CHAPTER 1

Introducing the study

1.1 Introduction
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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.
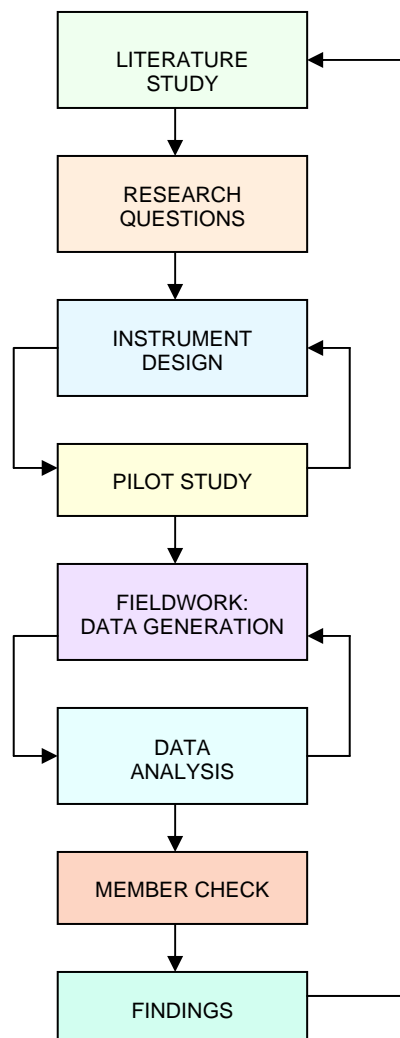

Figure 1.1: An overview

1.2   The focus of the inquiry
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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&AIDS[1] 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:
o   How do the children in my study express a sense of well-being?
o   What are the challenges and stressors that place the children in my study at risk?
o   How do the children experience distress and despair?
o   What are the children's psychosocial needs?
o   How are the children supported?
o   What are the children's coping responses?

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[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
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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 & Deverell, 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 & Deverell, 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 ARVs[2] 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

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[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
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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 setting[3]   for children affected by HIV&AIDS. As a unit of analysis, all nine children who live at this children's home were partners[4] 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.

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[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
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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
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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 qualitatitive 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 undertaken[5]:

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
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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

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[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):

o   Psychosocial generally refers to the social and emotional aspects of life.

o   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.

o   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.

o   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.

o   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
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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?	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?	o illness o orphanhood and residential care o stigma, discrimination and rejection o death and bereavement
3. How do children experience despair and distress?	o internalising and externalising behaviour
4. What are the children's psychosocial needs?	o nurturance o communication o socialisation
5. How are children supported?	o positive and enabling systems o positive intrapersonal characteristics
6. What are children's coping responses?	o spiritual or religious form of coping o disengagement, denial and detachment

1.9   Potential limitations of the study
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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
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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.