewer: *Yes, so it makes you feel like you want to send flowers to someone?*

Dimple: *Yes.*

Interviewer: *When would you send flowers to someone?*

Dimple: *When it is the person's birthday or at Christmas or at mothers day or fathers day.*

Interviewer: *Would you like to receive flowers?*

Dimple: *Yes.*

4.2.4.3 A future perspective

Some participants in this study (Michelle, Dimple, Lizzy, Meme and Kaemogetswe) seemed to have clear goals or plans for their future.

a) The future is going to be good

The prospect of a better future was implied in their thoughts about their future. These thoughts are substantiated by the following direct quotations from conversations with the children as well as their responses from an Incomplete Sentence Schedule. According to Kaemogetswe, *the future is going to be good when I am a doctor* (session 4:13). She further indicated a sense of social responsibility when she maintained that: *when I grow up I want to be a doctor* (session 11:301).

Lizzy's thoughts about her future included having a good life with a husband: *I often think about my self and my future and my live [life] well be good* (session 4:7), because she would have *a good family and she wished to have a good husband* (session 2:96-97) and she would become *a social worker* (session 2:102). Meme and Michelle both aspired to be *teachers* while Michelle also implied that having a *husband* (session 2:68-69) could mean a better life for her. Meme's other aspirations included, *One day I want to be a actor* (session 4).

In spite of the stressors and challenges that they were faced with on a daily basis (see Section 4.2.1) Harry Potter and Dimple reflected that their lives were good: *I think life is good* (Harry Potter, session 4:28); and *the future is good and colourful with me* (Dimple, session 4:13) because, *one day I want to be a senar [singer] in the wurd [world]* (session 4:25). Batman reiterated these thoughts in a simple way: *The future is a batr [better] laf [life]* (session 4:13). Meme too is hopeful for a better future: *The future is going to be good for me why: because I have a fimily [family]* (Meme, session 4:13). This could imply that while the other children talked about the future in terms of a new beginning with a new family, Meme talked about including her current family (grandfather and aunt) as a part of her future life.

On a metaphorical level, Dimple's optimism for her future is expressed in the words: *I like butterflies because I like their wings and when I'm good ... I know that I'm going to have some wings* (session 1:11-13). The implication is the freedom to choose whatever it is you want to do or to achieve in your life.

b) I imagine I am a mother

Having your own homestead where it is implied that you could be in control as it was your personal possession, was a need expressed by Michelle. She would have: *a husband and a house and furniture and work* (session 2:83-84). This need possibly alluded to the need for stability, security, and the implied power of being independent. During this session, Michelle referred to her dream about *having a husband* (session 2:67). Elsewhere in this study, Lizzy also expressed her desire for a husband: *Sometimes I imagine I am a mother of someone and have a husband* (session 4:10). As with Michelle, Lizzy's desire for a husband might imply a need to protect as well as to be protected.

4.3 Conclusion

In this chapter, I reported the results obtained in this study by presenting direct quotations, visual images and vignettes that depicted the themes that arose from a process of inductive thematic analysis of the raw data. In Chapter 5 I interpret the results of my study within the context of the relevant literature and my conceptual framework, thereby presenting it as findings.





CHAPTER 5

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, sub-themes 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:

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

o **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 child-headed 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 considered 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 non-orphaned 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 attachment-type 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,¹ 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

¹ 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 & Csikszentmihalyi, 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;
- o 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 articulated² 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

² 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.



CHAPTER 6

Recommendations and conclusion

6.1 Introduction

In the previous chapter, I presented the findings of my study by situating and relating my results within the existing literature base and the conceptual framework.

In Chapter 6, I provide a synopsis of my findings, offer recommendations and conclude in terms of my research questions as outlined in chapter 1. I begin this chapter by addressing the secondary research questions. Thereafter, while addressing my primary research question, I provide the potential contributions of my study to research and practice in field of educational psychology. In addition, I expound the potential strengths of this study. Potential limitations were discussed in Chapter 1. I also offer recommendations on future lines of inquiry associated with children affected by HIV&AIDS. I conclude this chapter with my final reflections.

6.2 Addressing my research questions

My purpose for this study was to explore, understand and describe how children who are affected by HIV&AIDS negotiate well-being in their lives. In Chapter 1, I posed research questions to guide this inquiry. In this section, I address the secondary research questions and in the process attempt to address the primary question as well.

6.2.1 Secondary question 1: *How did children in my study express a sense of well-being?*

In this study, well-being was found to be subsuming elements of hope, optimism, happiness, positive emotions, positive relationships and future-directedness. These facets of well-being seem to have been integrated without a clear distinction between the different constructs. The children in my study expressed their sense of well-being in direct and indirect ways as illustrated in their articulations, drawings and metaphors.

Hope and optimism emerged as protective factors for the children in my study and were visible in the children's metaphorical descriptions as well as in their articulations that they would have a better life in the future. Based on the results of my study, the constructs of hope and optimism with its inherent cognitive, emotional and motivational components may

be considered protective factors against psychological distress. It does appear as if the children in my study who displayed high levels of optimism and hope for the future, could also be the ones with temperate moods, were more persevering and had better health.

To the children in my study, hope and optimism featured as clear thought processes about their future, setting goals and considering ways to achieve those goals that were related to the children's desire for a better future. For example, Kaemogetswe seemed to have her mind set on becoming a doctor. She indicated that she had to study and perform well in her exams and then progress to studying at the university. Her plan for the future included working at a hospital and caring for children who were sick.

Another facet of well-being inferred in my findings related to the children's positive relationships with others around them. In addition to the friendships that the children had with other children in the home, they also seemed to have inculcated warm relationships with a number of other significant people in their lives such as substitute caregivers and community volunteers. A number of them described friendship with other children in the home as affording companionship, someone to talk to and socialisation, which seemed to curb loneliness and depression. For example, Batman stressed the practical value of friendship as his friend took care of him when he was sick.

I found that children's positive emotions depended on their moods, which impacted on their sense of well-being and seemed to be dependent upon specific events and incidents. I found that when children perceived rejection or were rebuked they exhibited sadness and they isolated themselves from interacting with others and from engaging in household activities. Generally, the children's experiences of happiness were expressed in relation to specific events such as the anticipation of gifts, a birthday party, forthcoming holidays, weekend visits to weekend and holiday parents and the expectation of rewards and treats from community volunteer workers.

From my findings, I have established that the dynamic nature of the children's environmental context as well as the interrelatedness of the children's positive and negative experiences within their environment could have contributed to their sense of well-being or distress. As such, based on my findings I theorise that well-being may be regarded as the interplay between the opportunities and challenges facing the children. Illustrations of positive and affirming experiences where the children perceived feeling valued, loved and protected appeared to enhance their capacity to achieve a sense of well-being. In other

cases, their negative experiences were expressed as distress and seemed to impede their movement towards well-being.

Based on my findings I posit that the children's well-being experiences may be categorised according to those that may be regarded as transitory in nature and those that could have the potential of being enduring. I consider the children's experiences of well-being related to future prospects and future-directedness to be enduring, as they seem to be goal-driven and intrinsically motivated. However, considering the complex and dynamic nature of relationships within the children's home, well-being as related to material possessions and positive relationships could possibly be momentary, fleeting and dependent upon the context at that particular time.

6.2.2 Secondary question 2: *What are the challenges and stressors that placed the children in my study at risk?*

I found in my study that the children's perceptions and experiences of challenges and stressors in their daily lives seemed to arise from their personal and social interactions with their caregivers, friends, peers, teachers and community workers.

On a personal level, challenges seem to be embedded in their individual experiences of orphanhood, residential care, stigma, discrimination, death and bereavement. While the older children in the study (aged between 13 and 15) overtly expressed their anguish about being orphaned, the younger children (aged between 10 and 12 years) alluded to the fact that not having parents affected their sense of well-being. In addition, I suggest that the children who had lost their parents some time ago and had been living in residential care from a young age (Superman, Meme, Batman, Michelle, Kaemogetswe, Harry Potter and Spiderman) might not be as severely impacted by the challenges of being orphaned, in comparison to a newly orphaned child (Dimple) and a non-orphaned child who had recently been admitted to the children's home (Lizzy). Rather, it emerged from my study that the children expressed more distress about living in residential care than about their orphaned status. It seemed as if a few children in this study had vague memories of their parents. In these cases, their challenges were seen in relation to missing family members such as grandparents, uncles and aunts. On a personal level, the children seemed to have developed individual coping styles to deal with their experiences of orphanhood, stigma and discrimination, death and bereavement. Coping styles included spiritual embracement and disengagement from challenging situations.

Aspects of death and bereavement featured in many stories of the children in the study. Based on this finding, I suggest that the children in my study who had lost other significant people might still be in the grieving stages. I find this view to be especially true for Dimple and Batman. I also suggest that children's cognitive awareness played an important role in their unresolved grief processes. For example, it is possible that although Kaemogetswe had lost her parents many years ago, she was still grieving as she did not seem to accept her orphaned status and had expressed a need for stability in her life. Based on these findings I theorise that vulnerable children who engaged in higher order thinking processes, constantly questioned critical events in their lives and subsequently were not easily accepting of their life situation.

On a social level, the challenges that faced the children in this study incorporated episodes of stigma, discrimination, rejection and humiliation from both caregivers and peers at school. Rejection was demonstrated by a caregiver in the form of discriminatory and racist comments which were not specific to HIV&AIDS. Among the peer group experiences of teasing and taunting seemed general in nature and not confined to the children's association with HIV&AIDS. Other challenges that some children alluded to were the aggravating symptoms of their physical illness as well as the side effects of antiretroviral medication.

The children also commented on the minimal information that they received about their health from their doctors and caregivers. In addition, they requested that they be kept informed of arrangements regarding their welfare by the caregivers and social worker. Usually impeded communication of information placed the children at risk for further confusion and uncertainty. Furthermore, misinformation had the potential of destabilising the children's sense of security and trust in their caregivers.

6.2.3 Secondary question 3: *How did the children express their despair and distress?*

I found that the children in my study expressed their distress and despair mainly by internalisation and externalisation of their thoughts, feelings and behaviours.

Internalisation of negative emotions included withdrawal, feelings and thoughts that alluded to a low self-esteem and self-concept, sadness, doubts about their future lives and negative affect. I found that a few children isolated themselves by physically removing themselves from a perceived threatening situation. In these instances, the children either retreated to their bedroom, outside or, as in the case of Dimple, up a tree. It seems that in the event of

stressful situations in the home these children coped by distancing themselves from the perceived threat to their well-being. A few children preferred to remain silent when they felt distressed or distraught. Children who chose not to respond or to comment when challenged by their caregivers or peers at home also seemed to be the children who manifested a low self-esteem, a low self-image and minimal future-directedness. In addition, while some of the children spoke explicitly about their fears related to their future lives and their relatives, others alluded to their fears of illness, death and their future lives in their stories and in metaphoric images.

Externalisation of the children's distress featured in their conversations, stories and in their play behaviour. A few children referred to their distress about living in residential care, their confusion surrounding their parent's death and issues relating to stigma, discrimination and perceived rejection by their caregivers. Furthermore, I regard a decline in their concentration levels as an externalisation feature, possibly indicative of their distress, despair or unhappiness.

From the results I posit that children in this study who internalised their emotions manifested a lower self-esteem than those who engaged in externalising behaviour. I suggest that the relationship between internalising and externalising behaviour and self-esteem is an area that could be considered for future research with children in terms of coping with HIV&AIDS.

6.2.4 Secondary question 4: *What are the children's psychosocial needs?*

In my study, I found that the children expressed a range of psychosocial needs relating to nurturance, communication and socialisation. A few children demonstrated a yearning for a mother-child relationship, which held connotations of warmth, love, compassion and protection. Related to nurturance, the children also concretely expressed their need to take care of themselves physically (personal hygiene and beautiful clothing) and medically. They emphasised the need to eat healthy and nutritious food, to exercise regularly and to adhere to their medications. A few children desired to take care of or nurture others, which seems to be related to the personal benefits of improved self-efficacy and a sense of accomplishment and altruism that arises from doing good for others. In this case, giving and receiving nurturance served as protective factors and buffers, which improved resilience for dealing with adversity. For example, if I take my medication daily, I will feel well. If I take care of others in my home, I will feel good about myself.

I found that the children in my study needed to communicate on two levels: Firstly, they needed to give information about themselves and to have someone listen to them; and secondly, they needed to receive information from significant other people such as their primary caregiver, their social worker and their doctor. Children expressed their need for an empathetic and understanding person who could listen and speak to them. On a daily basis, the children needed to speak to a concerned adult about matters pertaining to their schoolwork, friends and their health. A few of them wanted regular counselling sessions with their social worker, when they could inform her about their unhappiness regarding certain situations in their home.

Another finding in my study related to the disclosure of illness. Children expressed their need to receive information about their illness from their doctor and their caregivers. Generally, it seems that they were not pleased about being uninformed regarding their health. They expressed a need to know more about illness in general and specifically about HIV&AIDS.

Associated with their need for more information, the children requested that their caregivers and social worker collaborate with them regarding weekend visits to weekend parents and to their extended families during the school holidays. I suggest that whereas a lack of information and minimal sharing of information could have caused confusion and uncertainty in the children's lives which may have led to an increase in negative internalisation processes, collaborative sharing of plans and arrangements could lead to a sense of stability and security as children felt safe in knowing what to expect.

In addition, I found that the older children in this study (aged between 13 to 15 years) expressed a greater need for socialisation and peer group interaction. This need seems to be in line with their developmental phase as adolescents where peer group interaction plays an important role in shaping their identities. In particular, children in this age group expressed a desire to go shopping for clothing, to go to parties with friends and to have fun outside the children's home.

6.2.5 Secondary question 5: *How are the children supported?*

From an ecosystemic standpoint, it emerged in my study that the children were supported and bolstered at different levels of influence operating within the social context. From the level of the child's proximal relationships to societal levels, children are influenced by decisions made in their regard. I consider that in many instances, different levels of positive

and enabling systems collaborate and provide protection for the children under different circumstances. Such protective systems included caregivers at the children's home, teachers and peers at school, the community volunteer workers and the interrelationship between these contexts. In addition, and to lesser extent children were supported by their own positive intrapersonal characteristics.

The resources and potential protective factors in the lives of the children appeared to operate successfully at the local community level. To the children, the positive and enabling systems, including their community neighbourhood, was closely related to other influential proximal settings. These proximal settings refer to the social influences that acted directly on the children through interpersonal relationships that were immediate and ongoing. The settings that supported the children in my study, in which they experienced such relationships, were the family, the church, the peer group, the school, community volunteer workers, extended family and weekend parents. I suggest that the proximal relationships in the main settings within the local community, more especially the home and the school, mainly influenced how the children felt, thought and behaved in relation to their life worlds. In this regard the school, as the bridge to the broader community, played a vital role in the psychosocial care and support of the children.

The children's home could be conceived as a family unit with the primary caregiver, being the head of this family. The domestic helper and other substitute caregivers were also significant members of this family and contributed to the children's upbringing. In most instances, the children felt safe, secure and cared for within the strict confines and structures of this family. A further protective and buffering factor was that children in this home were being raised according to strict traditional morals and values that could be inherently part of their African culture. Such an upbringing could anchor the children in a secure base where they had a sense of identity and belonging.

On a societal level, the children in my study were protected by the Child Protection Act that controlled their admittance into residential care. Within the protection of this act, they received medical treatment, access to schooling and provision of material needs. Furthermore, since the rollout of anti-retroviral medication in South Africa, it seemed that the physical health of the children was being boosted with anti-retroviral medication, vitamin supplements and regular monitoring of their health by their doctor. Because of societal support and intervention, the children in my study were living in a protected home and those who were infected with HIV were manifesting minimal physical symptoms of their infection.

Another supportive structure in this study appeared to be the children's positive intrapersonal characteristics. The children demonstrated characteristics of perseverance, pride, self-worth, courage, faith and hopefulness. These characteristics could imply a manifestation of resilience traits that are inherently protective. In this study, it was demonstrated by the children that such resilience traits were built upon a network of interrelationships and support systems.

6.2.6 Secondary question 6: *What are the children's coping responses?*

I found that children in my study employed two main ways to respond to their psychosocial and emotional challenges. The one way was a spiritual or religious form of coping and the other one was disengagement, denial and detachment.

The children in my study seemed to have found solace and comfort in their religious beliefs and in religious routines and rituals. Meme and Harry Potter seemed to embrace God as the healer of illness and the One who would make things better. Others, like Kaemogetswe, Dimple and Michelle, adhered to a strict routine of bedtime Bible reading and prayer. From my interactions with the children and the caregivers at the children's home, I surmise that the children's strong faith and belief in God may be attributed to their strict Christian upbringing in the hands of their caregivers. In the context of my study I regard the children's religious and spiritual coping responses, which seemed to provide hope, as another protective factor in the children's lives.

Another way in which the children seemed to cope was by disengagement and detachment. The children seemed to disengage from the reality of their lives by fantasising, dreaming and wishful thinking. The boys in the study imagined themselves to be heroic action figures whilst a few of the girls seemed to have adopted members of royalty or members of their community as role models.

In certain instances, children in the study expressed their thoughts and feelings about their family members as though they were still alive. I assume that in these cases the children might be in denial of the reality of the death of their family members.

6.3 The potential contributions of my study

In this section I present the potential contributions of my study. Firstly, I discuss the potential contributions in terms of the existing theoretical and knowledge base of well-being

experiences of children affected by HIV&AIDS and of the role and significance of positive and enabling systems in the child's life. I then discuss the potential contributions of this study in terms of the research methodology that was utilised, specifically with regard to investigating the experiences of a group of children.

6.3.1 Potential theoretical contribution

By answering my primary research question, *how do children who are affected by HIV&AIDS negotiate obstacles to create pathways to well-being in their daily lives*, I assumed that the knowledge that was gained could possibly contribute to the literature base on psychosocial and emotional aspects related to children's experiences of HIV&AIDS. As expounded in Chapter 2, there seems to be a limited theoretical knowledge base examining the psychosocial coping of HIV&AIDS affected children who live in residential care. In particular, I posit that this study fills a gap in the existing literature base that adopts a positive approach to viewing children facing adversity within a particular setting (residential care).

Based on my findings, I regard the well-being of the children in this study as influenced by their psychosocial circumstances and environmental context, together with the interplay between their positive and negative emotions and experiences. In particular, the context of the family is seen as the primary influence on well-being, although peer influence and the relationships with teachers and peers within the school context are also important. In addition, from a social ecology perspective, well-being influences seem to extend beyond these proximal relationships to encompass the more distal contexts and relationships found in the community and in religious groups; in these social groups, children may be considered as key members.

From the children's perspective, the community may be best represented in terms of the quality of the relationships with teachers, neighbours, caregivers and peers. The expectations generated, the values taught, the levels of support and encouragement experienced, the activities deemed worthwhile and worthless are attributes that may be basic to all types of communities to which a child may be a member. This study has shown overall that the well-being of children depends on the degree to which they are integrated into their communities in a manner that promotes self-efficacy and creates opportunities for agency.

In my study, well-being may be regarded as more than just living a good life. It was about having meaning in life, about fulfilling the children's potential and about feeling that their lives were worthwhile. The essence of well-being as demonstrated by the children in my study related to having goals to work towards, a sense of place, belonging and acceptance, a coherent and positive view of the world and a belief that a good life would follow. Furthermore, well-being experiences amongst the children in my study manifested in feelings of optimism, trust, self-respect, gratitude and kindness that was expressed towards significant others.

I found that in this study, well-being was not a state of mind that was decided upon by the children. Instead, it was evidently determined by the social conditions within which the children lived; and these in turn were guided by broader governmental policies and practices. Thus, the construction of well-being experiences for the children seemed to be shaped by their personal circumstances and their interactions with others. Although genes could affect well-being mainly through their influence on the child's personality traits, this influence is not considered fixed and immutable. Instead well-being, as described in my study, seems to be shaped by the environment in which the children lived, their upbringing, their personal experiences and the general circumstances of their daily lives. In this regard, giving support to others in order to improve another person's well-being was considered just as beneficial as receiving a similar form of support from others.

My findings indicate that well-being comes from being connected and engaged, from being enmeshed in a web of positive relationships and interests. These give meaning to the lives of children, as they are deeply social beings. The intimacy, belonging and support provided by close and personal relationships seem to matter most and isolation does the most damage to children facing adversity. Therefore, well-being was shown in this study to be powerfully influenced by the children's perceptions, expectations and experiences of nurturing relationships.

Based on the results that I obtained in this study in regard to the children's perspectives of well-being, I theorise that a positive approach to viewing children facing adversities could entail recognising, developing, enhancing and sustaining the positive intrapersonal characteristics of the children and together with positive enabling systems, could serve as building blocks for resilient psychosocial coping. This in turn could buffer and protect against further risks, threats and vulnerabilities and boost the children's capacity for well-being.

6.3.2 Potential methodological contributions

From my review of the literature (Chapter 2) it was evident to me that there was still a strong preference in research methods to hold *subjects* at a distance in order to objectify reports and actions. The motivational and subjective bases of attitudes and behaviour remain detached and largely obscured when methods of inquiry are limited to such approaches. I posit that the field could be substantially advanced through the incorporation of participatory approaches in a research design with children, especially when investigating in the realm of sensitivity and vulnerability. I therefore put forth that the participatory approaches that were utilised in my study in the form of task-based data generation instruments and activities that mediated the informal and conversational interviews, are a potential methodological contribution to the field of qualitative research. In particular, the participatory methods that I utilised in my study could be adopted by researchers seeking children's self-expression.

Linked to the above discussion, I considered and appreciated the children in my study in terms of the nature and existing perceptions of childhood as advocated by the United Nations Convention on the Rights of the Child (CRC) (1989). By seeking the children's informed assent to participate in this study, I recognised them as competent and capable of making informed decisions to participate or withdraw from a study and to express their views on a range of subjects related to their lives. Linked to the nature of childhood, research methodologies should reflect the child-adult relationship in knowledge creation. I considered children in my study as real children in a very real situation. This idea permeated my thinking throughout this study.

6.4 The potential strengths of my study

I consider the extended time that I spent in the field with the children in my study to be a potential strength. My view is based on the rich, vivid and detailed data that were generated and the extent of the emerged themes that served to address the critical research questions. I posit that if my data generation stage had been limited, I probably would not have been able to uncover such nuanced and multilayered expressions of the children's perceptions and experiences. Furthermore, my prolonged engagement with the children meant that my findings might be considered authentic and believable.

As a qualified and practicing educational psychologist, I am of the opinion that the skills that I have acquired in working with children have benefited my facilitation of the interviews and

the participatory activities with the children. In particular, I found that I was able to conduct my study with the children in an empathic and cooperative manner by recognising and respecting the children's expressions, silences, willingness and reluctance to engage in data generation activities.

6.5 Recommendations

This study revealed children's perceptions and experiences of illness, HIV&AIDS and well-being in their lives. I found that certain themes emerged in my study that I had not anticipated and which I did not explore as they went beyond the scope of the study. In the sections that follow, I recommend possible areas for further research that could provide deeper insight into matters that were not explored in my study. I categorise these areas according to the focus areas that I have identified namely recommendations for future studies and for the future training of educational psychologists.

6.5.1 Recommendations for future studies

In this section I pose questions that could lead to future studies in the fields of HIV&AIDS as well as in research methodology.

6.5.1.1 Further studies associated with HIV&AIDS and children in residential care arising from my study

- a) What is the relationship between the well-being experiences of HIV&AIDS-orphaned children living in residential care and those who do not?
- b) What is the relationship between the well-being experiences of non-orphaned HIV&AIDS-affected children living in residential care and those who are living with extended families?
- c) Additional comparative case studies to explore similarities and differences in children's coping styles, support systems and well-being experiences.
- d) Comparative studies with the caregivers in residential care settings to explore their experiences of taking care of children who are affected by HIV&AIDS.
- e) An investigation of children's experiences of HIV&AIDS from an indigenous knowledge perspective.

6.5.1.2 Methodological recommendations

- a) By utilising a methodology similar to the one that was utilised in my study, research could be conducted with children facing other adversities in their lives, such as cancer, abuse or parental divorce.
- b) A participatory-action research where educational psychologists or social workers could design and conduct an intervention-based study with the focus on: How can children be taught to generate positive emotions while living in a context of adversity?
- c) I put forth that caregivers require emotional support in order to sustain consistent caregiving practices in a children's home. Therefore I suggest a participatory-action research that explores caregivers' emotional intelligence with a view to offering a workshop on enhancing caregivers' emotional intelligence.

6.5.2 Recommendations for future training of educational psychologists

Educational psychology practice has progressed from an individualistic office-based practice to a dynamic field that recognises and emphasises the role of family and community practice. Furthermore, within the new scope of practice for future educational psychologists, educational psychologists will be obliged to conduct community service training as part of their curriculum. I propose that in addition to the asset-based approach that is presently incorporated in the training of educational psychologists, their training could strengthen the positive psychological approaches to working with children facing adverse circumstances in their lives.

Furthermore, considering the snowballing HIV&AIDS trauma for children especially, I propose that future educational psychologists be encouraged to conduct research in the field of childhood HIV&AIDS with a view to constructing knowledge that could lead to improved psychosocial services to children in different settings. In addition I would also encourage future educational psychologists to explore the field of conducting research with children from a methodological standpoint in order to further enhance innovative and dynamic child research practices.

6.6 Final reflections

This study has demonstrated that children who are affected by HIV&AIDS and who live in a children's home have challenges and stressors on a day-to-day basis that extend beyond the

essential medical care and containment of their illness. More than ever, the challenge of treatment seems to lie in creating opportunities to pursue, support and sustain the holistic well-being of the child. For children facing adversity, such support may be perceived as living in an environment where adults feel a responsibility to protect, guide and respect the children's evolving capacities to participate in matters that affect their own welfare, albeit in an age-appropriate manner. This would require a shift in attitudes about children and a search for effective ways to engage them in activities that matter. Research can assist this process by revealing the elements of facilitating environments and supportive relationships for children, by demonstrating the benefits of strengthening the bonds to such contexts and affiliations. In addition, efforts should incorporate strengthening the intrapersonal characteristics of children to be able to effectively deal with their often stressful circumstances.

As demonstrated in my study, children's well-being experiences seem to exist on a continuum with well-being on one extreme and despair on the other. On daily basis children's thoughts, feelings and behaviours seem to oscillate on this continuum and many of these emotions and behaviours seem to be dependent on interpersonal relationships and perceptions of warmth, compassion, love and acceptance. Considering that positive and enabling systems emerged as a strong protective factor for the children for the future, it seems essential to engage the children in community life and to identify and enhance the environments and relationships that present and represent well-being experiences.

At this stage, it is noteworthy to consider that present strategies to enhance children's well-being might be at risk of being diverted by society's prevalent view of children as the next generation and, by implication, negating their present standing in society. The holistic well-being of children facing adversity would be contingent on a shift in attitudes that seeks to improve the environments in which the children are growing and by placing the responsibility of nurturing children's well-being in the hands of adults. Specifically in the context of HIV&AIDS, a shift in the approaches would require novel mechanisms and the creation of capacity that extends beyond the current. It would also mean thoughtful planning because some of the challenges of the epidemic that may arise in the next 10 to 20 years are likely to be different from those that are being experienced today. In the many roles that adults assume in the welfare of the children in the context of HIV&AIDS, the task of recognising or creating the appropriate circumstances for enhancing and sustaining the holistic well-being of children remains a great future challenge.

6.7 Conclusion: *Finding roses amongst thorns*

To conclude this thesis, I am reminded to revisit the metaphor in my title. I used this metaphor to illustrate that in spite of the adversities (thorns) that confront the children in my study who are affected by HIV&AIDS on a daily basis, we need to search beyond these difficulties to find the beauty (roses) that sometimes lies hidden or dormant. Figure 6.1 depicts my metaphor.

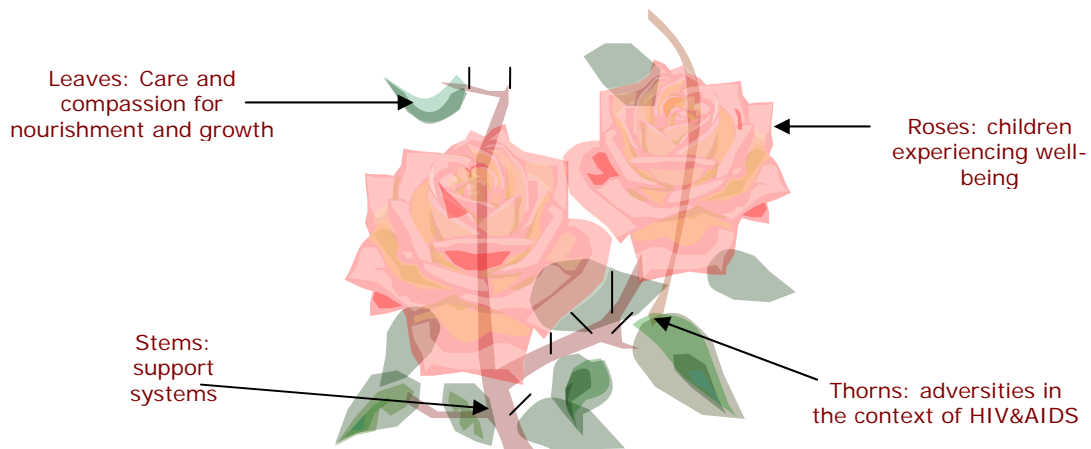


Figure 6.1: Finding roses amongst thorns

Once we have found these roses, we need to nurture and nourish them to reach full bloom. Children need love, care and compassion from supportive and anchoring caregivers to achieve well-being just as roses need stems, root, leaves as well as daily care in order to thrive. In the realm of the negativity that generally surrounds HIV&AIDS, I believe that we (adults) have a responsibility to encourage children to recognise and utilise all the beauty that they possess inside of them.

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