

**THE IMPACT OF ORPHANHOOD ON THE LIFE WORLD OF ADOLESCENT ORPHANED  
BY AIDS IN THE RATANDA AREA**

by

**NTOMBI EMILY NDHLOVU**

Submitted in part fulfilment of the requirements for  
the degree of

**MASTER OF EDUCATION - WITH SPECIALISATION IN GUIDANCE AND COUNSELLING**

at the

**UNIVERSITY OF SOUTH AFRICA**

**SUPERVISOR: PROF A C LESSING**

**JOINT SUPERVISOR: PROF M W DE WITT**

**MARCH 2009**

## ACKNOWLEDGEMENTS

My special thanks go to the following persons who jointly, and in various ways contributed to the success of this research.

- Prof. A.C. Lessing and Prof. M. De Witt for their supervision throughout this study.
- Dr. N. Mollema for editing the manuscripts.
- My husband, Buti Ndhlovu, our children Makhosazana and Zanele and my late mother for their untiring support and encouragement.
- Above all I thank the almighty GOD.

## STATEMENT

I declare that **THE IMPACT OF ORPHANHOOD ON THE LIFE WORLD OF ADOLESCENTS ORPHANED BY AIDS** is my own work and that all the sources that I have used or quoted have been indicated and acknowledge by means of complete references.

Signed \_\_\_\_\_.  
NTOMBI EMILY NDHLOVU

DATE: 13 March 2009

## ABSTRACT

### **The impact of orphanhood on the life world of adolescents orphaned by AIDS**

The purpose of this study was to explore the impact of orphanhood on the life world of an adolescent orphaned by AIDS, thereby improving the knowledge base and insight of all those who are involved in helping the orphans.

This qualitative study endeavoured to answer the following research question: “What is the impact of orphanhood on the life world of an adolescent orphaned by AIDS, in Ratanda area?”.

A literature study was done to give a theoretical overview about AIDS orphans specifically adolescents. A semi-structured interview was conducted from five different schools. Findings from the interviews was discussed and integrated with reference to the literature. A qualitative approach was used as this helped the researcher in understanding the functioning of the AIDS orphan in his natural environment.

The researcher aimed at documenting these impacts of orphanhood on the life world and to improve the helping professions' understanding of the phenomenon. This may lead to more successful intervention strategies for these adolescents.

Key terms: HIV/AIDS, AIDS orphans, adolescence, stigma, life world

## TABLE OF CONTENT

<b>CHAPTER ONE: INTRODUCTORY ORIENTATION.....</b>	<b>1</b>
1.1 BACKGROUND.....	1
1.2 PROBLEM ANALYSIS.....	3
<i>1.2.1 Exposition of the problem.....</i>	4
<i>1.2.2 Preliminary exploration of the problem.....</i>	6
<i>1.2.3 Research question.....</i>	9
1.3 AIM AND OBJECTIVES OF THE STUDY.....	9
1.4 DEFINITION AND EXPLANATION OF IMPORTANT CONCEPTS.....	10
<i>1.4.1 HIV: AIDS originator.....</i>	10
<i>1.4.2 AIDS: HIV after effect.....</i>	11
<i>1.4.3 Adolescence.....</i>	11
<i>1.4.4 AIDS orphan.....</i>	12
<i>1.4.5 Life world.....</i>	13
<i>1.4.6 Stigma.....</i>	13
1.5 RESEARCH DESIGN AND METHOD.....	14
<i>1.5.1 Literature study.....</i>	15
<i>1.5.2 Empirical research.....</i>	15
<i>1.5.2.1 Ethical measures.....</i>	16
<i>1.5.2.2 Measures to ensure trustworthiness.....</i>	16
<i>1.5.2.3 Method.....</i>	16
1.6 DEMARCATON OF THE STUDY.....	18
1.7 THE RESEARCH LAYOUT.....	18
1.8 CONCUSSION.....	18
<b>CHAPTER TWO: THE IMPACT OF HIV/AIDS ON ADOLESCENTS' LIFE-WORLD.....</b>	<b>19</b>
2.1 INTRODUCTION.....	19
2.2 ORPHANHOOD BY HIV/AIDS.....	19
<i>2.2.1 Orphan phenomenon.....</i>	20
<i>2.2.2 Poverty.....</i>	22
<i>2.2.3 The family.....</i>	24
<i>2.2.3.1 Extended family.....</i>	26

2.2.3.2 <i>Child headed family</i> .....	27
2.2.4 <i>Vulnerability to HIV/AIDS</i> .....	28
2.3 ADOLESCENCE.....	30
2.3.1 <i>The nature of adolescence</i> .....	31
2.3.2 <i>Physical maturation</i> .....	33
2.3.3 <i>Cognitive development</i> .....	34
2.3.4 <i>Psychosocial development</i> .....	34
2.3.4.1 <i>Establishment of an identity</i> .....	35
2.3.4.2 <i>Establishment of autonomy</i> .....	37
2.3.4.3 <i>Establishment of intimacy</i> .....	38
2.4 PHYSICAL IMPACT.....	39
2.5 COGNITIVE IMPACT.....	41
2.6 SOCIAL IMPACT.....	43
2.7 PSYCHOLOGICAL IMPACT.....	45
2.7.1 <i>Trauma and stress during parental illness</i> .....	46
2.7.2 <i>Stigma and shame</i> .....	49
2.7.3 <i>Psychological coping upon parental death</i> .....	51
2.7.4 <i>Bereavement and grief in adolescents</i> .....	52
2.8 CONATIVE AND SPIRITUAL IMPACT.....	57
2.9 CONCLUSION.....	59
<b>CHAPTER TWO: RESEARCH DESIGN.....</b>	<b>60</b>
3.1 INTRODUCTION.....	60
3.2 THE RESEARCH PROBLEM.....	61
3.3 THE AIM OF THE EMPIRICAL INVESTIGATION.....	61
3.4 RESEARCH DESIGN.....	61
3.4.1 <i>The nature of qualitative research</i> .....	61
3.4.2 <i>The research paradigm</i> .....	64
3.5 THE RESEARCH METHOD.....	64
3.5.1 <i>Data collection</i> .....	64
3.5.2 <i>Sampling method</i> .....	66
3.5.3 <i>The researcher as instrument</i> .....	67
3.5.4 <i>Ethical issues</i> .....	68
3.5.4.1 <i>Harm to experimental subjects or respondents</i> .....	68
3.5.4.2 <i>Informed consent</i> .....	68
3.5.4.3 <i>Violation of privacy, anonymity and confidentiality</i> .....	69

3.5.5 Measures to ensure trustworthiness.....	69
3.5.5.1 Truth value.....	69
3.5.5.2 Applicability.....	70
3.5.5.3 Consistency.....	71
3.5.5.4 Neutrality.....	71
3.5.6 Processing the results.....	71
3.5.6.1 Preliminary analysis.....	72
3.5.6.2 Data analysis.....	72
3.6 LIMITATIONS.....	73
3.7 CONCLUSION.....	73

## **CHAPTER FOUR: RESEARCH RESULTS.....74**

4.1 INTRODUCTION.....	74
4.2 SAMPLE DESCRIPTION.....	74
4.3 DISCUSSIONS OF RESULTS.....	75
4.3.1 THEME: Physical problems.....	76
4.3.1.1 Category: Nutrition and health.....	76
4.3.1.2 Category: Cognitive problems.....	78
4.3.1.2.1 Category: Poor performance.....	78
4.3.1.2.2 Category: Vulnerability.....	80
4.3.1.2.2.1 Category: High risk of HIV infection.....	80
4.3.1.2.2.2 Category: Abuse and exploitation.....	80
4.3.1.2.2.3 Category: Childhood deprivation.....	81
4.3.1.2.2.4 Category: Stigmatisation.....	81
4.3.1.2.3 Category: Psychosocial problems.....	82
4.3.1.2.3.1 Category: Loss of parents, parental guidance, love and nurturance.....	82
4.3.1.2.3.2 Category: Poor relationships.....	83
4.3.1.2.3.3 Category: Lack of adult supervision or support and neglect from caregivers.....	84
4.3.1.2.4 Category: Conative problem.....	85
4.3.1.2.4.1 Category: Less optimistic about their future.....	85
4.3.1.2.4.2 Category: Absence of parental mentoring.....	85
4.3.1.2.5 Category: Religious reasons.....	86
4.3.1.2.5.1 Category: Important resilience factor.....	86
4.4 FIELD NOTES.....	87
4.4.1 Physical problems.....	87
4.4.2 Cognitive problems.....	87

4.4.3 Vulnerability.....	88
4.4.4 Psychosocial problems.....	89
4.4.5 Conative problems.....	91
4.4.6 Religious reasons.....	92
4.5 SUMMARY.....	92
<b>CHAPTER FIVE: CONCLUSION, RECOMMENDATIONS AND LIMITATIONS.....</b>	<b>93</b>
5.1 INTRODUCTION.....	93
5.2 CONCLUSIONS.....	95
5.2.1 Conclusion on the literature study.....	95
5.2.2 Conclusion on the empirical investigation.....	96
5.2.2.1 Physical problems.....	96
5.2.2.2 Educational problems.....	96
5.2.2.3 Vulnerability.....	97
5.2.2.4 Psychosocial problems.....	97
5.2.2.5 Conative problems.....	98
5.2.2.6 Religious reasons.....	98
5.3 RECOMMENDATIONS.....	99
5.4 LIMITATIONS.....	100
5.5 SUMMARY.....	100
<b>BIBLIOGRAPHY.....</b>	<b>102</b>
<b>APPENDIX A.....</b>	<b>116</b>
<b>APPENDIX B.....</b>	<b>118</b>

**LIST OF FIGURES**

Figure 2.1: The impact of HIV/AIDS on adolescents – A Vicious Cycle.....	57
--	----

**LIST OF TABLES**

Table 4.1: Themes, categories and sub-categories are presented.....	75
---	----



## CHAPTER ONE:

### INTRODUCTORY ORIENTATION

#### **1.1 BACKGROUND**

The first official case of the Human Immunodeficiency Virus (HIV) surfaced in 1981 in the United States of America (Schoeff, 2001: 1402; UNAIDS/WHO, 2003: 1; Wojcicki & Malala, 1998: 101). The HIV infections progressed to the more serious illness of Acquired Immune Deficiency Syndrome (AIDS) which ultimately led to death. Over a quarter of a century after the manifestation of the HIV/AIDS epidemic, Africa is still struggling to come to grips with the impact of HIV/AIDS. It appears that Africa is the continent worst affected by HIV/AIDS. Many African parents have lost their children to AIDS, and many African children have been orphaned due to their parents dying of AIDS (Dadds & Hart, 2001: 11; Harding, Easterbrook, Higgison, Karus, Ravies & Marconi, 2005: 253; Kartikeyan, 2007: 7). Some African countries (Botswana, South Africa, and Uganda) have embarked on forceful programmes intended to reduce the HIV/AIDS impact. It is not surprising that South Africa is included among these countries. The impact of HIV/AIDS is increasingly apparent in the statistics. AIDS deaths in South Africa have already exceeded one million victims, and more deaths are expected by the end of the decade (UNAIDS/WHO, 2003: 3).

Brian (2003: 423) emphasises that in the two decades since AIDS first occurred, it has reached epidemic proportions. It has impinged on and still affects the health of millions, causing disintegration among families and threatening the social welfare of communities. The AIDS impact is far worse than ever predicted. Karim and Karim (2005: 29, 31) emphasise the severity of AIDS, declaring:

*“Undoubtedly, AIDS is the world's most devastating epidemic, the deadliest in the history of humankind, its impact already far worse than could first have been predicted. It is a pandemic whose impact on societies is without precedent in recorded human history”.*

Ruxin et al (2005: 110) avers that worldwide, AIDS is the foremost cause of death of 15 to 49 year-old people. He also states that the epidemic is rapidly creating an acute crisis of orphans and vulnerable children. According to Karim and Karim (2005: 352), as the pandemic escalates, the nuclear family unit is being vastly eroded. The role of household head is undergoing radical alteration as a direct consequence. HIV/AIDS is the main cause of orphanhood in South Africa, and leads to child-headed households more than all other causes (Ebersohn & Elof, 2002:78).

The AIDS pandemic is creating new family structures across the globe, especially in Africa and specifically Sub-Saharan Africa. Karim and Karim (2005: 354) state that the current South African young generation is forced to cope with the death of one or both parents. The number of AIDS orphans is projected to reach two million by 2010. Ruxin et al (2005: 110) assert that globally, the number of AIDS orphans is also likely to increase sharply in the coming years. He predicts that AIDS orphans will exceed 25 million by 2010 in the Sub-Sahara African region. The UNAIDS (2004: 1) envisages that the crisis for children will persist for decades to come due to the continual increase in the rates of HIV infection in many regions of the world. Their calculations conclude that the increase will continue to persist for a long time into the future even if at some point there are expansions of prevention and treatment programmes. A wave of HIV/AIDS contamination and death is already extensive through South Africa. The impact will be felt throughout the decade and beyond by many households that will be directly affected.

Naturally, children have a need of a stable and secure home environment with preferably both caring parents for maximum well-adjusted development. Adolescents require a family, school and community to prepare them to meet the demands of the future adult life. In order to fulfil their intense curiosity, adolescents seek knowledge about the nature and condition of the world and the social and environmental processes around them. However, orphanhood, poor schooling, negative social interactions and many psychological stressors impact negatively on the life, hopes, and dreams of the affected adolescents. The death of a parent is a major loss for a child. Children need parents in their formative years. Worden (1996: 9) explains that in effect, parents are

children's partners in negotiating the essential developmental tasks that would take them to adulthood. The loss of a parent in the home or family harms this core ideal.

According to Subbarao and Coury (2004: 16), HIV has not yet reached its peak in many countries. Therefore the number of children rendered vulnerable by the disease is still expected to increase. Moreover, because of the long incubation period of the disease (8 to 10 years), the adverse impacts of HIV/AIDS on children, households, and communities will remain for decades after the epidemic began to disappear (Subbarao & Coury, 2004: 7). In addition, Subbarao and Coury maintain that even if the rates of new HIV infections in adults were to fall in the next few years, the virus's long incubation period means that parental mortality rates would not stabilise until 2020. This means that the number of orphaned children will remain high until at least 2030 or even up to the end of the first half of the twenty-first century.

Karim and Karim (2005: 352) accentuate that the impact of HIV/AIDS on society, family and community is complex. They contend that the lives of orphaned children are increasingly circumscribed by the economic problems that beset the remaining family. Singhal and Howard (2003: 5) affirm this and state that the loss of a father usually indicates loss of financial security. As a consequence, educational opportunities for the children may be lost or reduced, while on the other hand their psychosocial distress and other difficulties increase. Furthermore, not having a mother, who loves, nurtures, and guides the child, is one of the most difficult things for any child to handle. These complications as a consequence of the HIV/AIDS pandemic causes suffering and can ultimately lead to the worst of outcomes.

This background shows that the impact of HIV/AIDS on society is manifold. In this study the focus is on the effect of orphanhood on the life-world of adolescents orphaned by AIDS in the Ratanda area.

## **1.2 PROBLEM ANALYSIS**

Prior to specifying the problem, the analysis of the problem is presented in this section. This analysis clarifies surrounding issues and explains the context of the study. It is a

stepwise process consisting of exposition, exploration and formal statement of the problem.

### **1.2.1 Exposition of the problem**

In many parts of the world, and more specifically in the Sub-Saharan Africa and South Africa, numerous school children (whether infected by HIV or not) are affected by HIV/AIDS. Referring to HIV/AIDS, Karim and Karim (2005: 43) hold:

*“There is no segment of society that can claim to have escaped its effects; it is devastating families and communities, overwhelming health care services and depleting schools of both students and teachers”.*

The impact of the HIV/AIDS epidemic on children and families has proved to be particularly hard to quantify, analyse and confront. It is even more difficult to put on the agendas of policymakers, philanthropic agencies, and political and scientific leaders (Essex et al, 2002: 665). It is also challenging to determine what the specific impact of HIV/AIDS is on the psychological development of the child.

As a teacher for nineteen years, this researcher encountered the AIDS pandemic personally. The very high death rate in neighbouring communes startled the researcher. Interest in researching the impact of AIDS orphanhood on adolescents was initiated after witnessing the escalation of the number of AIDS orphans in schools, especially in poor communities. Ruxin et al (2005: 111) affirms this observation and states that the rate of orphans caused by AIDS is progressively increasing in South African schools. According to Karim and Karim (2005: 352), the number of children in South Africa under the age of eighteen years who had lost one or both parents is expected to reach its peak at an estimated level of 5.7 million in the year 2014.

Rotheram-Borus et al (2005: 221) report that adolescents who have parents living with HIV are also affected emotionally. Foster et al (2005: 76) caution that the emotional turmoil affects children's ability to learn. They claim that teachers report that orphaned children are apathetic, listless, excessively reserved or inappropriately serious in the

classroom, and do not play and laugh as much as other children. These children are unable to mix unreservedly with their school-mates. Hartell and Chabilall (2005: 213) point out that HIV/AIDS has a definitive negative impact on the social and educational development of adolescents orphaned by AIDS in child-headed households. These adolescents are forced to abandon school because they have to take care of ailing parents and also assume adult responsibilities in their homes. Karim and Karim (2005: 352) conclude that the AIDS orphan challenge is an unfolding tragedy in which the erosion of family is set to continue for many years. The questions that arise are:

- How are these orphans experiencing their situation?
- What are the psychological effects of orphanhood due to HIV/AIDS?

These questions are linked to the researcher's observations of the prevalence of undesirable behaviours among these orphans. These include poor school performance; misconduct; aggression; bullying; late-coming; drug abuse; listlessness and tiring easily; being withdrawn; incomplete or no performance in daily class work; untidiness in appearance and school material; high school dropouts and becoming street children. Based on these perceptions, the researcher has to ponder upon the causes of these behavioural manifestations of which some may result from their poor life-world.

According to Mampa (1995: 7), research indicates that the family plays a major role in the development of children. In the family the adolescent has freedom to explore a variety of possibilities; to make mistakes and to experience successes. The opportunities and experiences in the family contribute to a great extent to the development of the life-world of the adolescent. Thus, forming an individual self-worth is significantly influenced by relationships within the family.

The question that came to mind from the above exposition is:

- What is the influence of a parent's or parents' death by HIV/AIDS on the life-world of an orphan?

### **1.2.2 Preliminary exploration of the problem**

Terminal illness and death are traumatic, regardless of the relation between people. Trauma is experienced whether it is a parent who loses a child or a child who loses a parent or in the case of teachers, learners or peers losing someone (Singhal & Howard, 2003: 5). According to Subbarao and Coury (2004: 1), children are particularly vulnerable when they have lost their parents because they do not necessarily yet have the emotional and the physical maturity to address the loss adequately and cannot bear the psychological trauma associated with parental loss. Gasa (2001: 15) explains that sudden death or unexpected news that a loved one is dead creates not only a predicament for most family members but may also contribute to some family members running the risk of long-term psychological damage. However, children are the worst affected in the families as they have not learned the skills to cope with death and also might not yet have any previous experience with death. The risk of psychological problems in children orphaned by HIV/AIDS is even greater, due to the adult responsibilities which they have to fulfil during their parents' illness and after their death.

The concerns revolving around the problems of AIDS orphans will continue to persist because of the following reasons, among others:

- There are many educators who are inadequately trained to deal with the bereaved or orphaned adolescents. Karim and Karim (2005: 357) state that in schools, teachers frequently encounter bereaved children, and in addition, have to cope with their own grief because of the death of their colleague, friends, or even family members. South African teachers were trained mainly to teach, and may have little or no idea how to help or what to say about bereavement. They often inadvertently make matters worse by adopting a “business as usual” approach, happy to believe that the young are resilient and that with time they will heal (Abrams, 1999: xv). However, Karim and Karim (2005: 357) point out that educators lack skills and the emotional or material resources to deal with these situations. The processes of grief are as a result simply disregarded.
- There is also a lack of community care and psychological support services, needed to be provided to orphans, to the primary caregiver and future guardians.

AIDS is a national crisis with its own patterns. The study interest was generated by the desire to understand how AIDS has affected the confidence of the children who are orphaned by it. Frost (2001: 18) maintains that everybody feels differently and reacts differently to the death of a loved one. He also states that there is no right or wrong way to react.

Frost (2001: 18) avers that children tend to find it difficult to explain the way they feel and that it must be kept in mind that unresolved or inhibited grief does not automatically disappear when people get older. This is in line with Gasa (2001: 2) who confirms that the past adversities may be resolved only when they have been dealt with; otherwise they saturate the present and threaten the future. According to Singhal and Howard (2003: 86), parental death is a crystal-clear insightful loss that can compromise children's normal psychosocial development.

In South Africa there is a fateful result that children who lack parental support may be forced to become breadwinners because of pressure of observing their younger siblings suffering from starvation. The children may be bound to work at an early age despite the law forbidding child labour. In many circumstances where parents died, children stay in their homes and adolescents not only take charge of their households but also are compelled to take on adult roles and positions of caregivers and breadwinners (Hartall & Chabilall, 2005: 213). One has to question the influence of these adult responsibilities on the nature of the adolescent's life-world. The choice made by the orphaned children and adolescents determine both their future and the future of their families, communities and societies (Foster et al, 2005: 76). Adolescents are still in need of parental and family support to grow to adulthood. Singhal and Howard (2003: 2) stress the importance of a family in a teenage life:

*"The family provides some of the movement from home to school to work, sets parameters for entry into society, and establishes the rules for marriage and the next generation".*

Further, Singhal and Howard (2003: 3) declare that childhood is a platform to learn and view social interactions, that a community's hope and aspirations are planted on their children and that children present possibilities.

The effects that parental illness and death have on a child's mental health and ability to cope are complex. Children's ability to cope depends upon their growth, resilience, and culture (Essex et al, 2002: 670). The nature of the life-world is most important for affected children to survive under these constraints. The type of ailment of a parent as well as the cause of death of parents may also be an important factor in the development of children because of the undesirable way in which the community may be treating and perceiving them. According to Rotheram-Borus et al (2005: 221) the illness of parents with HIV/AIDS has a substantial and prolonged developmental impact on the children; afterwards these children also have to cope with the death of the parent. The psychological effects of these causes of death may be massive for the orphans. Subbarao and Coury (2004: 19) as well as Essex et al (2002: 670) mention that the psychological aspects and the influence of orphanhood on the psyche of the children are often overlooked. The reasons may be:

- It is difficult to assess trauma;
- Trauma impacts are often not visible as they take different forms; and
- The after-effects of trauma may not arise until months after the traumatic events.

If the learners are not well supported and allowed to grieve, it may impede their psychological development in the long term.

Hartall and Chabilall (2005: 213) state that orphaned adolescent's development is inhibited by the extent of poverty, the lack of parental, social and educational support and social discrimination. These remain inhibiting factors throughout the lives of these orphans. If not addressed, it may contribute to a lack of confidence, especially with AIDS orphans who may remain with a backlog in their normal growth. With all these negative implications and undesirable effects, the researcher has identified a need to investigate the influence of orphanhood (caused by HIV/AIDS) on the psychological development of the adolescent, and more especially into the development of an

adolescent life-world. Research will be undertaken to determine the psychological effects on the life-world of an adolescent orphaned by AIDS.

### **1.2.3 Research question**

After interrogating the research problem using the preliminary literature study, it became apparent that the influence of orphanhood through AIDS on the life-world of adolescents needs to be examined. It is evident that adolescents who became orphans through AIDS experience problems that are unique to their situation (Essex et al, 2002: 668; Karim & Karim, 2005: 356; Rotheram-Borus et al, 2005: 219). These problems (see 1.2.2) may have an influence on the development of adolescents. Thus, the research question for this study can be formulated as follows:

- What is the nature of the life-world of adolescents orphaned by AIDS?

## **1.3 AIM AND OBJECTIVES OF THE STUDY**

The principal aim of this study is to gain a comprehensive understanding of the nature of the life-world and the possible influence of orphanhood especially due to HIV/AIDS, on the adolescent life-world. This will be done by means of a literature study, as well as an empirical investigation.

The overarching aim of the study can be subdivided into the following specific goals:

- Reviewing previous studies and literature on the phenomenon HIV/AIDS and issues regarding HIV/AIDS.
- Investigating the impact of HIV/AIDS on the family, society, welfare, economy and education.
- Studying the impact of HIV/AIDS on the emotional, physical, social, cognitive, spiritual and conative development of the adolescent.
- Attending to the vulnerability of the affected adolescents.
- Exploring feelings and thoughts of adolescents orphaned by HIV/AIDS.

- Collecting first-hand information by means of an empirical investigation from orphans on how they experience, comprehend and perceive the influence of their parents' illness and death on their life-world.

## **1.4 DEFINITION AND EXPLANATION OF IMPORTANT CONCEPTS**

To enhance a common understanding in the discussion, it is necessary that the concepts occurring frequently in this dissertation be defined before commencing with the literature study. These principal concepts are: HIV, AIDS, adolescence, orphan, life world and stigma.

### **1.4.1 HIV: AIDS originator**

Human Immunodeficiency Virus (HIV) is a virus that enters a person's body and attacks the immune system (Frost, 2001: 30). It is itself not considered to be a disease, but it enables diseases to attack a human body freely. HIV does this by killing an important kind of blood cell, the CD4 T lymphocyte, or T-cell. These T-cells are the quarterbacks of the immune system. It takes a few years for the virus to make the human body completely weak (Frost, 2001: 30). HIV can be present in the body usually for two to twelve years, but sometimes more years without producing any outward signs of illness. The period can be less for people who do not have a balanced diet or whose life pattern is without proper prevention of re-infection.

Over time, if HIV is not combated, HIV infection can weaken the immune system to a point where the system has difficulty fighting off certain infections. People infected with HIV develop symptoms that may be caused by other or less serious conditions. These conditions include enlarged lymph glands, tiredness, fever, loss of appetite and weight, diarrhoea, yeast infections of the mouth and vagina, and night sweats (World Book Encyclopedia, 1996: 179). According to Frost (2001: 30) and Soul City (2003: 2), among others, HIV is a germ or virus that causes AIDS. HIV is believed to be the principal cause of AIDS by destroying the immune system's ability to function properly.

### **1.4.2 AIDS: HIV after-effect**

When people with HIV attain infections or when their CD4 T-cell levels get too low, they contract Acquired Immune Deficiency Syndrome (AIDS). When HIV-related infections are contracted and the symptoms do not disappear, it could indicate AIDS (Frost, 2001: 30). AIDS strikes a person, on average, normally from five to ten years after being infected by HIV (Hope, 1999: 1).

AIDS sufferers die from normally minor illnesses (World Book Encyclopedia, 1996: 193). AIDS-related diseases include pneumonia; yeast infections of the oesophagus; tuberculosis; eye infection that can cause blindness; wasting (a patient becomes very thin because the body cannot absorb nutrients and rebuild itself); brain and nervous system infections; and some cancers. These illnesses are called opportunistic diseases since they take advantage of damage to the immune system (Frost, 2001: 30; World Book Encyclopedia, 1996: 179). At present, AIDS is still a fatal disease.

### **1.4.3 Adolescence**

Gillis (1994: 69) defines adolescence as the stage of a young person over the age of ten years searching for identity. He explains this stage as a psychological moratorium or ‘time out’. This stage, according to Gillis, allows the growing person ample opportunities to experiment freely with different roles, attitudes and personalities, prior to making important life decisions.

Louw et al (1998: 384); and Bamhart and Bamhart (1976: 29) define the term ‘adolescent’ as the developmental stage between childhood and adulthood. In line with this view, Barnhart (1995: 27) defines adolescence as the period of growth from childhood to adulthood. Louw et al (1998: 384) explain that the term ‘adolescence’ is derived from the Latin verb 'adolescere' which means “to grow to adulthood”. They see adolescence as a separate developmental stage which begins at any age from eleven to thirteen years, and could end at the age between seventeen and twenty years.

The World Book Encyclopedia (1996: 51, 52) explains an adolescent as a person who is no longer a child but not yet an adult. The book explains that adolescence roughly corresponds to the teenage years. It may be viewed as a stage of psychological development.

Peterson (1991: 419) elucidates that in essence, the adolescence concept entails the psychological developments related to the physical growth processes defined by the term 'puberty'. Puberty is described as the dramatic sexual development brought about by a sudden increase in the activity of certain glands, more especially the hypothalamus, the pineal, the pituitary and the sex glands (World Book Encyclopedia, 1996: 52).

In this study the adolescents under investigation are those persons still at school, and in the developmental stage of a human being from the age of thirteen to eighteen years.

#### **1.4.4 AIDS orphan**

According to Subbarao and Coury (2004: 3), an orphan usually refers to a child under the age of eighteen years whose mother or father or both of them are dead. The orphan is referred to as the maternal orphan if only the mother is dead. If only the father is dead, the orphan is referred to as the paternal orphan. If both parents are dead the orphan is referred to as the double orphan. This study does not differentiate the cases of being an orphan. That is, maternal orphan, paternal orphan and double orphan are all considered as orphans.

The study also considers the definition given by Singhal and Howard (2003: 15) who define an AIDS orphan as any child under the age of eighteen who has lost one or both parents to AIDS.

In consolidating the focus of the study and the definitions provided, the study shall consider the relevant AIDS orphans to be a person of any age from thirteen years to eighteen years of whose one or both parents died of AIDS.

#### **1.4.5 Life-world**

Life-world refers to everything that has meaning for the child, not only his/her geographical world but all his/her relationships with objects, ideas, people and even himself/herself. These relationships may be interdependent and interactive; they are always dynamic and ever increasing and changing (Van den Aardweg & Van den Aardweg, 1993: 143).

#### **1.4.6 Stigma**

Crandall (1991: 166) defines stigma as a mark, physical or symbolic, which elicits shame in the person with the mark and allows treating the bearer in a demonised fashion. The mark aims to disgrace the person. Stigmatised diseases, such as AIDS, are associated with shame and embarrassment. As a result, AIDS orphans may be perceived to be non-persons (Gillmore & Sommerville, 1994: 52).

Green (1995: 118) believes that stigmatisation could result in reduced confidence, where stigma is an undesirable or discrediting attribute that an individual possesses, resulting in the reduction of the person from a whole and usual person, to a tainted and discounted human being.

A person who is stigmatised is a person whose social identity or membership in some category calls into questions his or her full humanity. Such a person is often devalued, spoiled or flawed in the eyes of others. Stigmatisation arises from the perception that the person has violated shared sets of attitudes, beliefs and values (Brown et al, 2004: 52). Stigma revolves around the construction of blame and is fuelled by the need to punish others (Brown et al, 2004: 48). Joffe explains that stigma helps people to cope by projecting their worst fears onto identifiable out-groups. It serves as an identity protective function by increasing feelings of comfort and security and a sense of personal invulnerability to threats and dangers that might otherwise appear overwhelming (Campbell et al, 2005: 811). Blaming others to justify stigmatisation is based on an inflated fear of contracting the disease.

Negative meanings are associated with the disease and those who contract it, in order to allay anxiety about risk of infection. According to Alonzo and Reynolds (1995: 304), blaming is an emotional response to danger that people use to distance themselves from risk. People project negative effects they wish to avoid by blaming others for risking infection. It helps create a false sense of control, safety and immunity from danger. This illusion of control is achieved through attributing risk behaviour to others. Stereotypes deny that they are personally likely to be infected or blame others for contracting the disease (Link & Phelan, 2001: 365). Stigma may be deeply rooted in the domains of gender, race, ethnicity, class, sexuality and cultural constructions of diseases (Valdiserri, 2002: 3). In this study, it is entrenched in the fact that AIDS leads to orphanhood. It occurs within a particular socio-political historical context where it acquires social meaning influenced by social discourses to justify excluding AIDS orphans. Brown et al (2004: 9), as well as Parker and Aggleton (2003: 23), view stigma as a social process used as a powerful tool of social control. They argue that it is linked to societal power structures to reinforce existing social inequalities.

Stigma can be applied to marginalise, reject, blame, discredit, devalue, exclude and exercise power over those showing certain characteristics. It is an ideology explaining people's inferiority and accounting for the danger that they pose to others. Further, it is constructed to justify the stigma and the implementation of discriminatory practices towards those people. For the young person stigma can be overbearing, especially when it is continual, for it affects the life-world of an adolescent negatively.

## **1.5 RESEARCH DESIGN AND METHOD**

This study employs the qualitative approach to explore the life-world of an adolescent AIDS orphan of school-going ages from 13 to 18 years. According to Fouché and Delport (2002: 79), qualitative research aims at understanding social life and the meanings that people attach to everyday life. This type of research involves identifying the participants' beliefs and values that underlie the phenomena.

Fouché and Delport (2002:79) further describe the qualitative researcher as one whose concern is comprehension rather than explanation; naturalistic observation rather than controlled measurement. Subjective exploration of reality is made from the perspective of an insider. For these beneficial rationales, the researcher opted for the qualitative method. Learners in selected schools of Ratanda Township in Heidelberg in Gauteng Province of South Africa were decided on to fulfil this purpose.

An outline of the literature study, empirical research and the research instruments used to conduct this study (see chapter 3 for a more detailed discussion) will be furnished in this section.

### **1.5.1 Literature study**

According to Schmidt (2000: 48) a literature study compares research with previous research undertaken. It can be used to shed light on knowledge that already exists, on the theoretical paradigms that have already been constructed and on research that has already been done. It can be used to identify gaps, current differences and even conflicts within the field of study. As such it is employed to analyse and assess previous research studies. In this way it ascertains the value and relevance of the research while pointing out gaps or differences in the literature on the topic studied.

The literature study wants to determine the theoretical aspects of the impact of HIV/AIDS on adolescents. It exposes the theory pertaining to the life-world of AIDS orphaned adolescents. Many sources including published books, journal articles and electronic sources available on the Internet were utilized to obtain an understanding of the nature and meaning of the problem.

### **1.5.2 Empirical research**

The life-world of an adolescent can best be described in qualitative terms. Therefore, in order to understand the life-world of the orphaned adolescents it is necessary that questions be posed to provide qualitative descriptions. The empirical study was

intended to determine the nature of the life-world of the school going AIDS orphaned adolescents.

### **1.5.2.1 Ethical measures**

Paramount to this research is ensuring the well-being of the child which must be kept in mind at all times. It was ensured that the process of conducting this research in no way put the child at risk. The researcher informed all the participants that participation was voluntary and that the data would be used for research purpose only (see chapter 3).

### **1.5.2.2 Measures to ensure trustworthiness**

In this study, trustworthiness was ascertained utilizing Guba's model on trustworthiness (Krefting 1991:215). Guba identifies four criteria of trustworthiness:

- *Truth value* – Are the results of a true reflection of reality? This is about how credible the findings are.
- *Consistency* – Would similar studies yield the same results? Consistency is ensured if the findings of the research can be transferable to another setting or group of people.
- *Applicability* – Can the research results be applied to other settings? The researcher is reasonably sure that the findings would be replicable if the study were conducted with the same participants in the same context.
- *Neutrality* – This is the extent to which the researcher succeeds in bracketing personal biases.

### **1.5.2.3 Method**

The following methods were used to obtain the information required for this study:

- **Sampling**

For the purpose of this study, a type of non-probability sampling, i.e. purposive sampling, was used. Singleton (in De Vos et al, 2002: 207) explains purposive sampling as based entirely on the judgment of the researcher, in that a sample is chosen on the basis of what the researcher thinks to be an average person. The strategy is to select units that are judged to be typical of the population under investigation. This enables the researcher to identify information-rich participants who share commonality. The participants in this study were AIDS orphans of from 13 to 18 years of age, from Ratanda primary and secondary schools (see chapter 3).

- **Data collection**

In-depth semi-structured phenomenological interviews were conducted to collect data. De Vos et al (1998: 298) describe semi-structured interviewing as “social interaction between equals in order to obtain research relevant information. Qualitative researchers direct interviews by means of a definite research agenda in order to gain information on the specific phenomenon under study”. The researcher made use of this process because of her interest in the participants’ perceptions of AIDS orphans and their needs. For the interview, the researcher prepared a set of predetermined questions on an interview schedule. This was used as a guideline for the researcher to gain information that was relevant for the topic (see Chapter 3).

- **Data analysis**

Qualitative data analysis is a non-numeric analytical procedure to examine the meaning of people’s words and actions (Maykut & Morehouse, 1994: 121). In this study, the qualitative content analysis method will be used to analyse data. According to Weber (1990: 27), content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding. Content analysis reduces data to manageable proportions. It involves dividing data into categories and themes emerging and recurring, and determining meaningful ones. Once

themes have emerged, data relating to a particular theme is clustered under that theme (Neuman, 1997: 42). (See Chapter 3 for further details).

## **1.6 DEMARCATON OF THE STUDY**

This study entails a qualitative investigation of the life-world of aids orphans. It involved a group of 12 learners who are AIDS orphans. The research was undertaken in the Ratanda township schools in Heidelberg, Gauteng Province. Only learners aged 13 to 18 years were investigated.

## **1.7 THE RESEARCH LAYOUT**

Chapter one provides the problem analysis, objectives of the study, explains the statement of the problem, explanation of the main concepts and methodology are stated and discussed.

Chapter two provides the relevant information about the impact of orphanhood through AIDS on the life-world of adolescents.

Chapter three presents the research design and methodology.

Chapter four presents the study findings.

Chapter five presents a summary and the conclusions, and then proceeds to derive the recommendations.

## **1.8 CONCLUSION**

This chapter provided a background to the study, stated the research problem and described the study aim and objectives. The terms utilized in the dissertation were

defined and the research methodology and scope/demarcation of the study were briefly clarified. Lastly, the study layout was provided. The next chapter will focus on the literature review concerning the impact of orphanhood through AIDS on the life-world of an adolescent.

## **CHAPTER TWO:**

### **THE IMPACT OF HIV/AIDS ON ADOLESCENCES' LIFE-WORLD**

#### **2.1 INTRODUCTON**

The consequences of the escalation of AIDS are serious for society at large, but especially for children. In South Africa, many children are left parentless by AIDS. These orphans and the communities to which they belong face a profound financial and emotional burden. HIV/AIDS may cause extreme poverty, lack of social networks, as well as lack of sufficient psychological and economical support. There is a concern that AIDS orphans might come to constitute a “lost generation” of young people who have been marginalized and excluded for much of their lives. The fact that children orphaned by AIDS are more vulnerable than children orphaned in other ways will become clear in the detailed discussion of the implications on the life-world of orphans.

This chapter examines the possible impact of orphanhood by AIDS on the life-world of an adolescent. Various issues discussed include HIV/AIDS, adolescence, orphanhood, family, and physical; cognitive; social; emotional; and conative and spiritual impact. This chapter further considers the life-world and charactersitics of 13 to 18 year-old adolescents and the manner in which these persons are affected by AIDS orphanhood.

#### **2.2 ORPHANHOOD BY HIV/AIDS**

Becoming an AIDS orphan is rarely a sudden switch in roles. It is a protracted and painful process. The slowness and anguish mainly centres on the loss of a parent, and also the long term care which that parent's failing health may require. Children who care for ailing adults before the latter dies of AIDS may experience as if the world has gone seriously awry (Barnett & Whiteside 2002: 206).

In the following subsections the extent of HIV/AIDS orphanhood and the difficulties faced by AIDS orphans is reviewed under the following topics: orphan phenomenon, poverty, the family and vulnerability to HIV/AIDS.

### **2.2.1 Orphan phenomenon**

The HIV/AIDS epidemic in South Africa places a significant strain on societal resources. One of the most devastating social consequences of HIV/AIDS is the extensive number of children orphaned by AIDS illnesses. The HIV/AIDS epidemic is most likely to attack people in their productive years as caregivers (Christiansen, 2005: 173). As a result of the increase in orphaned children and escalating mortality rates among people in the productive years, an increase demand is placed on the community for adequate childcare.

UNAIDS defines orphans as children below the age of 15 who have lost either their mother or both their mother and father (Whiteside & Sunter, 2000: 80) These definitions contain two important elements and distinctions: on one hand, there is a child who may have lost one or both parents: on the other, there is an emphasis on maternal orphanhood, as it leaves infants in a particularly vulnerable situation.

Before 2002, UNAIDS defined AIDS orphans as children who before the age of 15 have lost their mother to AIDS. In 2002, UNAIDS changed their definition of AIDS orphans to children who before the age of 15 have lost either one or both parents to AIDS (Avert, 2003: 13). The definition was reviewed because if one parent is infected, it is likely the other will be infected too and will also die soon. Furthermore, the exclusion of paternal orphans was seen as a great oversight, bearing in mind the large amount of absentee mothers for paternal orphans (Barnett & Whiteside, 2002: 200).

The increase in AIDS orphaning is one of the major challenges facing many countries. According to North-West Population Trends and Development Report-HIV/AIDS Perspective (2004: 37) one of the worst consequences of AIDS is that large numbers of children are orphaned as a result of parents dying from AIDS. Some of these children

are HIV-positive themselves, having been infected by their mothers either at birth or through breast milk.

Pridmore et al. (2006: 11) and Kauffman (2004: 17) reports that Sub-Saharan Africa appears to be the most affected with AIDS casualties. He continues that South Africa has the largest absolute number of people living with HIV compared to any nation. According to UNAIDS (2004: 2) some countries have yet to experience the full impact of parental deaths as a result of AIDS. Barnett and Whiteside (2002: 210) state that there will be a boom in South Africa's AIDS orphan population during the next decade. South Africa currently has a high proportion of children who are not continuously cared for by either parents, and very high rates of care by aunts and grandmothers (Whiteside & Sunter, 2002: 2). Presently there are about 250 000 AIDS orphans in South Africa. This number is expected to rise to 1.5 million by 2010. In addition, the Medical Research Council estimates that unless significant action is taken, by 2015, about 15% of all children under the age of 15 will be orphaned.

Karim and Karim (2005: 351) again, predict that the numbers of orphans resulting from AIDS-related deaths in South Africa are predicted to rise to over five million by the year 2014. This approximation makes effective community responses to the epidemic essential. However, this estimate is based on the current pattern of AIDS death rates if the spread is not stopped. The HIV/AIDS epidemic represents an unprecedented health, economic and social threat that dramatically increases the nature and magnitude of people's risks and vulnerability (Subbarao & Coury, 2004: 7).

Pharoah (2004: 93) proclaims the crisis of orphans and other children made vulnerable by HIV/AIDS as a catastrophe of unprecedented scale and vast damage. Pharoah further envisages that the AIDS orphan dilemma will evolve into a large-scale; long-term; chronic problem that will extend through at least the first half of the 21<sup>st</sup> century. Accordingly, orphanhood is likely to have major implications for both the children left orphaned and vulnerable by HIV/AIDS and the society in which these orphans live.

Social scientists predict that HIV/AIDS will result in increased insecurity, with future generations being brought up with limited social attachment to significant others and

major impairments to their cognitive, social behaviour and moral functioning (Pharoah, 2004: 94). Hope (1999: 93) substantiates that many family structures are being disrupted by this illness. He emphasizes that there are growing numbers of children that are being born with HIV infection. According to Hope, many children are being orphaned by the premature death of their mothers or both parents from AIDS.

### **2.2.2 Poverty**

The deadly disease of AIDS is tragically affecting, specifically, the lives of children (Hope, 1999: 93; Foster et al, 2005: 93). Its bearing harms children at all levels of society. It creates and exacerbates physical poverty. The pandemic further leads to emotional, psychological and social poverty in the lives of many children (Pharoah, 2004: 94). Pharoah asserts that orphanhood has a severe effect on the life-world of these children, especially when they lose their parents.

According to UNAIDS (1999: 2), the onset of AIDS in many developing countries marked the beginning of a transition from poverty to complete destitution. Factors such as loss of households' incomes, the cost of treating HIV-related illnesses, and funeral expenses frequently leave orphaned children destitute. The reality is most bleak in the worst affected areas of Sub-Saharan Africa, where over 50% of the population live below the poverty line. Of the many vulnerable members of society, young people who have lost one or both parents are among the most exposed of all. Orphans generally are thought to run a greater risk of being malnourished and stunted, than children with parents who receive the care they need. In communities where adult deaths are high, food supplies often dwindle. Many face the constant difficulties of living with poverty and deprivation (UNAIDS, 2004: 3).

Resources available in AIDS-affected households decrease because of the deaths of productive members and the increased demands for household expenditure, medicine and food. Barnett and Whiteside (2002: 201-202) state that AIDS-affected households tend to be poorer, with smaller disposable incomes, thus less food is consumed. It is hardly surprising that children in these households are usually less well-nourished and have a greater chance of being wasted.

Children whose parents have already died are disadvantaged in numerous and often devastating ways. Many of the orphans live where poverty, malnutrition, and lack of water, sanitation, and basic health and education services already make children's lives risky. In addition, the trauma of witnessing the illness and death of their parents worsens their situation. They must grapple with the stigma and discrimination so often associated with AIDS, which often deprives them of basic social services. Many people are unable to take on the responsibilities of extra children because they are already strained (Barnett & Whiteside, 2002: 212; UNAIDS, 2004: 3).

According to Germann (2005: 70), a harsh consequence of HIV/AIDS for orphans and other children made vulnerable by AIDS is being refused space in schools and thus excluded from education. These orphans may face poverty-related exclusion and enforced exclusion (for example, enforced by relatives, refused by schools, or voluntary exclusion). When foster households are faced with limited resources, they tend to favour their biological children over foster ones and use the resources for them instead of the foster children. In the end, this denies the orphans proper access to basic needs such as education, health care and nutrition (Subbarao & Coury 2004: 15).

The South African experience in schools is that AIDS children are often excluded with poor excuses made by schools authorities such as being incapable of aiding the HIV-infected children. Barring may start occurring when the child whose parent is sick with AIDS has to receive continuous care. Such a child may have to stop attending school as caregiver for the ailing parent. Exclusion may also occur as a result of AIDS orphans being stigmatised and fearing to attend school. Therefore, the prohibiting of AIDS orphans from education may be enforced directly or indirectly.

Children from families with a parent who is sick with HIV/AIDS or related illnesses may be taken out of school because the families cannot afford the school costs (Poku, 2005: 96). The school turnout of children affected by HIV/AIDS drop or deteriorates because of financial problems caused by lack of income. Further, there is usually an increase of expenditure for medication, health services and other basic needs (Pharoah, 2004: 11). It is problematic for the children in the households headed by children to

continue schooling. The oldest one would try to earn money to keep their younger siblings in school (Poku, 2005: 96). Lack of finances often subjects the AIDS orphans to be at school without food. They are also unable to pay school fees.

Many children fear leaving their HIV/AIDS infected parents alone to attend school (Foster et al, 2005: 100-101). Their fear can also result in generalized or separation anxiety, including refusal to go to school. They recount terrifying experiences in which they come home from school to find their parents hospitalised. As a result they feel responsible for their parent's well-being. They feel they have to be at home in case their parent needs help.

According to Pharoah (2004: 11), children affected by HIV/AIDS may receive poor care and supervision at home. They may also suffer from malnutrition and may lack access to available wealth services. The social safety system has weakened because of HIV/AIDS and its resulting poverty. The affected children often end up in highly vulnerable situations (Germann 2005: 67). Generally, households affected by HIV/AIDS or with orphan members are more impoverished than others. The unmeasured consequences for the AIDS orphan generation are of great concern.

### **2.2.3 The family**

The final and most terrible effect of AIDS is death. Death of a child is painful for the surviving family members and parents. However, the death of a parent leaving children behind opens a gap in the support system of a family. A spouse may be left grieving while children and the entire family lack a breadwinner. Therefore, other dreadful AIDS impacts are widowhood and orphanhood.

Every individual is an important member and component of a family. As such, the adolescent constitutes an essential part of the family unit. When AIDS strikes a family member with death, individual members of the family are affected. Apart from the individuals in the family being affected when a family member dies of AIDS, the entire family is affected.

HIV is having a major impact on individuals and on community structures such as the family. Traditionally, the family is a fundamental unit of any society. The family is a major structure responsible for the health and well-being of its members. Family provides for its members. It nurtures, cares and socializes these members, and affords them physical, economic, emotional, social, cultural and spiritual security (Hope, 1999: 96; Karim & Karim, 2005: 352).

The African family's structure includes the nuclear family, the extended family and the clan (Spitzer, 1997: 24). The family is an intimate domestic group made up of people related to one another by bonds of blood and/or legal ties. It has been a very resilient social unit that has survived and adapted through time (Crewe, 2003: 14). The crucial factor to the sustenance of the African family in the midst of AIDS is the social structure. However, as the HIV/AIDS epidemic progress, this family community is being steadily eroded and destroyed by AIDS (Karim & Karim, 2005: 351).

The role of the head of the household in particular, is undergoing radical alteration (Karim & Karim, 2005: 352). In the 20<sup>th</sup> century, South African women were often effective single parents as fathers were working away from home. This may still be the case in many instances, but the so-called 'skipped generation' households, headed by a grandmother, have become increasingly common. The traditional absorption of orphans by the extended family is no longer a customary tendency because already strained communities struggle to cope with the increased burdens of HIV and AIDS (Karim & Karim, 2005: 351; Pharoah, 2004: 68-70). The AIDS epidemic in Africa, therefore, with its concomitant trauma of orphanhood, must be viewed as a problem of the family (Hope, 1999: 96).

The AIDS impact on the functioning of families affects the household's composition, economic decisions, social interaction and access to health care. According to Crewe (2003: 15), the family is associated with a series of assumptions and idealizations about the nature of the identities individuals should assume. The identities are the family life-cycle as a child, as a teenager or youth, as an adult, and as an 'elderly' person. The social belief is that children should live innocently, be nurtured and mostly untouched by responsibilities. However, the impact of HIV/AIDS compels children to battle with

adult responsibilities. Further, poverty makes it difficult for children to live an unmediated, idealized childhood.

Crewe (2003: 16) enlightens that HIV/AIDS causes a life of grinding poverty, loss of economic power, the burden of rearing the small offspring of sick or deceased adults, and a reduction in social status. Hope (1999: 98) and Poku (2005: 88) point out that AIDS-related poverty causes a degradation of the family's immediate environment. This multiplies health risks and reduces access to health care. The epidemic causes an increase of dying parents. It also increases the families headed by grandparents and others by children (Karim & Karim, 2005: 352).

#### **2.2.3.1 *Extended family***

If fortunate, grandparents may help to postpone orphaned adolescents' metamorphosis to become instant breadwinners. Hope (1999: 96) declares that the cohort of households headed by grandparents is often referred to as the grandmothers' syndrome. Through the syndrome, the elderly women have to attend to the ailing parents initially, and thereafter care for the children left behind. These elderly women nurture the children. They provide care and support; pay school fees; buy uniforms; and supply food and shelter for the grandchildren. Only when the grandmothers die, the children are left as orphans. It may then become the responsibility of the extended family to give assistance and support (Karim & Karim, 2005: 353; Pharoah, 2004: 67; Poku, 2005: 92).

Traditionally, when African children lose both parents, extended families absorb them and care for them. These are usually the aunts, uncles, cousins and grandparents (Karim & Karim, 2005: 353). However, HIV/AIDS induces new pressures on many families that increasingly find it difficult to cope (Poku, 2005: 97). According to Karim and Karim (2005: 353) and Pharoah (2004: 67), the general dictum is that there is no such thing as an orphan in Africa. This dictum was destroyed by the epidemic as the relatives are unable or no longer available to cope with the rising number of AIDS orphans. The capacity and resources are now stretched to breaking point, and those providing the necessary care, are in many cases already impoverished (Barnett & Whiteside, 2002: 199).

Relatives who care for orphaned children may suffer financial loss, emotional trauma, problems of housing, overcrowding and high stress levels. This can negatively affect the existing children in the households (Hope, 1999: 96; Karim & Karim, 2005: 353; Pharoah, 2004: 67, Poku, 2005: 92). Generally though, the extended families of the current era do not automatically take this responsibility. In this case, the children become responsible for themselves and other (younger) children.

#### ***2.2.3.2 Child-headed family***

The influences of Western lifestyles have ensured that a new type of African ‘family structure’ emerged. This includes failing to care for the children of the deceased’ relatives. An increasingly familiar pattern is the child-headed household where the eldest children look after younger siblings (Hope, 1999: 96; Karim & Karim, 2005: 353; Poku, 2005: 92, Pridmore et al, 2006: 11). Child-headed households exist because no relatives are left to care for the children. In other cases, the surviving relative is too burdened to care adequately for the children they have inherited. For the orphaned child, this is often a premature entrance to the burdens of adulthood, all without the rights and privileges, or the strengths associated with adult status (Barnett & Whiteside, 2002: 206).

Children often find themselves taking the role of a father or mother or both, doing the housework, looking after siblings and caring for ill or dying parent(s). Many children heading the households have little options except to seek work to support themselves and their younger siblings (Poku, 2005: 96). In other cases, the young orphan must leave school as the family struggle to make a living.

According to Karim and Karim (2005: 361) the child-headed household phenomenon exacts negative pressure on AIDS orphans. The children miss out on their childhood assuming adult roles at a young age when they are too young for adult responsibilities. The executive director of UNAIDS, Peter Piot notes (in Boseley, 2002: 1) that the impact of HIV/AIDS on the lives of children is the most tragic aspect of the illness. With the loss of their parent(s), these children have few resources to help them deal with

bereavement and its repercussions. In many countries there is nothing in place to assist AIDS orphans to effectively deal with the trauma brought about by the extended illness and death of the parents due to HIV/AIDS. They face the reality of family disruptions, and major problems with the loss of financial and emotional support and possible separation from siblings.

The AIDS pandemic is depleting entire communities of their most valuable resources, i.e. people. It kills men and women in their most productive years and in their reproductive years. It also deprives children of their basic needs and exposes them to extreme vulnerability. It leads to reduced power and denies them rights to life as youths. Further, AIDS increases the risk that orphaned children may end up on the street. In this way they may be sexually abused and also infected with HIV or caught up in criminal activities (Subbarao & Coury, 2004: 7). Growing under conditions of orphanhood and child-headed households raise serious concerns about the quality of life of these children and the prospect that they themselves will experience HIV infection at the time they are sexually active.

The medical treatment of AIDS leads to economic distress due to its chronic nature and expensive medication. Hope (1999: 93) indicates that poverty and economic distress in African countries have furthermore contributed greatly to the rapid spread of HIV/AIDS. The socio-economic impact of AIDS has far-reaching consequences. By selectively taking the lives of people who are in their most economically productive age groups (fifteen to forty-five), the pandemic is creating immense vulnerability to the victims. The two groups of survivors, who are highly vulnerable, are the elderly and young orphans who have lost their primary source of support (Hope, 1999: 97).

#### **2.2.4 Vulnerability to HIV/AIDS**

Adolescents affected by AIDS are vulnerability to various negative consequences. Possible outcomes include illiteracy, increased poverty, child labour, unemployment, sexual abuse, exploitation and HIV infection (Germann 2005: 73). Germann points out that the children from households that are affected by AIDS often lack adult protection from sexual exploitation by relatives or by males known to them in their communities.

These children's susceptibility to such exploitation increases during parental illness or after parental death because of the increased frequency of male visitors to affected households.

The death of a parent from AIDS leaves children without parental support. Thus the AIDS epidemic may force many young adolescents into drastically premature parenting roles. This deprives the young ones of their childhood. It thrust upon them the responsibilities of caregivers and guardians for their younger siblings (Karim & Karim 2005: 361). The movement of children out of their parental homes reduces community-based child protection mechanisms and increases the children's continued vulnerability (Germann 2005: 74). The reasons for these adolescents to become sexually active were economic needs, peer pressure, discovery, lack of parental guidance and supervision, as well as rape by relatives, teachers, or strangers in market places. As a result, young girls may become pregnant and therefore young, unemployed and illiterate mothers.

Many orphans may be aware of the existence of AIDS, but only few know how to protect themselves from HIV. Children nursing parents with a high viral load often lack the necessary skills or equipment to avoid infection (Germann, 2005: 92). The risk of contracting HIV is further increased by overcrowding and lack of sanitation. Germann concludes that if people do not prevent HIV infection, many more children may become vulnerable. He identifies orphans as a pool of at-risk children. He also states that the youth have an increased likelihood to contribute to the HIV/AIDS pandemic.

Adolescents often experience emotions of anger, resentment, hopelessness and depression. Losing a parent heightens those feelings. "They may seem to be coping, but at the same time they can experience depression, hopelessness and increased vulnerability", reports Children on the Brink (2004: 3). This can lead to a sense of alienation, desperation, risk-taking behaviour, and withdrawal. These behaviours can in turn further increase vulnerability to HIV (Youth Net, 2005: 5). Orphans become weaker being orphaned, and also increase in number. They may struggle to sleep; their immune system may decline and they may also exhibit anger and sadness.

To summarize this section, HIV/AIDS caused multiple deaths in thousands of households in South Africa, leaving behind to fend for themselves the most vulnerable - children and the elderly. Social roles have changed and children may be forced to take on adult responsibilities. Poverty is often a result of the loss of an income in the family, resulting in food shortages and stinting. Orphaned children often have inadequate clothing and may have limited access to schooling in some instances.

In many cases, traditional mechanisms for assisting orphans have been overwhelmed by the scale and scope of the problems. Communities have coped with children who have lost their parents in past generations. The expanding scale of the problems caused by HIV/AIDS and the weakening of community mechanisms render many previously successful mechanisms helpless. Child-headed households often are the result of an overburdened extended family network. The economic implications that taking in orphaned children may have for households often cause relatives to shy away from their responsibilities.

HIV/AIDS is an illness of loss, with severe consequences for all affected family members. One specific group of children, namely adolescents, appears to be particularly vulnerable, especially their life-world because of the role changes, stigma and expectations created by the death of their caregivers. It is in the light of this observation that the researcher will discuss the adolescent development phase in the next subsections in order to be able to fully understand the complex interplay between "normal adolescent development" and experiences very specific to the life-world of adolescent affected by HIV/AIDS related conditions. The physical, cognitive, psychosocial and spiritual impact of orphanhood in adolescents will also be discussed in the following sections.

### **2.3 ADOLESCENCE**

The life-world of adolescent orphans, who have lost a parent or parents because of HIV/AIDS, should be seen within the context of the developmental phase they are in. Adolescence in itself is a phase in which the young person has partially matured physically and cognitively, but still needs the involvement of parents or caregivers.

Some characteristics of adolescence, like uncertainty, fluctuating self-esteem, self-centeredness and incomplete reasoning ability, affects the ability of the adolescent to cope with normal teenage stresses. The researcher and several sources of literature therefore expect the impact of HIV/AIDS related conditions to have long-term implications for the young persons of South Africa.

A central factor in adolescents' health and well-being is their interaction with their environment, with people and settings in their daily lives. Call, Riedel & Hein referred to by Griesel-Roux (2004: 51) further state that adolescents play an active role in the selection of and interaction with the contexts of their immediate environment.

They have very little influence, however, over the macro-societal changes that impact on their health and well-being. It is vital to understand how these contextual changes, such as the HIV/AIDS pandemic, will influence the opportunities and choices that adolescents can make (Griesel-Roux, 2004: 51). Adolescence is a critical developmental period with long-term implications for the health and well-being of the individual and for society as a whole. Adolescence is the first phase of life requiring mature patterns of functioning. It differs in essence from earlier years in the nature of the challenges encountered and the capacity of the individual to respond effectively to these challenges. Failure to cope effectively with the challenges of adolescence may have negative consequences for subsequent development (Griesel-Roux, 2004: 51).

In the next subsections, adolescence will be discussed against the background of the preceding developmental phases in order to place it into perspective. The interaction between physical and mental development and the subsequent social development are also described in order to fully understand the normal developmental tasks of the adolescent.

### **2.3.1 The nature of adolescence**

Despite the familiarity of the term adolescent in everyday language, it proves remarkably difficult to define precisely what this stage entails. Adolescence is understood to be the stage of growth from an early age to adulthood. It is also defined as a dynamic period of change. These changes are not simply within the young person, but

within his or her complete social structure (Durkin, 1995: 506). However, delineating adolescence with chronological criteria fails to take account of the maturational differences among young people. One person of 12 years may be more advance in physical development than another of 14; one girl may start her periods at the age of 11, while another may be in her mid-teens or older before this major physical change comes about. There is no known physiological criterion that correlate perfectly with age, and no psychological state that is universally recognized as the marker of adolescence (Durkin, 1995: 506; Louw et al; 1998: 388).

It is equally difficult to determine when adolescence ends. Societal and economic criterions, like financial independence, achieving academic qualifications or age of majority can be seen as some form of boundary, but it is not applicable in every society (Durkin, 1995: 507, Louw, et al, 1998: 388). Adolescence thus appears as a developmental stage between 17 and 21years. The differences in age definition can be attributed to differences in cultural perceptions, rather than the use of chronological age. It is more accurate to say that adolescence starts at the onset of puberty and ends when the child attains his or her culturally appropriate social roles, psychological characteristic and legal age of majority (Louw et al, 1998: 388).

Blume and Zembar (2007: 3) describe adolescence as a complex and contradictory stage of development. In terms of behaviour, this stage encompasses many opposites and extremes in the adolescent person. Adolescence is also identified with obvious biological changes. Adolescents are growing children who must deal with maturing bodies that are subject to sudden bursts of growth and hormonal changes that affect their moods and the range of feelings they experience (Morgan, 1990: 91; Perschy, 2004: 3; Silverman, 2000: 55). According to Silverman (2000: 55) and Perschy (2004: 3), the stage of adolescence resembles a storm. It can be an uneven and choppy time since there is not always a synchronicity among cognitive, emotional and physical development. According to Morgan (1990: 92), for many youth the transition from childhood to adulthood is marked by an upsurge in depressive feelings, uncertainty about the future, and an increased risk of psychological disorder. Morgan (1990: 94) indicates that adolescents are often idealistic, critical, argumentative, self-conscious, self-centred, and hypocritical and subject to extreme emotional swings.

### **2.3.2 Physical maturation**

The onset of adolescence is heralded by two significant changes in development. First, children change dramatically in size and shape as they enter the adolescent growth spurt. They also reach puberty, the point in life when an individual reaches sexual maturity and becomes capable of producing a child (Schaffer, 2002: 159). The term ‘growth spurt’ describes the rapid acceleration in height and weight that marks the beginning of adolescence. In addition to growing taller and heavier, the body assumes an adult-like appearance during adolescent growth spurt. Perhaps the most noticeable changes are the appearance of breasts and a widening of the hips for girls, and broadening of the shoulders for boys. Facial features also assume adult proportions as the forehead protrudes, the nose and jaw becomes more prominent, and the lips enlarge (Schaffer, 2002: 160).

Adolescence is probably experienced as the most embarrassing time for many in the life cycle. At a time when teenagers are acutely self-conscious and unsure, certain that everyone is watching their every move; their bodies are constantly betraying them. Boys’ voices squeak unexpectedly, usually embarrassing them at a time when they are putting forth their best efforts to seem matured. Girls worry about the size of their breasts and about the possibility of getting menstrual blood in their clothes (Gething, Papalia & Wendkos Olde, 1999: 328).

The physical changes of adolescence appear to be more stressful for girls, as it is negatively associated with blood and discomfort. The impact of biological timing on psychology appears not to be the only causing factor when a girl develops problems in their adolescent years. It should only be seen as part of the developing person’s social context. Girls who grow up in conditions of protracted family stress may experience behavioural and psychological problems. Attachment insecurity is more likely under these conditions, and there is an association between family problems and developmental difficulties. Stressors could well have somatic consequences predisposing girls to internalizing disorders and hence lowered metabolism. Lowered

metabolism leads to weight gain, and weight gain leads to early menarche (Durkin, 1995: 509).

The biological changes of adolescence contribute in emotional, social and cognitive changes. These changes will henceforth be reviewed.

### **2.3.3 Cognitive development**

The life-world of adolescents orphaned by AIDS is closely linked to the manner in which they are able to understand the world around them and how they perceive themselves.

The development of the thinking and organizing systems of the brain is defined as cognitive development. The maturation of the nervous system (for example, the development of the senses of sight and hearing – eye-hand co-ordination and balance are particularly important in this regard) and the endocrine glands are prerequisites for cognitive development (Gouws & Kruger, 1994: 47). Some of the main domains of cognitive development are language, problem solving, memory development and reasoning (Gillis, 1999: 73; Lythgoe, 2004: 1).

A consequence of cognitive development is the development of the moral orientation of the adolescent. Kohlberg (in Herbert, 1993: 294) argues that moral development progress through a number of levels, with different stages at each level. At the lower stages, moral reasoning is characterized by its concrete nature and egocentricity. At the higher stages, moral reasoning is guided by abstract notions such as ‘justice’ and ‘rights’ and is much more social in orientation (Herbert, 1993: 294).

### **2.3.4 Psychosocial development**

This aspect appears to be the single most important developmental factor influencing the life-world of adolescents orphaned by AIDS, as it closely relates to the manner in which they perceive the world and themselves.

There are five recognized psychosocial issues that teens deal with during their adolescent years as developmental task. These include:

- Establishment of an identity
- Establishment of autonomy
- Establishment of intimacy
- Becoming comfortable with one's sexuality
- Achievement and career choice (Huebner, 2000: 2)

#### **2.3.4.1 Establishment of an identity**

The establishment of a clear sense of identity is one of the major tasks of adolescence (Herbert, 1993: 172). The search for information about the self and the future is associated with major new developments in reasoning capacity. It is generally agreed that the developments in reasoning capacity in adolescence enables the young person to think about the phenomena of the material and social world and his or her place in it. One of the consequences of the cognitive advances of adolescence is the greater capacity to focus on the self, but this pre-occupation can introduce its own distortions. Adolescents often enter a new phase of egocentrism (Durkin, 1995: 512).

Elkind proposes that adolescents are prone to entertain feelings of an imaginary audience, a sense of being on show, with the rest of the world focused on their thoughts, feelings and behaviour. Adolescent preoccupation with style of dress and physical structure are examples of the effects of the “imaginary audience”. Although the content may be banal, the process is important, because it suggests the manner in which anticipation of other’s scrutiny can influence social behaviour (Durkin, 1995: 512). As such, a conclusion can be drawn that the life-world of adolescents affected by the illness and death of a parent because of HIV/AIDS may also be magnified by the “imaginary audience” phenomenon.

A closely related feature of adolescences’ thoughts proposed by Elkind is the personal fable. The young person is so preoccupied with his or her own thoughts and significance to an imaginary audience that he or she develops a sense of personal uniqueness and

permanence. This gives rise to the egocentric belief that one is above many of the world's risks (I am different) (Durkin, 1995: 512).

As children develop, they not only increasingly understand themselves and construct more intricate self-portraits, but they also begin to evaluate the qualities that they perceive themselves to have. This evaluative aspect of self is called self-esteem. Children with high self-esteem are satisfied with the type of person they are. Children with low self-esteem view the self in a less favourable light. These children usually choose to dwell on perceived inadequacies rather than on any strength they may happen to display (Schaffer, 2002: 428).

Cognitive processes do not occur independently from the social context. Some of the institutions transitions of early adolescence, especially the shift to high school, appear to have unsettling consequences for at least some young people's self-awareness during this period. There are definite inconsistencies between how they see themselves and how they feel others see them. It appears as if major transitions temporarily can disrupt a child's organization of self-concept (Durkin, 1995: 13).

The multiple stresses of early adolescence have consequences for how the young person considers her/himself, particularly concerning their self-esteem. The change to high school is associated with changes in the self-concept and self-esteem; it drops substantially around this time especially in girls. Many girls are experiencing not only the institutional shift but also the onset of menstruation and accompanying physical changes together with changing parental and peer attitudes (Durkin, 1995: 513).

Erikson (Meyer et. Al, 1997: 219) views adolescence as a critical period for the formation of a sense of personal identity. He represents this stage as involving a conflict between the need to attain a sense of self-integration (ego identity) and the need to meet the diffuse external demands of society and determining one's own place within it (identity diffusion). It is only through the resolution of these uncertainties that an individual becomes equipped for the next stage of human development, attaining the psychological intimacy of adult relationships (Durkin, 1995: 516).

### **2.3.4.2 Establishment of autonomy**

Another developmental task is the establishment of autonomy from parents or primary caregivers. Parental acceptance of the process of separation with the simultaneous provision of information regarding physical changes and sexual behaviour, and the gradual loosening of parental control as the young person emerges as a peer, are all conducive to congruent development. Adolescents may portray a veneer of total independence, but they nonetheless need appropriate parental nurturance, friendship and fun (Dwivedi, 1999: 69).

During adolescence the amount of influence that parents and peers have, varies. Teenagers choose their friends based on similarities, specifically shared values and attitudes. Therefore, parents need to be aware that their values and attitudes will have a strong effect on which their child becomes friends with. In addition, parents who show higher levels of interest, understanding and helpfulness have been proven to have greater influence (Atwater, quoted by Stanton, 2004: 1).

Durkin (1999: 521) is of the opinion that the achievement of autonomy is one of the major developmental tasks of adolescence. Durkin suggests that the parent-adolescent conflicts reflect the parties' different roles in the family and their attempts to coordinate conflicting social cognitive perspectives.

During periods of stress, there is an intensified need to obtain proximity and soothing body contact with attachment figures. Even adults faced with the stress of loss, or disaster, seek the proximity of familiar persons or environment. If the attachment figure becomes rejecting, or is physically or emotionally unavailable and the degree and duration of distress is too intense in a vulnerable individual, the attachment behaviours can become indiscriminate, disguised or disorganized. This leads to a state of emotional confusion, where the desire to 'reach out and touch someone' can become so intense that it can become aggressive, violent, hurtful and even fatal (Dwivedi, 1999: 75).

The removal of healthy guidelines at an early stage will preclude the development of personal identity and a healthy internalized value structure (Dwivedi, 1999: 69). Stanton

(2004: 3) is of the opinion that family support is crucial to adolescents. Those who do not have a high level of support from their parents are more likely to become involved in undesirable behaviours.

It can thus be concluded that early, forced independence as in the case of adolescents orphaned by HIV/AIDS, may have a severe impact on their psychosocial development.

#### **2.3.4.3 Establishment of intimacy**

According to Durkin (1999: 528), the group formations and social identities of adolescents are forming part of the identity-seeking behaviour of adolescents. Strong identification with a particular group or sub-culture, distinguished by its differences from the adult society and other adolescents is common.

Peers do become increasingly important to adolescents, and they spend more time with them. The increasing involvement of adolescents in peer relationships does not displace the relationship with parents, though it does serve different functions and does present its own challenges (Durkin, 1999: 530). Adolescents spend more of their time in peer groups than with parents or adults. However, it is only until mid or late adolescence that friendship takes the role of intimate relationships. Cognitive changes now enable adolescents to see situations from another person's point of view. Because of these developments, individuals experience a greater need for intimacy and increase capacity to enter close relationships or peer groups (Castrogiovanni, 2004: 1).

Peers are more likely to be the source of advice in relation to peer group problems. Even so, parents are by no means out of the picture. They are still included as important intimate relationships, and remain the principal reference point for advice on major decisions (Durkin, 1999: 529).

Adolescence is a phase of life during which biology remits powerful messages (Durkin, 1999: 544). The biological upheaval of puberty brings about major hormonal changes. One transformation is increased production of androgens in boys and girls, which dramatically increases one's sex drive. The new urges the adolescents feel make them

increasingly aware of their own sexuality. That is an aspect of development that greatly influences their self-concepts. One major hurdle adolescents' face is figuring out how to properly manage and express their sexual feelings, an issue that is heavily influenced by the social and cultural context in which they live (Schaffer, 2002: 166).

In summary; adolescence is seen as a period in which physical, sexual, psychological and cognitive changes combine in social demands. Parents, family and friends play a major role in the adolescent's successful achievement of the developmental tasks. Their bodies undergo rapid adjustments, which in turn influence the way in which they perceive themselves and the world around them.

It is especially in this period of puberty where the young person needs guidance and reassurance. Premature withdrawal or loss of parental or family support will cause stress in the life of the adolescent. It thus becomes clear from this subsection, that the absence of a parental figure, grief and abnormal stress would present a major obstacle in the achievement of developmental tasks in the life of an adolescent orphaned by HIV/AIDS.

The following sections are devoted to the physical, cognitive, social, psychological and conative and spiritual influences of AIDS orphanhood on the life-world of an adolescent.

## **2.4 PHYSICAL IMPACT**

As professed through preceding research, the HIV/AIDS pandemic creates a number of social problems of which the resulting poverty is surely the most devastating for a child's development. AIDS affects children long before their parents pass away. The toll taken by the disease begins during the period of illness, continues through death and bereavement and will likely persist into adulthood if adequate support and protection are lacking. The absence of parental protection and care, combined with many other factors, has contributed significantly to the increase of deaths of children. This is likely to continue for the long term if nothing is done about the current situation (UNAIDS, 2002: 2).

Orphans generally are often thought to run a risk of being malnourished, stunted or not receiving the care they need than children who have parent to look after them. In communities where adult deaths are high, food supplies often dwindle. Many face the constant difficulties of living with poverty and deprivation (UNAIDS, 2004: 3; UNICEF, 2003: 2). Barnett and Whiteside (2002: 201-202) found that AIDS-affected households tend to be poorer, consume less food and have smaller incomes. It is hardly surprising that children in these households are usually less well-nourished and have a greater chance of being wasted. The resources that were available in AIDS-affected households decrease because of the death of productive members and the demands for household expenditure increase, for an example medicine and food (Barnett & Whiteside, 2002: 218-219).

Barnett and Whiteside furthermore maintain that without adequate material, economic and nutritional support, the children are vulnerable to malnutrition and infectious diseases. It is likely that orphans, who have been deprived proper nutrition when their parents were sick and dying of AIDS, may be stunted (Barnett & Whiteside 2002: 201). Stunting is caused by poor nutrition over an extended period. Stunting not only leads to poor physical conditions, but also compromised immune systems and mental functioning. The children's ability to benefit from education and to function socially and economically later in their lives is subsequently also affected.

According to Pharoah (2004: 68), children living with HIV-positive family members may suffer particularly poor health because the opportunistic viral and bacterial infections are able to spread rapidly through groups of co-habiting, immunologically compromised people. Adolescents living in affected households are more often exposed to opportunistic infections such as tuberculosis and pneumonia (Pharoah, 2004: 68). Francis (2003: 123) affirms this observation and asserts that children living in HIV-affected families are more exposed to opportunistic infections, disease-related poverty and psychosocial stressors. These have impacts on care giving practices as well as the child's well-being. Often, the primary caregivers who are infected are sporadically or terminally ill, while others such as grandparents are at times absent to attend community and family functions (Germann, 2005: 68). Children in such households are thus less

likely to get the medical attention they need and desire. This is another reason why these children are more likely to suffer repeated infections (Giese, 2002: 61). Adolescent orphans are not only more vulnerable to HIV infections themselves, but also more exposed to other sexually transmitted infections and unintended pregnancies because of absent parental guidance (Youth Net, 2005: 94).

Foster et al (2005: 106-107) state that it is likely that psychological disturbances in children be associated with parental HIV illness or death when they also have other chronic stress. The chronic stressors are poverty, exposure to violence, previous loss, or a history of other deaths of loved ones. Many chronic stressors have been found to affect children's mental health. When children are exposed to two or more stressors, they found to be four times more likely to demonstrate psychiatric disorder (Foster et al, 2005: 106-107).

Grief is another chronic stressor which affects adolescents in many ways. The emotional energy required during grieving often tires those in grief, both physically and emotionally. Adolescents' distress may manifest itself through a range of physical behaviour, including tiredness, lethargic behaviour, chronic tearfulness, no appetite or excessive eating and change in sleeping patterns (Louw et al, 2001: 20).

The physical impact thus may include malnourishment, stunted growth, child labour, physical poverty, premature parenting, vulnerability to sex and to being sex objects, and struggle to fall asleep, among others (Barnett & Whiteside, 2002: 212; Demmer, 2004: 40; Van Dyk, 2001: 334-335).

## **2.5 COGNITIVE IMPACT**

The effects that parental illness and death have on a child's mental health and ability to cope are complex and depend on the child's developmental stage, resilience, and culture (Germann, 2005: 19). Cognition refers to the process of coming to know and understand; the process of encoding, storing, processing, and retrieving information. It is generally associated with the question of "what" (e.g. what happened, what is going

on now, what is the meaning of that information). Cognitive life-world is the learners' appraisal of their academic competence (Taylor, Morley & Barton, 2007: 87). This reflects the extent to which learners believe in their intellectual abilities, performance and interest in school in general. According to Huitt (1998: 3), cognitive life-world relates to how well people learn. Cognitions are the basis for plans and ensuing action. Its importance can be inferred from strategies that are cognitively available to adolescents who encounter stress in vulnerable areas of interaction (Bosman, 1990: 47). Usually, stress causes loss of concentration and interest. This may lead to reduced performance for the AIDS orphans in school. Accordingly, the cognitive structural limitations of children narrow their fields of awareness and constrict their ability to understand themselves. Adolescents' greater cognitive maturity enables them to be aware of a broader array of experiences and to conceptualise themselves from perspectives unavailable to the pre-adolescent.

The trauma and psychological distress that HIV/AIDS causes orphans and other affected children can impair their capacity to learn. Foster et al (2005: 71) avers that there are four ways that HIV/AIDS can interfere with what school can do for orphans and HIV-affected children. First, these children can be prevented from attending school. Secondly, their ability to learn may be compromised if they do attend. Thirdly, their learning needs may be impeded by the ability of the school to address the plight of these orphans. One can thus conclude that HIV/AIDS generates special psychological and emotional needs.

The HIV/AIDS traumatised children's capacity to learn is imperilled by a combination of poor nutrition, hunger, trauma, and emotional distress in poor households further impoverished by AIDS. These factors have a negative effect on learning capacity. They impair thinking, ability to attend to environmental stimuli and performance on school tests when taken together (Foster et al, 2005: 75). The distress and barriers to learning faced by these children affected by AIDS is escalated by schoolmates who tease them and a lack of response by the school to their emotional needs.

According to Van Dyk (2001: 153), there is evidence that emotional difficulties suffered by AIDS orphans combined with social stigma tend to block their ability to learn at school. The infected or affected learners suffer from stigmatization that causes deep

wounds, which leads the orphans to question their efficacy and worth as persons. These affected adolescents may suffer from depression, unresolved anger, resentment, fears, worries and anxieties, which can cause behavioural problems such as excessive attention seeking, class disruption, fighting, ignoring school work, and risky sexual activity (Foster et al, 2005: 81). Coombe (2002: 20) states that the epidemic has made emotional and psychological trauma part of the educational environment. HIV/AIDS brings to school “increasing numbers of intellectually, socially and psychologically dysfunctional learners”. These pupils often have little ability or motivation to contribute to their educational development.

AIDS orphans experience stressors capable of producing symptoms such as confusion, anxiety, depression and behavioural disorders associated with adapting to social change. These symptoms may cause learning problems associated with lack of concentration in class, poor attention span, memory loss, inability to think clearly, lack of motivation, decrease interest in school and other activities, low self-esteem and consequent bad performance (Foster et al, 1997: 397; Louw et al, 2001: 20).

## **2.6 SOCIAL IMPACT**

The death of parents due to HIV/AIDS implies that the surviving children face deteriorating family conditions that hinder personal development and successful integration into society as productive citizens. Like all children, AIDS orphans need to acquire the cultural values and behavioural norms necessary for their integration into society. Lack of supervision, neglect from relatives and the community may have as a result early marriage, especially for girls. Child prostitution also surfaces in order to meet basic needs as well as drug and alcohol abuse. Children lack a role model to whom they can relate for support and advice. This may have long-term consequences when they as adults have to provide care for their own children. Children may also grow up with a fear for their own physical safety. The lack of security felt by girlchild caregivers may lead to their attachment to older men in the community, which makes them vulnerable to exploitation (Barnett & Whiteside, 2002: 212; Demmer, 2004: 40; Foster 1997: 10).

Webb (1997: 4) has generated evidence from Uganda that indicates that sexual activity usually starts earlier in orphans than in non-orphans. Inevitably, children also suffer from lack of guidance and affection which is vital for social and emotional development. This degenerates into delinquent behaviour for survival. They are subject to less stringent socialization pressures, which could lead to deviancy and vulnerability to HIV infection.

When parents die, children often act out their feelings of anger resentment in anti-social behaviour towards their guardians, teachers and friends. Some may be angry with God. Furthermore, stigma and stress may cause the AIDS orphans to dissociate from the usual mix with other children. Teachers also report that these orphans are apathetic, listless, excessively reserved or inappropriately serious in the classroom, and do not play and laugh as much as other children. They are often unable to mix freely with their schoolmates (Foster et al, 2005: 76). Louw et al (2001: 19) observe that if an adolescent is absent from school due to illness, hospitalization or because she/he has taken the role of the head of the household, isolation and rejection from the peer group could appear. The learner could also feel that she/he has nothing in common with other children. The important influence of a positive peer group will then be lost. The learner relationship with peers could be affected by behavioural problems; i.e. anger and aggression (Louw et al, 2001: 19).

Parental loss at early childhood creates negative social pressures. Children may find their way into the streets where they are exposed to a number of risks. Barnett and Whiteside (2002: 212) as well as UNICEF (2003: 2-3) argue that AIDS orphanhood will lead to a rise in the number of children living on the street, begging, scavenging and descending into a life of crime.

The social impact of HIV/AIDS often causes family and community paralysis, as per Germann (2005: 38). This is linked to the fear of the unknown, particularly where traditional coping patterns cannot address the orphanage problem. Fear is subsequently followed by stigmatisation of affected individuals and families. Further, there is also a stern shortage of prime-age adults because of AIDS deaths. It also has a dreadful consequence for the next generation because life expectancy has declined as a result.

Germann (2005: 68) indicates that the consequences of this shortage of prime-age adults is that instead of children being cared for by uncles and aunts, some orphans grow up in households headed by elderly or adolescent caregivers.

According to UNICEF (2003: 2) and UNAIDS (2004: 3), depression and alienation become common. Depression is regarded as the most general reaction to the announcement of a parent's HIV infection, AIDS and death. The social features are withdrawal, avoiding social contacts and outings, moodiness, feelings of guilt and inadequacy. Other aspects are loss of interest in activities that were previously enjoyed, becoming silent and not wanting to participate in social interactions, talk about suicide, thoughts about death and not responding to empathy and comfort of others.

## **2.7 PSYCHOLOGICAL IMPACT**

The specific behavioural and psychological impact of parental HIV/AIDS on children is a neglected area of research, but it is clear that the course of the disease can be remarkably disruptive to children. A study conducted by Oxford University and Cape Town Child Welfare in 2007 found that children orphaned by AIDS had significantly poorer psychological health and suffered levels of post-traumatic stress, than other children in the study.

Affected and infected orphaned children are often traumatized and suffer a variety of psychological reactions to parental illness and death (Pharoah, 2004: 11). Barnett and Whiteside (2002: 206) maintain that in taking care of the dying parent, the roles of parent and child become reversed as the young children take on the responsibility of supporting and caring for their parents. This, accordingly, has serious consequences for a child's life-world (Hope, 1999: 98).

Children tend to experience trauma and stress related to caring for terminally ill parents long before a parent dies (Germann, 2005: 71; Pharoah, 2004: 2; Poku, 2005: 94). Lack of consistent nurture has developmental after-effects for children. According to Karim and Karim (2005: 354), the psychological impact of having no parents may increase the likelihood of orphans ending up as school dropouts and street children. Orphans may

engage in anti-social behaviour and extended social instability that affect their life-world. According to Poku (2005: 94), orphans may feel abandoned and become susceptible to sexual abuse because of emotional turmoil of seeing a dying parent. They may feel helpless and stop caring for themselves as they used to.

Pharoah (2004: 2) further points out that reduced financial and emotional resources available to children causes trauma and alienation. It affectively limits the realistic aspirations of the affected youngsters. There is a general fear that the AIDS epidemic may create generations of disenfranchised and potentially dysfunctional youth who lack the socialisation necessary for constructive social engagement. Uncared for AIDS orphans may also behave irrationally due to stress and lack of guidance. Pharoah (2004: 6) assumes that children raised in difficult circumstances almost always suffer negative psychological, social and behavioural outcomes. Bauman and Germann (2005: 71) and Foster et al (2005: 93) construe that the emotional demands of HIV/AIDS on children's lives are heartbreaking.

### **2.7.1 Trauma and stress during parental illness**

According to Adams and Deveau (1995: 8), terminal illness experience is replete by different physical and psychosocial losses that have already occurred. The losses must usually be mourned. However, to mourn for altered relationships, lifestyles and dreams for the future will never be realised. A parent in poor health and often in emotional turmoil is usually unable to provide a stable emotional environment for the children (Sander & McCarty, 2005: 203). The prolonged period of illness also creates an emotional roller-coaster for these children (Germann 2005: 237). When a parent has a chronic and ultimately terminal illness, children's basic needs for love, trust, security and parenting tend to be threatened. Generally, under these conditions, the affected children do not usually experience normal childhood (Foster et al, 2005: 96). Germann (2005: 237) states that literature suggests that children who experience disruption to family routine and security that follows parental HIV infection tend to suffer a chronic trauma.

These children may suffer lingering emotional problems from attending to dying parents and seeing parents die (Hunter & Williamson, 2002: 17). Parents with AIDS display physical changes that are noticeable, AIDS' clinical course is marked by characteristics that can be enormously disturbing and disruptive to children, including marked physical changes (such as dramatic wasting and disfiguring dermatological disorders), behavioural and cognitive changes (such as AIDS Encephalopathy and AIDS Dementia complex, which can result in deterioration of short-term memory, mutism and loss of ability to walk, swallow or void), and often severe debilitation (Geballe & Gruendel, 1998: 50). Neurological complications and deterioration in mental functioning of the parent can be extremely disturbing to children (Van Dyk, 2003: 261). The impact of watching a parent or sibling die can be devastating and stress; depression; and hopelessness are common emotional effects (Smart et al, 2001: 93).

Another upsetting and disrupting factor for children in an affected household is the appearance and intervention of strangers, like home-based care workers or nurses in their homes, as the parent may become sicker. Even scarier to children is the discovery that a parent 'disappeared' to hospital (Geballe & Gruendel, 1998: 50).

For many AIDS patients, these physical and behavioural problems can result in the loss of a job and income, and eventually a home (Geballe & Gruendel, 1998: 50; Foster et al, 2005: 98). The child, who counts on the parent for stability and predictability, then tends to become unpredictable and erratic (Foster et al, 2005: 98). As stated by Foster et al (2005: 98), studies in the United States suggest that, compared to children with healthy parents, children of parents with HIV/AIDS are likely to be depressed and anxious. This internalises problems and causes more behavioural and conduct troubles ("externalizing" problems), as well as poor social competence and less ability to pay attention.

According to Germann (2005: 237), people are superstitious about death – if one speaks about death, one invites it into the home. The consequent silence leaves children confused, scared and anxious as the child becomes aware that the parent is terminally ill. The adult does not even attempt to explain what is happening, or why it is

happening. This compels children to gather information regarding their own parent's health status among neighbours and friends.

Germann (2005: 238) further holds that heads of the child-headed household are the children who were the primary caregivers during parental illness. This forces them to drop out of school, forget about recreation and other 'normal' activities and become responsible carers. This puts serious additional stressors on the children and increases risk of childhood, and probably later adult mental illness.

Parental chronic or terminal illnesses tend to stress the children immensely. It also increases psychological risk for children. The children's concern about the poor health of their parents bring about anxiety; fear of abandonment and chronic insecurity. Sometimes children resent their parent's illness. Their resentment can also lead to guilty feelings, anger and a low tolerance for frustration (Foster et al, 2005: 96). Child recovery depends on factors such as family and other social support as well as individual personal resilience.

Foster et al (2005: 98) state that many parents with AIDS are depressed. Depressive symptoms may be worsened as the implications of their HIV/AIDS become clearer and often have serious effects on the children. Some parents lose their cognitive abilities and no longer recognise their loved ones (Corr & Corr, 1996: 56). Children and adolescents of depressed mothers, compared with peers whose mothers are not depressed, have higher rates of psychological diagnoses, have poorer behavioural, emotional, and academic functioning, and have lower self-esteem (Foster et al, 2005: 99). Further, affected adolescents may experience depression, substance abuse and conduct disorder.

HIV/AIDS induces change in family roles to accommodate the parent's needs for care. When a parent is chronically ill, children and adolescents often assume special responsibilities. In extreme circumstances, children become parentified in which they assume the parent's role in the family system. They tend to care for their younger siblings and maintain the household (Foster et al, 2005: 101). Sometimes parentification includes the role reversal of the child acting as parent to the parent, and sometimes as parent to siblings. Role reversal may be a problem when caring for siblings if it is

prolonged or intense, for it may inhibit development and result in guilt and lowered self-esteem.

There is a disturbing lack of norms, and often an absence of clearly specified expectations and responsibilities (Adams & Deveau, 1995: 15). Children who provide personal care and emotional support to ill parents may have concerns about the future, have a limited social life, and lack parenting themselves. The possible outcomes will be inhibited development and depression (Foster et al, 2005: 102). The parental unavailability may mean that the child fails to develop cognitive, academic, social, or emotional skills (Foster et al, 2005: 103).

Children witness their loved one's progressive debilitation without power to stem its inevitable course (Adams & Deveau, 1995: 15). There is difficulty, especially for a child, in adapting to a condition of having a loved family member in the house, who is slowly dying. However, when the ailing one lives for an extended period of time, some adaptation may occur. This life demands for major re-adaptations and investments of self. These often constitute psychological conflicts, emotional exhaustion, physical debilitation and social isolation.

### **2.7.2 Stigma and shame**

The word stigma is derived from the Greek, meaning a tattoo or brand used in identifying a criminal or slave (Brookes & Gilmour, 2000: 541). According to them, stigma is synonymous with disgrace and being reproached, dishonour and shamed. Stigma has been a pervasive dimension of HIV/AIDS since the beginning of the pandemic. When it is identified in a person, it is predominantly associated with socially ostracised groups (Karim & Karim, 2005: 354). The psychological impact of stigmatization, as noted by Krauss, Godfrey, O'Day, Freidin and Kaplan (in Lyon & D'Angelo, 2006: 86) is that a person's identity formation depends greatly on how people react to him/her.

According to an international AIDS charity, (Avert, 2007: 11), children orphaned by HIV/AIDS often have to deal with the associated stigmatization by society due to their

association with AIDS. This is further exacerbated by the trauma of grieving for the loss of their parents. Avert notes that the distress and social isolation felt by these orphans is compounded by shame, fear and rejection.

When the affected families force the epidemic out of sight, HIV/AIDS-related stigma and discrimination obstruct prevention and treatment. It therefore contaminates the resolution of personal grief (Karim & Karim, 2005: 354). HIV/AIDS-related stigma comes from the powerful combination of shame and fear. Shame takes place because the sex and drug injections that transmit HIV are surrounded by taboo and moral judgments. Fear occurs because AIDS is relatively new and perceived wrongly, and considered deadly. Responding to AIDS with blame and abuse of people living with AIDS force the epidemic details to be kept underground. This enhances the ideal conditions in which HIV can spread and flourish. An effective way of making progress against the epidemic is to replace shame with solidarity, and fear with hope. Moreover, knowledge is a useful starting point.

Orphans endure exhaustion and stress from worry, stigmatization and insecurity because they assume that they too are infected with HIV or that their families were disgraced by the virus (Pharoah, 2004: 12). Families therefore, keep the presence of AIDS a secret because of the stigma, which causes them to feel ashamed, thus creating stress. They pile secrecy for religious or cultural reasons to avoid problems or to shield children from rejection by their peers, but it still affects the children (Adams & Deveau, 1995: 121).

Stigma leads to discrimination (Karim & Karim, 2005: 354-355). Discrimination against HIV-positive people hinges on various unsubstantiated perceptions and misconceptions of gender, race, socio-economic status, HIV-positive status and sexuality. Stigma also induces violations of human rights which in turn legitimises stigmas and perpetuates the cycle. Fear of stigma can produce acute anxiety about sharing one's HIV status with others and non-disclosure for HIV-positive people.

Children who survive family members who have died of AIDS tend to feel uncertain and shamed. Many others feel humiliated by a parent's AIDS diagnosis (Corr & Corr,

1996: 55). In schools, other children may tease the affected ones about their parents' illness to provoke fights. School staff may also be guilty of prejudices. Corr and Corr (1996: 55) and Foster et al (2005: 106) state that bereavement and successful grieving may be complicated by the effects of social stigma associated with HIV/AIDS disease. This stigma is a significant phase of the illness and death. It results in increased social stress related to issues of disclosure for children (Corr & Corr, 1996: 55). HIV infected individuals have greater internalised feelings of being stigmatised than those reflected in society. Many complex factors contribute to the internalised feelings. Failure of not having lived up to parental expectations and the guilt at having brought shame on one's family is another factor.

It is clear that a stigma impacts not only on the life-world of a person stigmatized, but also on the entire community. Since stigma encourages isolation and secrecy, this inhibits the open discussion of HIV.

### **2.7.3 Psychological coping upon parental death**

Death in the family constitutes the process of permanent and irreversible death of psychosocial aspects of themselves, their lives, their family and their world (Adams & Deveau, 1995: 15). The death of a parent is a devastating and powerful risk factor for psychosocial problems in children compared to children with living parents. Children who have experienced a parent's death have a higher rate of psychiatric disorder, more symptoms of depression, anxiety, withdrawal, attention problems, negative behaviour, suicidal ideation, school performance declines in the short term, and their disinterest in school persist (Foster et al, 2005: 99).

The family is an interactional unit in which members influence one another. It exists in a type of homeostatic balance. The loss of a significant person can imbalance this system (Worden, 1996: 34). In particular, the death of a parent has an impact on the entire family system. The role played by that person becomes a vacuum in the family. The loss of a highly valued person, such as a parent, is an excruciating experience. Adapting to such a loss, facing it and then finding a way to move on, is one of life's greatest challenges (Germann, 2005: 240). According to Murthy and Smith (2005: 3),

the death of a parent or other significant person during one's adolescence carries consequences that may last a lifetime.

Children of HIV parents have to come to terms with the pending loss of a parent. The loss of a parent has a distinctive effect on a child. Rotheram-Borus et al (2005: 221) explored the impact of HIV-related parental death on 414 adolescents. These researchers found that bereaved children had significantly more emotional distress, negative life events and contact with the criminal system than non-bereaved children. Furthermore, depressive symptoms, passive problem solving and risky sexual behaviour were found by these researchers to increase following the passing of a parent.

It is therefore imperative that children in the conditions where HIV/AIDS occur in the family obtain support from the time the ailment is detected up to a point where the child matures enough to care for himself/herself.

#### **2.7.4 Bereavement and grief in adolescents**

There is substantial evidence that survivors of HIV/AIDS are at risk of prolonged grief and psychiatric problems as they mourn an AIDS death (Demmer, 2004: 40). The terms grief, mourning and bereaved are defined differently. Murthy and Smith (2005: 3) define grief as one's personal reactions and coping mechanisms to a death. It is one's feelings, thoughts, actions and physical responses. Murthy and Smith reiterate that the reaction to grief is often referred to as mourning. According Goodkin et al (in Demmer, 2004: 40), grief refers to the emotional component of the bereavement process and includes specific emotions and behaviours in response to the loss, such as depression, loneliness, yearning and searching for the deceased. Grief work is the process and work of adjusting to irrevocably lost objects, relationships and dream. It is a universal and normal response to loss and it affects all aspects of an individual's life - physical, emotional, cognitive, behavioural as well as spiritual. Grief is a highly individualized experience and is influenced by a variety of factors including its context and concurrent stressors. It encompasses a broad range of societal, cultural and religious rituals for addressing death and its aftermath. Germann (2005: 239) defines a bereaved as one who has experienced a personal death or the state of being deprived of something.

Because of the unique situation of a loss due to AIDS, survivors are at an increased risk of complicated bereavement. Research has shown that individuals who grieve an AIDS death confront a host of issues that may complicate the grieving process. These issues include the nature of the disease, HIV status of the bereaved, multiple losses and inadequate support due to the social stigma associated with AIDS (Maasen in Demmer, 2004: 40).

Murthy and Smith (2005: 3) state that after the death of parents who had AIDS, the adolescents often find that their daily lives change in a number of ways. Adolescents' roles in the families are affected. Their relationships with their friends and other peers are dented. Many bereaved children have short-term problems at school. However, this could continue for a long-time scale, especially when it is not addressed urgently (Holland, 2001: 37). They have a normal tendency to experience academic difficulty and behaviour problems that place them at an increased risk of dropping out of school. In other words, grieving fundamentally affects smooth transition to adulthood (Holland, 2001: 37; Murthy & Smith, 2005: 4). Germann (2005: 240) suggests that the loss of a significant person during adolescence may delay the successful completion of the key developmental tasks associated with this period.

Experiences of parental loss or parental rejection were found to increase an adolescent's vulnerability to depression. Adolescence by nature is also a time in which one is likely to encounter loss, failure and rejection as well as accumulated negative events and hassles. Social alienation, excessive demands, romantic concerns, decisions about the future, loneliness and unpopularity and money concerns are some of the issues deeply affecting the adolescent. They are relatively inexperienced in dealing with these kinds of stressors. They may not have developed strategies for controlling the feelings of grief or discouragement that are likely to accompany stressful life events. Feelings of depression can also be intensified by accompanying hormonal changes. Young people may become convinced of their worthlessness, and this distortion of thought may lead them toward social withdrawal or self-destructive actions (Neuman & Neuman, 1997: 657).

Adolescents' reactions to bereavement fall into three broad categories, that is behavioural, emotional and physical and encompass problems experienced both inside and outside the family. Some reactions of children and adolescents in grief similar to those of adults are rejection, guilt, shame, anger and blame and so on (Dwivedi, 1999: 185). Most grief reactions in children are largely dictate by the child's developmental stage and may be carried forward into the next developmental phase as an unresolved issue.

Adolescents may feel angry and may express this through violence and aggression towards other children or adults. Others can become withdrawn or anxious about the changes that are occurring around them and may have eating and sleeping problems. They can become very anxious and insecure about their own health and that of other family members and wonder if they too might die. Some of these problems can lead to fantasies, which completely overtake their normal functioning and can inhibit their social and emotional development (Dwivedi, 1999: 186).

As a result, depressive reactions with suicidal features may appear. Alternatively, where nurturance has been withdrawn in earlier life, sex is often used as a means of securing nurturance. Inner controls are not established and rebellion, poor hygiene, avoidance behaviours or the development of dependencies on others, sex or substances may be noted. Psychiatric problems may be seen to continue, with a concomitant failure to establish intimate relationships by the use of a self-centred type lifestyle (Dwivedi, 1999: 70).

At times, some adults responsible for children are unable to recognize the cognitive, emotional and behavioural limitations of adolescents. Thus, adults may make demands upon adolescent children that may be beyond their cognitive, emotional and behavioural capacity. Being overburden with responsibilities beyond one's emotional capacity or the experience of neglect and abuse by the caregivers on whom one depends for emotional growth can have seriously emotionally damaging consequences (Dwivedi, 1999: 75).

This may be especially true in the case of an adolescent faced with the illness and death of parents because of HIV/AIDS. Some adolescents who head the household become

“super children” becoming involved in adult decision-making and household chores in order to avoid painful feelings. Other adolescents may distance themselves from the painful home environment by running away or staying out of the house for extended periods during the day (Foster, 1997: 11).

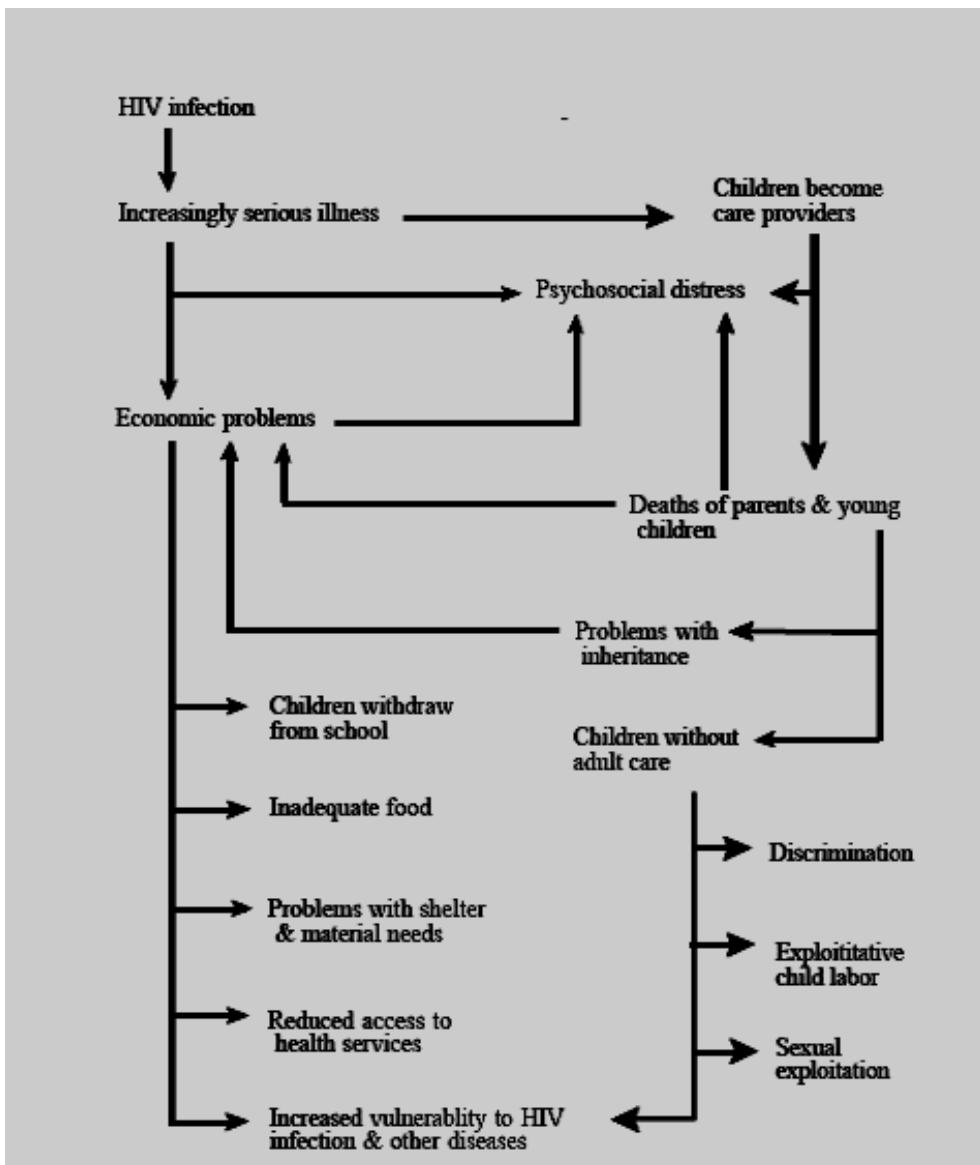
According to Karim and Karim (2005: 357), those who are bereaved are left unsupported to confront a bewilderment of pain, sadness and fear, avoidance by family and friends and by community or social networks. This is so mainly because of the generalized uncertainty and fears that shroud an AIDS-related death. Karim and Karim continue that the increasing burdens of HIV/AIDS are made worse by the stigma attached to the disease. This, among other effects, prevents those affected from being able to grieve openly. As a result, the traditional rituals associated with the death are often no longer followed as whole community denies the existence of HIV (Karim & Karim, 2005: 351).

The disenfranchised grief tends to occur when the loss is not socially recognized. The reason is that certain dimensions of that loss, for the griever, stigma and isolation intensify when they block public recognition of an AIDS-related death. AIDS deaths are not socially sanctioned, are left cloaked in a kind of invisibility and the unrecognised hidden grief can ironically intensify the loss and subvert the grieving. Grief is displaced by embarrassment and shame. The circle of silence, stigma and disenfranchised loss is perpetuated and intensified (Karim & Karim 2005: 357).

Children affected by HIV/AIDS can exhibit the full range of emotional and behavioural symptoms. These may include poor school performance or attendance, conflicted or absent peer relationships, conduct problems and depression and anxiety (Dwivedi, 1999: 186; Foster et al, 2005: 112; Holland, 2001: 37-38). For some, the type and severity of symptoms suggest a diagnosable psychiatric disorder. Others are episodic, short-term or mild and with even greater risk to themselves of HIV infection and social instability (Karim & Karim 2005: 354; Gerwirtz & Gossart-Walker, 2000: 315). Many children with psychological symptoms go untreated because it is difficult to recognize symptoms in children (Foster et al 2005: 112; Griesel-Roux, 2004: 38). According to Holland (2001: 39), bereaved children tend to experience problems in their later life.

Other adolescents have both guilt and low self-esteem after a parental death, even those who may later achieve notably in academic or professional spheres (Holland, 2001: 40).

Figure 2.1 (Levine et al, 2004: 7) provides a visual summary of the far-reaching impact of HIV/AIDS on the individual and society. From this figure it is noticeable how children, whose parents are infected by HIV/AIDS, can be caught up in a vicious cycle of poverty and problems such as physical, cognitive, psychological, conative and spiritual problems.



**Figure 2.1: The impacts of HIV/AIDS on adolescents – A Vicious Cycle**

## 2.8 CONATIVE AND SPIRITUAL IMPACTS

According to Ruiz-Casares (2001: 1), not only do children carry the emotional burden of watching a loved one suffer and die, but they also experience the trauma of the family unit collapsing. A family illness and death necessitate changes in responsibilities, routines, living conditions, and even place of residence. Such extensive environmental change can deprive children of the feeling of security and comfort they derive from familiar routines and settings. According to Doka (1994: 36) these children, given their environment, may experience developmental or behavioural problems.

Self-concept also has been linked to adolescents externalizing problems, including specific factors such as low expectations for success, low self-esteem, negative views of one's own behavioural conduct, and an imbalance between positive and negative aspects of the self (Henderson et al, 2006: 2).

This discussion reviews conation and how it is affected in the life-world of an AIDS adolescent. Conation refers to the intentional and personal motion of behaviour (e.g. the proactive direction, energizing, and persistence of behaviour). It includes the will or freedom of choice, which is an essential element of voluntary human behaviour. It is believed that human behaviour cannot be explained fully without it (Bandura, 1995).

Parents' praise of children is an important aspect of conation for learners to be able to do well in school. Thus AIDS orphanhood, being the absence of a parent for the adolescent, implies that this opportunity is not there. AIDS adolescents have mixed feelings of helplessness, confusion, disbelief, powerlessness, fear, shamefulness and anxiety (Pridmore et al, 2006:19). As a result, the senses of direction, energising, persistence and impacting conation do not function in a stable mind. Hence, they may not lead to positive results for this adolescent. AIDS adolescents generally consider themselves as inferior beings. They are overwhelmed by predominantly negative images and view themselves as either a source of trouble or in trouble. They live a stressful life and suffer much shame, neglect, abuse and confusion because their aspirations are usually being frustrated since they are not considered as complete or normal human

beings as other children. They usually do not cope in handling themselves, and cannot lead a meaningful life due to their AIDS orphanhood status. According to Louw et al (2001: 20) adolescents' sense of future is seriously affected due to HIV/AIDS. They may not plan for or look forward to the future.

In an unstructured and chaotic environment of an AIDS adolescent, children and youth need the conative skills in order to be successful as adults. In the absence of parents, educators are the only choice for these adolescents to stack activities that can develop these attitudes and skills into an already crowded curriculum. Failure to do so is to abandon these vulnerable youth to a life-world mournfully ill-prepared.

The spiritual impact refers to impacts that relate to the spirit or religion. According to Loubser (2007: 86), it is a reality that children live in traumatic situation where their hope is replaced by despair. They live in paralyzing fear, mistrust and deep grief and they carry burdens and responsibilities far too heavy for any child to bear. Deep in their spirit an overwhelming sense of hopelessness springs up, they see no opportunities to develop their God-given potential (Kilbourn in Loubser, 2007: 86).

A grieving child who was initially doubtful about the existence of a superhuman (e.g. God or ancestors) can have sufficient reason to conclude that such existence is a myth. The optimist child tends to lose hope, and may lose hope even in life. The child may also become easily vulnerable. Such children tend to believe in the extremes. They may accept every little promise even if it does not have any base, or they may refuse to accept help that is palpable. A child under these conditions becomes weak easily. He or she becomes easily vulnerable, and may miss opportunities for development. This causes their life-world to decline.

An idealist (or optimist) may tolerate hardships, but it is very rare, especially for a grieving adolescent. An optimist believes that the bad days will pass and be replaced by the good ones, and that people are there to influence them. If the AIDS adolescent becomes optimistic, he or she may decide to work and look after the younger siblings.

## **2.9 CONCLUSION**

The chapter demonstrated that HIV/AIDS is a family disease because it disrupts the family structure. The impact of AIDS on children is multifaceted and affects all aspects of a child's life. Children may be affected in their social context due to parental death. The traditional safety nets such as the extended family and community support mechanisms are increasingly under stress due to the impact of HIV/AIDS and poverty. Older children take charge of parental roles, often at an early age, for younger siblings and for terminally ill parents. Adolescents drop out of school due to reduced household income and the need to provide care and support to parents. The illness and loss of a parent is traumatic. Lack of parental support can have serious developmental affects. The life-world of a person develops from childhood through adulthood as a result of a person's interaction with his environment, which includes his peers, his parents, his teachers and the various tasks and responsibilities the person is assigned as well as the manner in which he copes with them. An adolescent who has lost his parents due to HIV/AIDS have, accordingly, a stunted life-world development. This situation may change, however, for whether the person develops a positive or a negative life-world depends on how he is treated and how he perceives such treatment.

## **CHAPTER 3:**

### **RESEARCH DESIGN**

#### **3.1 INTRODUCTION**

This chapter contains information on the design of the empirical research. It provides an explanation on the execution of the investigation. Inclusions in the methodology are assumptions and values that serve as the rationale for the research and the standards or criteria the researcher has used for interpreting and reaching conclusions. This study investigates the impact of orphanhood on the life-world of adolescents orphaned by AIDS, in the Ratanda area. The researcher chose the methodology that would be able to present the phenomenon under study in the clearest possible way. The researcher first provides the scope of the study. She then provides a description of the research process and the kinds of tools and procedures that were used. The specific tasks that are covered in this chapter include the design of the study, the description, the selection of participants, measures to ensure trustworthiness, ethical issues, data collection and analysis, and limitations.

#### **3.2 THE RESEARCH PROBLEM**

The life-world of AIDS orphaned adolescents is the foremost focal point of this study. Hence, HIV/AIDS is the source of the major problem of this study. It has been concluded from research that Sub-Saharan Africa is leading in terms of numbers of people infected by HIV and people dying of AIDS (Avert, 2009: 1, 7). South Africa also experiences this dilemma. For young children whose parents' die of AIDS, this leads to, among other problems, a high rate of orphanhood. Ruxin et al (2005: 111), assert that AIDS orphans are increasing in South African schools. Karim and Karim (2005: 352) stated that in South Africa, the number of children under the age of eighteen years who have lost a parent is expected to climax at an estimated level of 5.7 million in the year 2014. Further, Hartell and Chabilall (2005: 216) illustrate that HIV/AIDS has a negative impact on the social, emotional and educational development

of adolescents orphaned by AIDS. These sources concur that the AIDS orphan challenge is an unfolding tragedy in which the erosion of family is set to continue for many years, and that there is prevalence of undesirable behaviours among these orphans. Hence, this study intends to explore the nature of the life-world and orphanhood through AIDS.

### **3.3 THE AIM OF THE EMPIRICAL INVESTIGATION**

This study aims to provide scientific knowledge of the impact of orphanhood on the life-world of adolescents orphaned by AIDS. The aim of the empirical study for this research is to investigate the life-world of adolescents, Zulu and Sotho school learners of ages 13 to 18, in the Ratanda township in Heidelberg, Gauteng, through interviews.

### **3.4 RESEARCH DESIGN**

Mayer and Greenwood (1980: 67) define research design as a comprehensive plan of the sequence of operations that a researcher intends to execute in order to achieve a given set of research objectives. For the purpose of this research, this study uses a qualitative, exploratory and descriptive research design.

#### **3.4.1 The nature of qualitative research**

The qualitative research method used required data in the form of text, written words, symbols or phrases, which describe people, actions and events in the social context (Neuman, 2006: 457). The qualitative approach is anti-positivistic, meaning that it is interpretative, idiographic and holistic in nature. It is aimed at understanding social life and the meaning that people attach to everyday life (Fouché & Delport, 2002: 78). In other words, qualitative research uses qualifying words or descriptions to record aspects of the world. According to Creswell (1998: 21), a qualitative study is exploratory, and the researcher must seek to get a whole picture of a person's lived experiences and their ideas. The main purpose of qualitative research is to understand a phenomenon from a fresh point of view that, above all emphasises subjective meaning, perceptions and

experience (Creswell, 1998: 162). As stated by Neuman (1997: 12), qualitative researchers emphasise the importance of the social context for understanding the social world. The meaning of social actions or statements depends in an important way on the context in which it appears. The qualitative approach is premised on the assumption that human behaviour and actions are greatly influenced by the context within which they occur. To support this, Myers (1997: 242) discloses that individuals do not exist in a vacuum but in a whole life context. The context of the present study is the school, specifically at a primary and secondary level. Qualitative research always accepts the value and subjective meaning people place in their experiences. The rationale for using qualitative methodology was that the researcher intended understanding the life circumstances and the life-world of orphans. The best methodology of getting a deeper meaning of these children's life circumstances was by allowing them to give their accounts of their lives and experiences.

This research study follows the phenomenological research design or theoretical framework of qualitative inquiry. In a phenomenological study, the researcher explores or aims to describe the meaning of the lived experiences of individuals who share a common phenomenon, such as being orphaned through AIDS, through means of the individuals' accounts and opinions. The focus is therefore on the subjectivity of those viewpoints and experiences. The individual is viewed as an expert on his own life and interpretations of that life, and helps others to comprehend those unique experiences. According to Fouché and Delport (2002: 268), the purpose of phenomenological analysis is to clarify the meaning of all phenomena. It neither explains nor discovers causes, but it clarifies the phenomena. The goal of this approach is to understand and interpret the meaning the participants give to their everyday lives.

The phenomenological design is employed in this research because limited information on children orphaned by AIDS is available in South Africa. The specific nature of their needs and problems has not yet been fully documented. Therefore the design is important because it enables the researcher to explore and give insight to the phenomenon of AIDS orphans, that is, the life-world of the adolescents orphaned by AIDS. Focus was on the essence of the meaning that subjects give to their daily lives.

The purpose of the study is to describe the impact of orphanhood through AIDS on the life-world of adolescents orphaned by AIDS. This research is descriptive and by means of reduction, knowledge of the psychological essences or meanings of human experience can be obtained (Creswell, 1998: 3-4). Exploratory studies are used to make a preliminary investigation into relatively unknown areas of research. The goal that is pursued in exploratory research enables the researcher to have a broad understanding of a situation, phenomenon, community or person (Babbie & Mouton, 2001: 79; Bless & Higson-Smith, 2000: 41).

This study is also descriptive. Ary, Jacobs and Razavieh (1985: 323) define a descriptive research design as a study designed to obtain information concerning the current status of phenomena. It is directed towards determining the nature of a situation as it exists at the time of the study. This study is descriptive because it seeks to describe how adolescents are affected by HIV/AIDS.

In addition to the above, the research design was flexible. Steps of collecting data were not fixed and sequential. One interview informed and enriched the next. According to McMillan and Schumacher (1993: 374), such a process is an emergent design process with the processes of sampling, data collection and partial data analysis taking place interactively and more or less at the same time.

At the beginning of the data collection process, the researcher wrote and disseminated letters to D7 district of GDE and selected schools requested for permission to interview adolescent AIDS orphans. Pre-interviews were held with the latter to arrange the respective interview appointments. Interviews were conducted with individuals. The researcher was guided by a schedule of questions (see appendix) through every interview. Through analysis of the data of the previous interview, the approach for the next interview was enhanced and improved. However, if a similar research was carried out, the researcher could also use other methods, for example questionnaires, drawings and so on, and would not use the face to face interview as the only primary method of data collection.

### **3.4.2 The research paradigm**

The paradigmatic perspective of this study will be based on the existential, humanistic paradigm, focusing on the whole person theory and holism as outlined by Meyer et al (1997: 403). This theory advocates that the individual has freedom of will and choice, and it is this ability to make choices about life and oneself that makes the individual who they are. One must, however take into account constraints that influence an individual's decisions, for example the environment in which the individual finds themselves, and influences the way in which they develop their life-world. This life-world shapes the beliefs that individuals hold about their life and even their potential, but it also allows for the possibility of change.

We choose to be whom and what we are. Life, then, is not about the struggle to survive but the struggle to find meaning in life. The individual, then, is driven by the will to find meaning in life, to find out what is valuable and therefore meaningful to them. Each individual has the responsibility to make sense of, and to contribute to their life, striving for self-actualization, given their own limitations and those of their environment. The individual must be aware of these, but this is not to say that they cannot be overcome. The individual has an active role to create an environment where the individual can see and accept herself/himself and the environment (situation) as it is. The focus of the problem is the adolescents of ages from 13 to 18 years still at school.

## **3.5 THE RESEARCH METHOD**

This research method involves data collection, sampling method, the researcher as an instrument, ethical issues, and method to ensure trustworthiness and data analysis.

### **3.5.1 Data collection**

In order to attain insight into the experiences which result in certain self-perceptions, a semi-structured, individual, face-to-face interview is conducted with each research participant in the natural setting of the school. As maintained by De Vos et al (2002:

302), semi-structured interviews are used to gain a detailed picture of a participant's belief about, or accounts of, a particular topic. The researcher employed this process because she was interested in the participant's perceptions of being orphans through AIDS. She wanted to address the question: 'How does it affect their life-world?'

The interviews were initiated with the research question. A supplementary interview schedule was constructed on the basis of the literature review and the theoretical orientation on which the study was based. This is used as a guideline for the researcher to gain information. The researcher personally conducted the interviews using an interview schedule. The schedule was not rigid, however, as it allowed for the ventilation of feelings and the collection of additional information. All the interviews were conducted in Zulu and Sotho and subsequently translated by the researcher.

The interview schedule consisted of a timetable and a set of essential issues reflecting the actual inquiry. Yin (1994: 69) proposes that the schedule should have two characteristics. Firstly, the issues posed should enlighten the researcher about the information required and the reasons for it. Secondly, the issues should be accompanied by a list of probable respondents. These were the names and profiles of the people targeted for the semi-structured interviews. Respondents in this study were AIDS orphans in the various primary and secondary schools in Ratanda.

The interviews were recorded and transcribed afterwards. The researcher also made detailed field notes during the data collection period. According to Greef (in De Vos, 2002: 304):

*Field notes are written accounts of the things the researcher hears, sees, experiences and things he/she thinks about in the course of interviewing.*

Data collection took place in four of the nine schools of Ratanda namely Ratanda Primary, Fountain Five Primary, Sithokomele Primary, Kganya Lesedi High and Ratanda Secondary School.

### **3.5.2 Sampling methods**

A study population refers to the entire group of objects (including people) in which the researcher has interest. Such questions are able and would be available to provide the responses required in the study (Chia, 1995: 580; Eden & Huxham, 1996: 79; Hand, 1997: 129). In many cases the population is so large and inaccessible that it cannot be used in its entirety due to inability of the researcher to handle it. In this case a useful subset of the population was used for the study. The research population of this study can be defined as adolescents in the Ratanda area between the age of 13 and 18 (including both ages), who are orphaned because both parents died in HIV/AIDS-related circumstances or one parent died in HIV/AIDS-related conditions and the whereabouts of the other parent are unknown.

Haslam and McGarthy (2003: 114) explain that sampling methods refer to techniques used to select a useful sample from a study population. This study is an in-depth study that requires detailed responses from a few respondents who had insight information about the study topic (Haslam & McGarthy, 2003: 110). An in-depth study does not require many respondents. It requires the purposeful selection of few respondents who know the topic of this research well. Thus, this study focused on few respondents who possess plentiful information and would provide enough information to accomplish the study. As a result, it was decided that all the 12 AIDS orphans found in Ratanda schools be interviewed in order to extract information and clarify issues regarding the topic.

Singleton (in De Vos et al, 2002: 207) explains purposive sampling as based entirely on the judgement of the researcher, in that a sample is chosen on the basis of what the researcher thinks to be an average person. The strategy is to select units that are judged to be typical of the population under investigation. Purposive sampling was used in selecting the study respondents. This is a no probability sampling method used when a sample is collected by selecting only those elements from the population that have a particular, useful characteristic (Haslam & McGarthy, 2003: 110). The method was relevant and appropriate for this study that had a specific task to accomplish. The study explored the influence of orphanhood caused by AIDS on the life-world of Ratanda learners of ages between 13 and 18 years. These orphans were the study respondents.

At the time of interviews when the AIDS orphans of ages 13 to 18 years were sought, there were not enough available in any school in the township. Some schools did not have a single one fitting the description specified. As a result, finally, all the schools were visited and a request made to interview the orphans under the conditions specified. As a result, this study used a census of registered AIDS orphans at Ratanda schools to obtain the data needed. These were 12 in total. The information obtained from teachers was that there were much more than this number believed to be fitting the description. This could not be confirmed because disclosure and confidentiality are the decisions of the one who has the disease. Since the guardians had chosen not to register their foster children as AIDS orphans, schools were prevented from classifying them as AIDS orphans.

### **3.5.3 The researcher as instrument**

Padgett (1998: 18-19) pronounces that “if qualitative research is a voyage of discovery, then the researcher is the captain and the navigator of the ship”. Padgett proclaimed that the researcher as an instrument was a defining characteristic of qualitative research. Hence, the dynamic interplay between the researcher and the participants, each affecting one another in unforeseen ways, was one of the significant features of qualitative research (Padgett, 1998: 23-24). Often, in phenomenological interviews both the researcher and participant work together to “arrive at the heart of the matter”; however, it was important that the researcher suspend personal experiences that could possibly distort the participants’ contributions.

The researcher thus attempted to heed the advice of Grobler, Schenk and Du Toit (2003: 2) that whilst facilitating the semi-structured interviews, she should adhere to empathy, congruence and unconditional positive regard towards the participants, adolescents who are orphans through AIDS. In this regard, Padgett (1998: 21) cautioned that the interpersonal skills of empathy and sensitivity that are so important in the work of psychologists were put to somewhat different ends with regard to qualitative research. Therefore, instead of engaging with clients to achieve treatment goals, researchers become listeners seeking knowledge and understanding. The researcher therefore noted

that Monette et al (2005: 233) explained that her role as a participant observer in this study required her to be part of the activities being studied and also as a participant. The researcher as a participant was therefore able to influence the direction of the discussions, whilst simultaneously observing the responses of the adolescent orphans.

### **3.5.4 Ethical issues**

As indicated by Strydom (in De Vos et al, 2002: 64-75), there are certain ethical considerations that need to be kept in mind when conducting research. These aspects will be discussed below.

#### **3.5.4.1 Harm to experimental participants or respondents**

Dane (Strydom in De Vos et al, 2002: 64) claims that an ethical obligation rests on the researcher to protect subjects from any form of physical discomfort that may emerge, within reasonable limits, from the research project. Harm to respondents by a study done in the social sciences will be one of an emotional nature. Emotional harm to subjects is often more difficult to predict and determine than physical discomfort, but often has far-reaching consequences for respondents. To avoid this, the researcher informed respondents beforehand about the potential impact of the investigation. Such information offered the respondents the opportunity to withdraw from the investigation.

#### **3.5.4.2 Informed consent**

Obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages, disadvantages and dangers to which respondents may be exposed, as well as the credibility of the researcher must be given to potential participants or their legal representatives (Strydom in De Vos et al, 2002: 65). Further, it is emphasised that accurate and complete information must be given to subjects so that they fully comprehend the investigation and are therefore able to make a voluntary and thorough reasoned decision about their possible participation. Participants must be

legally and psychologically competent to give consent and they must be aware that they would be at liberty to withdraw from the investigation at any time.

The researcher explained to the orphans the need for their involvement. The reasons for the study were also discussed with the orphans. Through this discussion, any information required by the orphans was given by the researcher.

### **3.5.4.3 Violation of privacy, anonymity and confidentiality**

Privacy refers to anything that is normally not intended for others to observe or analyse. Privacy denotes to agreements between people that limit others' access to private information. This principle can be violated in a number of ways and it is imperative that the researcher safeguards the privacy of participants (Strydom in De Vos et al, 2002: 67). Confidentiality is a continuation of privacy. The privacy of participants and confidentiality of the consultations can be affected by using apparatus such as video cameras, one-way mirrors and microphones.

As a result of the above, the names of orphans who were interviewed during the semi-structured interviews are not provided in the study, that is, they are anonymous. As such, the researcher has kept details of AIDS orphans confidential.

### **3.5.5 Measures to ensure trustworthiness**

This section explains the fairness and accuracy of the conclusions reached through this study. In this study, the researcher combined Guba's model with the approach of Babbie and Mouton (2001: 276). They identify four criteria of trustworthiness; that is, truth value; applicability; consistency and neutrality.

#### **3.5.5.1 Truth Value**

Truth value investigates whether the researcher has established confidence in the truth of the findings for the subject and content in which the researcher was undertaken. The

researcher considers the study to be credible as interviews were conducted with AIDS orphans. Information obtained from the respondents regarding their life-world is the same information collected with the literature review (see Chapter 2). Credibility was again assured by using the following strategies:

- ❖ Prolonged engagement

According to Babbie and Mouton (2001: 277), researchers must stay in the field until data saturation occurs. The researcher established rapport and built a relationship with the participants. Consequently, data was collected after three visits; the participants were relaxed, and able to participate.

- ❖ Persistent observation

The researcher spent a great deal of time observing the research participants, while not only listening to their verbal responses but also interpreting non-verbal communications. Bodily mannerisms, postures, and facial expressions can be construed as unconsciously communicating their feelings or psychological state. The respondents' answers were thus compared with their body language and changes in positions.

- ❖ Referential adequacy

The researcher made use of a tape recorder and a writing pad to jot down notes. These were placed so as not to obstruct either the researcher's or the interviewee's view.

### **3.5.5.2      Applicability**

Applicability in qualitative research refers to whether it is fitting or transferable. It refers to the degree to which the findings can be applied to other contexts and settings or with other groups (De Vos et al, 1998: 331). It implies that the researcher should be able to generalize qualitative findings to other population groups. In this study the criterion is met since information obtained from the despondences (AIDS orphans) is transferable into context outside the current study situation.

### **3.5.5.3 Consistency**

The third criterion is the consistency of the data, that is, whether the findings would be consistent if the enquiry were replicated with the same subjects in a similar context. In qualitative research, instruments required for consistency are the researcher and the informants (Babbie & Mouton, 2001: 278). The criterion was met in this study because the same interview schedule was used in all the AIDS orphans yielding the same results. The technique was used to attain dependability in qualitative research is called inquiry audit. The researcher conducted in-depth semi-structured individual interviews, which were jotted down and audio taped to ensure an audit trail. The literature review verified the data analysis and interpretation.

### **3.5.5.4 Neutrality**

Lincoln and Guba (1985) as mentioned by De Vos et al (2002: 352) note that with this criterion there is a need to ask whether the findings of the study could be confirmed by another. In this study this criterion was met as information obtained entrenched the general findings conducted in other countries regarding the life-world of AIDS orphans (see Chapter 2).

In summary, the four criteria as set in Guba's model were met. It can thus be said that the trustworthiness of this study has been established.

## **3.5.6 Processing the results**

The researcher heeded the advice of Richards and Morse (2007: 171) in that the phenomenological data analysis was a process of reading, reflection; writing and rewriting that enable the researcher to transcribe the lived experience of the orphans. Data processing involves preliminary analysis and data analysis.

### **3.5.6.1 Preliminary analysis**

Preliminary data analysis refers to the initial stages of data analysis. It involves uncovering the indications of what the main findings would entail. It may start in an informal pattern. This makes the research a ‘reflective’ diary, necessary to establish and use (Kemp, 2001: 90). The reflective diary is usually used to record personal assessment, feelings, reflection and interpretations. Preliminary data analysis assists in determining the optimal approach for the main data analysis. After the final data analysis, the records from preliminary data analysis would then be incorporated into, and consolidated with the main data analysis records to compile a complete report.

### **3.5.6.2 Data analysis**

Data was analysed according to the steps described in De Vos et al (2002: 340). Lincoln and Guba’s approach (in De Vos et al, 2002: 351) was employed in order to evaluate the validity of the findings. Credibility, transferability, dependability and conformability were evaluated. Once data has been collected it needs to be assembled in some meaningful way. De Vos et al (2002: 339) define data analysis as a “process of bringing order, structure to the mass of collected data”. Data analysis enables the researcher to determine whether it provides the information needed in order to achieve the goal of the study.

Data was collected and prepared into text, using transcripts and field notes (Berg, 2001: 239). Data was first analysed in the language in which the interview were mainly conducted (Sotho/Zulu). Data was then copied into text using transcripts. The completed transcripts were given a code and the researcher read through all the transcripts to get a sense of the whole. The researcher continue to write down ideas as they come to mind while writing thoughts in the margin and identifying the major themes (De Vos et al, 2002: 346-347).

The themes were put into major categories whilst simultaneously identifying subcategories within major categories. During the process of analysis, relationship

between major and subcategories were also identified. The researcher then categorized the responses based on the sections of the semi-structured interview. Data was analysed based on literature control. The goal was to integrate these themes into a theory that offers an accurate, detailed interpretation of the study.

### **3.6 LIMITATIONS**

The limitations of the study can be listed as follows:

- The study was limited to 13 to 18 year old AIDS orphans in Ratanda. Other age-groups were not explored.
- Interviews were concluded in only Zulu or Sotho. AIDS orphans unable to converse in either these languages were thus excluded.
- The fact that the study was done at Ratanda, in Heidelberg, Gauteng, makes it difficult to generalise the findings for the whole of South Africa.
- Respondents might not have been very open, because of the sensitive nature of the study.
- Relevant literature was readily available to the researcher.

Despite the limitations of the study, the research process was scientific.

### **3.7 CONCLUSION**

The study discussed research and sample designs, data collection and analysis, and possible limitations of the study. In sampling design, research types, population and sample and sampling methods were discussed. Research design covered study coverage and instrumentation. Data collection included data gathering methods, persons involved, data management and study duration. Data analysis covered methods, data handling, and preliminary analysis. The next section discusses the result of the findings.

## **CHAPTER 4:**

### **RESEARCH RESULTS**

#### **4.1 INTRODUCTION**

This chapter presents the findings with reference to the literature in order to contextualise them. The main purpose of this study was to explore and describe the respondents' (who are AIDS orphans) experiences and the impact of orphanhood owing to AIDS on their life-world. The study identifies numerous problems from the empirical study. These problems can be categorised under the following themes:

- Physical Problems
- Educational Problems
- Vulnerability and Stigmatisation
- Psychosocial Problems
- Conative Problems
- Religious Reasons

#### **4.2 SAMPLE DESCRIPTION**

For this study, a purposive sample was drawn from the population of AIDS orphan adolescents. Convenience was necessary because the AIDS orphans first had to be identified from lists of all learners through learner records and then their participation was negotiated. These adolescents were from Ratanda which is situated in Heidelberg in Gauteng Province. Their ages were between 13 to 18 years of age. The sample comprised of 12 participants.

The educators could officially only provide information for this research study according to existing school records. This was understood even though it led to a limitation. The law does not permit the supplying of information concerning AIDS victims if the persons involved have not given their consent. It would also have been

unethical and illegal to access information from people without their permission. Hence, the AIDS orphans were protected in this way.

#### **4.3 DISCUSSIONS OF RESULTS**

Data was analysed according to the dominant themes surrounding the issues related to the life-world of adolescents orphaned by AIDS. The results will be compared concurrently to the relevant literature. Themes, categories and sub-categories are presented in Table 4.1.

**TABLE 4.1**

<b>THEME</b>	<b>CATEGORY</b>	<b>SUB-CATEGORY</b>
Physical problems	Nutrition and health	<ul style="list-style-type: none"> <li>• Experience chronic malnutrition</li> <li>• Poor physical conditions</li> </ul>
Educational problems	Poor performance	<ul style="list-style-type: none"> <li>• Loss of concentration, interest and attention problems</li> <li>• Poor school attendance</li> <li>• Emotional problems</li> <li>• Lack of adaptation</li> </ul>
Vulnerability	<ul style="list-style-type: none"> <li>• High risk of HIV infection</li> <li>• Abuse and exploitation</li> <li>• Childhood deprivation</li> <li>• Stigmatisation</li> </ul>	<ul style="list-style-type: none"> <li>• Frustration</li> </ul>

Psychosocial problems	<ul style="list-style-type: none"> <li>• Loss of parents, parental guidance, love and nurturance</li> <li>• Poor relationships</li> <li>• Lack of adult supervision or support and neglect from relatives</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of support system</li> <li>• Experience stress</li> <li>• Change in family structure and functions</li> <li>• Grieving</li> <li>• Subjected to cruel and dehumanising treatment</li> <li>• Lack cultural norms and behavioural norms and values</li> </ul>
Conative problems	<ul style="list-style-type: none"> <li>• Less optimistic about their future</li> <li>• Absence of parental mentoring.</li> </ul>	<ul style="list-style-type: none"> <li>• No hope</li> <li>• Lack of motivation</li> </ul>
Religious reasons	<ul style="list-style-type: none"> <li>• Important resilience factor</li> </ul>	<ul style="list-style-type: none"> <li>• Engaged in daily prayer and attend church every Sunday</li> </ul>

Following is a discussion of the themes, categories, sub-categories and field notes.

#### **4.3.1 THEME: Physical problems**

In the following subsections we will discuss the physical problems under the sub-categories of nutrition and health, experiencing of chronic malnutrition and poor conditions.

##### **4.3.1.1 Category: Nutrition and health**

The findings show that there was a lack of food in the households of these AIDS orphans. These orphans confirmed this by supplying information that they depended on

food support from neighbours and/or supplementary food programmes of donors. These children stayed with their grandparents, or relatives, others with their siblings (in child-headed households) and others are fostered by other families in the community. “The thing that makes me feel very bad is when I see how my sister has to beg and ask around for food everywhere for us. Then I think about my mother and feel very bad”. Judging by their physical appearance at face value, it was apparent that they lacked nutritious food in their diet.

**a) Sub-category: Experiencing of chronic malnutrition**

Most of the AIDS orphans experience malnutrition, which they claimed had been confirmed by medical reports. This was corroborated by their physical appearances. Malnutrition was clearly noticeable because the AIDS orphans looked stunted and wasted (Barnett and Whiteside, 2002: 201-202; UNAIDS, 2004: 3). “I go to school on an empty stomach and spend half the day hungry, waiting for the bread that I get from school”. Further, when asking them about their nutrition, one of them replied by saying: “We always eat pap if there is anything to eat”. “We always eat porridge and potatoes. We never eat fruits and meat”. “I always do not look forward to meals. They are not delicious”. In addition, most of them stated that most of the time they went to school without anything to eat. On such days they only got bread at school during break. Most of them said that it is tough most of the time - they go to sleep on an empty stomach except when it is a food parcel day which they collect from non-government organisations (NGOs).

**b) Sub-category: Poor physical conditions**

It is clear that the respondents lived with families where there was scarcity of food. In other words, the AIDS orphans consumed less food than they required. Most of them responded by stating: “we are always hungry, hunger makes us weak and, as a result, we are not able to work or perform at school”. “We sometimes had to look in the dustbins in town when we had nothing. We also tried the dumping site”. “We had no food. Everything we had to ask. Sometimes we only drank water. The worst was when the small ones ask for food and I have nothing to cook”. They stated that they lacked

sufficient energy for everyday life. It is evident that there is a lack of nutritious food in their diet. They eat pap without vegetables most of the time. According to them vegetables were scarce in their diet, because they were expensive and they could not afford them. As a result, they experienced poor physical conditions or chronic malnutrition. They also experienced fatigue, tired easily and had difficulty in normal functioning.

#### **4.3.2 THEME: Cognitive problems**

In the following subsection the cognitive problems will be discussed under the categories of poor performance, loss of concentration, interest and attention problems, poor school attendance, emotional problems and lack of adaptation.

##### **4.3.2.1 Category: Poor performance**

According to most respondents, poor performance was caused by the stress they experience due to their traumatic situation and the lack of supervision, care and support. “There is no one to help us with homework and other school activities”. “I always go to my neighbours for assistance. My granny is too old to help us and she is not educated”. “I’m responsible for cleaning the house, cooking and taking care of my brother and sister, there is no time to study and do my homework”. According to the respondents, loss of concentration and interest, attention problems, poor school attendance and emotional problems led to reduced performance in school.

###### **a) Sub-category: Loss of concentration, interest and attention problems**

The respondents indicated that hunger, neglect and stress result in their lack of concentration. They claimed that when they tried to concentrate, they tend to have disconcerting flashbacks, and were easily distracted by their problems or experiences. “I find it difficult to concentrate at school because I remember my mother a lot. If she was here, I would not be suffering. She was the best mother”. “It is difficult to learn on an empty stomach”. The respondents indicated that these conditions did not want to

improve, which angered them. Most respondents complained that they were unable to listen for long periods at a time. They stated that they were easily distracted in class. This was a problem for many of them. The narration of this was: “I try my best to listen but I’m unable to do that for a long period”. This is the reason why they were incapable of concentrating in class and a cause of their poor performance.

**b) Sub-category: Poor school attendance**

The progressive illness or death of a parent from AIDS had led to school poor attendance due to difficult circumstances at home. The respondents indicated that they could not leave their sick parents alone to attend to school. They had to care for them and also had to search for food and medication.

**c) Sub-category: Emotional problems**

The respondents indicated that they were aware that they were short-tempered, which was not a serious problem before. They indicated that they formed wrong judgments concerning other people’s comments to them and interacted uncomfortably with others. They stated that sometimes could not control themselves physically or emotionally, and cried easily with little provocation. They also indicated that they became stressed and fatigued easily.

**d) Sub-category: Lack of adaptation**

They were anxious about their environment. They stated that they were unhappy, worried, dejected, and fearful of new situations. They also experienced difficulty in making new friends and even to maintain old relationships. Many of them suffered from insomnia. Adaptation problems were mostly encountered because of a lack of emotional support.

### **4.3.3 THEME: Vulnerability**

Vulnerability is discussed under the following categories and sub-categories: high risk of HIV infection, frustration, abuse and exploitation, child deprivation and stigmatization.

#### **4.3.3.1 Category: High risk of HIV infection**

The respondents developed risk-taking behaviour, due to their personal experiences. They exhibit recklessness towards HIV infections, doing little or nothing to protect them. The pressure for basic survival such as finding food prevailed over potential contagion. As such, daily problems far outweighed the future orientation required to avoid infections.

##### **a) Sub-category: Frustration**

Frustration was another factor that led to potential contamination with HIV. The respondents resorted to unsafe sex for many reasons such as material things, the need to be loved (psychological need) and for security reasons. A young orphan girl stated that, “older men support me; they know that I’m supposed to eat as well as my family”. She went on to explain that “an older man assured me of his love and commitment”.

#### **4.3.3.2 Category: Abuse and exploitation**

Most responses indicated that the respondents were subjected to sexual or physical exploitation at some point, or most of the time. Others were working after school or during weekends in order to attain food. “After school I go and help Mam’ Sonto at her shebeen and go and stock cases of beer at a bottle store then she will pay me R5 every day”. These children lacked adult support and protection, and as a result experienced sexual and physical abuse and exploitation. Most girl respondents indicated that their sexual exploitation was committed by relatives or by males known to them in their

community. They claimed that due to this sexual abuse, they had isolated themselves because of lack of trust and fear.

#### **4.3.3.3 Category: Childhood deprivation**

The respondents felt that their particular situation deprived them of their childhood because of adult responsibilities being thrust upon them at an early age. They were accountable as caregivers to their parents before their deaths, and afterwards as guardians to their younger siblings as well as maintaining the household. The younger siblings who were cared for by their elder siblings indicated their appreciation for the older siblings' attempt to take custody of them. However, they pointed out that the older siblings were not yet parents and thus lacked essential parental conduct. They indicated that their older wardens were sometimes rough and strict, which they believed their real parents would not have done.

#### **4.3.3.4 Category: Stigmatisation**

The respondents indicated that, compared to children who were not AIDS orphans, they received bad treatment from everyone. They stated that the other children at school made dirty remarks about them in front of other people. They could not respond to these implied insinuations, as they were not stated explicitly. The teachers too, hurt these AIDS orphans in certain ways. They believed that some teachers were wounding them deliberately. Some scholars did point out that a number of teachers in their schools painstakingly fought stigmatisation. This fact provided them comfort in that they had the support of responsible adults: "I can go to my teacher. She really understands me and she is a Christian person. I talk to her".

#### **4.3.4 THEME: Psychosocial problems**

##### **4.3.4.1 Category: Loss of parents, parental guidance, love and nurturance**

Most respondents indicated that their agony began before they became orphans. This indicates that long exposures to illness and suffering of a beloved person endanger the healthy development of a child. According to the answers, taking care of a dying parent was a severe source of distress and hardship. Even before their parents' demise, the respondents were faced with the gnawing awareness that they will be losing one or both parents in short period of time.

The respondents were also asked what they missed most about their deceased parents. Most answers fell into the category of missing the love, affection, and advice from their deceased parent. One said, "Since my mother died, things are no longer the same. Nobody cares for me, they forgot about me. All they do is exploit me and beat me up". Another said, "My situation worries me, I am very vulnerable". It is evident that they lacked a support system and positive emotional care. This resulted in a subsequent lack of empathy for others (they develop antisocial behaviour). They experienced aggression, uncommunicative behaviour, withdrawn and alcohol abuse. Another one stated, "When I feel depressed or annoyed I go to relax at my friend's place then we will drink few bottles of beer".

##### **a) Sub-Category: Change in family structure and functions**

The sudden strained and desperate changes in their family structures and functions made these orphans vulnerable. They were obviously discontented because of fear for the unknown; things which they are not yet prepared for. They are very apprehensive about the future. The uncertainties they experience due to their unfamiliar situation led to sleeplessness. Many of these orphans reiterated that they were angry. They also appeared and sounded full of aggression. They further indicated that they want to run away from home.

**b) Sub-category: Experience stress**

The respondents found it difficult to talk about their worries or problems, more especially their personal experiences. Discussing these worries and frustrations causes more frustration that leads to vulnerability. They internalise their feelings of depression, anxiety, irritability, low self-esteem, moods, sense of failure and suicidal tendencies. Most of them shared how suicidal ideas crossed their minds particularly in difficult moments of their life: “I don’t have enough food to eat, I don’t have clothes like any child of my age and all this makes me feel that life is not worth living. It hurts me so much, especially when my aunt insults me, reminding me every day that I’m going to die just like my mother. Last time when she insulted me I thought of throwing myself in front of a moving car. It stresses me a lot.”

**c) Sub-category: Grieving**

The orphans assert that grieving for their parent was a main reason of worry. They state that they believed that the almighty God hates them and loves other children. “If He is good and powerful, and controlled death and life as people say, why did He not let me grow up first before letting my parents die? I do not trust the good things they say about Him anymore. If it is true what they say about Him, where is He when I suffer like this?” “We are grieving alone and none of us can figure out why it happened to us, especially us. The deaths of our parents make everyone to suffer, but because the cause of death is AIDS, we suffer more”. “It is clear that other orphans are not under strain like us, and they are treated normally as if they have parents. This is not the case for us, the AIDS orphans”.

**4.3.4.2 Category: Poor relationships**

Respondents had relationship problems. They held that it was difficult to make friends. Family and friends alike shied away from them and kept them at a distance. “They all of a sudden had reasons to stay away from me, and they also turn down my appointments when I want to visit them. In the past year they always accepted such initiatives to

‘chill’ with them”. These orphans gave the impression of being withdrawn and isolated because of the AIDS stigma. They have no trust in people. They are afraid to enter into relationships. They lack social skills because of the absence of mentoring parents. The participating adolescents appeared to be suspicious of their community members. In some cases, the community isolated the young person, which in turn led them to detach themselves more from the community. Young participants experienced feelings of being different and abnormal. They had the sense of constantly being observed. Adolescents with normal circumstances experience similar beliefs, however. “You get people who feel sympathy for me ... I don’t want their sympathy”. “They treat me as if I have some or other disease. I don’t have parents and they have parents ... I just want to live my life”. Most of the participants in the study identified friends as sometimes being the most important source of support for them. A few respondents appear to have trouble finding friends to trust. This is congruent with the views expressed in stated literature. “I used to have one friend, I trust her but she used my being an orphan to look better, you know, she said to other people; look at me I’m friends with an orphan. So I decided to stay on my own - no friends, no nothing. I can stay alone, I don’t need anyone”. “I have two friends. I like them and they like playing with me”. “I only have classmates, no friends”. “I have a best friend. We hang around, talk, listen to music or play soccer with other boys”.

#### **4.3.4.3 Category: Lack of adult supervision or support and neglect from caregivers**

The participants declare that they were treated differently. They were subjected to cruel and dehumanising behaviour. They were exposed to discriminative or harmful conduct such as child labour; favouritism and prejudice. As a consequence, they felt depressed, distressed and secluded. Other orphans were subjected to ongoing physical and verbal abuse, and neglect.

The AIDS orphans lacked adult supervision or support and were neglected by their relatives. The cultural and behavioural norms and values necessary for their integration into society were lacking. They responded more to peer pressure and they turned to delinquent behaviour for survival.

### **4.3.5 THEME: Conative problems**

#### **4.3.5.1 Category: Less optimistic about their future**

##### **a) Sub-category: No self-control**

The respondents indicated that since their parents' deaths they started experiencing lack of self-control, self-consciousness, will-power and free will. They held that they tended to lose focus in many instances. They also specified that they did not have the purposive creative thinking they had before their parents' passing away. Since the phenomenon of conation implies consciousness, volition and self-control, it can be concluded that the AIDS orphans suffered conative problems or have a deficiency in conative abilities. Again, enduring conative disorders connote that these AIDS orphans are bound to lose their optimism for life.

##### **b) Sub-category: No hope**

Since they cannot control themselves, these adolescents indicated that they had relinquished all up hope in making life work for them. They have lost hope in the social system, which does not provide help to them. They were on the verge of renouncing every alternative they used for survival. They knew that they lacked self-control, and were insensible to the necessary things to be done. In this case, they end up possessing no expectations. One line of reasoning regarding the lack of hope was, "How can an AIDS orphan in Ratanda be optimistic when there is no platform for us to be hopeful?" This is evidence for the AIDS orphans having lost hope in almost everyone and everything.

#### **4.3.5.2 Category: Absence of parental mentoring**

##### **a) Sub-category: Lack of motivation**

The respondents stated, "As AIDS orphans, no one takes us seriously; not the teachers,

not our fellow learners, not even the community. Why should I try to do good if it is not seen or recognised that way? I'd rather live my life loosely and enjoy it to the fullest. If I am reckless and die, let it be." This shows that the respondents have lost motivation and the will to do positive things for themselves in life. The death wish or pessimistic judgments give the impression that some AIDS orphans have or may have suicidal tendencies.

**b) Sub-category: Lack of direction**

The older siblings lacked parental abilities. They also cannot guide or give direction to the younger children in their charge regarding life skills. This was indicated by the many responses: "Even though our elder brother tries to give us care, he surely frustrates us because he shouts at us and does not allow us to socialise. He says that friends and sports will corrupt us. But he goes out to play and does not get corrupt. He is unnecessarily very strict on us." This also shows that it is not easy for the older siblings to manage the younger ones without any misunderstandings. The grown-up siblings frustrate the juveniles by trying to overprotect them. There is a little lack of direction in an attempt to manage the younger siblings.

**4.3.6 THEME: Religious reasons**

**4.3.6.1 Category: Important resilience factor**

**a) Sub-category: Belief in God**

The uppermost query dwelling in the respondents' thoughts was questions regarding their belief and faith in Lord God, the Almighty, as entrusted by their parents to them. They constantly asked themselves, "Why is this happening to me or anyone for that matter, if God exists at all?" "I sometimes blame God for what happened to my family, for losing both parents". "Why did it happen to me? Sometimes I don't believe in God and then I talk to my granny and she said, No, if God does something, He wants you to learn about life. I think I have learnt enough now". Their suffering led to probing the

existence of God, which may have implications for their future affiliation with activities relating to religion and to God. “I love God. I am very happy with God. He is very important in my life. There is no single night in my life that I don’t pray before I go to sleep”. In general, the youthful individuals were told that God has control over everything, which led AIDS orphans to believe that God was the direct cause of their parents’ deaths and their subsequent misery.

#### **4.4 FIELD NOTES**

The following section summarizes and elaborates on the responses given by AIDS orphans who participated in this study. These retorts were verified by literature control.

##### **4.4.1 Physical problems**

The communicated physical problems on AIDS orphanhood include lack of nutrition and health problems. These orphans are mostly supported by institutional or private donors; for example, NGO’S and neighbours. This sustenance is insufficient because the AIDS orphans are clearly malnourished. Barnett and Whiteside (2002: 201-202) underline that AIDS-affected households tend to be poorer, consume less food and have a smaller disposable income. It is thus hardly surprising that children in these households are usually emaciated and have a greater chance of being wasted. Their physical appearances reveal their undernourishment, and their despondency. They looked frustrated and lost, and they declared that they lacked energy. They indicated that they eat pap when they are lucky but most days they have nothing to eat. They experienced poor physical conditions and chronic malnutrition, fatigue, tiredness which led to difficulty in normal functioning.

##### **4.4.2 Cognitive problems**

The AIDS orphans experienced learning problems associated with concentration in class, poor attention span, and lack of interest (Foster, 1997: 397; Foster et al, 2005: 75;

Louw et al, 2001: 20). They showed loss of concentration and interest, attention span problems, poor school attendance and emotional problems. The AIDS orphans claimed that when they attempt to concentrate, they experience flashbacks. They are furthermore easily distracted because of their domestic problems or experiences. These conditions did not want to change for the better, and this caused many AIDS orphans to become angry. They were unable to listen for long periods at a time in class, and were easily distracted. They had emotive problems, such as a short temper. They usually made wrong judgments regarding other people and lacked self-control. They were miserable, worried, discontented, fearful of unknown situations, had trouble falling asleep and also had difficulty making new friends or even keeping old relationships. They could not adapt to new situations. Living with uncertainty poses a challenge to the secure psychological base essential to a child's development for a healthy and functional personality (Geballe & Gruendel, 1998: 51). It was interesting to note that all the young persons who participated in the study initially remained in their original homes after their parent's demise. They were removed or assisted by family only when serious problems arose. In some cases, the adolescents remained in their family home with mostly grandparents or maternal relatives. They also experienced adaptation problems because of lack of emotional support.

#### **4.4.3 Vulnerability**

These orphans became promiscuous and reckless in their life conduct, becoming easy sexual targets for older persons. This situation became risky for their abusers and exploiters dictated whether prophylactics would be used or not. They became vulnerable members of society who struggle for their survival at all cost. Food for sexual favours exchanges took place and no heed were given to possible HIV infections. In some cases, their abusers and exploiters were known people in the community, and included relatives. Others entered the cheap child labour market. Early entry into a harsh work market led to the deprivation of a normal childhood. The AIDS stigma was also commonplace for these orphans, which did not occur to other orphans.

#### **4.4.4 Psychosocial Problems**

The AIDS orphans were aware of the fact that the passing of their parents resulted in the loss of parental guidance. Since love is always experienced initially in the parental home, these orphans also suffered this type of primary love as well as the privilege of being nurtured at home. The family structures altered rapidly as a result of their parents' death, and the AIDS orphans were not prepared for these changes. Some of them had thoughts of fleeing their home. They underwent different types of stress. Their feelings included depression, anxiety, irritability, low self-esteem, mood changes and an immense sense of failure. They also had suicidal tendencies. Their grief led to frustrations. According to UNAIDS (2004: 3) and UNICEF (2003: 2), depression and alienation grow to be widespread in most AIDS orphans. It is not surprising that the majority of respondents noted that they feel depressed most of the time due to the ill treatment they received. This behaviour they juxtaposed with the love and care they used to have when their parents were still alive. Griesel-Roux (2004: 38) further supports this by stating that parental death reduces children's self-esteem and increase depression, anxiety, conduct disturbance, academic difficulty, somatic complaints and suicidal acts in the long term. Furthermore, children or adolescents may also learn depressed behaviours such as self-criticism and low self-esteem from their parents through modelling or where approval is contingent upon making self-deprecating remarks. They can feel self-worth only when they have received approval, love and support.

Participants in this study alluded that they experience various emotions such as sadness, loneliness, rejection and fault, especially blaming God. All of them mentioned that they miss their parents very much. Many authors agree that the emotional suffering of children usually begins with their parents' distress and progressive illness. Eventually the children suffer the death of their parents and the emotional trauma that results. This intensifies as HIV/AIDS cause drastic changes in family structure resulting in a heavy economic toll, requiring children to become caretakers and breadwinners (Hope, 1999: 98; UNICEF, 2003: 2; UNICEF, 2004: 1).

The research participants also indicated that they experience problems with relationships. Their associations with their cousins are characterized by conflict most of the time. They insinuate that many people do not understand them, especially their relatives. Most of them had poor relationships with friends and families. UNAIDS (2004: 3) asserts that many individuals do not understand the emotional anguish experienced by AIDS orphans. Even people who work with orphaned children struggle to understand the emotional anguish a child experiences as he or she watches one or both of his or her parents die. The illness and loss of a parent is very traumatic for a child and lack of consistent nurture can have serious developmental effects. They also lacked parental supervision and support. Some of these orphans felt that their caregivers neglected them. Some believed that they were being treated differently to other orphans. They were being subjected to cruel and dehumanising handling that led to feeling miserable, distressed and isolated. They were subjected to ongoing physical abuse, verbal violence and neglect. Peer pressure forced some of them to turn to delinquent behaviour for survival. The role played by peers in adolescents is very critical, according to Castrogiovanni (2004: 1). The function of the peer group in helping the adolescent to define his or her identity becomes very important in this developmental phase. Peer groups provide the opportunity to learn how to interact with others, opportunities to witness the strategies others use to cope with problems and emotional support. It appears however, that the strain of being an orphan may make young people even more dependent on friendship as would normally have been the case.

This is not always the case. Maputo (2004: 58) quotes McCarron (1994) concerning the difficulties orphaned adolescents may experience:

*Their anger at the unfairness of the world often contaminates their peer group relationship as they are likely to feel bitter that their friends have not had to cope with what they have had to deal with.*

Most of the participants in the study identified friends as sometimes the most important source of support to them.

It was noted that few of the respondents live in child-headed households. The majority of the respondents were living with extended families. This is in line with research conducted by UNICEF (2003: 1) who maintain that extended families are caring for 90% of all orphans. However, a number of authors such as Barnett and Whiteside (2002: 199); Van Dyk (2001: 334) as well as UNICEF (2003: 1) have noted that in recent times, the strands of the safety net provided by the extended family system have become increasingly frayed. Even those children, who are taken in by remaining extended relatives, still remain at risk. AIDS orphans put strain on households' resources. The majority of respondents indicated that their guardians are their grandparents who are too old to proffer proper care. Many authors such as Hope (1999: 96) as well as UNICEF (2003: 1) agree that caring for a grandchild or grandchildren may be an unwanted or difficult burden. Grandparents may be unprepared to take on the burden of total care for an orphan.

The respondents mentioned that most of the time role reversal takes place because they have to look after the grandparents or siblings. The respondents complained that they fulfil adult roles which affect their school performance, since they are deprived of study time at home. This is supported by Barnett and Whiteside (2002: 206) who aver that becoming an orphan of the epidemic is rarely a sudden switch in roles. When AIDS takes a parent, it usually takes childhood too, for if no other relatives' step in, the oldest child becomes the head of the household, taking the responsibility of supporting and caring for their siblings and other members of the family. This has serious consequences for a child's development.

#### **4.4.5 Conative problems**

The AIDS orphans were not optimistic about their future. They stated that they had lost self-control, which was not noticeable with other non-AIDS orphans. They stated that they experienced lack of will power and free will as well as consciousness. They lost focus in everything, and could not think creatively. Their lives were not purposeful with volition. Thus, the AIDS orphans possessed conative problems or lacked conative abilities. Without this aptitude, these AIDS orphans are bound to lose optimism/hope in life. They had no trust in the social system; some were on the verge of giving up. Due to

the absence of parental mentoring, the AIDS orphans lacked motivation and direction in life.

#### **4.4.6 Religious reasons**

The young adolescents had ambivalent reactions towards God and the church. It appears as if the support of the church often stops after the death and funeral of the parent, leaving the orphaned children to deal with their pain alone. The AIDS orphans were blaming God for the deaths of their parents, and questioned His existence. They also queried the fact why He took their parents away from them through AIDS. Some blame God for this for they believe that He is the cause of everything. They also seem to have lost faith in God.

### **4.5 SUMMARY**

In conclusion, Chapter four established that AIDS orphans are indeed experiencing problems which affect their life-world. The next chapter presents the interpretations, conclusions and recommendations to conclude the study.

## **CHAPTER 5:**

### **CONCLUSION, RECOMMENDATIONS AND LIMITATIONS**

#### **5.1 INTRODUCTION**

The previous chapter presented the findings of the research based on the analysis and interpretations of data collected from the respondents. These pertain to the effects of orphanhood through AIDS on the life world of adolescents.

The purpose of this chapter is to provide the conclusions, recommendations and the limitations of this research. Conclusions and recommendations are drawn from the literature study dealt with in chapter one and two, and from the empirical study covered in chapter four.

The goal of this study was to explore the effects of orphanhood through AIDS on the life world of an adolescent. The goal was achieved as the study provided information on the effects of orphanhood by AIDS on the life world of an adolescent. This information can also be utilized in the improvement of services to these affected children, as it indicated some of their actual felt need.

The formulation of a research question was relevant as the study was qualitative and exploratory. The following question summarized the objectives of the study:

**What is the impact of orphanhood on the life world of adolescents orphaned by AIDS in the Ratanda area?**

The study appeared to have been able to answer this question, as six themes were identified, namely:

- ✓ THEME ONE: Physical problems
- ✓ THEME TWO: Cognitive problems

- ✓ THEME THREE: Vulnerability
- ✓ THEME FOUR: Psychosocial problems
- ✓ THEME FIVE: Conative problems
- ✓ THEME SIX: Religious problems

It can be concluded that the HIV/AIDS pandemic has a damaging impact on the physical, social, cognitive, conative, spiritual and emotional status of the orphaned adolescent in the Ratanda area.

## **5.2 CONCLUSION**

### **5.2.1 Conclusion on the literature study**

From the literature study the researcher concludes that the epidemic has forced vast numbers of children into precarious circumstances, putting them at high risk of becoming infected with HIV. AIDS orphans are especially vulnerable to HIV infection for a host of social and economic reasons including poverty, sexual exploitation and violence, and lack of access to HIV information and prevention services. AIDS orphans (adolescents) are also particularly vulnerable to HIV infection because they often do not have available to them the basic healthy environment, that is food, shelter, education and health services, through which they can protect themselves from HIV and other infectious disease.

The extended family, which would have traditionally provided support for orphans, is greatly overextended in communities most affected by AIDS. It can no longer take care of its orphaned children. The consequence of this is that children are often socially isolated and deprived of basic social services. Many children are struggling to survive on their own in child-headed households, frequently carrying the burden of caring for family members living with HIV/AIDS. They do not know how to protect themselves and have no access to needed facilities.

Children in households with a HIV-positive member suffer the trauma of caring for ill family members. Seeing their parents or caregiver become ill and die can lead to psychosocial stress, which is aggravated by the stigma so often associated with HIV/AIDS.

HIV/AIDS will continue to affect the lives of several generations of children. The impact will mark their communities for decades as the number of impoverished children rise, their insecurity worsens, nurturing and support systems erode and mortality rises. All children especially AIDS orphans need love, care and support. As with adults it is important that they live healthy lives. Without adult guidance, life skill and means of sustaining their livelihood, these children become easy victims of exploitative and unhealthy child labour.

### **5.2.2 Conclusion on the empirical investigation**

The main aim of the study was to understand the effects of orphanhood through AIDS on the life world of the respondents. A qualitative, explorative and descriptive research design was employed to enable the researcher to gain insight into the respondents' effects of orphanhood in their life.

Data was gathered by means of in-depth, structured phenomenological interviews and field notes. Six themes emerged from the data analysis, namely:

#### **5.2.2.1 Physical problems**

Most of AIDS orphans experienced ill health after the death of their parents, for an example, headaches, lack of energy and lack of sleep). They experience chronic malnutrition due to lack of food or nutritious food. Children in these households are usually less well nourished and have a greater chance of being infected with HIV themselves. They need to be provided with healthy and balance meals.

#### **5.2.2.2 Educational problems**

Poor school performance and high failure rate: The emotional difficulties suffered by AIDS orphans combined with social stigma tend to block their ability to learn at school. They experience the loss of concentration and interest, poor school attendance and attention problem. Insufficient time to rest and study at home because of heightened home chores. AIDS orphans do not receive constant supervision and assistance with their schoolwork.

#### **5.2.2.3 Vulnerability**

AIDS orphans are at risk of being sexually abused. Sexually victimization of children contributes to the risk of suicidal attempts and delinquency, which may later develop into more serious criminal activity. They are vulnerable to the life of crime, HIV infections, abuse and exploitation; those are risks that most AIDS orphans are faced with. Parental loss during this stage creates negative social pressures. AIDS orphans are often deprived of their childhood. Roles are reversed because most of the time AIDS orphans take care of grandparents and other siblings. They occupy adult role and that affect their school performance as they are deprived of time to study at home.

#### **5.2.2.4 Psychosocial problems**

AIDS orphans are disadvantaged since they suffer from lack of guidance and affection, which are vital for their social and emotional development. Loss of parent, parental guidance, love and nurturance, change in family structure and functions, experience stress and they are still grieving. When parents die, these children often act out their feelings of anger, resentment in antisocial behaviour towards their guardians, teachers and friends. With the loss of their parents, these children have few resources to help them deal with bereavement and its repercussions. Therefore it is important that necessary structures be in place to offer necessary assistance. Stress is viewed as a major emotional problem amongst AIDS orphans. Most children become stressed as a

result of being unable to cope with problems they encounter. Some children experienced serious depression and some even attempted to commit suicide.

AIDS orphans have a tendency to isolate themselves. They experience various emotions such as sadness, loneliness, rejection, anger, guilt, fear and frustration.

Poor relationship: Lack of adult supervision or support and neglect from caregivers. AIDS orphans experience lack of support from both the family and community. Children grieving for dying or dead parents are stigmatized. They often experience rejection, lack of appreciation, affirmation and encouragement. They may personally experience the stigma of AIDS related illness, as they are teased by classmates or ostracized by peers and other parents.

#### **5.2.2.5 Conative problems**

Most AIDS orphans are less optimistic about their future, lack self-control, low self-esteem and had no hope. The self-esteem and confidence of AIDS orphans were viewed as often severely threatened. Rejection by significant others such friends, family and community usually cause one to lose confidence and thus experience reduced feelings of self-worth. They lack motivation and direction because of the absence of parental mentoring.

#### **5.2.2.6 Religious reasons**

AIDS orphans experience blame especially towards God. They mostly blame God for failing to prevent their parents' death. But most of them see church as an important resilience factor and believe in God.

The epidemic has forced vast numbers of children into precarious circumstances, putting them at high risk of becoming infected with HIV. AIDS orphans are especially vulnerable to HIV infection for a host of social and economic reasons including poverty, sexual exploitation and violence, and lack of access to HIV information and prevention services.

Many children are struggling to survive on their own in child-headed households, frequently carrying the burden of caring for family members living with HIV/AIDS. They do not know how to protect themselves and have no access to needed facilities. Children in households with a HIV-positive member suffer the trauma of caring for ill family members. Seeing their parents or caregivers become ill and die can lead to psychosocial stress, which is aggravated by the stigma so often associated with HIV/AIDS.

HIV/AIDS will continue to affect the lives of several generations of children. The impact will mark their communities for decades as the numbers of impoverished children rise, their insecurity worsens, education and work opportunities decline, nurturing and support systems erode, and mortality rises.

All children especially AIDS orphans need love, care and support. As with adults it is important that they live healthy lives. Without adult guidance, life skills and means of sustaining their livelihood, these children become easy victims of exploitative and unhealthy child labour.

### **5.3 RECOMMENDATIONS**

Based on the findings, the researcher makes the following recommendations:

- To ensure quality of care for AIDS orphans, intervention programmes such as life skills programmes should be promoted and strengthened. Life skill programmes both empower and equipped people with life skills that enhance their coping capacities. Successful programmes should impart knowledge, life skill as well as create social consensus on safer behaviours.
  - AIDS orphans life skills programmes necessitate a perceptiveness of the socio-emotional needs of AIDS orphan. This aspect of sensitivity is often missing in other life skills programmes
  - Life skills programmes should be age specific and developmentally appropriate.

- The programme should include life skills that promote healthy living. These abilities include problem solving, decision-making, critical thinking, communication and interpersonal skills, empathy, and methods to cope with emotions.
- Life skills can enable adolescents to develop sound and positive outlook on life. They can substantially improve substantially the emotional, social, cognitive and physical development of adolescents.
  
- Emotional support of all stakeholders. Everyone has a role to play. Orphans need the support of families, teachers, social workers and all other community members. Involvement in the care of AIDS orphans should be encouraged. It will break down the fear, ignorance and negative attitudes towards AIDS orphans.
  
- Emotional healing should be made available to all AIDS orphans.
  - Individual and bereavement therapy is necessary because of the emotional trauma AIDS orphans experience. They need to be helped to deal with unresolved feelings of hurt, pain, and bitterness.
  - Spiritual counselling is needed, especially if the children are blaming GOD.
  - Group therapy should be offered at school in the form of an open group. In this way, each adolescent would be able to access the support and therapeutic value of attending such a therapeutic group. Group assistance will enhance resilience.
  
- **FUTURE RESEARCH:** Another study which may contribute to this field of research is the effects of orphanhood by AIDS in the life world of an adolescent who is the head of the child-headed household.

#### **5.4 LIMITATIONS**

This study was limited to 13-18 year old AIDS orphans in Ratanda. Other age-groups were not explored. Further, it was limited to one method of data gathering that is an in-

depth interview, which focused on a small sample of adolescents, in Ratanda schools, thus the present findings cannot be generalised. Moreover, the researcher did not interview the caregivers, social workers and teachers.

## **5.5 SUMMARY**

When considering the pandemic proportion of the AIDS crisis in South Africa today, and the long-term effect of being orphaned in a society already overburden with orphans, one realises that something must be done to help these children. There are no easy answers or quick fix that can remedy the situation. The need is for planning for these orphaned children's futures. The uncaring consequences of the affected children will be felt by society for many generations to come. The battle against the HIV/AIDS will only be won by the involvement of all the community members.

## BIBLIOGRAPHY

- Abrams, R. 1999. *When parents die: Learning to live with the loss of a parent.* 2<sup>nd</sup> ed. London: Routledge.
- Adams, D.W. & Deveau, E.J. 1995. *Beyond the Innocence of Childhood: Helping Children and Adolescents Cope with Death and Bereavement.* New York: Baywood Publishing Company.
- AIDSmap News. 2007. *South African AIDS orphans and carers have greater depression, poorer health, need financial help.*  
<http://www.aidsmap.com/en/news>
- Alonzo, A.A. & Reynolds, N.R. 1995. *Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory.* Social Science and Medicine, 41(3), 303-315.
- Ary, D., Jacobs, L.C. & Razavieh, A. 1990. *Introduction to Research in Education.* 4<sup>th</sup> ed. New York: Hartcourt Brace Jovanovich.
- Avert, 2007. *HIV/AIDS in Africa.*  
<http://www.avert.org/aidsinafrica/>
- Avert, 2009. *The impact of HIV/AIDS in Africa.*  
<http://www.avert.org/aidsimpact.htm>.
- Babbie, E. & Mouton, J. 2001. *The Practice of Social Research.* Cape Town: Oxford University Press.
- Badr, H., Acitelli, L.K., & Taylor, C.L.C. 2007. *Does couple identity mediate the stress experienced by caregiving spouses?* Psychology & Health, 22(2): 211-229, February.

- Bamhart, C.L. & Bamhart, R.K. 1976. *The World Book Dictionary*. Vol 1. Chicago: Field Enterprises Educational Cooperation.
- Bamhart, R.K. 1995. *The World Book Dictionary*. Chicago: Field Enterprises Educational Corporation.
- Bandura, A. 1995. *Self-efficacy and changing societies*. New York: Cambridge University Press.
- Barnett, T. & Whiteside, A. 2002. *AIDS in the Twenty-first Century. Disease and Globalisation*. New York: Palgrave Mcmillan.
- Bauman, L. & Germann, S. 2005. *Psychosocial impact of the HIV/AIDS Pandemic on Children and Youth, in A generation at risk: The global impact of HIV/AIDS on orphans and vulnerable children*. G. Foster and Williamsen (eds).
- Berg, A.S. 1990. *The relationship between self-concept, family factors and academic achievement*. Med Dissertation. Johannesburg: University of Witwatersrand.
- Bless, C. & Higson-Smith, C. 2000. *Fundamentals of Social Research Methods: an African perspective*. 2<sup>nd</sup> ed. Cape Town: Jutas.
- Blume, L.B. & Zembar, M.J. 2007. *Middle childhood to middle adolescence: development from ages 8 to 18*.
- Bosman, H. & Jackson, S. 1990. *Coping and Self-Concept in Adolescence*. New York: Springer-Verlag.
- Brian, W. C. 2003. *Psychological aspects of HIV infection in children. Child Adolescent Psychiatric Clinic North America* 12 (3) 423-437.
- Brookes, I. & Gilmour, L. 2000. *Collins Gem: Thesaurus in A-Z form*. UK: Harper-Collins.

Brown, L., Macintyre, K. & Trujillo, L. 2003. *Interventions to reduce HIV/AIDS stigma: What have we learned.* 15(1), 49-69.

Campbell, C., Foulis, C.A., Maimane, S. & Sibiya, Z. 2005. "I have an evil child at my home" *Stigma and HIV/AIDS management in a South African community.* American Journal of Public Health, 95(5): 808-815.

Castrogiovanni, D. 2004. *Adolescence: Change and Continuity- Peer Group.*  
[http://inside.bard.edu/academic/special\\_proj/darling/adpeer1.htm](http://inside.bard.edu/academic/special_proj/darling/adpeer1.htm).

Chia, R. 1995. *From modern to postmodern organizational analysis.* Organization Studies, 16 (4): 579-604.

Christiansen, C. 2005. *Positioning children and institutions of childcare in contemporary Uganda.* African Journal of AIDS Research, 4(3): 173-182.

Coombe, C. 2000. *The impact of HIV/AIDS on the education sector (Part 5). HIV/AIDS on the education sector: The foundations of a control and management strategy in South Africa . Pretoria, June.*

Corr, C. & Corr, D. 1996. *Handbook of childhood death and bereavement.* New York: Springer Publication Co.

Crewe, M. 2003. *Extended AIDS review.* Pretoria: Pretoria University.

Crandall, C. S. 1991. *Multiple Stigma and AIDS: Illness Stigma and Attitudes toward Homosexual and IV Drug Users in AIDS-related Stigmatization.* Journal of Community & Applied Social Psychology, 1, 165-172.

Creswell, J.W. 1998. *Qualitative inquiry and research designs choosing among five traditions.* London: Sage Publications.

Crombie, I.K. & Davies, H.T.O. 1996. *Research in health care: design, conduct and I interpretation of health services research*. John Wiley & Sons: Chichester.

Dadds, M. & Hart, S. 2001. *Doing practitioner research differently*. London:Routledge.

Demmer, C. 2004. *Loss and grief following the death of a patient with AIDS*. Social Work/Maatskaplike Werk, 40(3): 294-315.

De Vos, A.S., Strydom, H., Fouchè, C.B., Poggenpoel, M. & Schurink, E.W. 1998. *Research at grass roots: a primer for the caring professions*. Pretoria: J.L. van Schaik Academic.

De Vos, A.S., Strydom, H, Fouche, C.B. & Delport, C.S.L. 2002. *Research at grass roots: For the social sciences and human service professions*. 2<sup>nd</sup> ed. Pretoria: J.L. Van Schaik Academic.

Doka, K.J. 1995. *Children mourning mourning children*. Washington: Hospice foundation of America.

Durkin, K. 1995. *Development Social Psychology – From Infancy to Old Age*. Cambridge: Blackwell Publishers Inc.

Dwivedi, K.N. 1999. *Group work with children and adolescents*. London: Jessica Kingsley Publishers.

Ebersohn, L. & Eloff, I. 2002. *The black, white and grey or rainbow children coping with HIV/AIDS*. Perspectives in Education, 20(2): 77-86.

Eden, M. & Huxham, C. 1996. *Action research for management research*. British Journal of management, 7 (1):75-86.

Essex, M., Mboup, S., Kanki, P. J., Marlink, R.G., & Tlou, S.D. 2002. *Aids in Africa*. 2<sup>nd</sup> ed. New York: Academic/Plenum.

- Fitzpatrick, J.J. 1999. *Nursing Research Digest*. New York: Springer.
- Foster, D. 1997. *Social Psychology*. In D.A. Louw and D. J.A. Edwards. *An introduction for students in Southern Africa, second edition*. Johannesburg: Heinemann.
- Foster, G., Levine, C. & Williamson, J. 2005. *Generation at risk: the global impact of HIV/AIDS on orphans and vulnerable children*. New York: Cambridge University Press.
- Fouche`C. B. & Delport, C. S. L. 2002. *Introduction to the research process*. In De Vos (ed) 2002. *Research at grassroots*. Second edition. Pretoria: Van Schaik Publishers.
- Frost, S. 2001. *HIV Positive: a book for caregivers to help children cope emotionally with HIV/AIDS, sickness, sadness, stigma, death, grief*. Durban, Northway: Media in Education Trust.
- Gasa, V.G. 2001. *The impact of disrupted family life and school climate on the self-concept of the adolescent*. Med Dissertation, Pretoria: University of South Africa.
- Geballe, S. & Gruendel, J. 1995. *Forgotten Children of the AIDS epidemic*. London: Yale University Press.
- Gerdes, L.C. 1989. *The developing adult*. Durban: Butterworths.
- Germann, S.E. 2005. *An exploratory study of quality of life and coping strategies of orphans living in child-headed households in the high HIV/AIDS prevalent city of Bulawayo, Zimbabwe*. Thesis Pretoria: University of South Africa.

- Gertwartz, A. & Gossart-Walker, 2000. *Home-based treatment for children and families affected by HIV and AIDS*. Child Adolescence Psychiatry Clinic North, 9 (2): 313-320.
- Gething, L., Papalia, S. & Wendkos Olde, S. 1999. *Lifespan Development*. McGraw-Hill Book Company: Roseville Australia.
- Giese, S. 2002. *Health, in impact and interventions: The HIV/AIDS pandemic and the children of South Africa*. J. Gow & C. Desmond (eds). Pietermaritzburg: University of KwaZulu-Natal.
- Gillis, H. 1994. *Counselling Young People*. Pretoria: Kagiso.
- Gillis, J.R. 2003. *Childhood and family time: a changing historical relationship*. (In Jensen. A.M., & McKee, L.(eds.) *Children and the changing family: between transformation and negotiation*, 149-164. London: Routledge/Falmer.
- Gilmore, N. & Sommerville, M.A. 1994. *Stigmatisation, scapegoating and discrimination in sexually transmitted disease: Overcoming “them and us”*. Social Science and Medicine 39(9): 1339-1358.
- Gouws, E. & Kruger, N. 1994. *Adolescent Development- An Educational Perspective*. Durban: Butterworth.
- Green, G.C. 1995. *Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be?* Social Science and Medicine, 41(4): 115-134.
- Griesel-Roux, E. 2004. *A case study exploring learners' experiential of HIV/AIDS programmes*. Unpublished D. Phil (Psych) Dissertation. Pretoria: University of Pretoria.

- Guest, E. 2001. *Children of AIDS: Africa's Orphan Crisis*. Pietermaritzburg: University of Natal Press.
- Hand, D.J. 1997. *Scientific and statistical hypotheses: bridging the gap*. In Mckenzie, G., Powell, J. & Usher, R. (eds.) *Understanding social research: perspectives and methodology and practice*: 124-136. The Falmer Press: Washington.
- Harding, R., Easterbrook, P., Higgison, I.J., Karus, D., Raveis, V.H. & Marconi, K. 2005. *Access and equity in HIV/AIDS palliative care: a review of the evidence and responses*. Palliative Medicine, 19: 251-258.
- Hartell, C.G. & Chabilall, J.A. 2005. *HIV/AIDS in South Africa: a study of the socio-educational development of adolescents orphaned by AIDS in child-headed households*. International Journal of Adolescence and Youth, 12: 213-229.
- Haslam, S.A. & McGarthy, C. 2003. *Research methods and statistics in psychology*. SAGE Publications: London.
- Hassard, J. 1991. *Multiple paradigms and organizational analysis: a case study* *Organizational Studies*, 12(2): 275-299.
- Henderson, C. E., Dakof, G. A., Schwartz, S. J. & Liddle, A. L. 2006. *Family Functioning, Self-concept and Severity of adolescent externalizing problems*. *J Child Fam Stud*. Springer Science+Business Media Inc.
- Herbert, M. 1993. *Working with Children*. Leicester: BPS Books.
- Holland, J. 2001. *Understanding Children's Experiences of Parental Bereavement*. Second Edition. Philadelphia: Kingsley.
- Hope, K.R. 1999. *AIDS and development in Africa: A social science perspective*. Binghamton: The Haworth Press.

- Huebner, A. 2000. *Adolescent Growth and Development*.  
<http://www.ext.vt.edu/pubs/family/350-850/350.html>
- Hunter, S. & Williamson, J. 2002. *Children on the Brink, Strategies to Support Children Isolated by HIV/AIDS*. Arlington USA: U.S. Agency for International Development (USAID).
- Huitt, W. 1998. *Self-concept and Self-esteem*. Educational Psychology Interactive: 21-24.
- Karim, A.S.S., Karim, A.Q. 2005. *HIV/AIDS in South Africa*. Cape Town: Cambridge University.
- Kartikeyan, S. 2007. *HIV and AIDS: Basic elements and practices*. Dordrecht: Springer.
- Kemp, P. 2001. *Empowering the supporters: enhancing the role of unqualified support workers in a housing scheme for people with mental health problems*. In Winter, R. & Munn-Giddings, C. *A handbook for action research in health and social care*, 88-101. Routledge, Taylor & Francis Group: London.
- Krefting, L. 1991. *Rigor in qualitative research: The assessment of trustworthiness*. *The American Journal of Occupation Therapy* 45, 214-222.
- Lerner, R.M. & Hess, L.E. 1999. *The Developmental of Personality, Self, and Ego in Adolescence*. New York & London: Garland.
- Levine, C., Foster, G. & Williamson, J. 2004. *Children on the Brink: A joint report of new orphan estimates and a framework for action*. New York: UNICEF.
- Link, B.G. & Phelan, J.C. 2001. *On stigma and its public health implications*. Annual Review of Sociology, 27: 363-385.
- Louw, D.A., Ede, D.M. & Louw, A.E. 1998. *Human Development*. 2<sup>nd</sup> ed. Pretoria: Kagiso.

- Louw, N., Edwards, D. & Orr, J. 2001. *HIV/AIDS: Care and support of affected and infected learners. A guide for educators*, Department of Health, Republic of South Africa, Government Printers, Pretoria.
- Lyon, M.E. & D'Angelo. 2006. *Teenagers, HIV and AIDS: Insight from youth living with the virus*. London: Praeger.
- Lythgoe, K. 2004. *Adolescence: Change and Continuity: Cognitive Transitions*.  
<http://inside.bard.edu/academic/specialproj/darling/adpeer/htm>.
- Mampa, L.L. 1995. *The self-concept and interpersonal relationships of student teachers*. Med. Dissertation. Pretoria: University of South Africa.
- Mayer, R.R. & Greenwood, E. 1980. *The design of social policy regards*. Englewood-Cliffs, NJ: Prentice Hall.
- Martin, A. J. & Debus, R. L. 1998. *Sef-reports of mathematics self-concept and educational outcomes: the role of ego-dimension self-consumerism*. *British Journal of Educational Psychology* (68): 517-535.
- Maykut, P. & Morehouse, R. 1995. *Beginning qualitative research. A philosophic & practical guide*. London: The Falmer Press.
- McMillan, J.H. & Schumacher, S. 1993. *Research in Education: A conceptual Introduction*. 3<sup>rd</sup> ed. New York: Longman.
- Meyer, W.F., Moore, C. & Viljoen, H.G. 1997. *Childhood and Adolescence*. Pacific Grove USA: Brooks/Cole Publishing Company.
- Meyer, W.J. & Engler, A. 1985. *In personality theories*. Boston: Houghton Mifflin.

- Monette, D.R., Thomas, J., Sullivan, T.J., & De Jong, C.R. 2005. *Applied social research: a tool for the human services*. 6<sup>th</sup> ed. Belmont, C.A: Brooks/Cole-Themsom Learning.
- Morgan, J.D. 1990. *The Dying and the Bereaved Teenager*. Philadelphia: Charles Press.
- Murthy, R. & Smith, L. 2005. *Grieving, sharing, and healing: A guide for facilitating early adolescent bereavement group*. Illinois: Research Press.
- Myers, M.D. 1997. *Qualitative research in information systems*. *Mis Quarterly* (21:2): 241-242.
- Neuman, L.W. 1997. *Social Research Methods: qualitative and quantitative approach*. 2<sup>nd</sup> ed. Boston: Allyn & Bacon.
- Neuman, P.R., Neuman, B.M. 1997. *Childhood and Adolescence*. Pacific Grove USA: Brooks/Cole Publishing Company.
- North-West Population-Trends and Development. 2004. HIV/AIDS Perspectives.
- Padgett, D.K. 1998. *Qualitative methods in Social work research challenges and rewards*. London, New Delhi: Sage Publication.
- Parker, R. & Aggleton, P. 2003. *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action*. Social Science and Medicine, 57(1): 15-24.
- Perschy, M.K. 2004. *Helping Teens Work through Grief*. 2<sup>nd</sup> ed. New York: Brunner-Routledge.
- Peterson, C. 1991. *Introduction to Psychology*. New York: Harper Collins.

- Pharaoh, R. 2004. *A Generation at Risk? HIV/AIDS, vulnerable children and security in Southern Africa*. Pretoria: Institute for Security Studies.
- Poku, N.K. 2005. *AIDS in Africa: How the poor are dying*. Cambridge: Polity Press.
- Pridmore, P. & Yates, C. 2006. *The Role of Open, Distance and Flexible Learning in HIV/AIDS Prevention and Mitigation for affected Youth in South Africa and Mozambique*. London: Libra Taylor/Panos Pictures.
- Putnam, R.W. 1999. *Transforming social practice: an action science perspective*. Management Learning, 30(2): 177-178.
- Raath, M.C. & Jacobs, L.J. 1993. *Dynamics of the self-concept*. Pretoria: Van Schaik.
- Richards, L. & Morse, J.M. 2007. *Readme first for a user's guide to qualitative methods*. 2<sup>nd</sup> ed. London: Sage Publications.
- Rice, F.P. 1992. *The Adolescents: Development, Relationship, and Culture*. 7<sup>th</sup> ed. Boston, MA: Allyn and Bacon.
- Rice, F.P. & Dolgin, K.G. 2005. *The Adolescent: Development, Relationship, and Culture*. 11<sup>th</sup> ed. New York: Ohio Wesleyan University.
- Rogers, C.R. & Engler, A. 1985. *In personality theories*. Boston: Houghton Mifflin.
- Rotheram-Borus, M.J., Weiss, R., Alber, S. & Lester, P. 2005. *Adolescent Adjustment Before and After HIV-Related Parental Death*. Journal of Consulting and Clinical Psychology. 73(2): 221-228.
- Ruxin, J., Binagwano, A. & Wilson, P.A. 2005. *Combating Aids in the developing world*. New York: Earthscan.

- Schaffer, R.D. 2002. *Development Psychology: Childhood and Adolescence*. Pacific Grove USA: Brookes Cole Publishing Company.
- Schmidt, D.E. 2000. *Writing in political science: A practical guide*. New York: Addison Wesley Longman, Inc.
- Schoeff, B.G. 2001. *AIDS action-research with women in Kinshasa Zaire*. *Social Sciences & Medicine*, 37(11): 1401-1413.
- Schon, J., Gower, L. & Kotze, V. 2005. *Elements of counselling: A handbook for counsellors in southern Africa*. Westhoven: ROCS.
- Sharp, S. & Cowie, H. 1998. *Counselling and Supporting Children in Distress*. London: Sage Publication.
- Singhal, A. & Howard, W.S. 2003. *The children of Africa confront AIDS*. Athens: Ohio University Press.
- Silverman, D. 2000. *Doing Qualitative Research: A Practical Handbook*. Thousand Oaks: Sage.
- Smart, R., Pleaner, P. & Dennil, S. 2001. *A primary HIV/AIDS Capacity Development Course for Government Planner*. Pretoria: Department of Social Development.
- Soul City 2003. *HIV/AIDS affect al children*. Jacana ISBN.
- Spitzer, T.E. 1997. *Adolescents' bereavement: The effects of family structure and parental relationship on adaptation to parental death*. MA dissertation. Michagan: UMI.
- Stansbury, J.P. & Sierra, M. 2004. *Risks, Stigma and Hondurian Garifuna Conceptions of HIV/AIDS*. *Social Science and Medicine*, 59(3): 457-471.

- Stanton, M. 2004. *Adolescences: Change and Continuity – Peer Influence.* <http://inside.bard.edi/academic/specialproj/daring/adpeer/htm>.
- Stanton, J.M. & Rogelberg, S.G. 2001. *Using internet/intranet web pages to collect organizational research data.* *Organization Research Methods*, 4(3): 200-217.
- Subbarao, K. & Coury, D. 2004. *Reaching out to Africa's orphans: A Framework for Public Action.* Washington: The World Bank.
- Taylor, J.L., Morley, S. & Barton, S.B. 2007. *Self-Organization in Bipolar Disorder: Compartmentalization and Self-Complexity.* *Cognitive Therapy & Research*, 31(1): 83-96.
- UNAIDS. 1999. *Children and HIV/AIDS: UNAIDS Briefing Paper.* Geneva, Switzerland.
- UNAIDS. 2002. *HIV/AIDS related stigmatization and discrimination. A review and suggested way forward to South Asia.* Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. 2004. Inter-agency Task Team on Education and HIV/AIDS in Geneva. 4 May 2004.
- UNAIDS/WHO. 2003. *AIDS epidemic update.* Geneva: Joint United Nations and World Health Organisation Programme on HIV/AIDS.
- UNICEF. 2003. *Africa's Orphaned Generations.* The United Nations Children's Fund.
- Uys, L. & Cameron, S. 2003. *Home-based HIV/AIDS care.* Cape Town: Oxford University Press.
- Valdiserri, R.O. 2002. *HIV/AIDS Stigma: An Impediment to Public Health.* American Journal of Public Health, 92(3): 341-342.

Van den Aardweg, E.M. & Van den Aardweg, E.D. 1993. *Psychology of Education: A Dictionary for Students*. 2<sup>nd</sup> ed. Pretoria: E & E Enterprises.

Van Dyk, A. 2001. *HIV/AIDS Care and Counselling: A Multidisciplinary Approach*. Pretoria: Pearson Education South Africa.

Van Dyk, A. 2003. *HIV/AIDS Care and Counselling: A Multidisciplinary Approach*. Second edition. Pretoria: Pearson Education South Africa.

Webb, D. 1997. *Helping Bereaved Children: A Handbook for Practitioners*. London: The Guilford Press.

Weber, R.P. 1990. *Basic Content Analysis*. CA: Sage Publications.

Whiteside, A. & Sunter C. 2000. *AIDS: The challenge for South Africa*. Tafelberg: Human and Rousseau.

Wojcicki, J.M. & Malala, J. 1998. *Condom use, power and HIV/AIDS risk: sex workers bargain for survival in Hillbrow/Joubert Park/Berea, Johannesburg*. Social Sciences & Medicine, 53: 99-121.

Worden, J.W. 1996. *Children and grief: When a parent dies*. New York: Guilford.

World Book Encyclopedia. 1996. Vol 1. London: World Book International.

Yin, R.K. 1994. *Case study research design and methods*. 2<sup>nd</sup> ed. SAGE Publications: Thousand Oaks.

Youth Net. 2005. *Adolescents: Orphaned and Vulnerable in the time of HIV/AIDS. Youth Issues Paper 6*.

[www.thi.org/youthnet](http://www.thi.org/youthnet)

**APPENDIX A**

**Permission to conduct research.**



**APPENDIX B****SEMI-STRUCTURED INTERVIEW SCHEDULE**

RESPONDENT NAME:

**BACKGROUND INFORMATION**

- ❖ Tell me about yourself.
  - Who was part of your family when you were born?
  - How did it change since you were born?
- ❖ Tell me about the household you live in.
  - How did it happen that you live with them?
- ❖ Tell me about children in the household you are living in.
  - Who are they?
  - How are they related to you?
  - Are they older or younger than you, or the same age?
  - Do you sometimes play together?
- ❖ Tell me about the adults in the household you are living in.
  - Who cares about you the most?
  - Who helps you, listen to you when you need someone?
- ❖ Tell me about the house you are living in? Is it safe?
  - Tell me about the space where you sleep.
  - Tell me about the space where you keep your own things and do your homework.
  - Is there someone at home who is troubling you or who makes you feel uncomfortable?
- ❖ Tell me about your day during the week.
  - What do you do first when you get up in the morning?
  - What do you do in the morning, afternoon and evening?

**TIME DURING PARENTAL ILLNESS AND DEATH**

- Did you have to look after your mother/father when they were ill?

- Tell me about it.
  - What do you remember?
- Do you have a photo and other valuables of your father and mother?
- Tell me about the manner in which your family supported you in the following situations:
- Before your mother/father died.
  - During your mother's/father's illness.
  - The day when your mother/father died

## RELATIONSHIPS

- ❖ Tell me about your friends
- Who is your best friend?
  - What do you do when you are together?
  - Do you have a friend who you can trust and depend on her/him?
  - Do you have time to spend with your friends?
  - Did your friends change towards you when your parents became ill and died?
  - Does someone in your class or neighbourhood gossip about you?
  - Who teases or bullies you?

## PHYSICAL HEALTH AND WELL-BEING

- ✓ What is your favourite food?
  - How often do you eat your favourite food?
  - What food do you eat most often?
  - How many times per week do you have less than enough or nothing at all, food to eat?
  - Where do you get food from?
  - Who cooks for you?
- ✓ Do you have problem sleeping? Or do you sometimes have dreams that upset you?
- ✓ Do you have problems physically?

- Any sickness
- ✓ Has someone told you about the changes that will take place in your body when you grow up?
- ✓ Has someone talked about HIV/AIDS and contraceptives with you?

## EDUCATION

- In what grade are you?
- Do you go to school every day?
  - What are your reasons for you sometimes missing school?
  - How often do you miss school?
- What problems do you experience at school?
  - Tell me about your school work.
  - Tell me about your performance.
  - How long can you concentrate in class or when you study at home?
  - Do you feel restless sometimes? How do you react then?
  - If you don't understand the teacher in class, how do you handle the situation?
- Are you able to do your homework?
  - Who ensures that homework is done?
- Do you give up easily when you struggle?
  - Do you ask other people for advice?
  - Do you take their advice?
- Who encourages you when you want to give up?
- Tell me about problems you sometimes face.
  - How do you solve them?

## EMOTIONAL NEEDS

- ❖ Tell me about the last time someone made you angry. What did you do and say?
  - I would like to know if you can discuss this or other feelings that you experience with your caregiver (grandmother/sibling).
  - If yes, how does that makes you feel?

- If no, what, in your opinion, makes you to be unable to discuss this with your caregiver?
- ❖ What problems do you experience regarding your emotions?
  - What are your emotional needs?
- ❖ What problems do you experience regarding your mental health?
- ❖ What problems do you experience regarding your support system?
- ❖ If you could change anything in your household to make life better, what would it be?

## RELIGION

- ✓ Tell me about your church
  - Your pastor
  - Support you get
  - Your participation