THE LIFE WORLD OF A TEN-YEAR-OLD CHILD BORN WITH HIV

by

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"I needed to speak of the spoken, of the said and the not said, of the heard, of the listened to. To speak of the said is not only to resay the said, but to relive the living experience that has generated the saying that now, at the time of the resaying, is said once more. Thus, to resay, to speak of the said, implies hearing once again what has been said by someone else about or because of the saying that we ourselves have done."

Paolo Freire

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ABSTRACT

"For too long we have closed our eyes as a nation hoping the truth was not so real. For many years we have allowed the human immunodeficiency virus to spread...At times we did not know that we were burying people that had died from AIDS, at other times we chose to remain silent. We face the danger that half our youth will not reach adulthood. Education will be wasted, the economy will shrink. There will be a large number of sick people whom healthy people will not be able to maintain. Our dream as a people will be shattered" (Mbeki, T 1999, in Dicks, B 2001:7). This quotation emphasizes the devastation and heartache that lies ahead for South African communities if positive action is not taken to prevent the spread of HIV/AIDS.

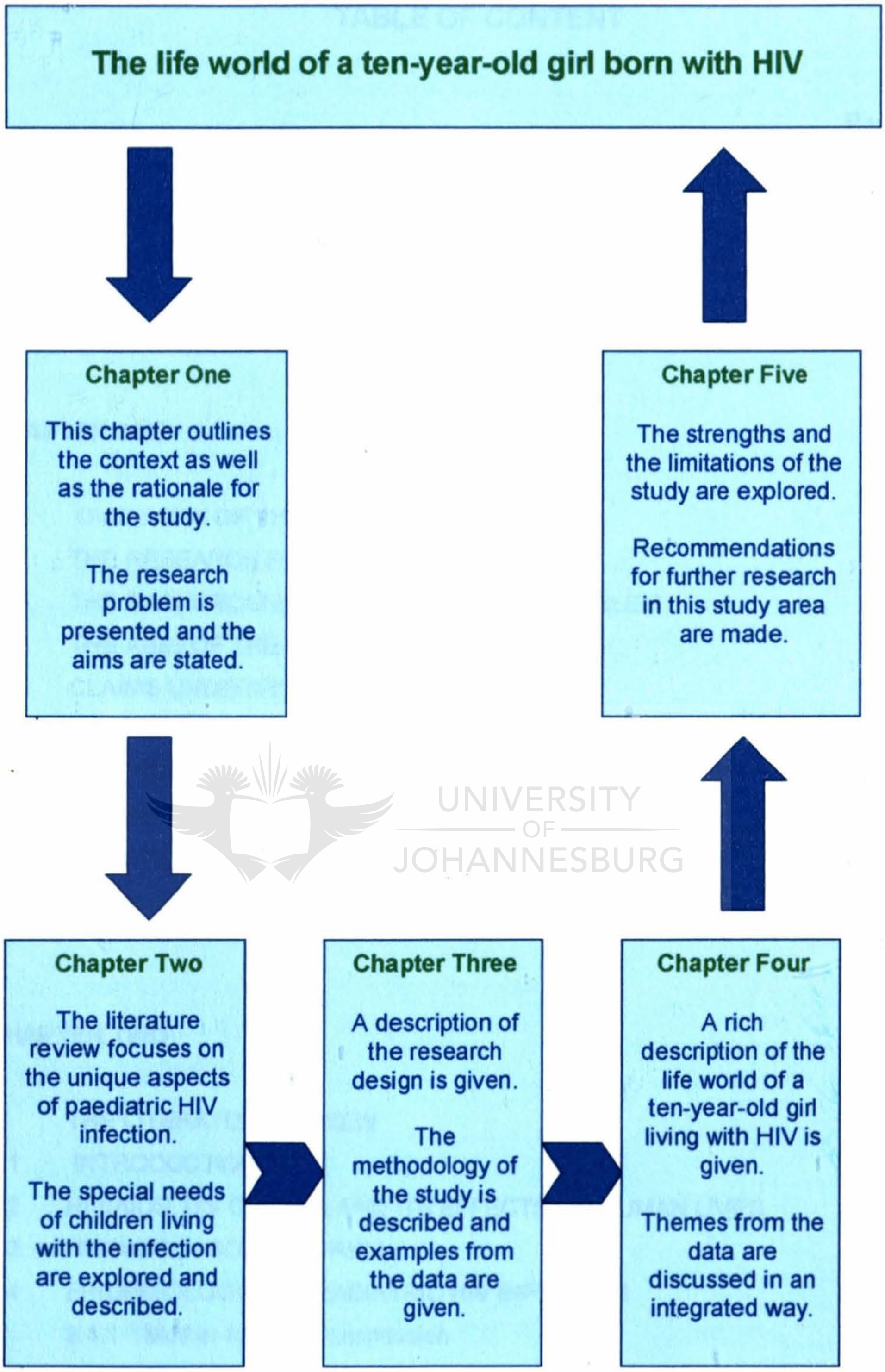
HIV/AIDS has become a serious threat worldwide. The focus of this research was to gain a thorough understanding of the life world of one child living with HIV. It therefore argues that the intervention programmes in South Africa focus mostly on sharing information about the prevention of HIV. However, the growing numbers of children who are living with the disease and attending school are overlooked. The life worlds of children living with HIV/AIDS and the special needs that they face every day, are areas of concern that need to be addressed. This study attempts to describe the life world of one ten-year-old girl living with HIV, in order to create a greater understanding of her unique needs. This study was based on a constructive, ecosystemic perspective to assist in creating a rich description of this unique life world. A critical discussion of the literature, focussing on children infected and living with HIV/AIDS, provides a framework for this study. The literature review emphasizes the unique needs and difficulties of children living with HIV. This highlights the deficits in health and educational services in South Africa and illustrates the need to implement specialised support for children living with HIV/AIDS.

The methodological design used to accomplish the research aim was a qualitative, descriptive case study. The sample was purposefully selected based on my own knowledge of a specific community. This design gave me access to the different systems involved in the life world of KD. The data that emerged was continuously interpreted and that assisted me in shaping the next step in the discovery process.

This approach helped me in accommodating the flexible and emergent nature of the research.

This mini dissertation proposes that the life world of a child living with HIV/AIDS is the most important aspect to consider, when designing programmes to support their special needs. It emphasises the need for policy makers in the departments of health and education to start planning beyond mere methods of prevention and information sharing. New programmes need to support and acknowledge the growing health and educational needs of children living with HIV/AIDS. However, this case study, alone does not hold the power to change social contexts, policies or governmental strategies, but it hopes to unlock a new perspective on the unique challenges that a child living with HIV/AIDS experience.

Organisational flowchart of the case study



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CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 THE RESEARCH PROBLEM

There has been limited research focusing on the experiences of children born with HIV in South Africa. Despite the publicity and interest generated by the media around this epidemic, most of the research focuses on a medical or economic perspective. This limited focus indicates a need for further research into the experiences of children who are HIV positive.

The research problem explored in this study examines the specific context of a child born with HIV. The problem statement in this study is as follows: There is a limited amount of information available about the experiences of children who are HIV positive and there is a need for information about these experiences as this could help inform teachers, counsellors and other caregivers about the barriers to learning these children may be experiencing and the special needs that they may have. Narrative information about the life world of a child born with HIV could assist care givers in better understanding and creating opportunities for these children in which they could realise their own potential and live a quality life.

The research question emanating from this problem statement is, "What does the life world of a ten-year-old child born with HIV look like?" The following sub-questions assisted in focusing the research on the experiences of a child with HIV:

- Where are the origins of HIV/AIDS and what are its effects on human lives?

- What impact does HIV/AIDS have on South Africa?

- What treatment and support options are available to children with HIV?

- What are the unique experiences of children living with HIV/AIDS?

- How does HIV/AIDS affect schools in South Africa?

1.2 THE BACKGROUND TO THE RESEARCH PROBLEM

HIV and AIDS have managed to unite people from around the world. The unifying factor is that all children born today, no matter where in the world, will live in a world where HIV exists. This unification of people leads to discussions on the impact of this killer disease on all spheres of our society, as well as research conducted on a disease that affects human life globally. However, HIV is not the first disease to spread around the world and to affect diverse societies. Six hundred years ago the black plague epidemic ravaged societies in Europe and the effects of the epidemic affected communities in North and South America and as far afield as Madagascar (Barnett & Whiteside, 2002:3-9).

Today, there are few people in the developed world who would give a disease like the plague a second thought, as prosperity and access to modern medical resources and technology have eradicated this disease from these societies and the minds of the people living there. The reality is, however, that in developing countries such as India where poverty is widespread and where people therefore do not have access to modern medical resources, communities are still under threat from the plague. Unlike the plague, HIV is the first disease that holds a global threat. This is the only disease that the United Nations has devoted a task team (UNAIDS) to, with the purpose of investigating and monitoring it worldwide (Barnett & Whiteside, 2002:3-9). The global situation of HIV/AIDS as described in a UNAIDS report at the end of 2002, can be summarised as follows:

In 2002 the number of individuals living with HIV/AIDS worldwide was estimated to be approximately 36 million. The picture darkens when you take into account that each individual infected with the disease directly influences the lives of at least four other people, which then implies that more than 150 million people are affected by this disease. Sub-Saharan Africa as a developing region seems to be most affected by HIV/AIDS (UNAIDS, 2000:a). Therefore, differences in economic status and the access to resources between developed and developing countries create a prevalence of HIV infections in developing countries. Anti-retroviral therapies make it possible to prolong a person's life and could mean some added quality of life for someone who is HIV positive. The discrepancy lies in the fact that these anti-retroviral therapies are available only to the fortunate few who are not caught in a debilitating cycle of poverty (UNAIDS, 2000:a).

The power that HIV holds globally divides the world into two teams, both playing to beat the hold that HIV has over them and that, by looking at them, appear to be evenly matched. Both teams consists of players from all walks of life, who have different spiritual and religious values, representing both genders, all ages and coming from different nations and races. However, the one team has a secret weapon, namely power: the power to fight the disease with money, access to resources and the backing of pharmaceutical companies to provide them with advice and new treatments. The other team, on the other hand, wants to play the game with the same vigour as their opponents but their progress is hampered by their lack of power and the cycle of poverty they cannot escape from.

Hope

The one aspect that unites these two teams in the fight to beat HIV is hope. Hope for quality of life, to grow old with families and loved ones and to lead a meaningful life. Daunting challenges that are experienced by people who are HIV positive marginalises the hope that exists. These challenges are not only felt by the infected people, but are felt in all spheres of society. Increasing educational demands are made on teachers, counsellors and other caregivers working with HIV positive children. The numbers of HIV positive children are increasing and with better treatment becoming available, more children born with HIV or infected early in life will live to attend school (Rose <u>in</u> Aronstam et al., 1998:65).

Teachers, counsellors and other caregivers need to be informed about the difficulties that HIV positive children may be experiencing in an educational setting and an awareness needs to be created in order to understand the barriers to learning that subsequently may occur because of this chronic disease (Orton, 1997:113-114).

The Education White Paper 6 of July 2001, which addresses special needs education in South Africa, proposes that "the development of an inclusive education and training system must take into account the incidence and the impact of the spread of HIV/AIDS and other infectious diseases" (Department of Education, 2001:23). This research study proposes that in order to address the special needs of children who are HIV positive, it is imperative to allow people infected with and affected by the disease to share their experiences and to incorporate these narratives into the action plans that flow from the policy decisions.

1.3 THE AIMS OF THE STUDY

The problem statement of this study is that there is a limited amount of information available about the experiences of children who are born with HIV. The main aim of this study is to describe and analyse the life world of a ten-year-old girl born with HIV. Therefore, this study aims to address the research problem through conducting qualitative research in the form of a single descriptive case study in order to gain a greater understanding of the experiences of a child infected with HIV (Babbie & Mouton, 2001:282). This research study must allow the reader the opportunity to stand in the shoes of an HIV positive child. Through this invitation to the reader to experience what it means to live with HIV, this study also aims to create awareness of practical steps that can be taken to help enrich and improve the quality of these children's lives.

1.4 CLAIMS UNDERLYING THE RESEARCH

Gaps in the existing policies and research around HIV exist due to the fact that parents, caregivers and HIV positive children have had few opportunities to have direct input in policy and research decisions when it comes to issues such as quality of life or education. A tendency exist to talk about children and not with them, therefore children in our society have silent voices.

However, it is understandable that in a country like South Africa where social issues such as poverty, unemployment, social inequality and violence are rife, less attention would be given to quality of life and educational concerns that HIV positive children might be experiencing. It seems as if more emphasis is being placed on "the expected enrolment and drop-out rates and the funding implications in both the short and long terms" (Education White Paper 6, 2001:23), than on the emotional well-being and support for HIV positive children and their parents/caregivers.

Therefore, the main claim of this study is that an understanding of the experiences of children infected with HIV can contribute positively to the development of action plans to implement the policy. However, this is not to say that one study will be able to instigate major policy changes. Hopefully, this study could assist in facilitating new perspectives around the contexts of children infected with and affected by HIV and could stimulate further research. Specific needs could then be addressed more assertively, if a better understanding of the problem is reached. Parents, teachers and other caregivers will feel more empowered if they realise that their experiences are being taken seriously. This feeling of empowerment could have a positive effect on other areas of their lives and could grow to influence whole communities.

"The idea of addressing barriers to learning and development is directly linked to a systems approach to understanding problems and development" (Engelbrecht et al., 1999:53) and therefore also to children who are HIV positive. This perspective can help teachers and parents/caregivers to identify the barriers to learning and development that HIV positive children might be experiencing, instead of regarding the children as having something wrong with them.

In this study, research methods were selected that would assist the researcher in conveying the experiences of a child born with HIV.

1.5 RESEARCH METHODOLOGY

This investigation into the life world of a ten-year-old child born with HIV is conducted from a qualitative perspective. Patton (in Merriam, 1998:6) postulates that "qualitative research is an effort to understand situations in their uniqueness as part of a particular context and the interactions there". The aim of the research is to understand the phenomenon under study through the eyes of the participants. This implies that the researcher doing qualitative research is not attempting to predict future happenings based on the data collected in a particular study, but that an attempt is made to understand the meanings that the participants attribute to their world (Merriam, 1998:6). Different phenomena dictate which type of research design should be implemented by the researcher.

For the purpose of this particular study, a case study design was selected. Merriam (1998:27) defines a qualitative case study "as an intensive, holistic description and analysis of a single instance, phenomenon, or social unit". The unit of analysis in this study is the life world of a ten-year-old girl born with HIV. The researcher attempts to remain true to the concepts that the participants use to describe and understand themselves. Therefore, the researcher's main effort lies in using the rich descriptive data to reconstruct the social world as described by the participants (Mouton, 1996:168-69).

Data for this investigation were collected through structured and unstructured interviews, participant observations, records, documents and physical artefacts. In qualitative research, it is imperative to understand the specific context of the participants. Interviews with her class teacher, her foster parents and her doctor aided the researcher in this endeavour. Observations of classroom interaction and the interpretations of photographs and drawings were included to triangulate the data obtained from interviews with the ten-year-old girl (Yin, 1993:69).

Ethical considerations are one of the great concems of this study and the participants were informed of the aims of the study and the fact that they are part of the whole process, which implies that they can decide whether to continue their participation or not. Diener and Crandall (in Singleton, Straits and Straits, 1993:475) distinguish four problem areas most often identified with regards to the ethical treatment of human participants. They argue that these problems arise when research practices violate basic human rights. The three problem areas that have been identified are: lack of informed consent, deception and the invasion of privacy.

In this study, great care has been taken to address these potential problem areas and exceptional care not to violate the human rights of any of the participants was taken. People living with HIV/AIDS do not have to disclose their status. Children with HIV/AIDS can therefore go to school and neither they nor their parents have to disclose any information to the school. In this case, however, the HIV status of this particular girl has been disclosed to the school and to her class teacher. The anonymity of the participants in this study is guarded through the use of pseudonyms and all identifying particulars are kept strictly confidential. None of the photographs or any other particulars, which might disclose the identity of any of the participants, are displayed in this study.

To facilitate a uniform understanding of the major concepts used in this study, it is important to clarify their meanings. It is also important to mention that I have used the words "she" or "her" throughout this dissertation. The main reason for using the feminine form of these pronouns is attributed to the fact that most of the participants in this study are female, however, these feminine forms can be used interchangeably with "he" and "him".

1.6 THE ROLE OF THE EDUCATIONAL PSYCHOLOGIST

Educational psychologists have an important role to play in supporting communities to promote inclusive, healthy environments (De Jong, 2000:349). According to De Jong (2000:351) educational psychologists should become actively involved in building a supportive psychosocial learning environment.

This perspective is supported by Engelbrecht (2001:22) who postulates that educational psychologists should be involved in "...building a positive teaching and learning environment and a responsive curriculum to minimise and address barriers to learning and development and promote the well-being of all learners". In this way, the educational psychologist contributes towards the development of a health-promoting school. The World Health Organisation defines a health-promoting school as one which aims at achieving healthy lifestyles for the whole school by developing supportive environments conducive to physical, psychological, social, environmental, economic and spiritual well-being (Engelbrecht 2001:22). It is with these statements in mind that this study within the field of Educational Psychology is embarked. This broader, more systemic perspective of the role of the educational psychologist (De Jong, 2000:349) diminishes any doubt that this study, which explores the life world of a ten-year-old girl born with HIV, should be placed within other fields of study. Engelbrecht (2001:27) states that the involvement of educational psychologists, school counsellors and learning support specialists within school contexts, enables and encourages them to, "...contribute towards the development of a healthy teaching and learning environment". This study also explores the collaborative nature of the role of the educational psychologist. This implies that the educational psychologist should share ideas and work across settings within an atmosphere of mutual respect and support (Engelbrecht, 2001:23).

1.7 CONCEPTUAL DEFINITIONS OF TERMS

For the purpose of this investigation a number of concepts need to be clarified in order to eliminate possible confusion and to facilitate a clearer understanding of these specific concepts.

Human Immunodeficiency Virus (HIV)

The human immunodeficiency virus infects mainly two systems of the body, the immune system and the central nervous system; therefore, the disease manifestations are principally based on damage to these two systems. Like other viruses, HIV can only reproduce itself inside a living, human cell, which it needs for purposes of reproduction. The main feature that distinguishes the HI virus from other viruses is the fact that this virus directly attacks the most important defensive cells of the human immune system, namely the CD4 cells. In attacking these cells, the virus diminishes the body's ability to ward off attacks from exterior disease-causing agents. The CD4 cells protect the body from invasion by bacteria, viruses, fungi and parasites. CD4 cells also protect the body against certain types of cancer cells. Opportunistic infections can only invade and overwhelm the body's own immune ability once the number of CD4 cells has become radically depleted (Van Dyk, 2001:6-11).

Acquired Immunodeficiency Syndrome

This disease, the Acquired Immunodeficiency Syndrome can be shortened to the acronym of AIDS, which can be explained as follows:

- The "A" stands for Acquired, which means that the virus is not spread through casual contact like flu or chickenpox is spread, and neither can this virus be inherited. In order to be infected, a person has to come into contact with the blood of an infected person, engage in unsafe sexual activity with an infected person or share needles with an infected person.
- "I" and "D" stand for Immunodeficiency. The virus attacks a person's immune system and renders it incapable of fighting infections. Thus, the immune system becomes deficient.
- "S" stands for Syndrome. AIDS is not just one disease, but presents itself in a number of diseases that occur when the human immune system is in a weakened state. Although the term 'disease' is used when talking about AIDS, AIDS cannot be defined by a specific illness because it is usually a collection of many different conditions that appear in the body at a given time. Therefore, it would be more accurate to refer to AIDS as a syndrome of opportunistic diseases, infections or certain cancers, which invades the body and has the ability to kill the infected person in the final stages of the disease (Whiteside & Sunter, 2000:1).
- AIDS is by definition the end-stage disease, when a person infected by the HI virus is no longer able to ward off opportunistic infections because of a depleted immune system (Van Dyk, 2001:5).

Caregivers

For the purpose of this study, the concept "caregivers" refers to informal carers who provide care and assistance to others without financial or material gain. This service usually occurs in the context of an ongoing relationship and can be described as an expression of concern and love for a relative, friend or fellow human being (Moroney, et al., 1998:103).

Parents

The term "parents" is used in the broadest sense to include legal guardians as well as caregivers such as grand parents and foster parents.

Life world

In this study, the concept "life world" could be used interchangeably with the concept "context". Graue and Walsh (1998:9) postulate that the "life world of a person is a culturally and historically place and time, situated here and now". Thus, it is the world as realised through a person's interaction with others in the immediate sphere that they occupy. Therefore, the life world of any individual is of importance, because everybody is influenced by their specific life world. "To try and think about children without considering their life situation is to strip them and their actions of meaning" (Graue & Walsh, 1998:8).

1.8 THE STRUCTURE OF THE RESEARCH REPORT

The following is a short overview of the content of this study.

Chapter One: Overview of the study

This chapter aims to introduce the study by presenting the research problem and the research questions, thus providing a contextual background to the research that can serve as the motivation for conducting this study. The theoretical evidence that supports the research problem is explored. This chapter examines the research methods used and looks at the epistemology underlying the study.

Chapter Two: Literature review

The literature review aims to develop a conceptual framework for this study. The literature review informs and structures this study. This chapter also presents the theoretical concepts that support the study. This is done to indicate the worth and validity of this study. Other related research on this topic is incorporated into the framework and focus of this study.

Chapter Three: Research methodology

The research methodology discussed in this chapter provides information about the research methods used, as well as the procedures and the methods of analysis.

Chapter Four: Discussion of the findings

The discussion of the findings is presented qualitatively in order to address the research question posed in the first chapter.

Chapter Five: Conclusions

This chapter explores the challenges, implications and recommendations deduced from this study.

1.9 CONCLUSION

HIV and AIDS are infecting and affecting people globally. Sub-Saharan countries are amongst the worst affected in the world. HIV/AIDS poses the single biggest threat to the economic, social, physical and emotional well-being of the people of South Africa. "We have reached such an advanced stage in the spread of the AIDS epidemic that there is almost no time left for merely feeling, thinking and talking. We are in the middle of a war that is wreaking havoc and destruction. Concrete action is required every day and every hour" (The Star, 2002:8).

The aim of the study is to address this research problem through conducting qualitative research in the form of a descriptive case study design. Furthermore, this study aims to describe the context of the unit of analysis in detail, in order to gain a greater understanding of the experiences of an HIV positive child.

The relevance of the study can be seen in the fact that parents, caregivers and HIV positive children do not have an opportunity to have direct input in policy decisions when it comes to issues such as quality of life or education.

Chapter Two presents a detailed description of the conceptual framework that was constructed. This framework helped to focus and inform this investigation. Furthermore, Chapter Two attempts to familiarise the reader with related research supporting this study.

CHAPTER TWO

THE LITERATURE REVIEW

> *"Deadlier than war, deadlier than tyranny, deadlier even than malaria, AIDS is silently tearing Africa apart. The epidemic is throwing millions of households into turmoil. Often the middle generation is wiped out, and children and the elderly are left to fend for themselves" (Guest, 2001:ix).*

2.1 INTRODUCTION

A mere two decades ago HIV/AIDS was an unknown horror waiting to trap the human race in its terrible grip. HIV/AIDS arrived on the global scene without warning (Van Dyk, 2001:iii).

At the start of this century, South Africa had the largest number of HIV-infected people of any country in the world and the distressing fact is that this number is increasing every day (Whiteside & Sunter, 2000:1). The HIV/AIDS picture in South Africa is bleak and, unfortunately, it seems to be getting bleaker. The number of people newly infected, falling ill, dying and leaving families and destitute children behind is rising. However, it is not the aim of this study to investigate the epidemic spread of this disease through South Africa, neither does this study aim to debate the impact that this devastating virus will have on the economic growth of the country.

One of the major claims made in Chapter One is that there is a limited amount of information available about the experiences of children who are born with HIV. As a result, the literature review constructed for the purpose of this study aspires to integrate and to synthesise the most relevant data on the topic of HIV/AIDS and, more specifically, the way in which this disease affects children in South Africa. Therefore, this literature review aims to raise awareness of the unique aspects of HIV/AIDS in children.

This chapter commences with a discussion of the disease and its epidemiology, which leads into an assessment of the current literature on the HIV/AIDS dilemma in South Africa. Within this discussion, an attempt is made to describe the magnitude of this dilemma and the effects it has on different systems in our society.

2.2 HIV/AIDS, ITS ORIGINS AND ITS EFFECTS ON HUMAN LIVES

According to Whiteside and Sunter (2000) and Van Dyk (2001), one accepted view of the origin of the HI virus is that the disease could have originated from monkeys in Africa. The HI virus then crossed the species barrier from primates to humans at some point during the previous century (Whiteside & Sunter, 2000:6). HIV is related to a virus called Simian Immunodeficiency Virus (SIV) found in primates. This could have happened when human blood came into contact with contaminated blood of a primate, such as a chimpanzee, possibly when contaminated animal blood entered open wounds on the hands of humans who were butchering SIV infected primates (Van Dyk, 2001:6). Although the initial spread of the virus was restricted to isolated communities, colonial, post-colonial and the development of a modern transport infrastructure accelerated the spread of this virus globally (Whiteside & Sunter, 2000:6).

Even though most scientists accept the explanation that HIV-1 (most commonly found strain) originated in Africa, other, more cautious scientists feel that there is currently not enough substantial evidence to support this hypothesis. These scientists feel that more research is necessary to determine the origin of this virus (Barnett & Blaikie, 1992: 3). However, scientists worldwide agree that the movement and migration of people across large distances, war and socio-economic instability have contributed to the spread of the virus (Evian, 2000; Leukefeld, 1987).

HIV is a slow-acting virus which forms part of the lentivirus sub-family of retroviruses. Characteristic features of this sub-family is its ability to reproduce itself exploiting the genetic material from the host cells, its immonusuppression qualities and the fact that this virus has a long incubation period (World Health Organisation, 2000). A number of retroviruses are known in the animal and insect kingdom, however, in the domain of human medicine, HIV is one of only four retroviruses known to infect humankind (Van Dyk, 2001:8). These viruses are:

HTLV1	Human T cell lymphotrophic virus; T cell leukaemia
HTLVII	Human T cell lymphotrophic virus; Hairy cell leukaemia
HIV-1	Human Immunodeficiency Virus; Immunosuppression, AIDS
HIV-2	Human Immunodeficiency Virus; Immunosuppression, AIDS (Claxton & Harrison, 1991:13)

The name "retrovirus" indicates that this specific virus does the exact opposite of what other viruses do. In nature DNA usually produces RNA. However, a retrovirus in a host body undergoes an unusual biological process in which the genetic material is able to transform RNA into DNA. Reverse transcriptase enzymes in all retroviruses enable them to perform this action (World Health Organisation, 2000). Another unique feature of the HI virus is that unlike other viruses, this one enters and destroys the CD4 cells that control and support the immune system. This feature enables the HI virus to immobilise the human immune system, thereby leaving the infected body defenceless against attack from other viruses (Claxton & Harrison, 1991:14).

Subsequent to entering the body, the HI virus attaches itself to practically any cell that possesses CD4 receptors on its surface. Once the virus has attached itself to the host cell's surface, it enters the cell and is then safe from the body's immune-system and is virtually indestructible. Now the virus-cell makes use of its transcriptase enzymes in order to transform the RNA into DNA. The newly constructed DNA integrates with the host's DNA and, through a process of manipulation, the host cell starts producing HIV viral protein. After attachment and entry into the CD4 cells, the HIV finally destroys the cell and then moves on to other CD4 cells. This means that that some of the most important cells of the body's immune or defence system are slowly destroyed. As a result, the immune system of infected people is slowly compromised and weakened, which leaves the body open to a number of other opportunistic diseases (Bryan, 2002:402-403).

The human immune system develops antibodies to the HI virus, but these antibodies are not identifiable in the blood during the early stages of infection. The phase after infection but before the body manufactures antibodies is called a "window period" and an infected person will already be able to transmit the virus. As soon as the body starts manufacturing antibodies, they are visible in the blood stream of the infected person. Although these antibodies are not able to defeat the virus they form the basis for HIV blood tests (Evian, 2000:9).

Every person infected with HIV responds differently to the virus. While some people may experience immune damage and illness earlier than others, there is a small percentage of infected people that will show no development of immune deficiency at all (World Health Organisation, 2000). According to statistics used in Whiteside and Sunter's (2000:9) work, the incubation period of the HI virus in South Africa has been estimated at between six and eight years. These authors argue that infected South Africans face a shorter incubation period compared to infected people from developed countries, due to the fact that people have to contend with more diseases here. Therefore, the more challenges to the immune systems of infected people, the greater the risk of opportunistic infections. A person is described as having AIDS when the immune system is so severely compromised by HIV-related immune deficiency that various life threatening infections and/or cancers occur (these conditions only occur because the immune system is weakened). A reality that many infected people in South Africa have to face is the inevitable: that their life expectancy from the onset of AIDS to death may be as brief as one year or less.

2.3 HIV/AIDS IN SOUTH AFRICA

South African history makes for interesting reading. People living here have had a precarious relationship with exploitation, disorder and inequality. These unstable conditions on political, social, economic and emotional fronts form part of the building blocks of South African society.

The HIV/AIDS epidemic currently raging through South Africa emulates the history of this country. The apartheid system forced a scheme of ruthless social engineering on the majority of people. This system, aimed at benefiting a minority of the overall population, subjected the majority to migration, poverty and inferior education. Governmental laws allowed South Africa's black labour force to temporarily reside in "white areas" for as long as they provided labour there. Migration of labourers between the homelands and places of work created a breakdown in family and cultural structures. It was not uncommon for children to be separated from their parents and to grow up with caregivers. Migration assisted in isolating adult individuals in single-sex hostels on the mines or in makeshift rooms in someone's backyard; laws prevented them from having their families with them, and these very laws assisted in creating a culture of rural and urban wives and prostitution. The children growing up without the support of their parents were often subjected to abuse and child prostitution, and family break-ups became a widespread occurrence (Barnett & Blaikie, 1992:10-15). Migration aided the spread of the HI virus and still continues to assist. Migration was encouraged by apartheid, which aided in creating a social environment of inequality.

In 1993 in South Africa, the richest 10% of the population received 47.3% of the income, while the poorest 40% of the people shared 9% of income generated (Whiteside & Sunter, 2000:64). Even after all the democratic changes that took place on a political level in 1994, inequality still dictated South Africa's economic future and no immediate lessening of monetary inequality was implemented (Barnett & Whiteside, 2002:153). Although the monopoly of the previous government was eradicated, some seeds of apartheid are, notwithstanding positive changes, still growing in South African society and scars that were left are still healing.

People living in South Africa live and grow up with the legacy left by the country's history. The violence that typified the end of apartheid has created a philosophy of fatalism where people feel "what will be, will be". Barnett and Whiteside (2002:153) postulate that this fatalistic philosophy reduces individual worth, responsibility and accountability. People live for today and little value is attributed to the future. These fatalistic views of South African society can be seen as characteristic of a risk environment.

A risk environment is one that is more susceptible to the impact of HIV/AIDS. There are a number of other risks in South African communities that make them extremely vulnerable to the spread of HIV/AIDS, such as crime, rape, sexual abuse and gang violence (Whiteside & Sunter, 2000:65). The impact of the HIV/AIDS epidemic on South African communities is devastating. While this epidemic is creating havoc in communities, debates are raging about the concept "community". Different authors hold different opinions about "what makes a community". The concept of a "community" as described by Donald et al. (1997) can be seen as a group of people living in an area that is considered as a "whole" and who share some important common interests and concerns. Others like Barnett and Whiteside (2002: 194) share the view that there is no definition to aptly describe what a "community" is, because no two "communities" are alike. In a broad sense these two views, describe communities in South Africa.

A unique feature of South African communities is the fact that some are riddled with adversity and inequality, while others are prosperous and affluent. South Africa is a country of social contrasts and inequalities in which only a small percentage of the population live with the advantages that modern technology and financial prosperity can provide (Smart, 1999:10). These advantages are secured through the fact that these South Africans have steady incomes, access to modern amenities and some level of education. In these communities, people have the financial means to uplift and secure themselves through education and through the benefits that financial security brings (Barnett & Whiteside, 2002:182). On the other side of the coin is a picture of the majority of South Africans: most of the disadvantages and inequality that they experience is related to poverty in one way or another. Donald et al. (1997:143) hypothesise that the poverty experienced in the majority of South African communities can be attributed to the history of power relationships which have disadvantaged particular groups in this country. In disadvantaged communities in South Africa, people are trapped in a cycle of poverty (Donald et al., 2002:205).

Your own personal view of the concept of "community" will determine your stance on the impact of HIV/AIDS on a community and the role that communities can play in the prevention of HIV/AIDS. HIV/AIDS is a disease that affects families and communities and presents a challenge to our society (Department of Health, 2000:4-5). Every major disease humankind has ever faced generally produces two faces: the disease itself and the physical suffering it entails and society's reaction to and concern about this disease (Institute of World Concerns, 1998:1). Of particular concern in South African communities is the evidence that the social circumstances of persons newly identified with HIV infections are worsening. Communities may grow or divide around issues of HIV/AIDS. Barnett and Whiteside (2002:195) postulate that the level of social cohesion in a community could determine the susceptibility to HIV/AIDS. Therefore, "communities" that view themselves as united might be able to address the challenges that the disease brings in a positive manner. According to Barnett and Whiteside (2002:194), united communities show openness and a willingness to talk about the disease and to give support to those infected.

Whiteside and Sunter (2000:82) argue that communities could play a vital role in the implementation of a successful prevention of the spread of the virus, but the concept of "community" should not be used as a quick fix. Not all communities are similar and where some communities are able to unite, others, because of poverty, might be divided and powerless. Support structures and interventions that take the diversity of communities into account should be implemented. An intervention that could have a dramatic impact on the fight against this disease is anti-retroviral therapy.

Currently, anti-retroviral therapy is not available in the public sector. The Department of Health is investigating the possible use of anti-retroviral medications for HIV positive persons and as a possible therapy to prevent mother-to-child transmissions.

2.4 EPIDEMIOLOGY OF PAEDIATRIC HIV INFECTION

The HIV epidemic continues to expand in South African communities. The most severe manifestation of the HIV infection is acquired immunodeficiency syndrome (AIDS). AIDS is not a single disease, but a syndrome that may involve several pathological states and it can be transmitted in the following known ways:

- Sexually, by contact with infected semen, genital secretions or blood.

- Parenterally, by shared contaminated needles or other sharp instruments, accidental blood exposure, transfusions of blood or blood products, or tissue or organ transplants.
- Perinatally, either during pregnancy, during delivery or during breastfeeding (Pierret, 1992:66).

Pregnancy and HIV infection is an important aspect to consider, as women often find out that they have HIV infection during pregnancy.

2.4.1 Mother-to-child transmission

For most people, the ability to have children and to see them grow up is a basic expectation and an important component of their identities. HIV/AIDS prevents these expectations. I believe that one of the most serious implications arising from mother-to-child transmission is the fact that most of these infected mothers in South Africa die before they can see their children grow up. The tragedy of AIDS does not end with the death of the sufferer. It continues through the lives of the children, those who are orphaned and those who are living with HIV/AIDS (Guest, 2001:1).

According to the World Health Organisation's Fact Sheet on HIV/AIDS (2001), women face a two to four times higher risk of becoming infected with the virus during unprotected intercourse than men. It seems that women are more susceptible to infection of the HI virus, since women are exposed to semen for a longer time during intercourse. There could also be a higher concentration of HIV present in semen than in vaginal fluids. From a paediatric perspective, this statistic is particularly alarming, since at least 85% of paediatric AIDS cases can be attributed to perinatal transmission (World Health Organisation, Fact Sheet on HIV/AIDS in South Africa, 2001). Perinatal (or vertical) transmission of HIV is the transmission of the virus from an HIV infected woman to her newborn child. Vertical transmission from mother-to-child can occur before, during or shortly after birth. Post-natal transmission of the HI virus can occur through the ingestion of breast milk from an HIV positive mother (Claxton & Harrison, 1991:5). About 25-30% of perinatal transmissions occur during gestation (in utero), about 70-75% occur during delivery and some cases are reported as a result of breastfeeding (Evian, 2000:163).

The majority of developed countries around the world have drastically reduced the number of perinatal HIV transmissions (Bryan, 2002:83). In South Africa, however, the same positive trend cannot yet be observed. Due to an overburdened health system and inherited social inequalities (see 2.3), vertical transmission can be viewed as one of the most prominent ways of spreading the HI virus in South Africa (World Health Organisation, Fact Sheet on HIV/AIDS in South Africa, 2001). Maternal risk factors for vertical transmission are more pronounced in areas where poverty and inadequate health facilities are observed. Some of the maternal risk factors that are more acute in these circumstances include:

- Failure to receive AZT preventative therapy
- Prolonged rupture of membranes
- Vaginal deliveries
- Low birth weight or prematurity
- Placental inflammation
- Firstborn twins
- Maternal injecting drug use
- Bloody amniotic fluid
- Breastfeeding

Most babies born to HIV positive mothers will only be tested for the virus once they are about fifteen to eighteen months old. According to Van Dyk (2001:61), the following tests are commonly used: ELISA, Western blot or rapid tests. If these HIV tests were done on babies that are younger, it would be impossible to determine whether the antibodies in the baby's blood belonged to the baby or the HIV positive birth mother. Pregnant, HIV positive women transmit their maternal HIV antibodies passively across the placenta to the fetus during pregnancy. These maternal antibodies can be detected in the baby for up to eighteen months. However, more sophisticated, albeit more expensive tests, are available on the market. These tests can establish the HIV status of a baby within approximately thirty days of its birth. Because of the expensive nature of the P24 antigen and the PCR tests, it is often only used in the cases of abandoned babies who might be up for adoption (Van Dyk, 2001:61).

"Fifteen years of epidemiological data and studies indicate that there is about a twenty five percent chance that a child born to an HIV-infected mother will be infected" (Evian, 2000:200). According to the UNAIDS epidemiological fact sheet on South Africa for the year 2000, most of the learners younger than thirteen infected with HIV, are as a result of the transmission from an infected mother to her child, either during pregnancy or through breastfeeding. These statistics also include reported cases of children becoming infected with the virus through blood transfusions and sexual abuse (Evian, 2000:157).

In South Africa, this information translates into the following reality. In the year 2000, 420 000 people were living with HIV/AIDS, of which 95 000 were children between the ages of nought and fifteen years (UNAIDS, 2000:b). It is estimated that about half the number of HIV-infected infants will develop severe illnesses during the first year of life. Infected infants surviving the first year will be at risk of AIDS or AIDS-related illnesses for the rest of their lives (Aronstein & Thompson, 1998: 7-10). "30-40% of those learners who progress to AIDS only after infancy will probably remain in good health into their late childhood or early teens" (HIV&AIDS Support Department of Health).

According to Dr C. Evian (2000:158), the clinical course of HIV infection differs significantly in children as compared to adults. The period from infection to the development of AIDS, and finally to death, is generally much shorter in children than in adults. Another difference can be seen in the fact that a larger proportion of children could develop serious illnesses which could ultimately lead to these children's deaths within the first year or two of their lives. A third significance is that an estimated 75% of all HIV infected children will die before their fifth birthday (Department of Health, 2000a: 7). Consequently, the provision of care and services to HIV infected children is a particularly complex and multifaceted process (Boyd-Franklin, Steiner & Boland, 1995:19).

2.4.2 The treatment and support of HIV infection in children

The clinical presentation of the HI virus varies considerably in children. As experience in working with children infected with HIV accumulates, a wide spectrum of the presentation of the disease has emerged, from asymptomatic carriers through to children with mild illness and to those with classic signs and symptoms of AIDS (Roberts & Cairns, 1999:11). There are those children born with HIV who progress very rapidly to AIDS-defining conditions and have a rapid loss of CD4+ cells. They are usually symptomatic by six to twelve months of age. These rapid progressors develop more severe illnesses and mostly die within the first two years of life. Some children born with the HI virus are called slow progressors, as these children only develop symptoms after the first year of life. Characteristics of these slow progressors are the fact that they do not suffer severely from opportunistic infections and they often survive to older childhood ages and even into their early teenage years (Department of Health, 2001:38).

According to South African statistics, 30-40% of children born with HIV are rapid progressors and 60-70% fall into the category of slow progressors (Evian, 2000:159). However, it has also been noted that children with HIV often present with non-specific conditions, which are commonly found in general paediatrics. The difference is that symptoms common to many treatable conditions such as diarrhoea, recurrent fever and dermatitis are likely to be more severe and persistent in HIV-infected children. At present HIV infection is not curable. There are specific anti-retroviral (ARV) therapy combinations available that are able to suppress the HIV activity in the body. Anti-retroviral (ARV) therapy combinations can slow down, or even stop, the process of the disease (Van Dyk, 2001:42). Unfortunately these medications are very expensive and are currently not provided in the public health sector. Thus far, the public health sector suggests that people infected with HIV should follow a holistic path that includes social, psychological and physical well-being, in order to help them cope with the infection. The following guidelines are given by the Department of Health (2000:a) to significantly improve the child's quality of life and survival time:

- History and physical examination of HIV-infected children with a regular follow up.
- Education and counselling
- Social support co-ordination
- Nutritional support management
- Immunisation
- Treatment of common clinical problems.

- Prophylaxis against some common and severe infections.
- Laboratory monitoring
- Palliative and terminal care

The management of HIV infection in children aims to keep the child well and symptom-free for as long as possible. This includes trying to keep the child at home and out of hospital for as long as possible. According to Evian (2000:167), the management of children with HIV infection includes, regular medical and growth checks, treatment of infections and abnormal conditions, the prevention of opportunistic infections, anti-retroviral treatment (where possible) and the provision of counselling and support.

Currently the South African Health Ministry is considering aspects of a new treatment plan for HIV/AIDS. The stance that the government is taking is that the current treatment options in the public sector should be augmented by a greater focus on nutrition, food supplementation and the use of immune boosters in order to delay the progression from HIV to AIDS (The Star, June 11 2003). National debates between the Health Ministry, Non-Governmental Organisations and AIDS activists, like the Treatment Action Campaign, are raging on. Contrary to the government's approach, activists argue that anti-retroviral (ARV) therapy should be available in the public health sector to the benefit of all (The Star, March 14 2003). HIV/AIDS activists suppose that a feasible option to South Africa's HIV/AIDS dilemma exists on two levels. This first consists of the availability of anti-retroviral therapy to all South Africans and the second that HIV infected people should be able to have access to basic nutrition and care. Findings of a new study reconfirm the dilemma facing people infected with HIV in developing countries: anti-retrovirals are effective and are relatively cost effective, but the money in the public health sector is simply not there (Boyles, 1998).

Thus, the reality for millions of South African children infected with and affected by the virus is adversity. A wide range of circumstances helps to construct adversity during childhood. On the one hand, these circumstances consist of structural causes, which can include poverty and political inequality and, on the other hand, there are circumstances that transpire through interpersonal contexts, such as the family, or through accidents and illnesses (Dawes & Donald, 1994:1). On the other side of the continuum, developed countries around the world are reporting on the changing nature of HIV/AIDS for children. The number of children who become infected as newborns has dropped wherever HIV-infected pregnant women have received optimal anti-retroviral treatment for their own care, as well as to decrease transmission to their infants. Reports state that the number of HIV-infected children who survive to school age and adolescence has risen wherever these children received anti-retroviral therapy (UNAIDS, 2002). Hope for the future lies in collaborative efforts between the government and community support structures to provide a sustainable holistic support framework for all children infected and affected with HIV/AIDS. As mentioned previously, the provision of care and services to HIV infected children is a particularly complex and multifaceted process (Boyd-Franklin, Steiner & Boland, 1995:19). Non-specific manifestations of HIV infection such as failure to thrive, skin disease, diarrhoea, lymphadenopathy and developmental delays are common and frequently represent the presenting symptoms of HIV infection in children. Neurological dysfunction, opportunistic infections and respiratory infections have been reported in a large number of children with advanced HIV infection (Crocker; Cohen & Kastner, 1992:10).

2.4.3 Neuropathology of HIV infection in children

Although relatively little published research documents the effects of HIV infection on neuropsychological functioning, there is increasing recognition that neurological involvement is a common feature of paediatric HIV/AIDS. Neurological dysfunction has been reported in a large number of children with HIV infections. A variety of developmental delays has been noted, from mild delays in attainment of milestones to developmental regression (Department of Health, 2000:23). The HI virus is both lymphotropic, affecting the lymphoid system, as well as neurotropic, colonising and affecting the central nervous system. In children with HIV the nervous system can be damaged in a number of ways:

- The virus can directly affect the brain (Encephalopathy).
- The virus can affect the development of the maturing nervous system (Microencephaly) or the developed brain (Atrophy).
- The virus can cause opportunistic infections of the central nervous system.

- The virus can cause lesions that may be primary to HIV infection, but whose relation to the virus is still unknown.

The damage caused to the central nervous system may begin early on in the course of the disease. Its course is chronic, often dangerous and, given sufficient time, devastating (Kozlowski in Crocker; Cohen & Kastner, 1992:25). Where HIV infects the nervous system, the effect on each child will be different according to the stage of development of the central nervous system at the time of the infection. Whilst the central nervous system is still developing in younger children, the most common neurological signs are delay or loss of motor milestones and certain language delays. In older children, impairments of perceptual-motor function, attention, memory, concentration, expressive behaviour and language are commonly noticed. Older children may also show deteriorating cognitive skills, lose previously acquired milestones, show soft neurological signs (i.e. lack of coordination and balance, slight tremors, confuse left and right) and experience psychological difficulties (Hanna & Mintz in Boyd-Franklin, Steiner & Boland, 1995:30).

This knowledge of the severity of central nervous system involvement in HIV-infected children brings to light the fact that parallel to the immune deficiency that makes this virus fatal, is the slow, deterioration of the central nervous system. This unrelenting deterioration of the central nervous system is even possible without any overt signs of immune deficiency, due to opportunistic infections (Kozlowski in Crocker; Cohen & Kastner, 1992:25). Increased effectiveness of anti-retroviral therapies for HIV infection could result in temporary functional benefits but may not alter the systemic and neural replication of HIV. This could result in an increase in children with developmental disabilities who will need specialised and extensive care (Evian, 2000:182).

The HIV/AIDS epidemic has a profound impact on children in South Africa. The virus attacks not only the immune system of infected individuals, but their central nervous system as well. This disease has affected many people who suffer from multiple risk factors. The result is a multifaceted route of opportunistic infections, neurological impairment and sociological and psychological stressors (Roberts & Cairns,1999:29). It is important to view these stressors (poverty, poor nutrition) from an ecosystemic perspective in order to understand their full impact on all the systems. According to

Donald et al. (1997) and Engelbrecht (1999) systems are patterns of organisation whose identity becomes more than simply the sum of their individual parts. Any individual person or situation can be seen as being simultaneously both a discreet entity and a part of a number of other systems. For that reason, it is important to keep all the different systems in mind when working with a child living with HIV. Therefore, the management, treatment and assessment of HIV infection in children poses complex challenges for any professional dealing with families infected with and affected by HIV (Mok in Claxton & Harrison, 1991:37).

2.5 UNIQUE ASPECTS OF HIV/AIDS IN CHILDREN

Childhood is a time to learn, experience and grow. This is the one developmental phase in which a human being is expected to be happy, to have fun, to explore and to dream big dreams for the future. It is a time to be nurtured, valued and protected (Orton, 1997:1). Regrettably, for many children in South Africa, childhood is a time of difficulty because of complexities caused by HIV/AIDS and other risk factors. Each child infected with HIV presents a unique picture. Consequently, health care professionals and educators need to constantly assess the individual child's situation and potential in order to be able to plan an appropriate course of action.

Children with HIV infections may experience an array of difficulties: immunological, physical, developmental, neurological, sensory, social, behavioural and/or educational. Holistic assessments should form an integral component of the evaluation and management of children with HIV/AIDS. As in other aspects of care for children infected with HIV, the diagnostic assessment should take the ecosystemic context of the child into account. Each HIV-infected individual's difficulties are unique and cannot be understood outside the social context in which they occur. The social context does not only influence the causes of the specific difficulty and therefore has a bearing on the prevention of this difficulty; it furthermore affects the nature of the special needs that results from that specific difficulty (Donald, Lazarus & Lolwana, 1997:268). Thus, given the numerous medical, social and developmental difficulties with which children with HIV/AIDS may present and the complex social and educational issues that should be addressed, a coordinated, holistic approach is vital (Cohen & Diamond in Crocker; Cohen & Kastner, 1992:25). The following components could form part of such an holistic assessment:

- **General medical assessment**

  In light of the extensive range of medical symptoms that could manifest in children with HIV/AIDS, it is important to consult with a specialist in the field of paediatric HIV/AIDS. Given the common finding of motor disabilities among children with HIV infection, an assessment by physical and occupational therapists is a vital part of any medical assessment (Cohen & Diamond in Crocker et al, 1992:56).

- **Neurodevelopmental assessment**

  Hanna and Mintz (in Boyd-Franklin, Steiner and Boland, 1995:35) argue that a neurological assessment is essential in order to ascertain the degree and extent of neurological difficulties that might be present. Correlation with the outcomes of psychometric evaluations is relevant, as this allows for a more integrated interpretation of the results, which then leads to a more relevant framework of support.

- **Psycho-educational assessment**

  A psychological assessment forms an integral part of the evaluation and support of neurological deterioration in children infected with HIV. The psychometric tests used in an assessment of this nature could help establish a picture of the cognitive abilities and actualised functioning of a specific client. The outcomes of such an assessment can guide the medical team in evaluating the efficacy of anti-retroviral therapies. Parents, caregivers and educators can benefit from this kind of assessment in that the feedback obtained regarding the cognitive functioning of the child can assist them in establishing realistic expectations for behaviour and self-help skills (Hanna & Mintz in Boyd-Franklin; Steiner & Boland, 1995:35). An assessment of this nature can also assist in identifying the emotional and social needs of the child. Once these have been identified, therapeutic support can be given to the child, the family and other systems involved. Furthermore, an educational assessment will provide educators and other roleplayers with the opportunity to determine what a child's specific educational needs may be and what specific interventions may be necessary. Traditional psycho-educational tests could be used in conjunction with dynamic assessment techniques that take the context of a specific child into account. These assessments can assist in planning educational programmes for individuals that take their special needs and abilities into consideration (Engelbrecht, 2001:70).

- **Speech, hearing and language assessment**
  Being able to communicate with others and the environment has an important place in every individual's life. Recurrent ear infections, developmental speech delays and second language learning make audiological and speech and language assessments imperative. These assessments can broaden the scope of the planned support programme for children with HIV/AIDS (Cohen & Diamond in Crocker et al, 1992:58).

- **Nutritional assessment**
  HIV infections in children are synonymous with failure to thrive, potential for a variety of nutritional deficiencies and the possibility of feeding difficulties. In the light of this knowledge it is important that children with HIV/AIDS follow a recommended diet that provides for their special nutritional needs (Evian, 2000:159).

There is a definite need for support structures that address the special needs of children infected with HIV. Education support professionals have traditionally operated from a typically medical deficit approach to special needs (Engelbrecht, 2001:18). This implies that these professionals tended to convey to the client with special needs that they are the problem and that the answer to this problem could only be given by the professional support providers.

The challenges that children born with HIV bring to professional support providers call for a different approach. Holistic support is needed. This means that the infected learners should be supported physically, academically, emotionally and socially. Collaboration between professional support providers, together with parents and teachers is necessary to address all the unique needs of children living with HIV/AIDS. "The dynamic interconnectedness of the systems necessitates a move away from a fragmented and uncoordinated approach to support" (Engelbrecht,

Engelbrecht & Green, 2001:21). Coordinated support efforts focus on finding ways to support the unique needs of learners by building the capacity of the roleplayers involved and not through changing the child to "fit in." The child should have a voice in these attempts.

2.6 CHILDREN'S EXPERIENCES OF LIVING WITH HIV/AIDS

In South Africa, the majority of children infected with HIV acquired the infection from their mother (World Health Organisation, Fact Sheet on HIV/AIDS in South Africa, 2001). In a family affected by HIV/AIDS, the child faces problems probably long before she realises that she is infected with the same virus that caused the deaths of other family members. Psychosocial stress could start when the child becomes aware that her parent/s are infected, which could lead to worries about the future (Department of Health, 2001:25). Losing a parent is a very traumatic experience and many economic and emotional difficulties can result from this. Although some children contract the virus after receiving contaminated blood products and blood transfusions or through sexual abuse, most children become infected with the virus when it is transmitted in utero or perinatally through their mothers (Leukefeld et al., 1987:52). That the virus is passed from mothers to their children is probably one of the most painful aspects for children to come to terms with. However, not only must the children deal with knowing they got the disease from an infected parent, many parents must also learn how to cope with the knowledge that their behaviour has affected the life of their child (Orton, 1997:114).

As this disease progresses from HIV to AIDS, the infected child experiences a variety of changes. Once the child starts developing actual symptoms of AIDS as a result of opportunistic infections, their bodily experiences might change from neutral and pleasurable sensations to ones of fatigue, pain and discomfort, all with the added burden of the unpredictability of their physical functioning (Evian, 2000:162). With the realisation that everything is not going as it should, a child living with AIDS could experience a variety of emotions such as fear of the unknown, fear of pain and suffering and the possible fear of losing family and friends. The child may also express unpredictable mood swings, with anger most often directed at caregivers and people closest to them. Temper tantrums can erupt and at other times, the child might just be irritable and cranky. These tantrum episodes may represent some regression in the child's behaviour as she attempts to cope in a manner befitting somebody much younger (Tartler in Armstrong-Dailey & Zarbock-Goltzer, 1993:153).

Children infected with and affected by HIV/AIDS are one of the most vulnerable population groups in society. The nature of the infection means that significant aspects of their lives have already been decided for them (Roberts & Cairns, 1999:63). Children not affected by or infected with HIV/AIDS might never have to deal with the issues of disclosure, losses, stigma and questions about death in quite the same manner as children living with HIV/AIDS.

2.6.1 Disclosure

Tasker (in Aronstein & Thompson, 1998: 316) posits that many caregivers refrain from discussing the child's HIV status with them in order to try to protect them. The caregivers' fears about disclosing the HIV status to the child are a natural response to protect the child. Conveying the news of a terminal disease to the child can be daunting. Not knowing how the child will respond is an issue and there is also the worry about whether their own abilities as a carer will be adequate to comfort and reassure the child.

The fact that caregivers want to avoid discussing issues such as how the child was infected and/or discussions about death ensues from a need to protect the HIV positive child (Orton, 1997:113). Many caregivers want the HIV-infected child to have a happy childhood for as long as possible without having to live with the knowledge of a life-threatening disease hanging over their heads. A lack of trust may develop between the child and the caregiver if the child realises that certain issues cannot be discussed with the caregiver. Hence, the disclosing of the HIV status to the child is generally more of a problem for the caregivers than for the child. The child may actually experience some relief that the web of silence is finally broken, and the people around them will answer their questions honestly (Ahmed, 1992:38).

Keeping secrets can become a way of coping for many affected families. Keeping secrets about the child's HIV status often happens because parents and caregivers are frightened of how such a disclosure could affect the child's friendships, relationships and education. Pressure is put on the child living with HIV/AIDS to guard the secret and the child becomes isolated, with nobody to talk to: if nobody can know about the disease then there is nobody to talk to about it (Orton, 1997:114). However, one of the most difficult issues encountered when working with children living with HIV/AIDS has to do with the disclosure of the diagnosis to the child living with the disease. Pollock and Thompson (in Boyd-Franklin, Steiner & Boland, 1995:131) argue that the decision to disclose this diagnosis to the child is a very complex one, and should be done by the child's parents. This should happen with the support of a health care professional, for the sake of the parents/caregivers as well as the child. A health care professional, collaborating with the parents/caregivers, could assess the child's level of functioning, the stage of the infection and the context of the child living with HIV/AIDS.

Pollock and Boland (1990 in Boyd-Franklin, Steiner & Boland, 1995:131) state that there are guidelines that health care professionals should consider with regard to disclosure: Children are less threatened by the truth than they are by the unknown, but it is important to keep the developmental level of the child in mind. The information needs to be presented in such a way that it makes sense to the child. Parents/caregivers and health professionals should keep in mind that disclosure is a process and not only a once-off discussion. Therefore, it is important that health care professionals collaborate with parents in order to make counselling available to the child and other individuals involved in the process.

Disclosure of a child's HIV status is welcomed in South African schools. Disclosure in a safe environment can create a scenario in which the special needs of the child can be catered for and assistance for the caregivers can be provided. Special care should be taken to keep any medical information regarding a child's HIV status confidential and it should be remembered that no child, or parent, are obliged to disclose the HIV status to the school. However, any child above the age of fourteen living with HIV, or her parents, are free to voluntarily disclose the child's HIV status (Department of Health, 2001:10). Together with issues of secrecy surrounding HIV/AIDS, parents and children living with HIV/AIDS have to battle with many questions about death and dying.

2.6.2 Questions about death and dying

It is out of the ordinary, even in a developing country like South Africa, that a child's life ends before they are able to reach adulthood. It is a natural parental aspiration and biological necessity of all species that each new generation will mature into the future that their parents started for them (Evian, 2000:157).

Children living with HIV/AIDS face the great risk of not reaching adulthood, because of the severity of the disease and the fact that no cure has yet been discovered (The Star, July 14 2003). Because HIV/AIDS is such a devastating illness for families and children to contend with, most families affected by this disease are in a state of denial. This denial can often be seen in the parents' or caregivers' refusal to seek help and their refusal to discuss the consequences of the disease with the child living with HIV/AIDS (Kuykendall, 1991:152). The denial that the parents are often experiencing could result from the possibility that they themselves are living with HIV/AIDS and have given it to their child. Infected and affected families therefore need a great deal of support but the support that these families need will differ from context to context.

In the same way as different contexts will determine different intervention strategies when supporting families, children living with HIV/AIDS will have different emotions and questions about death and dying. Part of living with HIV is being sick, enduring painful medical treatments, hoping to get better, and knowing that you might not. Children living with HIV/AIDS must deal with their own death, that of their parents, siblings and friends who also have the disease (Orton, 1997:116). Black (in Barnard, Morland & Nagy, 1999:68) postulates that young children may view the loss of a parent as abandonment and that they may be concerned about who will take care of them when their parent is gone, while older children may react with confusion, anger and desperation, which are mourning responses connected to the loss. Children who must face their own mortality will grieve the loss in different ways depending on their age. Dyregrov (1990:83) states that some children may worry about their declining health and whether they will have enough energy to fight the disease, others wonder whether they will experience relief once they are dead. Some children express the wish that when they die, they hope that they will be able to see all the other people that have died before them in heaven.

Orton (1997) proposes that children who are living with HIV/AIDS need a great deal of love and support, as well as opportunities to express their feelings. She further suggests that children living with HIV/AIDS need to know that they can confide their fears and their hopes to a concerned caregiver who will listen and understand, whether they are at home, in hospital or at school.

2.7 THE CURRENT SITUATION IN SOUTH AFRICAN SCHOOLS

Schools occupy a central position in communities, with children spending a major part of their time there. Therefore, it is important to realise that schools have a significant role to play in partnership with parents, families and the broader community when it comes to assisting children living with HIV/AIDS (Department of Health, 2001:75).

Unfortunately, little research has been done in South African schools that focuses solely on school-related issues concerning children infected with HIV/AIDS. Health care professionals and others involved with the care of children living with HIV/AIDS are aware and distressed about the inconsistent levels of knowledge and support. Schools are made aware of the existence of HIV through information leaflets distributed by various departments, for example, the Department of Health shares information on the virus itself and the preventative measures that can be taken to protect yourself from the disease, while the Department of Education focuses on making changes in the curriculum and policy documents to accommodate all learners who experience barriers to learning. In South African communities, where HIV/AIDS seems to be at the root of so many barriers to learning it could be imperative to address the issues of HIV/AIDS more assertively (Department of Education, 2000:79). More is needed than just incorporating the teaching of HIV/AIDS prevention in Life Skills classes. Being made aware of the standard precautions against the disease may well be an acceptable starting point from which to address the barriers that are created through HIV/AIDS but it is only a start. More concerted effort and research is necessary to address the specific barriers created by HIV/AIDS in South African schools. Progress is seen in schools where prevention is taught and networks between the school and community-based support structures exist and where staff members are encouraged to attend training in the field of HIV/AIDS. However, few schools have created an open atmosphere of trust whereby partnerships with infected and affected families and learners can be established (Roberts & Cairns, 1999:31).

Nonetheless, in contrast with the slow turning wheels of bureaucracy, the number of children and adolescents who have become infected with HIV has increased to alarming levels (Department of Health: 2001:3). This increase has directly affected school communities across South Africa. Since the start of the HIV epidemic, the inclusion of children who are HIV positive has been very controversial. Susan Taylor-Brown (in Aronstein & Thompson, 1998:361) believes that the controversy reflects a complex labyrinth, consisting of multiple factors. As discussed previously, many children with HIV/AIDS experience chronic illness, developmental delays, speech difficulties, and hearing impairments, to mention but a few issues, therefore the role of the educators will have to change in order to facilitate the special needs that learners infected with HIV bring to a school community. These changes are necessary to support these learners (Cohen, Papola & Alvarez, 1994). Furthermore, earlier identification and advances in treatment have improved the survival rate of paediatric-acquired HIV children. Hence, more children living with HIV/AIDS will need education and their individual needs will place more demands on existing educational services.

2.8 CONCLUSION

The HIV/AIDS pandemic has had a profound effect on all levels of South African society. The impact on children has been more pronounced, because of their natural vulnerability and inability to look after themselves. Children are more susceptible to the HI virus as their immune systems are still growing and maturing. The virus destroys not only the immune system of infected children, but attack their central nervous systems too. Communities in South Africa have to deal with many adversities that increase the risk of contracting the virus. The result is a complex pattern of opportunistic infections, neurological impairment and psychological and social disadvantage to the orphan crisis surrounding HIV/AIDS in children.

The key to preventing HIV infection in children clearly lies in preventing their parents from acquiring the disease. Unfortunately, all indicators show that this pandemic will be with us for a long time. Holistic efforts need to be directed at the biomedical, socio-cultural and economic aspects of preventing the spread of this virus. In South Africa HIV infection amongst children under the age of ten years is slowly evolving from a rapidly progressive, fatal disease to a chronic infection in which moderately effective therapy prolongs survival (Evian, 2000:157). HIV/AIDS has severely disrupted all spheres of society, but hope must be directed to the future where collaborative efforts can bring about changes to the spread and impact of this epidemic.

Chapter Three introduces and presents the research methods applied in this study.

CHAPTER THREE

THE RESEARCH METHODOLOGY

"What is it you want to buy?' The Sheep said at last, looking up for a moment from her knitting.
'I don't quite know yet', Alice said, very gently. 'I should like to look all around me first, if I might.'
'You may look in front of you, and on both sides, if you like,' said the Sheep, 'but you can't look all round you – unless you've got eyes at the back of your head.'

Lewis Carroll

3.1 INTRODUCTION

The focus of this investigation is to describe the experiences and the life world of a ten-year-old child born with HIV. Therefore, this chapter discusses the research design of this study. The research design is also examined in relation to the research questions posed in Chapter One. To assist the researcher in this empirical investigation, a research design with a qualitative focus was constructed. My personal motivation for this study, as well as my role as researcher, will be discussed together with the research method, methods of data collection and the techniques that were used in processing the data. This chapter will also explore the issues of validity, reliability and the ethical considerations involved in this investigation.

3.2 THE RESEARCH DESIGN

A research design allowed me to construct guidelines that could assist me in answering the research questions. In answering the research questions, I gained a greater understanding of the research problem (Mouton & Marais, 1994:103). With the construction of a qualitative research design, I hoped to gain insight into the life world of a specific ten-year-old girl, who was born with HIV. A qualitative design allowed me to focus on the process of the investigation and enabled me to understand specific social actions in terms of a specific context, which allowed me to gain a better understanding of this phenomenon (Babbie & Mouton, 2001:270-271).

As a researcher, my involvement in this investigation grew out of a personal awareness of this phenomenon, my own experiences of working with children and my interest in the philosophy of Phenomenology that emphasises experience and interpretation.

3.2.1 The context of the research

This study is informed by a constructivist-interpretive paradigm (Denzin & Lincoln, 2000). As this paradigm assumes a relativist ontology that recognises multiple realities and a subjective epistemology, I shall attempt to understand this phenomenon as well as the experiences and contexts that are involved, not through any given perspective, but through the eyes of those participating in this study. Margot Eyring (in Bennet de Marais, 1998:142-143) postulates that all human beings collect experiences through living their respective lives and that they have the ability to reflect upon these experiences. Upon reflection, it becomes possible for people to interpret these experiences and, in doing so, make changes to certain aspects of their lives. My aim as a researcher is therefore to "enhance the process of reflection and interpretation, so experiences can be understood more richly" (Bennet de Marais, 1998: 142).

Through this qualitative study, I shall attempt to understand this phenomenon in its uniqueness as part of a particular context (Merriam, 1998:6). This study will therefore assist me in expanding my own knowledge base. A common denominator amongst human beings is our constant effort to increase our knowledge of the world around us and to understand others and ourselves better (Babbie & Mouton, 2001:4). The world around us consists of various forms of human knowledge. Knowledge can be divided into categories ranging from experiential knowledge at the one end of the continuum to scientific knowledge at the other.

A person's experiential knowledge of HIV/AIDS could be derived from the fact that this person is HIV positive and she feels and understands the impact that this disease has on her body. These experiences are real to her and she can see how this disease influences other aspects of her life. Through these experiences, this person will gain more experiential knowledge, which would help her cope in a different way. Babbie and Mouton (2001:16) postulate, "Experiential knowledge is driven by the very practical concern of how to cope better in the world of everyday life". Therefore, this kind of knowledge is very personal and would differ between individuals on the basis that everyone has different experiences.

At the other end of the continuum, scientific knowledge "is the outcome of a rigorous, methodical and systematic inquiry into a specific phenomenon" (Babbie & Mouton, 2001:6). Scientific knowledge is part of everyday life and is not restricted to laboratories or other controlled environments. This point can be illustrated by the fact that most people have knowledge about human immunodeficiency, a chronic disease that is acquired through a virus.

Another human characteristic that people share is our continued search for "truth". A researcher will go about searching for "truthful knowledge" in a methodical, organised manner. Knowledge is accepted as "truthful" when there is enough evidence to support the hypothesis that was made and there is one "truth" for everybody (Babbie & Mouton, 2001:4-16). This perspective on research methodology is based on a positivistic view. The aims of a researcher conducting research from a positivistic point of view lies in the fact that she wants to create an exact replication of the world in the phenomenon that she is studying, in the hope of producing perfect data through the use of uniform interviews (Silverman, 1998:99). On the other hand, a researcher conducting research from a social constructionist perspective bases her study on the belief that no interview can create precisely the same context as described in the interview. This perspective will also include the view that the narratives derived from interviews "are context-specific, invented, to fit the demands of the interactive context of the interview, and representative of nothing more or less (Silverman, 1998:99).

For the purpose of this research study, neither of the abovementioned perspectives was discarded, but both were critically appraised. The theoretical method used for this study is symbolic interactionism. Symbolic interactionism studies the subjective meanings that individuals give their life worlds and the contexts in which they function (Flick, 1998:17). This research method enables the researcher to view the world from the perspective of the participants involved in the study.

3.2.2 A qualitative approach

The use of a qualitative approach for this study was deemed appropriate "owing to the fact of the pluralization of life worlds" (Flick, 1998:2). Pluralization requires the researcher to look at the increasingly fast pace at which everything in the world is changing. Social researchers are confronted with issues of "diversification of life worlds and growing individualization of ways of living" (Flick, 1998:8). The diversification and individualization of life worlds implies that the researcher works from a position of not knowing. The researcher's main concern is therefore to understand social action in terms of its specific context (Babbie & Mouton, 2001:270-271).

In order to gain a greater understanding of the life world and the experiences of a ten-year-old girl born with HIV, this research design follows a traditional approach of presenting a problem, asking questions, collecting data to answer these questions and analysing the data in order to understand the phenomenon in its unique context (Creswell, 1998:17-19). The nature of the research question and the aims of the study influenced the choice of a research strategy. The research question, "What does the life world of this ten-year-old girl, born with HIV, look like?" guided the research in the direction of utilising a case study method. Yin (1993:3) argues that a phenomenon under study that is not readily distinguishable from its context implores the researcher to embark on the research journey using a case study design.

Merriam (1998: 27&29) defines a case study as an integrated system with clearly defined boundaries. This "bounded system" does not exist in a vacuum and it is important to note that case study research is very much dependant on the context that this bounded system occurs in. This study of the life world and the experiences of a ten-year-old girl born with HIV is descriptive in nature as the researcher aims to "illustrate the complex nature" of the context of the participants. A descriptive case study method allows the researcher to see the world through the eyes of the participants and furthermore affords the researcher the opportunity to describe and interpret the phenomenon holistically. The case description will therefore also support the reader in knowledge construction (Stake, 2000:439). In order to be able to establish a conceptual framework for this study it is important to review the existing literature that grounds and explains the hypothesis that was made in Chapter One of this study.

3.3 DIFFERENT ASPECTS OF THE QUALITATIVE DESIGN

3.3.1 Literature review

Thornton (1993 in Merriam, 1998:48) postulates that theory is necessary in every qualitative study in order to help the researcher to see things that she would have otherwise missed and, furthermore, it allows the researcher to anticipate and make sense of events that are encountered. Mouton (1996:119) suggests that a literature review provides the researcher with guidelines in terms of the design that should be followed.

Although I agree with the views of both Thornton and Mouton, I consider the concept of a literature review to be more than "a map of the terrain that is being studied" (Mouton, 1996:119). Akin to Flick's hypothesis on the value of a literature review for a qualitative study, I deem a literature review to be a circular process (Flick, 1998:43). Therefore, a literature review is not a task that is done at the beginning of a research project, never to be repeated. A literature review, when viewed as a circular process, influences the researcher to engage in reflective practice. All researchers enter their field of study with some understanding of the phenomenon that they intend to study. Through reading existing research literature and researching a specific phenomenon, every researcher contributes to the existing base of knowledge. For the purpose of this study books, policy documents, reports in academic journals and data from the internet were utilised. Reviewing the existing knowledge base does not only happen once in the research process.

The literature review for this study (as seen in Chapter Two) gave me a conceptual framework from which to start this journey. It enabled me to construct my own knowledge of the HIV phenomenon and in turn, I am able to contribute to existing knowledge base in this field. Throughout this research process I went back to the existing literature in order to gain a greater understanding and focus. In the same way in which the hypothesis guided this study in a qualitative direction, the use of a descriptive case study method and the literature review led me to use purposive sampling methods.

3.3.2 Sampling procedures

Sampling procedures refer to the methods that the researcher uses to enable her to choose participants for the study (Mouton, 1996:132). Flick (1998:72) states that sampling decisions oscillate between the need of the researcher to investigate as big a field as possible and the need to analyse the field in an in-depth manner. Therefore, it is important to allow the research to guide the selection of sampling methods appropriate to the particular study that is being conducted.

The aims and the purpose of this study guided me to select a purposive sampling method. Babbie and Mouton (2001:202) state that purposive sampling is a method of non-probability sampling in which the researcher selects the most appropriate sample. A single, descriptive case study was selected in order to gain an in-depth understanding of the experiences of the participants. I based the selection of a sample for this study on my own knowledge of the population. My first consideration in selecting a sample was to draw on my knowledge of the population and I realised that a possible sample had to consist of participants who possibly had experiences of the phenomenon that I wanted to investigate and who were willing to engage in a study of this kind (Merriam, 1998:61-62). Through my work as an intern Educational

Psychologist, my path crossed that of KD, a ten-year old girl born with HIV. Gaining access to KD involved several steps:

- I had to obtain consent from the head of the institution where KD resides.
- A letter was submitted that explained the right to voluntary withdrawal from this study at any time, the purpose and the aims of the study were explained and the methods of data collection were mentioned.
  (Appendix 1)
- As a researcher investigating the sensitive stories surrounding a minor born with HIV, I also discussed the ways in which the confidentiality of the participants would be protected. (See 3.6 Ethical Considerations)
- Support was also suggested in the form of counselling and names and telephone numbers of relevant professionals were supplied (Creswell, 1998: 115-116). I explained to KD that it could happen that she experienced confusing emotions after I had been to visit her and that if this should happen, that there was somebody that would like to talk to her about these emotions. I attempted to explain to her that this person would also be there to talk to her about issues that she felt she could not discuss with anybody else.

The sample selected consisted of a ten-year old girl born with HIV, two caregivers at the institution where she lives, her foster mother, her Grade 3 class teacher and the doctor that oversees her medical care. Employing a single, descriptive case study design allowed me to draw on multiple sources of information as a means of collecting data for this study (Creswell, 1998: 62).

3.3.3 Data collection

A case study involves the widest array of data collection as the researcher attempts to portray an in-depth picture of the case (Yin, 1993:20). The case study design opted for in this investigation allows the researcher to approach the collection of data in a variety of ways. It is important to understand this case holistically and therefore more than one method of data collection was used (Merriam, 1998:134). The different methods of data collection employed in this study were aimed at gathering relevant information and therefore to enable the researcher to answer the emerging research questions (Creswell, 1998:110).

In this study, two types of data collection methods were utilised, namely, observations of participants and individual interviews conducted with the participants. These methods of data collection helped the researcher to describe the phenomenon within its specific context (Yin, 1993:5).

3.3.3.1 Participant observation

Participant observation techniques were implemented for the purpose of this study. These techniques provide the researcher with the opportunity of being a part of the situation being studied while simultaneously being able to investigate the situation (Babbie & Mouton, 2001:293).

As a participant observer, I drew a lot of attention, and the first couple of sessions that I had organised with KD and her housemates were an opportunity for the children to become accustomed to my presence. I used these sessions for them to ask me questions, to see how the tape recorder worked and to have a look at my notebook. The children asked me questions; I answered these in order for them to understand what I would be doing there. I encouraged them to try to write down things that they wanted to remember from our time together. They loved these interactions and I believed that after these sessions that I had gained their trust. Furthermore, I asked all the children's permission. Their permission was granted in the form of a picture of themselves with their signatures, accompanied by my own (Holmes, 1998:15-17).

I observed KD's interaction with her peers at school and at home. This proved to be quite a challenge as I was engaged in activities with the children while at the same time trying to write down, or even just notice interactions happening around me. I agree with Merriam's (1998:103) statement when she notes that "participant observation is a schizophrenic activity in that the researcher usually participates, but not to the extent of becoming totally absorbed in the activity". I found it difficult to observe the context and the interactions around me, as well as participate in the process of taking notes. Therefore, I relied on my memory and wrote field notes directly after an observation session.

Here is an example of field notes that were made after observing KD with a few of her fellow housemates. The three housemates varied in ages between six and thirteen years.

Place: Outside on veranda
Time: 15:30
2003/02/03

Participants: KD (10) girl
M (13) girl
T (9) girl
H (6) boy

Three girls and one boy playing "Mom, dad and two children". They are playing on a veranda. H is the dad, KD the mom and M is child 1and T is child 2.

I am sitting on a small chair next to the doll's house. I am able to make eye contact with all the participants. KD comes up to me and asks, "What are you writing?" I show her my notebook and following the words with my finger, I read to her what I have written...that seems to satisfy her and she goes back to the group...

The group is organising the play area...
H: This is where we will eat...
K.D: No, I am the mom, I make food, we eat here...
H: You always the boss, what can I do? He?

While this is going on, the other two, M and T, found some pictures to colour. They are lying on the floor...M is hearing impaired and she is teaching T how to sign the names of the different colours. A lot of giggles and squeals can be heard from them.

KD: You (H) can go and play with the children... [she is busy preparing food and she is singing softly]

H comes and wants to sit on my lap...because of the lack of space; he and I sit on the floor.

H: I do not want to play no more, I want to sit with you, what you do?

A: I am trying to write your story down on paper, every thing you say I want to write. [With my finger, I show him the words]

H: I can write too? [I give him a piece of paper and he starts writing]

One of the advantages of using observational techniques as one of the methods of data collection, was the fact that this technique afforded me the opportunity of collecting information in an informal way, in a setting that formed a natural part of the participants' everyday lives. The other advantage is the fact that KD is not a first language English speaker and this technique helped me to collect more information in a context where she was able to enjoy herself in play (Gillham, 2000:48). Although the formal layout of this study suggests a linear plan of action in terms of data collection, the actual process of data collection occurred in a circular fashion. Ideas and question that arose during the observations informed the interviews that I conducted.

3.3.3.2 Interviews

Robert Stake (1995: 64-65) postulates that many things around us that we cannot observe for ourselves are being observed by others. Using case study designs in research enables us to collect the descriptions and observations of others. In this case study, I aim to portray an array of different perceptions that contribute to the multiple realities of the life world of a ten-year old girl born with HIV. Through interviews with four participants, I was able to collect the data needed to understand the multiple views of the participants.

Rubin and Rubin (1995: 34-41), argue that an interpretative approach to collecting data means that the researcher acknowledges that "not everything that is important can be measured with precision" (p.35). I agree with this argument and in aiming to come to a better understanding of the experiences of a ten-year-old girl born with HIV, an interpretative approach to interviewing was used in this study. According to Rubin and Rubin (1995:41), this implies that the researcher allows ideas and questions to develop from the experiences and stories that the participants bring to the interviews. This approach to interviewing contributed to the circular process of the collection of data: the observations informed the interview that was to follow and in return, information gathered in the interview directed the next observational session. One of the reasons for choosing a case study method was that I was aiming to describe the experiences of the participants within the specific context that they occurred, therefore, the participants' words and trains of thought lead me in the interview process (Merriam, 1998:71-83).

The qualitative nature of this study allowed me to establish a rapport with the participants through the interviews that I conducted. Maykut and Morehouse's (1994:80-83) suggestion of initiating an informal conversation with the participants helped me a lot. I kept the focus of the inquiry, namely "the experiences of a ten-year old girl born with HIV", clearly in mind. The participants that I had chosen for the interviews represent different systems of the life world of a girl born with HIV. This implied that each individual interview had a unique approach and different questions were asked in each interview (Marshall & Rossman, 1995:82). This assisted me in collecting the unique experiences of each individual participant. The questions listed below were used to initiate the semi-structured interviews with the foster mother, two caregivers at Little Haven, the Grade Three class teacher and KD's medical doctor:

- I want to write a story about your life, what can you tell me about yourself?
- What are the experiences of a teacher teaching HIV positive children?
- What narrative views do caregivers have about HIV positive children in their care?
- What are the experiences of a medical practitioner working with HIV positive children?

For the purpose of this study, the participants were asked about their experiences of HIV in order to gain more insight into this phenomenon. During the interviews with the adult participants I made use of active listening and reflecting skills, as described in Gerard Egan's book "The Skilled Helper". These listening and reflecting skills helped me to stay focused on the main aim of the interview, but guided me in allowing the participant to do the talking. In conducting the interviews I used both indepth unstructured techniques, as well as semistructured methods. For the purpose of these interviews I tried to forget about the rules of conducting good interviews and I tried to work as creatively as possible. Jack Douglas (1985 in Denzin & Lincoln 1998:62) hypothesises that creative interviewing allows the participants to express themselves more freely.

During the interviews, I found it helpful to take some notes. However, some participants made it noticeable through their body language and tones of voice that the note taking made them feel uncomfortable. In these situations, I refrained from taking notes during the actual interview. I then had to rely on my memory to write down these observations, feelings and thoughts as soon as the interview was concluded. A tape recorder was used to ensure that I would be able to retrieve all the verbal data collected. With the participants' permission, the interviews were recorded and transcribed, after which the data was processed and analysed. Here are some biographical information (See Table 3.1) about the adult participants that contributed to this study and the format of the interviews that were conducted.

Table 3.1 Biographical information

Participants	Background details	Interviews
Foster mother (B)	- Career minded - Married, with one adult child - No formal training in caring for a child living with HIV. - Got involved in KD's life, through her church.	- Three, fifty minute interviews - Indepth unstructured: Interview 1: 2003/02/03 Interview 2: 2003/02/04 Interview 3: 2003/02/05
Caregiver (ST)	- Sixty years old, no children of her own. - Working at Little	- One interview: Three hours - Semi-structured:

	Haven for five years. - Living with breast cancer - Involved in the care of children for forty years - No formal tertiary training	2003/02/07
Caregiver (L)	- Thirty years old, no children of her own - Currently busy with a diploma in childcare - No formal training in caring for children living with HIV. - She has been working at Little Haven for three years.	- Three, fifty minute interviews. - Indepth unstructured: Interview 1: 2003/02/11 Interview 2: 2003/02/13 Interview 3: 2003/02/14
Grade Three Class Teacher	- Married, no children of her own. - B.Prim (Ed) qualification - First year of teaching. - No formal training in assisting children who are experiencing barriers to learning.	- One interview: one hour - Semistructured: 2003/02/14
Medical practitioner	- Employed at a state	- One interview: one

	hospital. - Working as a paediatrician for fifteen years	hour - Semistructured: 2003/02/20

One of the biggest challenges concerning this investigation was the interviews that I had to conduct with the children. For me the challenge lay in the fact that I wanted to be as creative as I was with the adult interviews, but some barriers existed. In accord with Holmes (1998:22-29), I found using a tape recorder to record our interviews to be of little use, for the following reasons:

- The interviews took place either in the designated homework area or the outside veranda, which means that there were always other children and noise around.

- Children enjoy moving around and because I wanted the interviews to occur in the participants' natural environment, I moved around with the child. On other occasions, I would stay in the same position with the tape recorder and I would write observations down and write down the conversation that we had just had while the child went off to play. In attempting to stay with the natural rhythm of the children, I felt that I was able to gain their trust and they accepted me as part of the group.

In spending time with KD conducting the interviews, I also realised that being a second language English speaker sometimes hindered her in saying what she really wanted to say. Whenever she felt that she did not know how to express herself in English she would say what she wanted to say in Zulu. Subsequent to our conversation I would ask one of the Zulu-speaking caregivers to translate those phrases for me. I tried to adapt my questions and my conversations to accommodate the language competency of the participant with whom I was interacting. According to Janice Morse (<u>in</u> Gubrium & Holstein 2002:317-327), conducting interviews with participants who are ill can prove to be challenging to qualitative researchers. The challenges are highlighted in the following statements:

- Participants who are ill could be silenced because of the physical and emotional trauma that they have experienced (Morse in Gubrium & Holstein 2002:318).

- The treatment that these participants have to undergo takes priority over interviews and research (Morse in Gubrium & Holstein 2002:319).

As a result, qualitative researchers engaging with participants who are ill should equip themselves with relevant knowledge about different ways in which to overcome the abovementioned challenges. In this particular study, I found that KD was not hampered in the interview process by the fact that she was born with HIV. There are a number of positive factors in KD's favour: Since the beginning of 2001, KD has been receiving anti-retroviral therapy and she is enjoying good health. She is living in an environment where she is happy and where she is accepted, loved and well cared for. During the interviews with KD, I tried to convey to her that the time we spent together was her time and that in my role as researcher, I was following her lead. I followed a nondirective approach in this process, where I waited for KD to show me the next step. I waited for her to reveal her story in her own time. I relied on open-ended questions that helped me to clarify KD's stories and responses. Below is an extract from an interview with KD:

Place: Playroom at Little Haven
Time: 14:30
2003/02/24
Interviewer: A
Interviewee: KD

Page 1

2 A KD, look here I brought a medicine bag and some dress up
3 clothes....
4 (KD proceeds to look through the bag, at the stethoscope etc.
5 Without saying a word she starts to put a white, long
6 sleeved shirt on and she puts the stethoscope around her neck)
7 A Mmmm, I see your are the doctor....
8 KD Who is sick?......(Looking around)
9 This bear is sick//

A Ooo, you have found a sick bear....
KD This is a sick girl, she is very sick, where is her mom?
(Looking around the room)
You can be her mom. (Pointing at me)
A Ok, I am the sick girl's mom. What is her name?
KD I am the doctor, you are her mom, you know her name and
then tell me.
A Good morning doctor, this is my daughter Kate. She is very
sick....
KD (Speaks in a deep voice)
Good morning.
Bring Kate here and tell her to stop crying—I will not hurt her....
I am going to look in her throat and her ears.....
(KD leaves the bear on a chair and comes and whispers in
my ear)
Don't say anything to ....mmm Kate, but I am also going to take
blood from her arm.........
(As she speaks she shows me the place on her own arm)
A Doctor how can I help Kate?
KD You cannot help her now, only the doctor can.....................
(KD proceeds to examine the bear and she starts looking for the
syringe, while she is busy doing this she starts making soft
crying noises)
KD Come and hold Kate on your lap. She is scared and this hurts.
(KD draws blood from the bear's arm, while the bear is on my
lap)
There, there it is finished, now you can stop crying, now I can
give you medicine.
You have to clean her ears very good every night in the bath
and this is for her throat.........
(Shows me the medicine that she is talking about)
I have something for her skin, but she must stop scratching it....

In this interview, I made use of role-play and specific props (medicine bag, dress up clothes and so on) to guide KD's narrative in the direction that I wanted to explore, "otherwise you tend to collect numerous personal anecdotes with no connecting theme" (Holmes, 1998:24). For the purpose of this study I wanted to explore KD's experiences with illness which is why I choose the role-play material accordingly. Other tools that I used to direct the interactions that I had with KD were art activities (Oaklander, 1988) and a disposable camera (Seligman, 1996:114).

Art activities enabled me to establish a comfortable rapport with KD and this gave her the opportunity to express herself in a non-threatening manner (Orton, 1997:152-154). KD used a disposable camera to take photographs of the world around her and how this world made sense to her. Once the photos had been developed, KD had the opportunity to tell me about the pictures that she had taken. I made notes of these stories and these physical artefacts assisted me in gaining a richer understanding of her life world. Figure 3.1 is an example of a drawing made by KD on the 8th of February 2003. She titled this piece, "This is me."

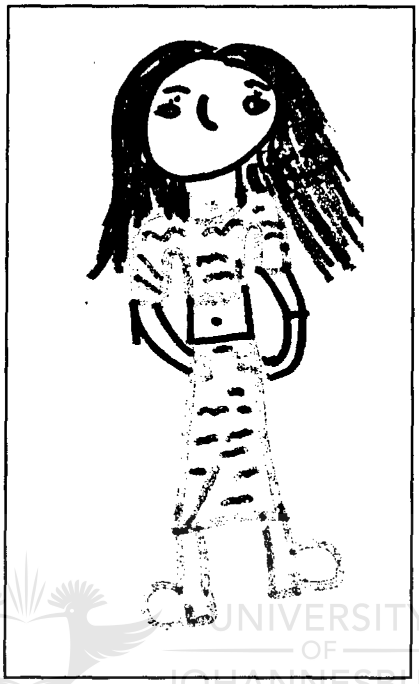


Figure 3.1 "This is me"

The flexible manner in which I approached the interviews with KD meant that I spent a significant amount of time with her. The empathy that I felt for her and the other participants in this study sometimes made it difficult for me, as a researcher, to stay focused and not to get to emotionally involved with the participants. Keeping a reflective and a research journal helped me to overcome this barrier.

3.3.3.3 Reflective and research journal

Rubin and Rubin (1995:118-121) maintain that it is not possible for any researcher to be totally aware of their personal feelings and reactions towards participants during observations and interviews or to be aware of the impact that they have on the context. Therefore, I found it not only helpful, but also necessary to keep a reflective journal with a record of my own experiences and thoughts evoked by the observations and the interviews.

Writing down my feelings, thoughts and fears in my own personal journey helped me to become more aware as a researcher. For example, some of the entries made me realise that I was afraid of asking the caregivers in-depth questions about the illnesses and suffering that KD had to endure. With this awareness, I consciously set out to ask questions that I found difficult in previous interviews. I found that it helped me to write these questions down. During the actual interview, I could read the questions that I wanted to ask. An example of such a question that I wrote down, is, "Please tell me about the suffering that accompanies HIV/AIDS?"

No person is totally self-aware at all times, so in addition to writing down my thoughts and feelings I discussed my feelings, thoughts and some of the journal entries with colleagues, which helped me to gain perspective on and distance from this process. This, in turn, helped me to grow as a researcher and as a person. Knowing your own blind spots as a researcher and the manner in which you respond to issues that might arise during the process of investigation could help to highlight the areas in the analysis of the data where bias may enter into the research.

In this research study, I made a distinction between a research and a reflective journal. While my reflective journal consisted of emotions and personal thoughts that I had during and after the interviews and observations, my research journal formed part of my field notes. In this research journal, I wrote down questions that I needed to ask in order to clarify certain aspects of a participant's story, questions to myself, new ideas that came to mind and reminders about certain concepts that I had to go and read up on. My research journal helped me to keep my focus in terms of my research, and it also assisted me in keeping a circular process (see 3.3.1 Literature Review) going. Through a circular process, I was able to gain greater insight and my conceptual knowledge developed through constant cross-references to existing theories and resources. The existing resources on data analysis assisted me in analysing the data that I had collected for this study.

3.4 DATA ANALYSIS IN CASE STUDIES

Data analysis entails organising what you have read, observed and heard in order for you to make sense of these experiences (Glesne, 1999:130). A qualitative research design presupposes that the process of data collection and data analysis does not happen in a linear fashion. It is rather, as stated by Merriam (1998:151) a simultaneous process: the analysis of the data occurs as the first interview is conducted and the first observation is made. Flick (1998:178) describes data analysis as an interwoven process where the interpretation of the data helps the researcher to contribute to the development of theory and at the same time, informs the researcher on additional data that should still be collected and on the best procedure to follow in order to reach the aims of the particular study.

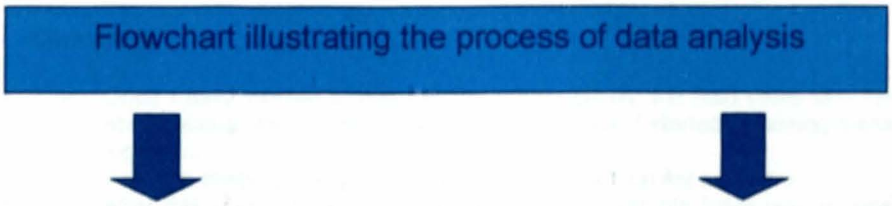
A qualitative case study design is an intensive, holistic description and analysis of a single, bounded unit. According to Merriam (1998:193) and Stake (1995:78) the main aim of the researcher in analysing the data collected in a case study is to convey an understanding of the case. As I started with the process of collecting data for this study I knew what the aims of this study were and I realised that I had to collect data that would address these specific aims. In order to achieve this outcome, I attempted to simultaneously collect and analyse the data. I experienced that the early data analysis that I did at the same time as collecting the data enabled me to focus and to shape the study as I proceeded (Glesne, 1999:130).

In this process of the early analysis of the data, I made use of an elementary coding scheme that enabled me to organise the data that I had already collected (Maykut & Moorehouse, 1994:122). In my search to make meaning from the data that I had collected, it was important to merge my observations, field notes, the participants' stories, and my own interpretations and reflections into a rich and believable descriptive narrative (Smith, Harré & Van Langenhove, 1995:5). One of the essential characteristics of qualitative research is the inductive manner in which the data is analysed. It is inductive in nature in that I attempted to discover order, structure and meaning from the data collected (Glesne, 1999:152).

The first step in the process of discovering order and meaning in the data involved the transcriptions of the interviews that were conducted. Silverman (2000:136) postulates that the process of transcribing interviews is more than merely collating data: it is the researcher's first steps in analysing the data that was collected. No standard norm has been established to give guidelines in terms of how transcriptions should be done (Flick,1999:175). Flick does, however, suggest that the research should lead the researcher in determining how much data to transcribe and how to analyse the data (Flick, 1999:175). However, this still did not give me anything concrete to work with. I had read about quite a few different methods of analysing data where some methods were more prescriptive in nature, for example the constant comparative method suggested by Maykut and Morehouse (1994:126) based on the work of Glaser and Strauss (1967), while others relied more on the researcher's "intuitive and interpretive capacities" (Marshall & Rossman, 1999:51).

In my mind, I attempted to put together all the pieces of information. I agreed with Glesne's (1999:152) hypothesis that data in a qualitative study is inductive in nature and that the data leads to the manner in which it should be analysed. Therefore, I worked in the following manner: I firstly organised the data that I had collected. I read and reread all the field notes, observational notes and the transcripts that were made. I tried to put all of this in order according to date. I then attempted to generate categories, themes and patterns from the organised data. This was possible using codes and colours. The size of this study allowed me to use elementary codes. The literature framework constructed in Chapter Two assisted me in creating critical questions that helped me to keep focused on the aims of the study (Marshall & Rossman, 1999:152). Table 3.2 is an example of the steps that I followed in analysing the data:

Table 3.2



An example of raw data

Place: Grade Three class
Date: 2003/02/14
Interview: 1
Class teacher (T)

139 **T** Ja, in class she battles: reading, writing and maths, she is so far
140 behind, I do not think that she is going to cope.... she tries
141 and some days I think that she is managing, but then the very
142 next day it is as if she has forgotten everything that she knew
143 yesterday....I do not know, in class she enjoys
144 the art lessons and her manners ----she is always well behaved
145 she is always willing to help clean and do other tasks in the
146 class....she works well in groups, but she----she gets teased
147 a lot, when her skin is full of sores and when she has a
148 discharge from her ears, I try to help and to stop the others from

Codes and colours given to the identified themes

(Examples taken from the interview with the class teacher)

● Teasing and taunting (T&T)

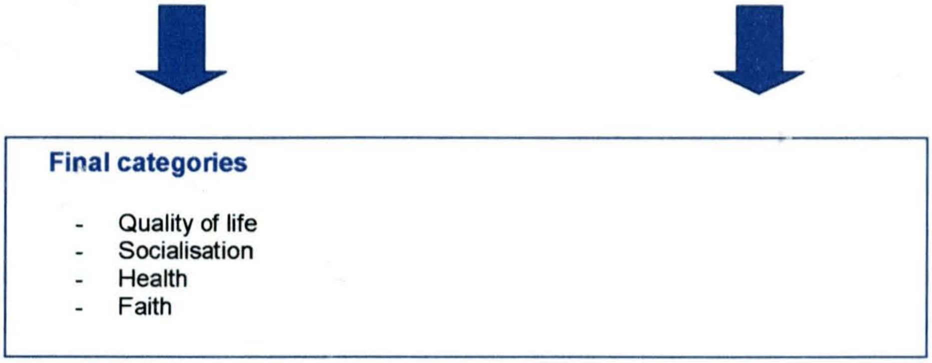
1T: 146 she gets teased a lot,
1T: 148 I try to help and to stop the others from

● Medical issues (Mi)

1T: 147 when her skin is full of sores and when she has a
1T: 148 discharge from her ears

Clustering

- Once I have worked through all the transcriptions, the field notes and the observational notes, colour coding all the themes, I started clustering these together.
- This was done by using the "cut an paste" function on my computer.
- After this I had pages for every cluster. For example there was a page labelled "Medical issues" with extracts from all the data related to this cluster.
- Now it was time to refine these clusters into the final categories.



Final categories

- Quality of life
- Socialisation
- Health
- Faith

The final step in the process of data analysis was writing about what I had heard, seen, experienced and understood. Writing up everything forms part of analysing the data; while busy writing the report I rethought and reflected on the data once more and this led me to new ideas, insights and understanding (Glesne, 1999:158). However, no qualitative report has any meaning without the assurance that the research results can be trusted and were obtained in an ethical manner.

3.5 TRUSTWORTHINESS OF THE RESEARCH

The ability to trust and have confidence in the outcomes of a particular study rests on the assumption that others can believe the findings (Maykut & Morehouse, 1994:145). In order to ensure the trustworthiness of a study it is important to provide detailed information about the purpose of the study, the way in which the participants became part of the sample, the context, the methods of data collection and analysis that were used and, lastly, it is important to provide a detailed report on the findings (Glesne, 1999:158).

To describe this case I attempted to present a significant amount of incontestable data descriptions and interpretations. In order for data to be considered valid and reliable, the descriptive and interpretive statements that I wanted to use in the report had to be triangulated (Stake,1995:109-110). Yin (1993:69) postulates that the triangulation of data means that the researcher asks the same question of different sources of evidence: if all sources point to the same answer, you have successfully triangulated your data.

The combination of interviews, observations from the field, field notes and reflections taken from a research journal assisted me in understanding the phenomenon that I was studying from different perspectives. "Convergence of a major theme or pattern in the data from interviews, observations and other reflections lends a strong credibility to the findings" (Glesne, 1999:159). However, Flick (1992 in Stake, 1995:111) and other qualitative researchers have come to realise that triangulation is more than the verification of a specific pattern from various sources. Triangulation has come to be the search for additional interpretations more than the confirmation of a single meaning.

The participants in a case study not only provide the opportunity for observation and are the main sources of data, but also play a significant role in the triangulation of the observations and the interpretations. In this study, I shared the interview transcripts, analytical thoughts and drafts of the final report with the research participants to make sure that I represent their stories and their ideas accurately. In sharing my work with the participants of the study, it is also important that I continuously build an audit trail (Stake, 1995:111).

The audit trail for this study consists of my research journal, the original interview transcripts, field notes, and some evidence of the way in which the data was analysed. This trail of paper enables others to understand the path that I have taken which would enable them to judge the trustworthiness of this study (Glesne, 1999:32). It is not only important for the study to be considered trustworthy, but it is just as important for the researcher to have support in her endeavours.

I found that peer-discussion helped me to clarify my own thoughts and ideas on this research process and that they also gave me valuable input when I had difficulties with certain aspects of the work. Peer interaction helped me to stay motivated. When my levels of motivation were low and some stories or experiences of participants haunted me, I found it helpful to talk to a professional person about these feelings and emotions (Merriam, 1998:204). Qualitative research allows the researcher to become part of the research. Therefore, it as important for me to clarify and be aware of the research biases that I bring to this study. I reflected on my own subjectivity and my peers and my supervisor made me aware of how I could use this subjectivity to my advantage in this study while also assisting me in monitoring it in my work. As a qualitative researcher, I realised that subjectivity was part of this study from the time that I started thinking about this research topic. Wolcott (2001:25) supports the idea that being attuned to your own subjectivity as a researcher means that you are in touch with your emotions. In turn, your emotions assist you in recognising when your subjectivity is engaged.

Qualitative research demands of the researcher to acknowledge that in investigating a specific phenomenon, the researcher becomes personally involved with the participants and their specific context. The personality of the researcher and the specific approach that she employs while conducting the research greatly affects the outcomes of the study (Mouton, 1996: 148-149). Therefore, it is important for the researcher to adhere to ethical considerations.

3.6 ETHICAL CONSIDERATIONS

Ethical considerations can be viewed as "the general agreements shared by researchers about what's proper and improper in the conduct of scientific inquiry" (Babbie, 1995: 448). Therefore, to ensure that the participants were treated fairly and with dignity, the purpose and the aims of the study were explained. The following statement describes my personal feelings about the participants that I had worked with: "All researchers, by virtue of a personal or professional code of ethics, are painfully aware of protecting the rights of their participants" (Holmes, 1998:24).

Hence, for the purposes of this study, the following ethical agreements were adhered to:

- Voluntary participation, after the participants had been carefully and truthfully informed about the research and their role in it. The nature of this study cautioned me to take extreme care to avoid any harm coming to the participants. This means that the participants could withdraw from the project at any stage and counselling opportunities were available to participants who felt that they needed support (Fontana & Frey in Denzin & Lincoln, 1998:70).

- People living with HIV/AIDS have the right to confidentiality and privacy about their health and HIV status. Any person involved in working with people infected with and affected by HIV/AIDS is legally and ethically bound to keep all information about clients or patients confidential. Information about a person's HIV status may not be disclosed to anybody without that person's fully informed consent. Any person to whom such information has been disclosed must keep the information confidential (Van Dyk, 2001:404). Thus, the anonymity of the participants in this study was guaranteed and confidentiality assured.

- Pseudonyms were used for all the participants and none of the participants were photographed or videotaped.

- Permission to use the information collected from the interviews and the observations was obtained from all the participants.

- Children seldom have the responsibility of giving their own consent to participate in a study like this. Consent for the participation of the children was given by the caregivers and the institutions (Holmes, 1998:15-16). Although this is true, I explained to the children what this study was all about and I did ask for their individual consent.
(See 3.3.2.1 Participant observation).

3.7 CONCLUSION

This chapter has focused on the research methodology applied in this study. A qualitative approach was chosen for this study to enable the researcher to give a descriptive, holistic account of the phenomenon. A major portion of this chapter dealt with the methods employed to collect data and the manner in which the data was analysed. An attempt was made to illustrate the interactive and holistic nature of qualitative research methodology. The main aim of this study is to gain a richer understanding of the life world of a ten-year old girl born with HIV. Therefore, the narrative writing in Chapter Four will be descriptive in nature to provide the reader with the opportunity of experiencing a feeling of "I understand better what it is like for someone to experience that" (Polkinghorne, 1998:510).

Chapter Four presents a detailed description of the case study. The analysis of the data is shown and a discussion of the interpretations of the major themes that arose from this study follows.

CHAPTER FOUR

THE PRESENTATION AND INTERPRETATION OF THE DATA

"Where shall I begin, please your Majesty? she asked. 'Begin at the beginning,' the King said, gravely, 'and go on till you come to the end: then stop.'"

Lewis Carroll

4.1 INTRODUCTION

This purpose of this chapter is to attempt to identify and discuss the information gathered from the various methods of data collection that were employed. I have so far examined the literature related to HIV/AIDS and the special needs of children infected with the disease in order to provide a framework for discussing the life world of a specific ten-year–old girl born with HIV. In this section, I shall attempt to validate my original argument, namely, that the life world of children born with HIV plays an important role in the design of special support programmes for children living with HIV/AIDS. In order to do so I shall describe and integrate the body of data that I have collected.

This section starts with a "thick description" (Merriam, 1998) of relevant histories, contexts and activities pertaining to the research question. For the purpose of this study, I have embraced a qualitative descriptive approach to this case study. I feel that the main aim of qualitative research is an attempt to observe the behaviour of people in a specific context in order to gain a greater understanding (Wolcott, 2001:10). What follows, therefore, is a narrative description of my study of the life world of a ten-year-old girl born with HIV. The analysis and integration of the participants' interview transcripts, field notes, observational information, photographs and artwork produced four main themes. These themes are presented against the specific context of the life world of a ten-year-old girl born with HIV.

4.2 PRESENTATION OF THE CASE STUDY

The life world of KD

KD's home is situated in a busy, somewhat derelict, suburb in one of South Africa's biggest cities. Driving there, the most recent hi-jacking statistics would most definitely be flashing through your mind. Behind the steering wheel of your car you would wonder what the best course of action would be, should you encounter any potential hi-jackers. If you entered the main gates of KD's home, on a January afternoon in 2003, you would immediately be confronted with peace and serenity. Away from the hustle and the bustle of inner city pavements where street vendors sell their wear, pedestrians are crowding the narrow pavements, motorists are waiting for red to turn green and the yellow African, summer sun is beating down on everything below, you will find a place nestled away from noise and people, which is where KD lives. In the heart of a busy city, fighting to keep crime and poverty at bay awaits a piece of heaven. Surrounded by heavy stone walls and huge iron gates, lies a sturdy stone church, manicured gardens and a modern looking double-storey house. The shade of majestic oak trees welcomes you and beckons you to come and take a rest from the scorching sun.

In your relief to get away from the heat, you decide to sit down on one of the wooden benches, scattered around the garden. Now you will have an opportunity to appreciate your surroundings. Within the stone walls stands a church. Beautiful stained glass windows attract attention and a tall bell-tower stretches out against the clear summer sky. A few people drift in through the heavy wooden doors towards the dark, cool interior, shrouded in silence and mystery. Quietly, so as not to disturb the peace, you follow a brick pathway past green lawns and flowerbeds to reach a group of laughing children splashing about in a swimming pool. The sound of their laughter echoes across the lawns, to let visitors and friends know that this is a place of love and hope. This is KD's home. She might not have been born here, but this is the place where she feels safe and cared for.

KD was born in a tiny little room to a mother already riddled with opportunistic infections because of HIV. Nobody knows whether she has any siblings or family, because KD's mother died shortly after she was born and no other relatives could be traced. The first couple of weeks of her life were spent in a government hospital where she was treated for failure to thrive and oral thrush. Although this baby certainly received adequate medical care, there were no loving hands to touch her, nor were there gentle arms to rock her to sleep when she was crying. Health care workers have their hands full and there are plenty of orphaned and abandoned babies to be taken care of. KD showed some signs of recovery and had started to feed better after the worst of the oral thrush had cleared away. A nursing sister, Sister K developed a keen interest in this little fighter, named KD. Against all odds, this tiny mite became stronger and she was showing that she wanted to live. Sister K was only too aware of the odds of finding a foster family for KD, because of her presenting symptoms (pointing to her being HIV positive) and the fact that her mother had died of AIDS-related infections. However, through her church, Sister K heard about a home for HIV positive babies and children. Arrangements were made by the pastor and social workers at the hospital and eight weeks after her birth, KD made her way to Little Haven.

Little Haven was founded in the late 1800s by the Roman Catholic Church. To this day, it is financially supported, run and staffed by the church. It was originally run as an orphanage, but in the early 1990s the focus of the Haven changed and children infected with and affected by HIV/AIDS were accommodated. Although the staff has had no formal training in caring for children born with HIV, they have learnt through experience. Health care professionals like doctors, social workers and physiotherapists have generously spent time at Little Haven to assist where possible. The staff members have learnt a great deal from watching these professionals work and they know that there is always somebody that they can call if they need assistance. The people working at Little Haven make this an extraordinary place to live and to visit. Their motto is "With love and faith, we shall make a difference." ST at Little Haven believes that children living with HIV/AIDS need healthy food, fresh air, exercise, and lots of love. These ingredients were part of KD's care when she met B at Little Haven. B was a host mother to H and she spent quite a bit of time at Little Haven. A special bond grew between H and KD. When H grew ill and started to become weak, he did not want to spend time apart from KD, which meant that KD started going to B's over weekends. As H became weaker, a special bond formed between KD and B. With H's death, B and KD consoled each other and B started hosting KD. B too realised that KD was a fighter and seeing her battling through one opportunistic infection after another, she decided that she was going to raise money to provide anti-retroviral treatment for KD. With the generous support from people in her church community, KD has been able to receive ongoing treatment for more than a year. The treatment, the loving care at Little Haven and her host family made all the difference to her life.

KD attends school with the other children from Little Haven. The HIV positive status of all the children has been disclosed to the school community. The caregivers at Little Haven feel that this helps the children: the teachers are able to understand their circumstances better and they now have more compassion for their absenteeism, serious developmental delays and other special needs. Although the school has not implemented any support programme for the children, the caregivers believe that the children are receiving support at school. With the input from the school, KD's caregivers realised that she had serious developmental and emotional difficulties that hampered her progress emotionally and educationally. The assistance of an educational psychologist and an occupational therapist was called on. With the support of these health care professionals, KD is making steady progress at school and on an emotional level.

Although all the caregivers, the teacher and the medical doctor feel that KD is making progress, there are no records of the progress kept. It seems as if little collaboration exist between the different systems involved in her life. The caregivers at Little Haven keep mental records of her developmental, scholastic and medical progress. Therefore, KD's teacher finds it difficult to gain insight into her unique needs. Although the medical doctor in charge of KD's care keeps detailed medical records, he feels that he does not have the time to share these with the teacher or the individual caregivers. KD's host mother (B) is very worried about KD's slow academic progress; she took KD for a psycho-educational assessment. B however, did not collaborate with the class teacher or the caregivers at Little Haven about the feedback given at this assessment. It seems as if each of the caregivers involved in KD's life is making an individual attempt at assisting her. For the purpose of this study I conducted eight scheduled interviews with KD. These interviews occurred between 2003/02/03 and 2003/02/27. I spent time with KD in the afternoons after school, our time together varied in length (30 minutes – an hour and a half), depending on how tired she was. Observations were done on the occasion that KD felt tired.

4.3 THEMATIC STRUCTURE

Four main themes were identified, each of which consisted of several related clusters within a specific theme (See Table 4.1). For the purpose of this study, I attempted to describe the themes in a holistic manner and not to analyse each theme and related clusters individually. This was done in an effort to continue the descriptive and narrative flow of the study.

Table 4.1 Main themes

1. Quality of life	**2. Socialisation**	**3. Health**	**4. Faith**
RELATED SUB-THEMES WITHIN EACH MAIN THEME			
1.1 Secrecy	2.1 Issues of disclosure	3.1 Health of the child living with HIV/AIDS	4.1 Faith of care givers
1.2 Questions about death	2.2 Stigma	3.2 Treatment and medication	4.2 Issues around the child's faith
1.3 Interpersonal relationship of the caregivers and the child	2.3 Uncertainty in the child's life	3.3 Issues around the caregivers' health	4.3 Hope

4.4 INTEGRATED VIEW OF THE THEMES

An integrated view of the themes is presented. Vignettes from the transcribed data and some of KD's artworks are used to highlight the life world of KD.

4.4.1 Quality of life

For the purpose of this study, the participants described the concept of "quality of life" as the opportunity for a person to fulfil her own potential in life. It was felt that KD's life world did not always enhance her quality of life. The caregivers' views on "quality of life" were further organised in related clusters, which included: secrecy, questions about death and the interpersonal relationships of the child and the caregivers.

Secrecy

One of the single most important issues to the caregivers was secrecy. The caregivers were all able to explain, in detail, the manner in which they neglected to openly discuss the nature of KD's illness with her. This illustrates the challenges around keeping the illness a secret from the child:

"We do not talk about HIV and AIDS here. We do talk about being ill and then we pray. We want to teach the children that Jesus is with them and will look after them, even if we die, Jesus is still there for us."

(Interview 1:ST: 78-82)[1]

"I think KD knows about HIV/AIDS and it frightens her, especially after the death of her brother. Every time she is sick, she panics and then she would almost regress in behaviour, to that of a much younger child.... I know this, but yet I do not know how to talk to her...."

(Interview 2:B: 99-101)[2]

Lipson (1996) argues that the great majority of HIV positive children will have been exposed, to a greater or lesser extent, to media coverage of HIV/AIDS. According to a study done in inner city schools in New York, primary school children have reported

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[1] Taken from first interview with caregiver ST (see Table 3.1). Lines 78-82.

that they have been subjected to jokes about AIDS. Some children have complained that they have missed certain activities at school because the other children said that they have AIDS. Furthermore, discussions about HIV/AIDS have been introduced into the Life Skills syllabus of all schools in South Africa. It is therefore necessary to consider the effect of such information being discussed in class. If caregivers are informed about the discussion in class in advance, they can work out what the best course of action for their child is.

It is also not known what sort of information about HIV the child has already picked up from caregivers and others. Children glean information not only from what has been said explicitly but also from making inferences. Tartler (1993:54) suggests that not telling the child tends to isolate her, depriving her of knowledge and making the whole subject of her illness taboo. Children mature at different rates, but it may be kinder for children to know their HIV status before they leave primary school. After primary school, it is more difficult to influence the child's environment. When children go to high school, they are exposed to a wider social environment. They will have more teachers and will be exposed to more information. Therefore, it could become more difficult to know what information about HIV they are acquiring. It is important to establish a close bond with a child in order for the child to feel that she can discuss problems with the caregivers. In order to establish this bond of trust, caregivers must share information in an open and honest manner.

Although the caregivers in this study did keep the nature of KD's illness a secret from her, they all felt that if they had the knowledge of how to tell her, they would. They asked for guidance from professional health care workers regarding how to tell a child about a terminal illness.

Questions about death

".... I get scared of dying.... so many people that I love die. I think I will also die, ST says so, she says all of us will die. Do you think...."

(Interview 7: KD: 30-37)[3]

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[2] Taken from second interview with caregiver B (see Table 3 1) Lines 99-101

[3] Taken from seventh interview with KD Lines 30-37

Elizabeth Drelich (in Boyd-Franklin, Steiner & Boland, 1995:179) postulates that as children receiving prophylactic treatment live longer, these children and their caregivers have to come to terms with anticipatory loss and the challenge of living with a terminal illness.

Although KD is part of a loving, supportive environment, there is still the omnipresent potential for multiple losses because of the context that she lives in. According to her caregivers, she has experienced the death of a number of children around her. These children were her brothers and sisters and they died. Death scares KD, as it is something that happens with regular intervals around her. Although nobody talks to the children about HIV/AIDS, KD knows that she is sick and seeing her brothers and sisters around her becoming sick, growing weaker and dying scares her. This feeling of being scared is being created by her lack of understanding about the disease. At this moment in her mind, death occurs randomly and there is nobody to guide her through these feelings of angst.

Despite the efforts reported by the participants to maintain normality of life, at least to some degree, the reality that they describe is one of being in limbo: trying to live a normal life, but at the same time preparing themselves emotionally for the painful inevitability of the death of yet another child. Unfortunately, these caregivers are not affording the children, like KD, the same opportunity. She might have many questions about illness and death, but there is nobody close to her who is ready to discuss these issues with her.

Interpersonal relationships of the caregivers and the child

McMillan (1992:66 in Anderson & Wilkie, 1992) suggests that HIV/AIDS in children, the treatment of the virus and the related opportunistic infections can create severe emotional problems for the child and the caregivers. Caregivers need to be kept fully informed of the nature of their child's treatment and become actively involved in the child's health care when possible. Roberts, Towell and Golding (2001:193) postulate that the manner in which individuals cope with HIV/AIDS will be influenced to a large degree by the amount and the type of support they receive from others. Most caregivers felt that their interpersonal relationships were strained because of their work and association with children living with HIV. Some felt that they were unable to discuss their work and the emotional stress that it created at home, because people from their own communities were afraid of them and the disease that they worked with.

"People at home are scared of this AIDS.... They do not know about it, they think that you can get it just by working with these children.... Now they are scared of me too, in my community I do not have friends...."

(Interview 2: L: 103-108)[4]

Another participant felt that her personal relationship with her life partner suffered because of her involvement with children living with HIV.

"UL does not understand how enriching it feels to work with these children and to allow them into your heart. All he sees is the time that I am not with him....He does not want to get emotionally involved, as he believes that they are all just going to die. This upsets me and then he says he does not know how I can be happy working with them."

(Interview 2:B: 150-155)[5]

Caregivers described their own quality of life as being enhanced by caring for and loving children living with HIV, although they felt that they did not get enough support from the broader community. This made it difficult for them to sustain quality relationships outside Little Haven. They felt that the stigma attached to HIV/AIDS made people afraid of associating themselves with others caring for children living with HIV/AIDS. All the caregivers agreed that KD found it difficult to form relationships with others, especially with adults. KD verbalised that she felt especially close to two of the older girls that also lived at Little Haven. She felt most comfortable talking to these two girls as they understood her. She explained that she did not have friends at school and she felt that this made her feel lonely. However, KD explained that B loved her and she often referred to her as "My mom".

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[4] Taken from second interview with caregiver L (see Table 3.1) Lines 103-108.
[5] Taken from the second interview with caregiver B (see Table 3.1) Lines 150-155.

Although KD received loving care from the caregivers at Little Haven, she did not feel a sense of belonging there, her home was with B and UL. With them, she could laugh, be a little girl and build dreams for the future.

"My family is me and B and UL. We have dogs and sometimes B's daughter comes to visit.... They say I am their special, brave girl."

(Interview 2: KD: 3-7)[6]

One of the most amazing aspects of this study was learning how the caregivers' quality of life was enhanced, despite being burdened with such tremendous suffering. Many of the caregivers involved personified strength and courage.

4.4.2 Socialisation

Roberts and Cairns (1999:63) state that children with HIV are one of the most vulnerable population groups in society. Because of the nature of their infection, significant aspects of their lives may already be decided for them. The participants in this study felt that KD's ability to socialise within a larger context, for example at school, was hampered by three main concerns. These were issues of disclosure, the stigma attached to the disease and uncertainty in the child's life.

Issues of disclosure

When issues around disclosure were discussed, it seemed as if the participants had more questions than actual workable solutions. Their questions correspond with the findings of research done by Pollock and Thompson (<u>in</u> Boyd-Franklin, Steiner & Boland, 1995:131) amongst the caregivers of children living with HIV/AIDS at a state hospital in New York. The participants in this study feel that they do not know how to answer the following questions:

- Should a child be told that she is HIV positive? If she is told, when should she be told and by whom?
- How much information about the disease should be given to the infected child?
- How should questions about life and death be dealt with?

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[6] Taken from second interview with KD. Lines 3-7.

"I think KD is too young, how do you tell a little girl of ten, that she is terminally ill.... I do not know how to tell her.... I think I should tell her, but then I think maybe ST...."

(Interview 2: B: 121-127)[7]

The implications of disclosure weigh heavily on the caregivers' minds. Although they felt that they could not talk to KD about the virus that she is living with and the way in which this virus created special medical and educational needs for her, they felt that by not disclosing KD's HIV status to the school, they unintentionally assisted the stigma around the disease to grow.

Stigma

These caregivers described that children living with HIV/AIDS have to meet a number of challenges. They believed that one of the biggest challenges of HIV/AIDS is tied to the fact that a lot of stigma surrounds this disease. Anderson (1992:ii in Anderson & Wilkie, 1992) confirms this statement when he claims that children living with HIV/AIDS have to cope with the pain and difficulties in everyday living which accompany any serious illness. However, at the same time, they have to deal with the social stigma that has been attached to HIV/AIDS.

Although KD lives in such a protected environment, her caregivers still felt that she might have experienced discrimination at school. They felt that this was happening because of a lack of correct information and education amongst teachers, parents and learners.

"I was at a school function and I overheard a conversation by a group of parents.... they were talking about children with HIV and AIDS. They were saying that they did not want infected children to play sports with their children, because of the sweat...."

(Interview 2: L: 37-41) [8]

The stigma attached to KD's life world is twofold: on the one hand, she has to live with the stigma attached to her HIV status and on the other hand, she has to come to terms with the fact that she is an orphan. Both these components make her different

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[7] Taken from second interview with caregiver B (see Table 3.1) Lines 121-127.

from the other children in her class. KD's caregivers were very aware that this kind of stigma surrounding HIV/AIDS is a heavy burden to live with. Caregivers were left feeling that they had to protect KD in some way. Some of them admitted that in their attempts to protect her, they were actually stifling her independence and conveying a message that she is incapable of doing things for herself. Because of the socialisation difficulties that KD experiences, she finds it difficult to decrease her dependence on her caregivers. She has not been able to increase her contact with the world outside her family.

Uncertainty in the child's life

Biegel, Sales and Schultz (1991:23) argue that whatever sets of beliefs individuals use to make sense of the experience of discovering that they are HIV positive, they are still faced with the task of living continuously with a large degree of uncertainty about how the future will turn out. This uncertainty is a source of stress, and often makes a significant difference to an individual's experience of the world.

KD lives a life of uncertainty. She does not live with her host family permanently as some weekends and holidays she spends with them and others she spends at Little Haven. Although her heart is with her host family, her home is at Little Haven. Because of this instability, KD's behaviour can sometimes be described as that of a much younger child. B felt that because of all the uncertainty in KD's life, she finds it very difficult to attempt new tasks on her own. The teacher at school felt that uncertainty was created by the fact that KD was absent on a regular basis. She felt that this created an atmosphere of ...

"...not knowing where she fits in... She does not really have an opportunity of getting to know the children.... Now with all the group work, she will be at school to start a project with her group, but then say, she will be absent to go to the hospital and her group would have finished the project without her...."

(Interview 1:T: 97-103)[9]

Not only did her classmates not understand what was going on and teased her, KD also expressed that not being at school made her different. Her teacher expressed

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[8] Taken from second interview with caregiver L (see Table 3.1) Lines 37-41.

concern about the fact that KD missed a lot of class work, which could not be made up because of time constraints and the large number of learners in her class.

Issues of socialisation were central to the lives of the people affected by HIV/AIDS. These participants felt that a significant part of every day life was the way in which they socialised with others around them. The way in which they are able socialise directly affects the quality of their lives.

4.4.3 Health

In our interviews, the caregivers often spoke about issues surrounding health, not only KD's health, but also their own. Their sense of health included both emotional and physical aspects of health. KD's caregivers expressed an holistic understanding of health. They spoke about a number of aspects involving health and how this affected all the spheres of their lives.

Health of the child living with HIV/AIDS

During periods when KD is ill, her caregivers are worried and usually very anxious.

"When KD gets sick, Little Haven phones me....I hate those phone calls. Most of the time, I expect the worst....I know I should not, she is healthy and we are taking good care of her. There are so many people that love her, but with HIV, you never know. With HIV.... I suppose with any other terminal illness, love is not enough...."

(Interview 2:B: 60-64)[10]

Sometimes the caregivers expressed their feelings of helplessness with the situation, for example when KD refused to eat.

"When one of the children gets sick, I try and make all that one's favourite food, but.... sometimes, because of their... especially KD, with oral thrush, she found it difficult to swallow. It is hard then to watch as she suffers and you see that she is not eating and you think 'I can see how she is growing weak and thinner."

(Interview 3:L: 12-18)[11]

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[9] Taken from interview with Grade Three teacher, T (see Table 3.1.

Treatment and medication

According to the doctor who treats KD and oversees her anti-retroviral therapy, treating a child with HIV is especially challenging because of the complications that this disease superimposes on the need of the child to thrive and grow. The complications of diarrhoea, fever and feeding problems can all contribute to malnutrition. This creates further problems, as once a child is suffering from malnutrition, she is more prone to infections. Nutrition presents particular problems in children with HIV/AIDS as they require a high number of calories in order to maintain their growth rate. High protein, high calorie feeds and vitamin supplements may be required. Doctor B felt that it is especially important for the caregivers to subscribe to an holistic path when it came to KD's treatment.

The caregivers, though, expressed their concern about the uncertainty of KD's health. They remember her as a sickly, weak baby that was brought to them a couple of years ago. Because anti-retroviral therapy is so expensive, KD is the only child at Little Haven receiving this kind of therapy. The anti-retroviral therapy that KD receives keeps her CD4 cell count high, and she is healthy. The caregivers are amazed at the difference that the therapy makes to her health.

"I could not believe my eyes, she is so healthy. She has not suffered from any infections since she started on the anti-retroviral treatment. No ear aches, no rashes, nothing...."

(Interview 3:B: 10-12[12]*)*

The caregivers all described how they felt scared when they were phoned with the message that KD was sick. Although, KD is healthy and thriving at this point in time, her caregivers feel that this run of good luck is not going to last forever and that she too, like so many others that they have cared for, is going to fall prey to opportunistic infections brought on by AIDS. The medical doctor suggested that KD should take her medication regularly, that she should eat healthily and that she should try to live a

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[10] Taken from second interview with caregiver B (see Table 3.1).
[11] Taken from third interview with caregiver L (see Table 3.1).
[12] Taken from third interview with caregiver B (see Table 3.1).

happy live. Everybody, including KD, agreed that Little Haven is the right place to help KD fulfil all the doctor's instructions.

The caregivers ensure that KD receives her medication regularly and ST at Little Haven believes that:

"Children with AIDS need love, care, healthy food, fresh air and exercise, to keep them healthy and happy."

(Interview 1:ST: 56-57)[13]

At this moment, KD might be healthy, but because of previous experiences with children living with HIV/AIDS, the caregivers were hesitant to accept KD's good health as something that was going to stay. It was as if their past experiences of children dying from AIDS-related infections were haunting them.

"...He died you know. I loved him and cared for him and. he grew weak and ill and he suffered terribly.... I can not forget how he suffered...."

(Interview 2:B: 79-82)[14]

Although the caregivers battled to overcome previous experiences of children being very sick due to AIDS-related illnesses, they took great care in ensuring that KD received the best care and an abundance of love. Intuitively, KD realised that the treatment and the good food is keeping her healthy. She loved to discuss healthy eating habits and while paging through magazines, she would point out healthy and unhealthy foods.

Although she did not enjoy going to the hospital, in her own way she knew that the medication was keeping her healthy. One of the only negative experiences that KD had, surrounding her treatment and medication, was the fact that going to the hospital meant that she had to miss school and she felt that this made her different from the others in her class.

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[13] Taken from interview with caregiver ST (see Table 3.1).
[14] Taken from second interview with caregiver B (see Table 3.1).

Issues around the caregivers' health

The caregivers worried intensely and this affected their health negatively. Talking to others also involved in KD's care helped them to relieve some of the stress and worries. It seemed that they took comfort from the fact that if one of them were having a bad day, there would be somebody that understood how they were feeling and would be able to support them. This support usually took the form of talking or praying together. This group of caregivers felt that the support helped them to keep themselves emotionally healthy.

"If it was not for Little Haven----the people here, I mean, I would not have anybody to talk to about HIV and AIDS. Everybody here understands and they know about the hurt and the heavy days. I work, talk, cry and laugh with these people.... I think that is what keeps me happy and healthy...."

(Interview 1:L: 74-80)[15]

The caregivers described themselves as being physically healthy because of the fact that they were very aware of healthy eating habits. Although the caregivers experienced the heavy burden that caring for a child living with HIV placed on them, all of them agreed that their faith gave them the courage to go on and gave them hope for the future.

4.4.4 Faith

One of the most amazing and enriching experiences of this study was seeing how the caregivers and the children in their care survived and coped with such tremendous burdens that they have to bear. Many of the caregivers and the children showed that their faith carried them through the difficult times and helped them to hope for a better tomorrow.

".... The love of our Mother Mary and her son Jesus led me to care and love for KD and others like her...."

(Interview 1:ST: 52-54)[16]

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[15] Taken from first interview with caregiver L (see Table 3.1).

[16] Taken from interview with caregiver ST (see Table 3.1).

Faith of the caregivers

The caregivers felt that it was not only the individuals with HIV/AIDS that experienced great distress from their disease, but they themselves were confronted by a profound emotional burden during caregiving activities. This emotional burden was especially heavy when they had to witness a child in their care die. The caregivers felt that their faith gave them a number of coping skills that they were able to utilise in times of emotional hardship and stress. They felt that they found it easier to care for a terminally ill child because they knew that this child's spirit was going to go and live with Jesus and that Mother Mary was there to continue taking care of the child.

"I know that a child that dies from AIDS, is going to a better place, a place where there is no illness and no tears.... That helps me to cope---Jesus and the Mother Mary; they dry my tears and give me strength to go on. To go on this difficult way of helping children with AIDS...."

(Interview 1:L: 134-138)[17]

The strong faith that the caregivers showed in God helped them to make sense of KD's illness.

Issues around the child's faith

It seemed as if KD was comforted by the fact that her brother, who had died a year ago, was with the angels. KD was able to describe what this place looked like and she felt that her brother was now happier than he was before:

".... He is not sick anymore and he does not have to go to the hospital. Now he can play and laugh all day...."

(Interview 7: KD: 13-15)[18]

KD's direct environment exposed her to issues of religion, for example, attending services on a Sunday, singing in the church choir and listening to stories from the Bible. Although she was exposed to these stories, she did not show real understanding yet. She hoped that when people died they went to heaven, which

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[17] Taken from first interview with caregiver L (see Table 3.1).
[18] Taken from seventh interview with KD.

she understood to be a place in the sky where nobody is sick and everybody is happy and has many friends. Even though she clung to this, she still missed the people who had gone away, leaving her behind. The fact that she was not afforded the opportunity to talk about her illness made her unsure of her own life and what the future holds.

Even if KD found comfort in the knowledge that there is a place called heaven and that people who died went there and were happy there, she needed to talk about the people in her life who had died. The concept of heaven was still vague and difficult for her to understand completely. Although she knew about heaven and Jesus, the thought of people dying and leaving her behind made her feel scared and lonely.

Hope

"When I am big, I want to be a teacher, so I can help children to read and count...."

(Interview 8:KD: 7-8)[19]

Hope for the future helped the caregivers and KD to carry on. A need to hope existed amongst them, which assisted them in keeping some of the negative images about the disease out of their minds. Having hope for KD's life and her health helped them to concentrate on her future. With this hope, they were able to move forward. They sought help and support from professional health care workers to assist them with KD's special needs. As one of the caregivers said:

"Hope keeps us going, if we stop hoping, we are dead."

(Interview 2:B: 101)[20]

Peplan (1995:ix) argues that when persons who are ill, injured or under pressure feel hope, their recovery tends to proceed more smoothly. Catastrophe evokes numbness; hope reconstitutes the will to struggle and to survive. The caregivers described that help they got from health care professionals such as educational psychologists, occupational therapists and medical doctors helped them to rekindle hope for KD's future. These professionals assisted them in providing support for KD and her special needs. The caregivers were very aware of the fact that KD's health and well-being is frail. Not only does the virus affect her overall health, but KD also

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[19] Taken from eigth interview with KD.

experiences developmental difficulties. These concerns created stress and the caregivers felt it was difficult to hope for a bright future. It seemed as if the participants experienced tension between feelings of hope and hopelessness. They related this to the fact that their lives consisted of equal doses of certainty and uncertainty. Even though they lived with the stress of illness and suffering every day, they believed that working with children affected by and infected with HIV/AIDS helped them to grow as human beings. Because of this faith, they were able to continue hoping for an enhanced life for each of the children in their care.

4.5 CONCLUSION

In this case study the narrative views of a ten-year-old girl born with HIV, her caregivers, teacher and doctor were described. The main aim of the study was to gain a clearer understanding of the life world of one ten-year-old girl living with HIV. According to the HIV Policy Guidelines of the Departments of Health, Welfare and Education (2000), 75% of learners in South Africa who are vertically infected will only live to about the age of five years. However, a very small group of infected learners will remain healthy for a much longer period and may survive into their early teens (Evian, 2000:159). Because of this, more and more children infected early in life will live to ask questions about the disease, attend school and plan a future.

Both the case study and the available literature suggest that more children infected with and affected by HIV/AIDS will grow up and require specialised medical, educational and emotional support to provide for their unique needs. In reading the research literature, it is evident that the experiences of the caregivers and the child born with HIV in this case study are consistent with other literature available on this topic.

Firstly, it can be seen that the medical treatments available in developed countries are improving all the time. Although anti-retroviral therapy is not readily available in public health facilities in South Africa, this study has shown that these drugs can make a difference in an infected child's life. Therefore, the life expectancy of

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[20] Taken from second interview with caregiver B (see Table 3.1).

terminally ill children is improving all the time. KD's story illustrates the need for anti-retroviral therapy.

Secondly, the caregivers' concerns about quality of life, socialisation, issues around health and faith concur with opinions in current literature about the special needs of families infected with and affected by HIV/AIDS. One of the biggest areas of concern flowing from the abovementioned themes is the lack of knowledge about the unique emotional needs of a child living with HIV.

Caregivers also spoke of their concerns about the stigma attached to this illness and the consequences that it holds for communities. In discussing this sub-theme, the caregivers voiced their concerns about the obstacles that this created in establishing a good relationship between the home of an affected family and the broader community, for example the school. This indicates that the HIV/AIDS-related stigma forms a significant part of South African society today. In order to be able to address the special needs of families affected by HIV/AIDS, it would be of the utmost importance to address this issue. Although the participants in this study felt that they had to disclose KD's HIV status to the school in order for the school to address her special needs, they were unable to openly discuss this illness with her.

One of the golden threads running through this case study was the issue of faith and hope. These two qualities that all the participants spoke of assisted them in dealing with the unique needs of a child living with HIV/AIDS. This theme is unique to KD's context.

Chapter Five presents an evaluation of this study. In this evaluation the strengths of the study are discussed and the limitations that were observed are presented. The chapter concludes with some recommendations for further research in this field of interest.

CHAPTER FIVE

CONCLUSIONS

"Alice…went on. 'Would you tell me, please, which way I ought to go from here?' 'That depends a good deal on where you want to get to,' said the Cat."

Lewis Carroll

5.1 INTRODUCTION

In this study, I have endeavoured to understand and to portray the life world of a ten-year-old girl born with HIV in a South African context. In order to do this, I have drawn on my own experiences as a beginner psychologist working with children. My attention was drawn to children affected by HIV/AIDS. I became interested in this field mainly because of the huge impact that HIV/AIDS has on our society. I was also fortunate enough to work with a family affected by HIV/AIDS and this experience made me realise how little I actually knew about this epidemic and the effects it has on people. Thus, I became interested in understanding the life world of a child born with HIV.

My research began with an examination of the literature to determine the validity of my claim that a thick description of the life world of a ten-year-old child born with HIV would provide me with a greater understanding of her life and her unique needs. In order to be able to gain a greater understanding of a particular life world of a girl born with HIV, I had to investigate a number of different aspects of HIV/AIDS. Firstly, I was interested to know where this disease originated and what effects it has on human lives. Secondly, I wanted to know more about the epidemiology of paediatric HIV infection, seeing that I was focusing on the life world of a child.

Focussing this study was extremely difficult because of all the information available about HIV/AIDS, and this investigation took some time. This helped me to understand that although there are a number of similarities between HIV infections in adults and in children, there are just as many differences. These unique aspects of paediatric HIV infections need to be understood by all professionals working with children.

The literature review was followed by a qualitative investigation of the research problem. A qualitative approach was utilised to obtain the data necessary for this study. This afforded me the opportunity to gain new insight and theories from the data that I collected through observations, interviews, photographs and art. This notion that theory is created from the data is consistent with my view that a child is subjective in nature and that her understanding, knowledge and meanings are therefore subjective and only surface in interaction with other people in a specific context (Greig & Taylor, 1999:43). In this study, the theory was grounded in the data that I collected and through the interpretation of this data, I attempted to understand the social world of this one child. My understanding of her life world was facilitated through her eyes. The theoretical framework that I used for this study further assisted my understanding.

The theoretical framework that I adopted for this study was based on ecosystemic and constructivist beliefs. An ecosystemic perspective offered me a foundation from which to view the individual in her life world. Not only is she an individual, but she is also part of a bigger context. Therefore, her personal experiences have an influence on people around her and, in turn, the experiences of others influence her. A constructivist perspective proposes that individuals create their own realities by allocating specific meanings to their experiences. Consequently, different individuals will attribute different meanings to their experiences (Donald, et al. 1997). This paradigm enabled me to view the individual experiences of people and the subjective meanings they attributed to events within a specific context.

In this final section, the strengths that I have identified in this study will be discussed. The limitations that were discovered during the course of this case study will be examined. I will also identify areas for further research pertaining to this research subject.

5.2 STRENGTHS OF THE STUDY

I believe that the greatest strength of this study lies in the fact that it focuses solely on the unique experiences of children infected with HIV/AIDS. Although the HI virus infects and manifests in the same way in both children and adults, children infected with this virus are affected more rapidly. Since some children are born with HIV and others acquire this virus only later in life, it is also very important that the developmental stage of the child be taken into account. This aspect was also highlighted in the literature review.

In light of current statistics, it is clear that more children born with HIV are going to survive for longer. This implies that educational and health professionals should be made aware of the special needs that children infected with HIV/AIDS have, in order to support these needs. The literature review in this study attempted to convey information about the disease that pertained specifically to children and it also set out to investigate the implications of children infected with HIV/AIDS for schools in South African communities. This literature review could serve as a reference to teachers and other health care professionals to assist them in gaining more knowledge about the effects of the virus on children. Although the focused literature review is seen as one of the strengths of this study, it does not imply that it is a complete and comprehensive account of all the literature and theories available on HIV/AIDS and children living in South Africa.

This study focused on children with HIV/AIDS in a South African context. This aspect of the study can be regarded as a strength as a lot of literature and theories available on HIV/AIDS focuses on American or European contexts. Even though there is a lot of knowledge and insight to be gained from literature generated in developed countries, a developing country like South Africa faces different challenges and South African research and case studies are necessary to address these. Therefore, it is important that we stay up to date with new developments in developing countries, but that we generate our own theory, grounded and relevant to a South African context.

As mentioned previously a qualitative design was used for the purpose of this study. Another strength of this study lies in the fact that this approach allowed for the individual experiences of each participant to be fully explored, thus providing the reader with a rich description of their stories. This gave the reader insight into their life worlds and helped them obtain a better understanding of the experiences of a ten-year-old girl living with HIV.

Finally, this case study aimed at providing a thick description of the life world of a ten-year-old girl born and living with HIV and in no way were any attempts made to answer questions about the virus or to influence policy decisions. I feel that because this study is descriptive in nature, it allows the reader into the life world of a child born with HIV and this facilitates a greater understanding of the special needs and difficulties experienced. Through better understanding, people can go forth after having read this study and invest more time and energy in the care of children affected by HIV/AIDS.

In the field of Educational Psychology, it is important to understand the life world of a client in order to understand and learn from that specific client. Gone are the days when psychologists professed to have all the answers to clients' problems. Answers need to be found within the unique life world of every individual client. In order to achieve this, educational psychologists need to follow a research process when investigating the life world of a new client. If this process is followed the psychologist can learn from the client and this knowledge can then contribute to the existing body of knowledge in this field. In this way an Educational Psychologist can develop an evidence-based practice. Another strength of this study is the fact that it shows Educational Psychologists how to create an evidence-based practice.

There are many reasons for conducting a research project. As a beginner researcher, one of my main reasons for attempting this specific study was to gain a deeper understanding of the life world of a child born with HIV/AIDS. Although I believe that I have certainly gained more insight and understanding into the life world of a ten-year-old girl born with HIV, there are, in my view, a number of limitations to this study.

5.3 LIMITATIONS OF THE STUDY

The research may lack objectivity or distance for a number of reasons. In the first instance, the research focused on my limited experience and knowledge of working with children living with HIV/AIDS. Therefore, it is possible that I could have overlooked areas where I could have asked more questions. These questions could in turn have led me to data that I have maybe not discovered.

In the second instance, the findings are influenced by my own thoughts and feelings about children living with HIV/AIDS. Because of the qualitative nature of the study, this limitation is to be expected as this method of research leads to the researcher becoming directly involved with their own thoughts and feelings as well as those of the participants.

Limits are also set by my own theoretical orientation and paradigm. This ensured that the study pursued a specific path and it influenced the way in which the data was analysed and interpreted. The fact that I am a novice researcher, with this case study being my first attempt at conducting a research project, also influenced the way in which I managed the case. Therefore, another, more experienced researcher, with a different theoretical orientation and paradigm, may have focused on different experiences and may have elicited different themes from the data.

I acknowledge that this study's descriptive nature and the repeated pleas for a greater understanding of the unique needs of children affected by HIV/AIDS may be misleading, in the sense that I might have implied that the intricate crisis presented though HIV/AIDS is easily solved and that the solution lies in the unique needs of children of school going age, living with HIV/AIDS. The limitations are tied up in the complex nature of the HIV/AIDS epidemic. Understanding the unique needs of children born with HIV is perhaps only the first step to unravelling this complicated issue that permeates every level of our society.

I feel that these limitations need to serve as an encouragement to engage in vigorous research in order to collect data and establish theories that will enable us to address some of the challenges presented by HIV/AIDS.

5.4 RECOMMENDATIONS FOR FUTURE RESEARCH

HIV/AIDS is the greatest challenge facing South Africa, something that is increasingly recognised. It is clear from the case study conducted that this specific area of research could provide many opportunities for future research.

The recommendations that follow must be viewed in light of the fact that this case study constitutes a qualitative analysis of the life world of one ten-year-old girl born with HIV. The aim of the study was never to single-handedly change policies or to influence governmental decision-making. The aim of this case study was to describe the life world of a ten-year-old girl born with HIV in order to gain a better understanding of the context in which she lives. Therefore, on its own, this case study cannot describe the experiences of all children born with HIV in South Africa. Similar studies could be conducted, where the number of participants could be increased and where the group could consist of a less homogenous group. Other methods of analysis for example narrative and discourse analysis could be used to add more value to this type of research.

It could be valuable to conduct this type of study at a particular school and from the data collected attempt to create policies and support programmes for that particular school. I believe that this type of study would not only address the unique needs of children living with HIV/AIDS, but would also be able to expose issues of special needs amongst all children. In this way, children not affected by and infected with HIV/AIDS are not excluded from special support. The school as a whole could benefit in this way, as policies regarding the way in which special needs are handled would be in place, based on the actual needs of that specific school. These needs can then be addressed through teacher training and community involvement.

It is evident from the strengths and the limitations of this study that there is a broad area of possible study which could provide many opportunities for future research. I hope that more research in this area would result in answers on how to address this epidemic in South Africa.

5.5 CONCLUSION

The purpose of this case study has been to provide a descriptive narrative of the life world of a ten-year-old girl born with HIV. Through this, I hoped to challenge the current health and educational programmes designed to address the issues of HIV/AIDS in South Africa.

The main aim of this study was to give a descriptive view of the life world of a ten-year-old girl born with HIV. There were more complex ways of addressing the data collected, but the aim of this study allowed me to present a descriptive study based upon a clear social problem (Silverman in Denzin & Lincoln, 2000:825).

The framework constructed and the data collected for the purpose of this study focused specifically on the experiences of a ten-year-old girl born with HIV. The methods used for data collection, data analysis and data interpretation were chosen specifically to enable the researcher to gain an in-depth understanding of the life world of a particular ten-year-old girl living with HIV.

I have suggested that more emphasis should be placed on children living with HIV/AIDS and the specialised support that they need. I have also highlighted that HIV/AIDS is a devastating illness for children and families to cope with. In view of the fact that there is currently no cure, children infected with this virus often receive a death sentence even before they get an opportunity to live to their full potential (Orton, 1997:118). This study has supported the views of health and educational departments insofar as their endeavours to educate people about the prevention of HIV and informing people of the standard precautions when it comes to dealing with blood at school, home or the work place. However, this study has argued that children living with HIV/AIDS need more specialised programmes and support. In advocating more specialised programmes, specifically geared to address the unique needs of children living with HIV/AIDS, this study does not criticise the efforts of any body in their attempts to fight this disease.

I have attempted to demonstrate in this case study that it is time that the focus of HIV/AIDS programmes shifts. Although there is a still a great need for the implementation of prevention campaigns and the sharing of information pertaining to HIV/AIDS in rural communities, more and more children of school-going age are living with HIV. Therefore, special attention must be given to the development of adequate support structures to accommodate the special needs of these children. I acknowledge that there are no ready-made answers to the problems posed by the life world of a ten-year-old girl born with HIV, since the HIV/AIDS epidemic is complex and affects all spheres of society. However, if we want to help solve the problems created by HIV/AIDS we will need to start working in our own communities, with the hope that our joint efforts will be able to make a difference.

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ADDENDUM A

Template of consent form

______November 2002

Dear____________________

I am a Masters student at the Rand Afrikaans University (RAU) where I am completing my degree in Educational Psychology. My specific area of interest is in the field of HIV/AIDS in South Africa.

The focus of my research is on studying the context of a child born with HIV. I intend doing a case study, which implies that I shall be investigating the different systems involved in the life of one specific child living with HIV. The different systems that I shall be studying will involve the caregivers of the child, the medical professionals involved with the case and the class teacher at school. I intend to explore these systems in order to gain an in depth understanding of the context that the child is living in.

My main aim is to understand the life world of one child born with HIV. Through the research, I hope to gain more insight into the experiences and to write a descriptive narrative about this unique context.

HIV/AIDS is a very sensitive topic and therefore the protection of the participants' rights and privacy are of the utmost importance. All identifying particulars of the participants will be omitted and the utmost confidentiality will apply. I would like to record the interviews on audiotape, but this will only happen with each individual participant's permission. No video cameras will be used. You retain the right, to terminate your participation in this research study at any time.

If you are willing to participate in this study or if you need more information about the study, please contact me on 000 000 0000.

Kind regards

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