

**THE EXPERIENCES OF ADOLESCENTS  
ORPHANED BY HIV/AIDS RELATED  
CONDITIONS**

Dissertation presented by

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## **ABSTRACT**

### **The experience of adolescents orphaned by HIV/AIDS related conditions**

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The goal of this study was to explore the experiences of adolescents who were orphaned by HIV/AIDS related conditions, thereby improving the knowledge base and insight of social workers that will enable them to render more effective services.

The objectives of this study was:

- To build a knowledge base of existing literature on the impact of HIV/AIDS related circumstances on orphaned adolescents.
- To conduct an empirical study of the experiences of adolescents on the following terrains, namely Belonging, Mastery, Independence and Generosity.
- To make recommendations about the experiences of adolescents orphaned by HIV/AIDS related conditions to be considered during formulation of intervention plans by social workers.

This qualitative study endeavoured to answer the following research question: "What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande region of Mpumalanga?"

The researcher aimed to document these experiences to improve the helping professions' understanding of the phenomenon. This may lead to more successful intervention strategies for these adolescents.

The study was feasible, as it was within the financial and practical means of the researcher. She had access to the target group and she had permission from the Department of Health and Social Services to conduct the study, using their resources, clients and data.

Three themes emerged from data analysis, namely:

- \* THEME ONE: Sources of support, hurt and anger
- \* THEME TWO: My life changed after I became an orphan
- \* THEME THREE: Parents' illness and death

From the research findings, recommendations were made on a micro, macro and meso level. On a micro-level, this included improved foster parent screening, life skills camps, improved awareness campaigns and the establishment of support groups.

On macro-level, the researcher is of the opinion that the strengthening of Home Based Care Groups, After- school centres and Children's Homes should receive attention.

On a meso-level, legislation changes and improved provision of medication to ill parents are recommended.

### KEY WORDS

Adolescent orphans  
 Adolescence  
 HIV/AIDS  
 Adolescent developmental tasks  
 Psychosocial development  
 Grief  
 Anger  
 Loneliness  
 Poverty  
 Changed social roles

### KERN WOORDE

Adolossente weeskinders  
 Adolossensie  
 MIV/VIGS  
 Adolossente ontwikkelingstake  
 Psigo-sosiale ontwikkeling  
 Rou  
 Woede

Eensaamheid

Armoede

Veranderde sosiale rolle

## OPSOMMING

### Die ervarings van adolossente wat wees gelaat is in die Gert Sibande Distrik van Mpumalanga weens MIV/VIGS

deur

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Die doel van hierdie studie was die eksplorering van die ervarings van adolossente wat wees gelaat is as gevolg van MIV/VIGS in die Gert Sibande distrik van Mpumalanga en om daardeur die kennisbasis van maatskaplike werk uit te brei sodat beter dienste aan hulle gelewer kan word.

Die doelwitte van die studie was:

- Om vanuit 'n literatuurstudie die impak van MIV/VIGS op die adolossent te bestudeer.
- Om empiriese navorsing te doen oor die ervarings van adolossente wat wees gelaat is as gevolg van MIV/VIGS in die Gert Sibande distrik van Mpumalanga.
- Om aanbevelings te maak aan maatskaplike werkers in die praktyk ten einde dienslewering aan die geaffekteerde adolossente te verbeter.

Die navorser was daarop uit om die volgende navorsingsvraag te beantwoord, naamlik: "Wat is die ervarings van adolossente wat wees gelaat is as gevolg van MIV/VIGS in die Gert Sibande distrik van Mpumalanga?". Die navorser wou hierdeur die begrip van maatskaplike werkers oor die fenomeen verbeter ten einde by te dra tot verbeterings in dienslewering aan die geaffekteerde teikengroep.

Data is versamel deur middel van 'n semi-gestruktureerde onderhoudskedule wat saamgestel is uit beginsels van Ontwikkelings Assessering. Onderhoude is opgeneem op band, getranskribeer en daarna verwerk. Data insameling is gedoen in Piet Retief, Carolina, Ermelo, Hendrina en Chrissiesmeer.

Nie-ewekansige steekproef metodes is gevolg om die 15 mees gepaste deelnemers te identifiseer. Die navorsing was uitvoerbaar, aangesien dit binne die finansiële en logistiese vermoëns van die navorser was.

Vanuit die verwerking van die data, is drie hoof temas geïdentifiseer, naamlik:

TEMA EEN: Bronne van ondersteuning, hartseer en woede.

TEMA TWEE: Dit is hoe my lewe verander het toe ek wees gelaat is.

TEMA DRIE: My ouers se siekte en dood.

Vanuit hierdie resultate is die navorser in staat gestel om aanbevelings vir die praktyk te maak. Op 'n mikro vlak word verbeterde pleegouerkeuring en ondersteuning voorgestel, saam met meer kultuurvriendelike inligtingsprogramme. Ondersteuningsgroepe vir die geaffekteerde adolosente word ook op die vlak voorgestel.

Op 'n makro vlak word aanbeveel dat aandag gegee word aan die ontwikkeling van Gemeenskapsgebaseerde organisasies en Naskoolsentrums. Die uitbreiding van die kapasiteit van kinders in die Mpumalanga Provinsie word ook voorgestel, ten einde voorsiening te maak vir toenemende getalle kinders wat nie in die gemeenskap versorg kan word nie.

Op meso vlak word veranderings in wetgewing voorgestel ten einde families in staat te stel om vinniger toegang tot staatshulp te verkry. Die verskaffing van gepaste medikasie aan siek ouers word ook aanbeveel, ten einde die lewenskwaliteit en lewensverwagting van ouers te verbeter.

## TABLE OF CONTENTS

Acknowledgements  
Dedication  
Abstract  
Opsomming

### **CHAPTER ONE : INTRODUCING THE STUDY**

1.1 INTRODUCTION AND PROBLEM FORMULATION .....	01
1.2 PROBLEM FORMULATION .....	04
1.3 PURPOSE, GOAL AND OBJECTIVES OF THE STUDY .....	06
1.3.1 The purpose of the study .....	06
1.3.2 Goal of the study .....	06
1.3.3 Objectives of the study .....	06
1.4 RESEARCH QUESTION .....	07
1.5 RESEARCH APPROACH .....	07
1.5.1. Selection of a researchable topic .....	07
1.5.2. Final formulations .....	07
1.5.3. Planning .....	09
1.5.4. Implementation .....	10
1.5.5. Interpretation and presentation .....	11
1.6 TYPE OF RESEARCH .....	11
1.7 RESEARCH STRATEGIES AND METHODOLOGY .....	11
1.8 PILOT STUDY .....	12
1.8.1 Pilot test of interview schedule .....	12
1.8.2 Feasibility of the study .....	13
1.9 RESEARCH POPULATION, BOUNDARIES OF THE SAMPLE AND THE SAMPLING METHOD .....	13
1.9.1 Research universe and population .....	13
1.9.2 Sampling .....	14
1.10 ETHICAL ISSUES .....	15
1.10.1 Voluntary participation .....	15
1.10.2 Informed consent .....	15
1.10.3 Confidentiality .....	16
1.10.4 No harm to participants .....	16
1.10.5 Deceiving of subjects .....	16
1.10.6 Release of the findings .....	17
1.10.7 Restoration of the subjects .....	17



1.11 DEFINITION OF KEY CONCEPTS.....	17
1.11.1 Adolescent.....	17
1.11.2 Orphan/s .....	18
1.11.3 HIV/AIDS.....	19
1.11.4 Experiences.....	19

## **CHAPTER TWO : THE HIV/AIDS PANDEMIC**

2.1 INTRODUCTION .....	21
2.2 HISTORY OF THE PANDEMIC .....	22
2.3 THE GLOBAL EXTENT OF THE PANDEMIC .....	24
2.4 THE IMPACT OF THE HIV/AIDS PANDEMIC .....	26
2.4.1 Factors contributing to the spread of HIV/AIDS .....	26
2.4.1.1 Low condom use and unsafe sexual behaviour .....	27
2.4.1.2 Poverty .....	28
2.4.1.3 Social factors .....	29
2.4.2 Perception of sexuality and illness in traditional Africa.....	34
2.4.3 Effects of HIV/AIDS on the South African society.....	38
2.4.3.1 Impact on health care and social services .....	39
2.4.3.2 Impact on education .....	41
2.4.3.3 Demographic Impact .....	41
2.4.3.4 Economic and macro-economic impact .....	45
2.5 RESPONSES TO THE HIV/AIDS PANDEMIC .....	48
2.6 SUMMARY .....	51

## **CHAPTER THREE: THE EXPERIENCES OF THE HIV INFECTED PERSON AND THE CONCURRENT INFLUENCE OF THE ILLNESS ON EXTENDED FAMILY MEMBERS**

3.1 INTRODUCTION .....	53
3.2 HIV/AIDS INFECTION .....	55
3.2.1 The physical consequences of HIV infection.....	55
3.2.1.1 Types of HI Viruses.....	55
3.2.1.2 Transmission.....	56
3.2.1.3 Development and symptoms of the illness.....	58
3.2.1.3.1 Adults .....	58
3.2.1.3.2 Children .....	61
3.2.1.4 Testing .....	63
3.2.1.5 Treatment and care.....	64
3.2.2 PSYCHOSOCIAL EXPERIENCES OF THE INFECTED PERSON .....	66

3.2.2.1 Shock.....	66
3.2.2.2 Fear.....	66
3.2.2.3 Loss.....	67
3.2.2.4 Grief.....	67
3.2.2.5 Guilt.....	68
3.2.2.6 Denial.....	68
3.2.2.7 Anger.....	68
3.2.2.8 Anxiety.....	69
3.2.2.9 Low self-esteem.....	69
3.2.2.10 Depression.....	69
3.2.2.11 Suicidal behaviour or thinking.....	70
3.2.2.12 Obsessive conditions and hypochondria.....	70
3.2.2.13 Spiritual concerns.....	70
3.3 THE ORPHAN PHENOMENON	
3.3.1 Introduction.....	71
3.3.2 Food, food security and education needs.....	73
3.3.3 Housing, clothing and bedding.....	74
3.3.4 Schooling.....	74
3.3.5 Health Care.....	75
3.3.6 Psychological distress caused by an AIDS illness and death in a family.....	75
3.3.6.1 Disturbing clinical course of HIV/AIDS.....	76
3.3.6.2 Uncertainty.....	77
3.3.6.3 Multiple losses.....	78
3.3.6.4 Stigma, silence and family secrets.....	80
3.3.6.5 Complicated grief.....	82
3.3.7 Developmental delays.....	87
3.3.8 Changed Roles.....	88
3.3.9 Discrimination, abuse and neglect.....	90
3.3.10 Child-headed households.....	93
3.4 IMPACT ON THE ELDERLY.....	98
3.5 STRENGTHENING RESILIENCE AS COPING STRATEGY FOR THE ORPHANED CHILD.....	98
3.6 SUMMARY.....	102

## **CHAPTER FOUR : THE ADOLESCENT DEVELOPMENTAL PHASE**

4.1 INTRODUCTION.....	104
4.2 ADOLESCENCE IN CONTEXT.....	105
4.2.1 Development defined.....	105
4.2.2 Developmental stages preceding adolescence.....	105
4.2.2.1 Stage one: Birth to six months.....	106
4.2.2.2 Stage two: Six to 18 months.....	107
4.2.2.3 Stage three: 18 months to three years.....	108

4.2.2.4 Stage four: Three to six years.....	109
4.2.2.5 Stage five: Six to twelve years.....	109
4.3 ADOLESCENCE DEFINED .....	111
4.4 PHYSICAL MATURATION .....	112
4.4.1 Physical changes in girls.....	113
4.4.2 Physical changes in boys.....	115
4.4 COGNITIVE DEVELOPMENT .....	116
4.5 PSYCHOSOCIAL DEVELOPMENT.....	117
4.5.1 Establishment of an identity.....	118
4.5.2 Establishment of autonomy.....	122
4.5.3 Establishment of intimacy.....	124
4.5.3.1 Sexuality as form of intimacy .....	124
4.7 ACHIEVEMENT AND CAREER CHOICES .....	129
4.8 THE GRIEVING ADOLESCENT .....	130
4.9 SUMMARY .....	133

## **CHAPTER FIVE: RESEARCH FINDINGS**

5.1 INTRODUCTION .....	134
5.2 GOAL AND OBJECTIVES OF THE STUDY.....	134
5.2.1 Goal of the study .....	134
5.2.2 Objectives of the study .....	134
5.3 RESEARCH QUESTION .....	135
5.4 RESEARCH METHODOLOGY.....	135
5.5 DATA COLLECTION .....	136
5.6 DATA ANALYSIS.....	136
5.7 PRESENTATION OF FINDINGS.....	138
5.7.1 Biographical profile of participants .....	138
5.7.2 Themes and sub-themes.....	146
5.7.2.1 Theme One: Sources of support, hurt and anger.....	146
5.7.2.2 Theme Two: My life changed after I became an orphan.....	158
5.7.2.3 Theme Three: My parents' illness and death.....	167
5.8 CONCLUSIONS.....	169
5.9 SUMMARY .....	171

**CHAPTER SIX : SUMMARY, CONCLUSION AND RECOMMENDATIONS**

6.1 INTRODUCTION .....	173
6.2 EVALUATION OF GOAL AND OBJECTIVES	
6.2.1 Evaluation of the goal of the study .....	174
6.2.2 Objectives of the study .....	174
6.2.2.1 Objective One .....	175
6.2.2.2 Objective two .....	175
6.2.2.3 Objective three.....	175
6.3 EVALUATION OF THE RESEARCH QUESTION .....	176
6.4 RESEARCH METHODOLOGY.....	176
6.4.1 Phase 1: Selection of a researchable topic.....	176
6.4.2 Phase 2: Formal formulations .....	177
6.4.5 Phase 3: Planning.....	177
6.4.6.Phase 4: Implementation .....	178
6.4.7.Phase 5: Analysis, interpretation and presentation .....	179
6.4.8 Conclusions and recommendations.....	179
6.6 FINDINGS REGRADING THE EXPERIENCES OF ADOLESCENTS ORPHANED BY HIV/AIDS RELATED CONDITIONS	
6.6.1 Theme One: Sources of support, hurt and anger.....	180
6.6.2 Theme Two: My life changed after I became an orphan.....	180
6.7 RECOMMENDATIONS .....	182
6.7.1 Recommendations for the improvement of services on a micro- level.....	182
6.7.2Recommendations for the improvement of services on a macro- level.....	184
6.7.3 Recommendations for improvement of services on a meso- level.....	185
6.8 SUMMARY .....	186
<b>BIBILIOGRAPHY .....</b>	<b>188</b>
<b>APPENDIXES</b>	
APPENDIX 1	
Consent Form.....	198
APPENDIX 2	
Semi-structured interview schedule .....	200
APPENDIX 3	
The application of the Developmental Approach with respect to assessment and programmes for children and youth.....	219

APPENDIX 4  
Permission to conduct research..... 223

## LIST OF FIGURES

FIGURE 2.1 The links between socio-economic, bio-medical and behavioural determinants of the spread of AIDS in Africa .....	34
FIGURE 5.1 Theme one and sub-themes .....	139
FIGURE 5.2 Theme two and sub-themes .....	139
FIGURE 5.3: Theme three and sub-themes .....	140
FIGURE 5.4 Main sources of income .....	156
FIGURE 5.5 Staple food of adolescents .....	158

## LIST OF TABLES

TABLE 2.1 Estimated HIV prevalence among antenatal clinic attendees, by Province .....	22
TABLE 2.2 The actual demographic impact of HIV/AIDS on the South African population .....	40
TABLE 2.3 Comparison between the South African and African HIV/AIDS infection rates. ....	41
TABLE 3.1 Convention on the Rights of Children .....	88
TABLE 5.1 Profile of Research Participants .....	131
TABLE 5.2 Emotions expressed by participants .....	154

# CHAPTER 1

## RESEARCH METHODOLOGY

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### 1.1 INTRODUCTION AND PROBLEM FORMULATION

“ If AIDS takes a parent, it usually takes a childhood too...for the children who have lost their parents to AIDS, grief is only the beginning of their troubles “ (Newsweek, 2000:42).

HIV/AIDS poses a unique challenge as it kills adults in the prime of their working and parenting life. It reduces the workforce, fractures and impoverishes families, orphans millions and shreds the fabric of communities (Department of Social Development, 2003: 4).

Sub-Saharan Africa is severely affected by the HIV/AIDS pandemic. Approximately 2,4 million people died of AIDS during 2000 in this region of Africa, according to the World Health Organization and UNAIDS (Smart, Dennil & Pleaner, 2001:74).

It is difficult to quantify the extensiveness of the pandemic in Southern Africa as it is not a reportable disease, but Whiteside and Sunter (2000:53) estimated that 4,2 million South Africans (19,9% of the population) were HIV positive in 2000.

According to the Mpumalanga Population Unit, 320 000 to 352 000 persons in Mpumalanga are infected with HIV or have AIDS. (Department of Social Services, Population and Development, 2000:10) This represents 11% of the population in the province. According to the Population Unit, there is a proven relationship between poverty and HIV/AIDS. With a poverty rate of 57% and the antenatal HIV prevalence close to 30% in the year 2000, it is clear that the Mpumalanga Province is extremely vulnerable to HIV/AIDS and its consequences. The Actuarial Society of South Africa calculated that 46 231

children would be without their mothers in 2004 in this province (Department of Social Services, Population and Development, 2000:10).

It is however, not the statistics that make the orphan crisis one unseen before. Biya (2004) agreed with Cross (2001:134) that the children who often watched their parents die alone and in pain, are left in a world where AIDS unravelled the traditional safety nets such as the extended family. In situations of poverty, adult responsibilities within households are often shifted to children (Gouws, 2004 ; Selepe, 2004).

According to Noeth (2002:143) among the many vulnerable members of society, young people who have lost both their parents are among the most exposed of all. This is particularly true in Sub-Saharan Africa, where few social support systems exist outside of families and where basic social services are largely inadequate. An additional concern is that orphans enduring the grave social isolation that accompanies AIDS when it strikes a family are at far greater risk of eventually becoming infected themselves. Often emotionally vulnerable and financially desperate orphans are more likely to be sexually abused and forced into exploitative relationships.

Literature agrees that societal structures such as the extended family system have met most of the social, mental and emotional needs of children, including orphans, and provided a protective social environment in which they could grow and develop. (Nelson Mandela Children's Fund, 2001:13; Noeth, 2002:146).

Barnett and Blaikie (1992:119) are of the opinion that orphans are mostly cared for by grandparents who often experience financial problems. The health and general well being and development of these children may be neglected as grandparents, the extended family, fictive kin such as social workers and even communities may not be able to carry the burden of so many orphaned children (Mabutho, 2004:68; Selepe, 2004).



Unfortunately, there are clear indications that the integrity, cohesion, capacity and efficiency of the extended family as a social support network are being undermined by a range of factors including social upheavals, rapid urbanisation, poverty and over-stretched resources (Nelson Mandela Children's Fund, 2001:5).

Thus, along with the high number of adults dying from AIDS, and reduced capacity of communities to support and care for children, is a changing family structure and care giving patterns where the burden of care often falls on those who have the least capacity to provide parenting, support and care for themselves and other children: the adolescent orphan (Biya, 2004). Adolescents also have several complex developmental tasks on a physical, cognitive and social level (Louw, 1998:379) that will be complicated.

Strode and Grant (2001:3-32) conducted research in 2001 to determine the level of stigmatisation and discrimination children experience in South Africa because of HIV/AIDS. They concluded their study with the most common emotional experiences of children affected and infected, which are:

- Seriously diminished sense of self-worth
- Attitude of powerlessness
- Unresolved and unventilated grief
- Worry about ill parents, the future and poverty.

LoveLife (2000:9) sums up the situation by saying "As the illness becomes impossible to conceal, household members are more likely to experience rejection, fear of contagion and anticipatory grief."

The rationale of this study can thus be formulated as the social worker's lack of knowledge regarding the experiences of adolescents orphaned by HIV/AIDS related circumstances. This research can contribute to the knowledge base of social workers and guide social work intervention according to the challenges and needs of these adolescents.

## 1.2. PROBLEM FORMULATION

The work environment of social workers of the Department of Health and Social Services in the Gert Sibande area of Mpumalanga, is riddled with new and complex social problems, often draining the available resources. Personnel in rural areas are confronted with huge numbers of orphaned children in need of urgent statutory intervention, mostly because of the economic burden brought about by their "orphan" status (Biya, 2004 ; Selepe, 2004). Very little time can be spent on the socio-emotional care of these children, as the emphasis largely falls on the provision of basic needs, like grants, school uniforms and food. According to Badenhorst (2004) approximately 3500 children are presently in alternative care (mostly foster care) in this region.

Adolescents are often called upon to become functional heads of households, whilst still being mere children themselves. Others have to rely on already poverty stricken extended family members for support and nurturing. Some adolescents are nursing terminally ill parents or siblings (Biya, 2004). Normal developmental tasks for them are complicated by added stress brought about by their orphaned care status.

Adolescents in this situation have to cope with the deprivation of a childhood and have to cope with the need to be a child and the imperative to assume adult responsibilities as household provider (Nelson Mandela Children's Fund, 2001:27). Mathuna (2004) indicated that the adolescents become angry, depressed and desperate for love and attention. They are unable to cope in school and only live one day at a time without dreams and plans for the future.

The experiences of adolescent orphans are not clearly described in literature. Available literature mostly describes first-world experiences. The word "orphan" is used as a collective term, including all children from birth to young adults, not taking into consideration their different developmental tasks and needs. Literature has a lot of statistics and references to the provision of

basic needs like food, clothing and shelter, disregarding the socio-emotional aspects of the children it aims to assist.

According to Harber (1998:23), current social welfare interventions progress slowly and are subject to setbacks. It does not provide immediate relief to needy children. She also indicated that assistance should not only focus on survival, but also on the psychosocial, educational and moral aspects of deprivation. For this to be possible, an understanding of the experiences and needs of children directly affected by HIV/AIDS related circumstances are necessary (Biya, 2004; Gillwald, 2002). It is also necessary to refer more specifically to the developmental stages of children, instead of grouping all children together as “orphans”.

It became apparent that the available literature often only vaguely refers to the African situation. Literature about European and American experiences is available, but has little bearing on the South African context (Robertson & Donaldson, 2003:01). The vast differences in the availability of resources and the magnitude of the HIV/AIDS pandemic make it difficult to relate the documented experiences of children to those in South Africa. A void exists around the emotional and social impact of HIV/AIDS related circumstances on the South African adolescent.

In view of the fact that orphaned adolescents are often becoming functional heads of households or are dependent on poverty stricken family members, a situation arose that necessitated an investigation into the experiences from the perspective of the adolescent orphaned by HIV/AIDS related conditions.

It was very difficult to determine if a child is orphaned because of HIV/AIDS, as death certificates usually do not state that as the cause of death (Gouws, 2004; Mathuna, 2004). For the purposes of this study, it was only possible to verify that the parents were ill with AIDS-like symptoms and that the family was supported by an HIV/AIDS Home Based organisation.

It is in the light of the above context that an exploratory qualitative study was seen as appropriate to provide a working knowledge and understanding of the experiences and challenges facing orphaned adolescents in a poverty - stricken society like Mpumalanga.

### **1.3. PURPOSE, GOAL AND OBJECTIVES OF THE RESEARCH STUDY**

A goal and an objective are defined by Webster's Third International Dictionary quoted by De Vos (1998:6) as: " The end toward which effort or ambition is directed: aim, purpose".

#### **1.3.1 The purpose of the study**

The study was exploratory by nature, as it explored the experiences of adolescents directly affected by HIV/AIDS related conditions. According to Bless and Higson-Smith (in Fouché, 2002:109), exploratory research is: "...conducted to gain insight into a situation, phenomenon, community or individual." The study also had a descriptive nature, as the experiences of the adolescents were described. Bless and Higson-Smith (2000:154), see descriptive research as: "social research with the primary aim of describing (rather than explaining) a particular phenomenon".

#### **1.3.2 Goal of the study**

The goal of this study was to explore the experiences of adolescents who were orphaned by HIV/AIDS related conditions, thereby improving the knowledge base and insight of social workers that will enable them to render more effective services.

#### **1.3.3 Objectives of the study**

The following objectives had to be achieved to attain the aim of the research:

##### Objective 1:

To build a knowledge base of existing literature on the impact of HIV/AIDS related conditions on children left behind, orphanhood, deprivation and adolescent development and challenges

Objective 2:

To conduct an empirical study on the experiences of adolescents in terms of the following themes derived from the Developmental Assessment Framework: Belonging, Mastery, Independence and Generosity.

Objective 3:

To produce a qualitative research report about the experiences of adolescents orphaned by HIV/AIDS related conditions.

#### **1.4 RESEARCH QUESTION**

A research question can be defined as: "...concerned with a single variable or with the relationship between two variables" and that: "...a good research question is one that can be answered by collecting data and whose answer cannot be foreseen prior to the collection of data" (De Vos, 1998:116).

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

**What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande Region of Mpumalanga ?**

#### **1.5 RESEARCH APPROACH**

The research approach was qualitative. This decision was based on the guideline of Marshall and Rossman (in De Vos, 2002:80), describing situations where the qualitative approach would be the preferred one:

- Research that cannot be done experimentally for practical or ethical reasons
- Research that delves in depth into complexities and processes
- Research for which variables have not yet been identified
- Research on unknown societies or innovative systems

Bless and Higson-Smith (2000:156) define qualitative research as: "Research conducted using a range of methods which use qualifying words and descriptions to record and investigate aspects of social reality".

The research approach was thus qualitative by nature, as the information was gathered using words and descriptions to give meaning to the social reality as experienced by adolescents orphaned by HIV/AIDS related conditions.

The research process utilized in this study was derived from the five phases of the qualitative research framework outlined by Fouche and Delport (2002:84-85).

#### **1.5.1.PHASE 1: SELECTION OF A RESEARCHABLE TOPIC**

The identified research problem formed the basis of this study. This research problem was identified from:

- Literature study
- Practical experience of the impact of the disease on the services of the Mpumalanga Department of Health and Social Services (Badenhorst, 2004; Biya, 2004).

#### **1.5.2 PHASE 2: FORMAL FORMULATIONS**

The research approach was qualitative. This decision was based on the guideline of Marshall and Rossman (in De Vos, 2002:80), describing situations where the qualitative approach would be the preferred one:

- Research that cannot be done experimentally for practical or ethical reasons
- Research that delves in depth into complexities and processes
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- Research on unknown societies or innovative systems

Bless and Higson-Smith (2000:156) define qualitative research as: "Research conducted using a range of methods which use qualifying words and descriptions to record and investigate aspects of social reality".

The research approach was thus qualitative by nature, as the information was gathered using words and descriptions to give meaning to the social reality as experienced by adolescents orphaned by HIV/AIDS related conditions.

A research question was formulated as the study was qualitative. The research question was: "What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande Region of Mpumalanga?"

### **1.5.3. PHASE 3: PLANNING**

#### *Research strategy:*

The researcher decided on phenomenological study as the most appropriate strategy to conduct the research as the research aimed at describing the meaning experiences of the phenomenon (HIV/AIDS related conditions) have for various adolescents.

#### *Preparation for data collection and analysis:*

The preparation for data collection involved decisions about the sites of data collection, the population as well as sampling procedures. The researcher decided upon the Gert Sibande District in Mpumalanga, as this was the most accessible to her. Purposive non-probability sampling was decided upon as the sampling procedure. Sampling criteria were identified as seen under 1.9.2. Selection was done with the assistance of social workers of the Department of Health and Social Services and Home Based Care Coordinators.

#### 1.5.4. IMPLEMENTATION

The researcher conducted a literature study as first objective of the study of the implementation process in order to assess the research findings against the background of existing literature (Fouche en Delpont, 2002:91).

Data was collected by means of semi-structured interviews. "In general, researchers use semi-structured interviews to gain a detailed picture of a participant's beliefs about, or perceptions or accounts of, a particular topic" (Greef, 2002:302). The researcher personally conducted the interviews, using an interview schedule. The schedule was not rigid, however, as it allowed for ventilation of feelings and the collection of additional information. In some instances, the caseworker of the particular young person was requested to assist with translation of questions or answers.

The Developmental Assessment Model, developed by the Inter Ministerial Committee for Young People at Risk (Department of Welfare, 1998) currently used by the Department of Health and Social Services, was used as a basis for the interviews. The schedule included questions on the experiences of adolescents on the following terrains: belonging, mastery, independence and generosity. The interviews was recorded and transcribed afterwards. The researcher also made detailed field notes during the data collection period. "Field notes are a written account of the things the researcher hears, sees, experiences and thinks about in the course of interviewing" (Greeff, 2002:304).

Data collection took place in three of the seven municipal districts of the Gert Sibande Region, namely Msukaligwa (Ermelo), Albert Luthuli (Carolina, Elukwatini) and Mkhondo (Piet Retief). Two interviews were also conducted with young people at the Hendrina Secure Care facility for Children Awaiting Trial.

The different offices of the Department of Health and Social Services, nominated respondents, using the sampling criteria as guideline.



### **1.5.5. INTERPRETATION AND PRESENTATION**

The data was analysed according to the steps described in De Vos (2002:340). Lincoln and Guba's approach (De Vos, 2002:351) was employed in order to evaluate the validity of the findings. Credibility, transferability, dependability and confirmability were evaluated.

Data analysis was guided by the methods described by Creswell, (1994:153). Data was managed by transcribing the interviews onto paper. The researcher read carefully through all the transcripts to get a sense of the whole. From the transcripts, categories of information were identified, as well as prominent themes. Sub-themes were also recorded and grouped together. Interpretation meant making sense of the data. The final phase presented packaging of what was found in text, tabular and figure form (De Vos, 2002:340-344).

### **1.6. TYPE OF RESEARCH**

Applied research was undertaken, as the researcher's primary motivation was to "...assist in solving a particular problem facing a community" and to "...assist the community to overcome the problem or design interventions, which will help to solve it" (Bless & Higson-Smith, 2000:38).

With this study the researcher aimed to document the experiences of adolescents orphaned by HIV/AIDS related conditions to improve the helping professions' understanding of the phenomenon. This may hopefully lead to more successful intervention strategies for affected adolescents.

### **1.7. RESEARCH STRATEGIES AND METHODOLOGY**

Phenomenology was seen as the most appropriate strategy to conduct the research. Creswell (in De Vos, 2002:273) regards a phenomenological study as one that describes the meaning experiences of a phenomenon, topic or concept have for various individuals. The research was therefore conducted

from a phenomenological strategy. The researcher utilized this approach to reduce these experiences to a central meaning of the experience. The product of the research is a description of the experiences of adolescents, orphaned by HIV/AIDS related conditions.

De Vos (1998:349) explains the concept of a research procedure as: "... by observing the problem and studying naturally occurring innovations and other prototypes, the researcher can identify procedural elements for use in the intervention".

## **1.8 PILOT STUDY**

Bless and Higson-Smith (2000:155) defines the pilot study as: " a small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate." The importance of the pilot study lay in the testing of the research questions and methods. New issues arose after the pilot study was completed (De Vos 2002: 282).

### **1.8.1 Pilot test of interview schedule**

For the purpose of this research, the interview schedule was tested with one adolescent who fitted the selection criteria in a location near as possible to the researcher. The adolescent did not form part of the final sample used for the research. " By testing the nature of questions in an interviewing schedule in the pilot study, the qualitative researcher is able to make modifications with a view to quality interviewing during the main investigation" (De Vos, 2002:337).

In some instances, the sequence of the schedule was varied to accommodate children who appeared to be uncomfortable or shy. The researcher started with less private questions about their favourite food in order to allow the respondents to settle down.

### 1.8.2 Feasibility of the study

The study was feasible, as it was within the financial, time and practical means of the researcher. The researcher had access to the target group and she had permission from the Department of Health and Social Services to conduct the study. The researcher is a qualified practitioner of the Developmental Assessment Model and has experience in the use of the model.

## 1.9 RESEARCH POPULATION, BOUNDARIES OF THE SAMPLE AND THE SAMPLING METHOD

### 1.9.1 Research universe and population

- *Universum*

Arkava and Lane (1983:27) described the term “universe” as “all the potential subjects who possess the attributes in which the researcher is interested”.

The universum of this study were adolescents who are orphaned by HIV/AIDS related conditions in South Africa.

- *Population*

McBurney (2001:248) explained that a research population can be defined as the sampling frame. A population is the totality of persons, events, organisation units, case records or other sampling units with which the research problem is concerned. The Terminology Committee for Social Work (1995: 45) describes a population as the “total number of units from which a sample is selected”.

The research population of this study can be defined as:

***Adolescents in the Gert Sibande Region between the ages 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.***

### 1.9.2. Sampling method

The New Dictionary for Social Work (1995:55) sees a sample as the number of units, which are representative of the total number of units in the population concerned.

Non-probability sampling was used in this study. In qualitative studies non-probability sampling methods were utilised and, in particular, purposive sampling techniques rather than random sampling are used because the researcher sought out individuals where the specific process being studied is most likely to occur (De Vos et al., 2002:334). Stratified sampling, defined as: "The grouping of units composing a population into homogeneous groups or strata before sampling" (Rubin & Babbie 1989:7) was also used in combination with purposive sampling, in order to improve the representativeness of the sample.

A combination of purposive and stratified sampling was thus used to identify 15 adolescent participants in the study. Singleton (De Vos et al., 2002:207) described purposive sampling as a sampling method entirely based on the judgement of the researcher. The sampling method was used to find elements that contained the most characteristic, representative or typical attributes of the population.

The following criteria determined inclusion or exclusion of a person from the sample:

- Ability to understand English
- Age: adolescents between 13 and 18 years
- Care status (orphaned or not)
- Person and circumstances of the family known to or nursed by a registered Home Based Care Group.
- Willingness to participate
- Orphaned for a period exceeding six months
- Confirmation of the AIDS-like symptoms of the parent before he/she passed away from a family member or health service provider

- Registered as a client at the Department of Health and Social Services, Gert Sibande Region.

### **1.10. ETHICAL ISSUES**

Ethical guidelines: " ... serve as standards and the basis upon which each researcher ought to evaluate his own conduct" (De Vos et al.,1998:24; Rubin & Babbie, 2001:470 and the Ethical Code of the South African Council for Social Service Professions, 1986).

The researcher is registered at the South African Council for Social Service Professions as a social worker. She was able to do the research, as she was daily in contact with the target group as part of her tasks as social worker.

The following ethical concerns received attention:

#### **1.10.1 Voluntary participation:**

Researchers should be especially sensitive to implied sanction when subjects do not want to participate in the study (Rubin & Babbie, 1989: 51). Participants were informed in writing prior to the interview that their participation were voluntary and that they were under no obligation to participate. One young person at Hendrina Secure Care did not feel safe enough to participate and withdrew from the study.

#### **1.10.2 Informed consent**

According to Mark (1996:40), the principle of informed consent is at the heart of efforts to ensure that participation is truly voluntary. Participants were therefore fully informed of the purpose of the research, content of the interview, use of tape recorder, possible consequences e.g. secondary trauma before written consent was sought from the adolescents themselves.

### **1.10.3 Confidentiality**

Mark (1996:48) outlined the following criteria to assist the researcher to maintain confidentiality:

- Information about participants has to be kept confidential, unless where participants gave written permission for it to be revealed;
- Information solicited and recorded could only be that which is necessary for the study to achieve its purpose;
- All the participants' identifying particulars were removed after coding;
- Transcribed interviews will be safely stored and destroyed after the completion of the study.

### **1.10.4 No harm to participants**

According to Rubin and Babbie (1989:52), it is possible for subjects to be harmed psychologically in the course of the study. The researcher was aware of the often-subtle dangers and guarded against them. The respondents were thoroughly informed beforehand about the emotional impact participation in the research may have. No subjects had to be withdrawn from the research because of apparent harm. The Developmental Assessment Model is designed to assist young persons to tell their story without feeling threatened or forced.

### **1.10.5 Deceiving of subjects**

Deceiving people is unethical (Rubin & Babbie, 1989:54). No facts were misrepresented whilst informing the participants of the nature and content of the research. No person was involved who was unable to give informed consent. No participant was coerced into participation.

### **1.10.6 No harm to subjects**

The information of the participants was obtained with a high regard for confidentiality and privacy. Persons were interviewed individually in a private

room. Subjects were informed that the interview was recorded and that the information will be dealt with confidentially. They had the choice using a pseudonym throughout the interview, even though none of the participants chose to do so. Participants were also informed of what the research report will be used for and who will have access to it. Audiotapes will be destroyed after the conclusion of the study.

#### **1.10.7 Release of the findings:**

The final written report is accurate and contains the essential information without giving too much information about individual respondents. The researcher tried by all means possible to give information in a clear, unambiguous manner.

#### **1.10.8 Restoration of the subjects:**

The researcher took time after all interviews to make sure that respondents' misconceptions or fears could be rectified. Debriefing and counselling was arranged with a registered social worker of the Department of Health and Social Services for three young persons who appeared distressed during the interview.

### **1.11. DEFINITIONS OF KEY CONCEPTS**

The following concepts were identified as central to the research topic, namely:

#### **1.11.1 Adolescent**

"Life phase beginning at puberty and ending in adulthood" (New Dictionary for Social Work, 1995:02).

“A person in the age of adolescence, i.e. the period between childhood and maturity” (The Shorter Oxford English Dictionary on Historical Principles, 1992: 27).

For the purpose of this report, the researcher defined adolescence as:

**The developmental stage that commences with puberty and ends with adulthood, in which sexual maturation and social, psychological and physical changes occur.**

### **1.11.2 Orphan/s**

“Refers to children who have become vulnerable because their parents or caregivers can no longer care for them because they are either very ill or have died because of HIV/AIDS” (Department of Social Development, 2003: 33).

“One deprived by death of father or mother or both” (Oxford English Dictionary, 1992:1465).

“An orphan is defined as a child below 18 years who has lost one (single parent) or two (married couple) biological or adoptive parents... Children who are abandoned or dumped and their parents cannot be traced are termed as social orphans” (Division of Social Welfare, Botswana, 1999:02).

“In the context of the HIV/AIDS epidemic in South Africa an orphan is defined as a child under the age of 18 years whose primary caregiver has died” (Department of Social Development, 2003:33).

The researcher defined an orphan in the following manner:

**The term “orphan” refers to a child between 0 and 18 years, after the death of his or her primary caregivers, or the death of one caregiver and the disappearance of the other.**



### 1.11.3 HIV/AIDS

“Acquired Immune Deficiency Syndrome – A syndrome is a collection of diseases that results from infection with HIV” (Smart, Dennil & Pleaner, 2001: vi).

“ HIV affects the body by affecting the immune system. The immune system is the body’s defence against infection by micro-organisms (bacteria and viruses) that cause disease... HIV is able, by attaching to the surface of the CD4 lymphocyte, to enter, infect and eventually destroy the cell. Over time, this leads to a progressive and finally profound impairment of the immune system, resulting in the infected person becoming susceptible to infections and diseases such as cancer” (Smart, Dennil & Pleaner, 2001: 35).

For the purpose of this research, HIV/AIDS related conditions are defined as:

**HIV/AIDS is a cluster of symptoms and illnesses that result from infection with the HI virus. The virus destroys the immune system of the patient, resulting in eventual death because of opportunistic illnesses.**

### 1.11.4 EXPERIENCES

“Something, which happens to someone or which someone has experienced or undergone, actual knowledge or contact (Grobbelaar, 1989:835).

“Seeing or living through an event, happening, etc.; knowledge obtained in this way; an event that has given one knowledge, skill, etc.; skilled in or having knowledge of (Manser, 1984:134).

For the purpose of this study, the researcher ‘s understanding of experience was:

The holistic knowledge and skills that the adolescents obtained by something that has happened to him or her (life story/ narrative) and the influence thereof on his life at present.

## CHAPTER 2

### THE HIV/AIDS PANDEMIC

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#### 2.1 INTRODUCTION

“AIDS is the stuff of all our nightmares, triggering many of our deepest fears” (Watts, 1980 in Van Dyk, 2003:254).

During the past decade, the HIV/AIDS pandemic has entered the consciousness of all communities as an incomprehensible calamity. It has claimed millions of lives, inflicting pain and grief, causing fear and uncertainty and threatening the economy. The AIDS pandemic in Southern Africa is not only a major public health crisis but also a threat to economic development and social solidarity. More than one in five adult South Africans are HIV-positive and AIDS deaths are expected to rise sharply until 2010. Over a million children could be orphaned by 2015 as a result. Such health shocks are devastating, not only for families and communities but for the broader society and economy (Natrass, 2004:13).

The HIV/AIDS pandemic is the most important challenge facing South Africa since the birth of democracy in 1994. The challenge comes at a time when the country is faced with many other needs competing for funding and attention. Examples of this, are redressing the challenges of the past, transforming a society, as well as integrating South Africa into the global economy (Smart et al., 2001:30).

The HIV/AIDS pandemic differs from other infectious diseases, as it does not affect mostly small children and the elderly, but young adults between the ages of fifteen and forty-five. According to Smart, Dennill and Pleaner (2001:30) young adults make up 90% of those infected in South Africa.

In this chapter, the pandemic will be discussed holistically. The history as well as the impact of the disease on all spheres of society will be described. Special attention will be given to the factors contributing to the rapid spread of HIV/AIDS in South Africa.

## **2.2 HISTORY OF THE PANDEMIC**

Van Dyk (2003:06) reports that there are many far-fetched theories about the origin of HIV/AIDS. These range from a belief that the virus was developed as an instrument of biological warfare to a view that the virus is being used by aliens from outer space to kill the people from Planet Earth. A more sober view now generally accepted by scientists is that HIV crossed the species barrier from primates to humans at some time during the twentieth century. HIV is related to a virus called SIV (Simian Immunodeficiency Virus), which is found in primates such as chimpanzees, and Macaque and African green monkeys. The virus probably crossed over from primates to humans when contaminated animal blood entered open lesions or cuts on the hands of humans who were killing these animals for food. While the initial spread of HIV was probably limited to isolated communities who had little contact with the outside world, various factors, such as migration, improved transportation networks and multiple sexual partners ultimately caused the virus to spread all over the world.

The extensive spread of HIV1 began in the late 1970's and early 1980's. The first populations to be affected were:

1. Men and women with multiple sexual partners in East and Central Africa
2. Men having sex with men in some urban areas of Western Europe, the Americas and Australia (Van Dyk, 2003:06).

Historical and scientific landmarks are identifiable in literature, namely:

**1981:** The Morbidity and Mortality Weekly Report from the Center of Disease Control (CDC) in the United States of America reported a sudden increase in the diagnosis of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma in gay men. Health workers in Central Africa also identified a new disease

characterized by diarrhea and severe weight loss. They called it "Slims Disease".

**1982:** The disease was named the "Acquired Immune Deficiency Syndrome." The first two AIDS cases were diagnosed in South Africa.

**1983:** French Scientists isolated the virus causing AIDS, namely HIV1. They named it the "Human Immunodeficiency Virus." They also confirmed the routes of transmission.

**1985:** The first AIDS death was recorded in South Africa. Blood tests were developed through which it became possible to identify antibodies to HIV in the blood.

**1986:** HIV2 was identified. Until recently, this strain of the virus was confined to West Africa and where it is mostly acquired heterosexually.

**1987:** The USA Food and Drug Administration approved the first antiretroviral drug, called AZT.

**1992:** The first trials using combination therapy started.

**1993:** A classification system to define the stage of AIDS in which a patient is, was introduced. This system uses CD4 cell counts to define the effect of the virus on the immune system.

**1994:** The first clinical trials to reduce mother to child transmission commenced. At this stage, 16 million people globally were infected since the first identification of the infection in 1981.

**1995:** Approximately 9000 cases were reported in South Africa since 1982.

**1996:** Highly Active Antiretroviral Therapy (HAART) was shown to be effective in prolonging life and improving quality of life of AIDS sufferers.

**1998:** 5,8 million new infections occurred worldwide during this year.

**1999:** 18 million deaths occurred worldwide since 1981. One Hundred and fifty thousand children have been orphaned in South Africa since 1981.

**2000:** 3,6 million people are now living in South Africa with HIV. 330 000 people are AIDS sick in South Africa. 2500 new infections occur in South Africa daily.

**2001:** 19,9 % (approximately 4,2 million people) of the South African adult population is infected.

It is clear that the epidemic continues to grow dramatically, despite enormous scientific advances (Compare Smart et al., 2001:27; Nelson Mandela Children's Fund, 2000:11; Department of Social Development, 2000:62; Reuter 2005:6).

### 2.3

#### THE GLOBAL EXTENT OF THE PANDEMIC

**Sub-Saharan Africa** is the worst affected region, having around 70% of the global total of HIV-positive people. Most of these infected populations will die in the next 10 years, adding to the 13,7 million Africans already claimed by the epidemic. Around 80% of deaths from AIDS in 2000 occurred in Southern Africa. The predominant mode of transmission is heterosexual (Reuter, 2005:6).

**South Africa** is second only to India in number of people living with AIDS, yet India has twenty times the population of South Africa (Department of Social Development, 2001:61). Smart et al. (2000:95) is of the opinion that South Africa will have an estimated 800 000 orphans in 2005, which will grow further to 1.95 million in 2010. According to the South African HIV Clinicians Society (Reuter, 2005:5) 13,2 million children have been orphaned since the beginning of the epidemic.

Based on its sample of more than 16 000 women attending antenatal clinics across all nine provinces, the South African Department of Health estimates that 27,9% of pregnant women were living with HIV in 2003. The provinces that recorded the highest HIV rates were KwaZulu-Natal, Mpumalanga and Free State. Earlier results showed that until 1998 South Africa had one of the fastest expanding epidemics in the world. The 2003 survey confirmed that the trend has since changed, so that the level of HIV prevalence is now growing more slowly. The most encouraging finding concerns teenage girls, among whom prevalence has been declining since 1999 (HIV/AIDS orphan statistics, 2005:01).

**Table 2.1: Estimated HIV prevalence among antenatal clinic attendees, by Province**

<b>PROVINCE</b>	<b>2000 PREVALENCE %</b>	<b>2001 PREVALENCE %</b>	<b>2002 PREVALENCE %</b>	<b>2003 PREVALENCE %</b>
KWAZULU-NATAL	36.2	33.5	36.5	37.5
GAUTENG	29.4	29.8	31.6	29.6
FREE STATE	27.9	30.1	28.8	30.1
MPUMALANGA	29.7	29.2	28.6	32.6
NORTH WEST	22.9	25.2	26.2	29.9
EASTERN CAPE	20.2	21.7	23.6	27.1
LIMPOPO	13.2	14.5	15.6	17.5
NORTHERN CAPE	11.2	15.9	15.1	16.7
WESTERN CAPE	8.7	8.6	12.4	13.1
<b>NATIONAL AVERAGE</b>	<b>24.5</b>	<b>24.8</b>	<b>26.5</b>	<b>27.9</b>

(HIV/AIDS orphan statistics, 2005:04).

The HIV epidemic is spreading rapidly throughout **Asia** where the predominant mode of transmission is heterosexual. Intravenous drug use also plays a significant role in HIV transmission in Northern Malaysia, Vietnam,

Thailand, Southern China, Burma and India. It has been estimated that by the year 2000, most HIV infections in the world will be occurring in Asia, and that one in four of the world's infected individuals will be living in this region (Reuter, 2005:6).

In **North America**, the epidemic's early spread mostly affected males having sex with males, before spreading to women, minority groups and the disadvantaged. Intravenous drug use also played a major part in the spread of HIV. Since 1996 there has been a decrease in the number of new AIDS cases, mostly because of effective prevention programmes (Reuter, 2005:7).

Reuter indicates that the epidemic in different stages can be seen throughout **Europe**. In Western Europe the incidence of AIDS increased rapidly throughout the 1980's and stabilized in 1995. It has been on the decline since then. Intravenous drug use accounts for most of the new infections in Eastern Europe (Reuter, 2005:8).

In **South America** the spread of the infection is slower than elsewhere, but increasingly affects the age group 15 to 24. Infections continue to rise, mainly due to heterosexual transmission. Intravenous drug use also accounts for up to 50% of new infections in Argentina and Brazil (Reuter, 2005:8).

The HIV epidemic was introduced relatively late into the **North African and Middle Eastern countries**. 75% of all cases are from only five countries, namely Djibouti, Morocco, Saudi Arabia and Tunisia.

## 2.4 THE IMPACT OF THE HIV/AIDS PANDEMIC

### 2.4.1 FACTORS CONTRIBUTING TO THE SPREAD OF HIV/AIDS

Smart et al. (2001:30) is of the opinion that there are no simple explanations as to why some countries are more affected by the epidemic than others are. HIV/AIDS can not be separated from broader developmental issues like



poverty, illiteracy, high rates of other STD's, the frequency of identified risk behaviors and the inferior position of women in society all of which contribute to high rates of infection and transmission.

The factors determining the rate at which the HIV epidemic is propagated at an individual, group or societal level, is termed "susceptibility."

Examples are:

1. Infra-structural factors such as the development of a road;
2. Environmental factors such as a drought resulting in unusual population movements;
3. Cultural factors such as a particular sexual practice or belief, or a change in these;
4. Economic factors such as the closure of an industry resulting in job losses or the opening of a construction site with an influx of migrant workers;
5. Social factors such as civil war (Webb, 1997: 12).

Lukoda (in Levine, 2001:6) also writes about the World Bank/World Vision's six drivers of AIDS proliferation- poverty, silence, gender inequality, low condom use, poor health infrastructure and cultural practices.

#### **2.4.1.1 LOW CONDOM USE AND UNSAFE SEXUAL BEHAVIOUR**

Dorkenoo et al. (2002:30) describes unsafe sexual behaviour in the SADC region as unprotected sex with multiple partners, poor and inconsistent condom usage, dry sex, anal sex and sex while infected with another Sexually Transmitted Disease.

Prostitution or sex work is widespread throughout sub-Saharan African. For many women, especially those without education or other skills, it is the only economic option open to them in a context of high unemployment and poverty. Many women (though not all) engage in sex work to support themselves and their children. A growing problem throughout SADC countries and in particular Angola, which has been bedevilled with a long civil war, is the use of children by adults to prostitute for a family income. Child

prostitution is a growing social problem particularly in South Africa (Dorkenoo et al., 2002:43).

Sex workers face greater risks of HIV infection as the nature of the work implies that they must have sexual intercourse with as many customers as possible. Sex workers can be considered as a very important vector in the sexual transmission of HIV infection in South Africa (Dorkenoo et al., 2002:43).

#### **2.4.1.2 POVERTY**

Poverty is more than financial deprivation. This is recognised by the United Nations Development Programme, whose first report in 1990 opened with the statement: "The real wealth of a nation is its people. And the purpose of development is to create an enabling environment for people to enjoy long, healthy and creative lives" (Barnett & Whiteside, 2002:274).

HIV/AIDS and other sexually transmitted diseases are often more common in socio-economically depressed communities where high levels of unemployment force men to migrate to the cities, where the traditionally low status of women does not give women the authority to negotiate safe sex practices, where extreme poverty often forces women to sell their bodies for sexual purposes in order to obtain money to survive, where living conditions are calamitous and access to health services is either intermittent or non-existent, where ignorance, illiteracy and poor education are widespread, where alcohol abuse (which lowers thresholds of inhibition and so compromises sensible decision making) is rife, and where the old traditions that created cohesion and mutual help in communities have either been undermined or have disappeared altogether (Van Dyk, 2003:33).

More recent research focuses on the immune system's response to HIV as a key determinant of HIV transmission. There is now a strong body of biomedical evidence showing that 'malnutrition and parasite infection (Malaria, bilharzias, intestinal parasites) increase HIV susceptibility, not only to opportunistic infection after HIV infection, but also to HIV transmission, just as

they increase susceptibility to other infectious diseases (Stillwaggon in Natrass, 2004:29).

Given that malnutrition is a product of poverty, there is thus good reason for assuming that poverty helps to hasten the spread of HIV in sub-Saharan Africa. The situation is made worse by inadequate health care – itself a function of poverty and low levels of development. Weak policy responses by most African governments no doubt also contributed to the spread of the AIDS pandemic. Poverty made the pandemic harder to fight, but it does not absolve the governments of responsibility for not acting faster and more aggressively against it. This is especially the case for South Africa, which had more resources than other African countries to combat the epidemic. Most African governments themselves are now weakened by AIDS as the disease lowers productivity and efficiency, undermines the capacity to deliver services, and possibly even threatens democracy itself (Barnett & Whiteside, 2002:295-315).

#### **2.4.1.3 SOCIAL FACTORS**

- **Gender inequality**

Little control over condom use, monogamy or decisions regarding childbearing are signs of poor status of women. Other symptoms are high incidence of rape, violence against women and poverty that can drive women to sex for money (Smart et al., 2001:67).

Dorkenoo et al. (2002:11) writes that women and girls in rural areas often have to carry a double burden of generating income for the home whilst caring for a sick person.

In the macho image nurtured among men in most patriarchal African cultures, men perceive themselves as superior to women and can therefore have multiple partners with the number of sexual conquests being generally equated with the concept of masculinity (Dorkenoo et al., 2002:42). Some men, particularly migrant miners, also believe that regular flesh-to-flesh sex is

necessary for a man's good health. Another example of women's lesser role is the practice that polygamous husbands demand matrimonial sexual rights with their spouses often without condoms. The final decision to use a condom is usually made by men.

The majority of women in sub-Saharan Africa are not employed formally and they often have to rely on men as breadwinners. Consequently, many women live under conditions of immense poverty and have very limited choices when it comes to negotiating sexual relationships with men. A problem arises when male partners either have sex with prostitutes or engage in multiple relationships. Their female partners or spouses cannot insist on them using condoms when they have sexual intercourse due to the fear of losing their main source of livelihood. Faced with no alternative to earn their livelihood, many women are left unprotected from HIV infection from their promiscuous male partners (Dorkenoo et al., 2002:42).

- **Vulnerability of the youth**

Many young people are sexually active, but do not have the concomitant life skills to deal with sexual negotiations, particularly around safer sex. Some other risk factors are:

- Sexual abuse, rape, date rape, transactional sex or sex for favours;
- Poverty: sex in exchange for money, gifts or payment for education;
- Actual condom use is particularly challenging for an inexperienced male youth;
- Urban legends, for example that sex with a virgin can cure AIDS.

A very common practice in sub-Saharan African countries is that older men have sex with young girls. This is known as age mixing. Since the older men would have been sexually active for many years and they are likely to be infected by HIV or Sexually Transmitted Infections or STI's. This increases the risk of infection for young girls. One of these practices is that wherein male schoolteachers coerce their female students into having intercourse with them. Another of these practices is the common belief some men hold that if

they have sex with a virgin it would cure them of HIV infection or from developing full-blown AIDS. These practices often lead to infection of the young females as their reproductive systems may still be immature and tend to be easily injured during sex, which makes it easier for infection to occur (Dorkenoo et al., 2002:44-45).

- **Access to health care and health status**
  - Sexually Transmitted Diseases may go unnoticed due to a lack of or inaccessibility of facilities
  - Poor health status may result from under-nourishment
  - Access to drug therapies, particularly for pregnant women, is limited or simply not available (Smart et al., 2001:68).
  
- **Migration**

SA's population has a high geographical mobility as well as an extensive migrant labour system. Both factors are important in understanding the spread of HIV/AIDS in the country. Migration does not cause HIV/AIDS, but it is a risk factor. It exposes both the 'mover' and the 'stayer' to transmission and infection (Smart et al., 2001:68). The State of the South African Population Report, (Department of Social Development, 2001:63) indicated that many men who work away from home for long periods have a culture of purchasing sex from sex workers.

South Africa's well-developed system of transportation routes also influences the geographical mobility of its population. South Africa's air, rail and road transportation network provides excellent corridors for the more rapid spread of the disease across the country.

Dorkenoo et al. (2001:11) confirms that HIV/AIDS is becoming a greater threat to rural areas because of migrant behaviour. Rural communities that are sources of migrant labour to urban areas or those situated along truck driver routes are highly vulnerable. Furthermore, rural communities largely endure

the costs of HIV/AIDS as HIV-infected urban dwellers of rural origin and migrant labourers often return to their communities when they fall sick.

- **Social dislocation and war**

The State of South Africa's Population Report (2001:61) mentions the Jaipur paradigm as a method of explaining the unexplained global variability of HIV prevalence in terms of social and economic characteristics of societies, by using the basis of social cohesion patterns (homogeneity of societies) and the distribution of wealth as basis. High cohesion and good distribution of wealth decreases the vulnerability of a population. Countries like South Africa with inequalities in both wealth distribution and social cohesion are the worst hit. African women turned out to be the most adversely affected, as they are often vulnerable and powerless because of poverty, patriarchy and violence.

The rapid spread of HIV also can be attributed to the African continent being embroiled in decades of intermittent military and chronic civic violence. War and unrest create the perfect conditions for the rapid transmission of HIV, as it is associated with sexual violence against girls and women, rape, prostitution and other dehumanizing and ethnic cleansing acts. Refugees, war veterans and other persons in the path of war are unlikely to see the risk of HIV as a significant, additional threat to their lives. War fits well into the Jaipur paradigm, since it represents the final breakdown of social cohesion, thus serving as an accelerating factor in the spread of AIDS (State of South Africa's Population Report 2001: 63).

Soldiers in war situations have a need for sexual intimacy as a counter-balance to the violence they experience. The non-availability of condoms; having disposable income; being away from home and a willingness to take risks all increase the spread of HIV. Rape is a manifestation of war, as it is an expression of hostility. Sex can also become transactional in times of war, especially when people have minimal access to food and health care (Smart et al., 2001:68).

- **Incarceration in overcrowded prisons**

One of the highest risk situations to contracting HIV infection in most sub-Saharan countries including the relatively wealthy South Africa is being incarcerated in prison. Consensual, coerced or forced sexual activity among male prisoners in South Africa is related to the psychological effects of being 'demeaned' from masculinity to femininity. Although usually denied among Africans, anal sex between men in prison takes place. The relationship between sex and power could lead to sexual violence and coercion with implications for the transmission of HIV infection. In accounts of prison sex, where it can be exchanged for a cigarette or protection from death, incarcerated adolescents frequently report previous sexual intercourse, intercourse with multiple sexual partners, rape, gang rape, and inconsistent condom use. It is then possible that, in order to regain his manhood, such an inmate will direct his aggressive sexual attitude to the community, resulting in rape upon release (Dorkenoo et al., 2002:49).

- **Substance abuse**

Although there is very little local empirical evidence in the South African Developing Countries (SADC) region to support the hypothesis showing the link between substance abuse and HIV infection, a number of international studies have advanced the 'alcohol-risky sex' hypothesis and found some evidence to support it. It appears that alcohol intake increases sexual risk-taking behaviour. Accordingly, the argument has been that when alcohol, and indeed any other illicit drug, is consumed in excessive amounts it inhibits people's ability to engage in safer sex practices such as using condoms correctly. There is therefore a need to emphasize the links between alcohol or illicit drug consumption and unsafe sex among young adults in order to prevent the spread of HIV infection (Dorkenoo et al., 2002:49).

#### 2.4.2 PERCEPTION OF SEXUALITY AND ILLNESS IN TRADITIONAL AFRICA

It is important to understand what health, sickness and sexuality mean in traditional Africa, as these factors can also be directly linked to the rapid spread of HIV/AIDS in Africa.

Van Dyk (2003:112) explains that if something bad happens to a traditional African, he or she will not attribute it to bad luck, chance or fate. They believe that mental as well as physical illness can be caused by disharmony between a person and the ancestors, by a god or spirits, by witches and sorcerers, by natural causes, or by a breakdown in human relationships.

Ancestors form a very important and intrinsic part of the daily lives of traditional Africans. Ancestors are seen as benevolent spirits who preserve the honour and traditions of a tribe, and they usually protect their people against evil and destructive forces. Ancestors can, however, punish their people by sending illness and misfortune if people do not listen to their wise counsel, if certain social norms and taboos are violated, and if culturally prescribed practices and rites are neglected or incorrectly performed (Van Dyk, 2003:112; Mhlanga, 2005).

In some cases, it is believed that ancestors do not actually send illness themselves but that they merely allow it to happen by withdrawing their protection. People are then open to attacks by witches and sorcerers. This is seldom fatal, and traditional Africans are usually quick to restore their relationship with their ancestors through offerings and sacrifices (Van Dyk, 2003:112).

Witchcraft is believed to be the causal agent in HIV transmission, AIDS and death in many African countries, especially among the rural poor or people with the least education. The psychological rationale of blaming witchcraft for the breakdown of African societies is therefore understandable and helps to make sense of the horrors and disruptions caused by HIV/AIDS. This blaming of external factors such as witches serves to console family, victims and



society as a whole. It also serves as an explanatory hypothesis that is comprehensible in terms of the traditional African worldview, and so it helps to alleviate feelings of guilt and anxiety (Van Dyk, 2003:115).

Witchcraft beliefs nevertheless also have negative implications for AIDS counselling and education in Africa. The belief that everything that happens to a person can be attributed to external, supernatural beings (an external locus of control) implies that the individuals cannot be held accountable for their own behaviour. As a result, many people in Africa do not consider their own behaviour to be a possible reason for HIV infection. Because of this misconception, they cannot appreciate the need for using HIV-preventative methods (Van Dyk, 2003:115; Smart, Dennill & Pleaner, 2001:30).

Sex not only serves as a biological function in African societies. For the traditional African, sex also symbolises immortality. Traditional Africans acquire personal immortality through their children. After physical death, people continue to exist as 'living-dead' for as long as they are personally remembered by name by relatives and the friends who knew them during their life and who have survived them. So long as they are alive in the memories of those who knew them, they are in a state of personal immortality (Dorkenoo et al., 2002:49; Van Dyk, 2003: 32).

Unless a person has a close relative to remember him when he has physically died, then he is nobody and simply vanishes out of human existence. Therefore, it is a duty for everyone to get married, and if a man has no children (or only daughters), he finds another wife so that through her, sons may be born who would remember him (Van Dyk, 2003:110).

Children are not only valued for ensuring immortality. They are also very important in the day-to-day existence of traditional Africans, because they can only prosper on the land of their ancestors if they have many wives and children to help them work their lands. There are many duties, such as looking after the cattle, babysitting, working in the fields and fetching firewood and water, which cannot be adequately performed if the family is too small. In

Africa, a man's wealth depends on the growth of his tribe (Van Dyk, 2003:120).

Hadden quoted by Dorkenoo et al. (2002:33) indicates that the use of condoms is seen as 'unnatural' in some African cultures. It is seen as a 'waste' of sperm and that this conflicts with the emphasis on fertility in African culture. Taylor (1990) quoted by Van Dyk (2003:122) found that resistance to condom use in Rwanda had nothing to do with ignorance, but with very specific social and cultural dimensions of the Rwandan sexuality. They believe that the flow of fluids involved in sexual intercourse and reproduction represents the exchange of 'gifts of self', which they regard as being of utmost importance for the relationship. There is also a widespread belief in many parts of Africa, such as East Africa, the Democratic Republic of the Congo and among the Zulus in South Africa that repeated contributions of semen are needed to form or 'ripen' the growing foetus in the womb. It is believed that semen contains important vitamins, which are necessary for the continued physical and mental health, beauty and future fertility of women (Van Dyk 2003:123).

Population control remains a sensitive issue in Africa because it negatively impacts on the growth of a tribe, it deprives parents of needed labour and undermines traditional beliefs and values. However, while having many children is still important for Africans, many women nowadays do accept the idea of birth spacing and maternal protection (Van Dyk, 2003:121).

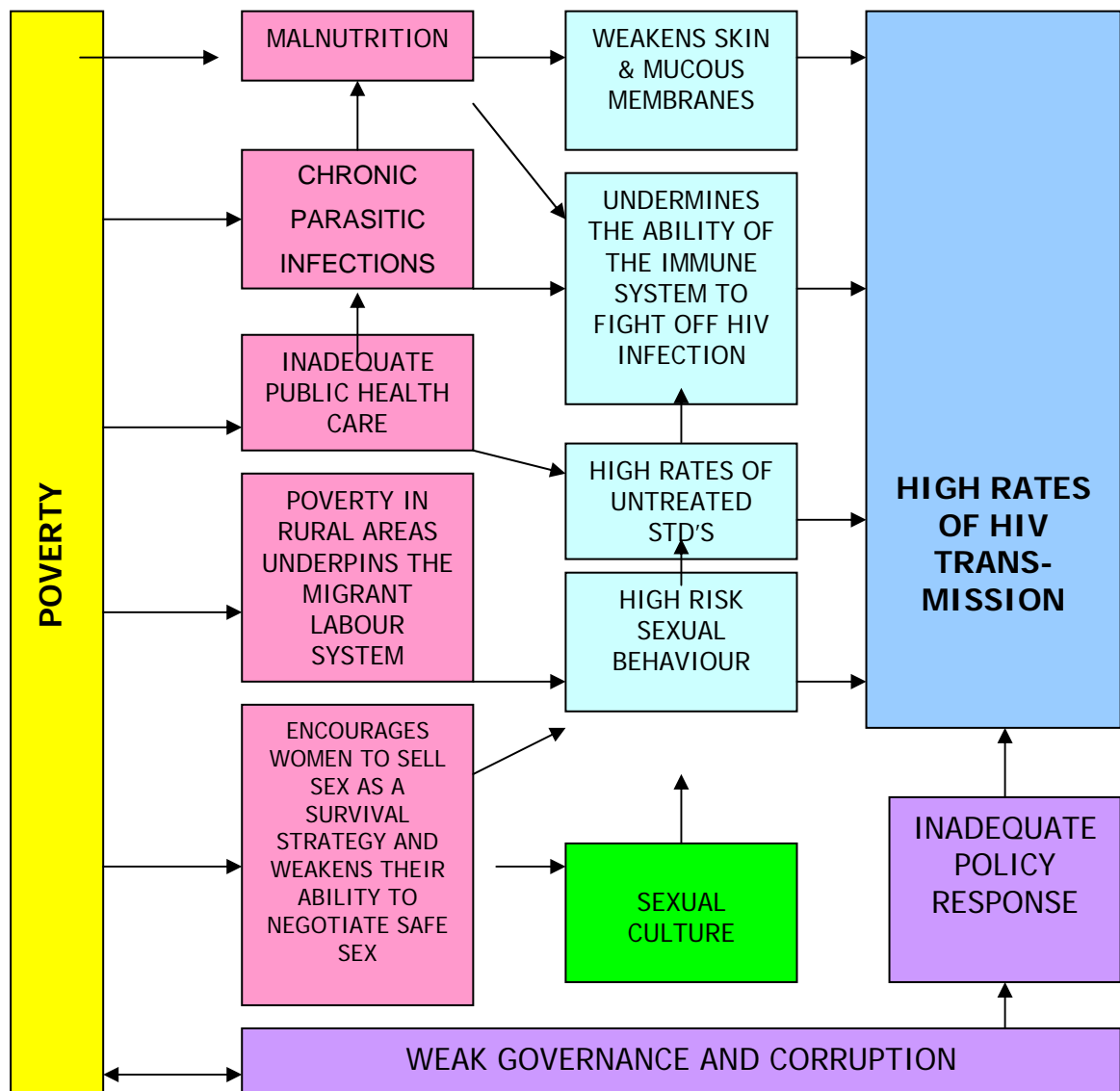
Similarly, some religious groups, especially Roman Catholics, discourage the use of condoms as well as other methods of contraception (Dorkenoo et al., 2002:33).

Circumcision has been practised in various forms among various ethnic groups, especially among youths who have reached puberty in various tribes such as the Xhosa, Ndebele, Pedi, South Sotho and Venda. These rituals are often conducted under non-sterile conditions and the same instruments are used on several of the initiates. In some cultures, circumcised males are

encouraged to engage in pre-marital sex with women they do not intend to marry (Smart, Dennill & Pleaner, 2001:30).

The link between socio-economic, biomedical and behavioural determinants of the spread of AIDS in Africa was summarised by Natrass (2004:30) in the following diagram:

Figure 2.2 . The links between socio-economic, biomedical and behavioural determinants of the spread of AIDS in Africa



Natrass (2004:30).

### 2.4.3 EFFECTS ON HIV/AIDS ON THE SOUTH AFRICAN SOCIETY

It is useful to begin thinking about impact as a continuum between a sharp shock and slow and profound changes. An example of a sharp shock is the death of the main breadwinner or the main carer in a household or family. This results in immediate and marked decline in living standards and welfare. Similarly, the death of a strategically important and hard to replace individual in an organization, will have a shock impact upon the operation of the organization (Barnett & Whiteside, 2002: 161-163).

A slow but complex series of changes- some of them very subtle- results from gradual accumulation of impacts. This is illustrated by an example from the health system:

- TB is a frequent opportunistic infection associated with AIDS. It spreads to the wider population;
- AIDS first affects the availability of treatment for non-AIDS illnesses;
- There are additional pressures on health staff who suffer burn-out and emotional exhaustion;
- Resources are constrained and the health of those in need of non-AIDS medication suffers. TB infection rates increase in the general population;
- The result is an overall reduction of people's health status;
- Society bears wider costs. These are either direct costs of care or indirect costs associated with decreasing health status and consequent knock-on effects to education attainment, social functioning, and trauma associated with the premature death of relatives from TB.

This example of gradual change shows how cumulative and linked effects may be severe but difficult to measure over the long term and that the chain of events does not stop there (Barnett & Whiteside, 2002: 161-163).

### 2.4.3.1 IMPACT ON HEALTH CARE AND SOCIAL SERVICES

Implications for health care systems are alarming. Projections for South Africa indicate that HIV/AIDS could potentially consume between 35% and 84% of the public health expenditure in 2005, as well as 30 to 70% of beds in State hospitals. This would also drastically increase the need for social grants.

It is projected that by the year 2000, almost 330 000 people were AIDS sick (each AIDS patient will have at least eight of the major illnesses that are associated with death) and there will be 2500 new infections daily. It is estimated that by 2009, South Africa will reach the figure of six million deaths from AIDS (State of the SA Population Report, 2000:62).

Dorkenoo et al. (2002:26) indicates that sickness and death caused by AIDS is increasing rapidly among health care personnel. This increases absenteeism, reduces productivity, and lead to higher levels of spending on treatment, death benefits, additional staff recruitment and training of new health personnel.

Households can often not afford even basic medicines to treat opportunistic infections or to make patients more comfortable (Hunter & Williamson, 2002:16). They are also of the opinion (2000:12) that the added strain and pressure that coping with HIV/AIDS places on families and households may result in increased child abuse and neglect. In many of the countries most heavily affected by HIV/AIDS, social service and welfare agencies are the most understaffed and under funded parts of the government, and the safety net for impoverished and stressed families is nearly nonexistent. If these types of agencies are strengthened, they can play an important role in assisting children, families, and communities; preventing abuse; and fostering cooperation among nongovernmental and community-based organizations.

Demmer (2004:40) describes the health dilemma in very clear terms, by saying: "...health services are most available to those who need them least.

Those who need health services the most have inadequate access to it." A local AIDS researcher Henderson quoted by Demmer (2004:40), sums up the desperation: "We can't afford to spend money on people who are going to die". The same author is of the opinion that it is expected that the number of people seeking care is likely to grow substantially, 'crowding out' those who suffer from non-AIDS related illnesses. This may result in a non-functional health care system.

The same kind of crisis is looming in the Social Welfare Sector. According to Demmer (2004:40) the South African social welfare system is unable to adequately meet the basic needs of those suffering from AIDS and their families. Many individuals (including children) who are trying to cope with their loss must summon the energy and determination to embark on the often frustrating and draining process of applying for minimal government benefits. It can take an extremely long time (sometimes up to several years) to process welfare applications and the lack of appropriate documentation (birth and death certificates, identity documents) prevents many people from applying for and receiving welfare support. This can be a life or death situation for some bereaved families who have no food or shelter (Demmer, 2004:40).

The same author is of the opinion that social workers can become overwhelmed by the plight of individuals and families affected by AIDS and they may experience frustration themselves at not being able to do more for them. A number of voluntary organizations serving those with AIDS and their families have emerged over the past few years, but they are also largely under funded and under staffed.

#### **2.4.3.2 IMPACT ON EDUCATION**

There are an estimated 258 000 HIV infected learners in the South African school system (Smart et al., 2001:66). It is clear however, that the impact of HIV/AIDS goes beyond the infection rate of learners. In addition, schooling may suffer due to the ill health and death of teachers. For example, in 1999, 860 000 primary school children lost at least one teacher to AIDS in sub-

Saharan Africa. About 12% of educators were estimated to be HIV-positive in South Africa in the year 2000 (Dorkenoo et al., 2003:25).

Griesel-Roux (2004:40) writes that the epidemic's impact on schools and education reduces the supply of education by reducing the numbers of educators who are able to conduct their work in the classroom, and the resources available to them. The high rate of disease among teachers, health workers and other professionals will make replacements increasingly hard to find, and there will be fewer to educate and care for children. Added to this, the epidemic affects the quality of education because of the strains on the material and human resources of the education system as well as on the health and the mere presence of learners.

Dorkenoo et al. (2003:21) postulates that education is an essential building block in a country's development. A study conducted in Zimbabwe found that in situations where most farm worker deaths are attributed to AIDS, 48% of the orphans of primary school age who were interviewed had dropped out of school, usually at the time of their parent's illness or death, and not one orphan of secondary school age was still in school. Furthermore, a child's schooling may be temporarily interrupted by a shortage of cash brought about by spending on a parent's ill health or by periods of working at home to assist ill parents. By the time these children become orphans they are likely to be over the age for their class even if they are still in school. Being older than their classmates was in turn associated with a higher rate of dropping out of school for a number of other reasons. This included pregnancy and the need to take paid work. Many of the marriages that led to drop out were arranged, so it was quite possible that relatives themselves saw marrying a girl off as a painless way of ensuring that she would be cared for.

#### **2.4.3.3 DEMOGRAPHIC IMPACT**

Smart et al., (2001:66) is of the opinion that South Africa's population is ordinarily characterized by:

- Relatively high but declining fertility and population growth rates (compared to developed countries, not developing countries)
- Low overall (but high infant and maternal) mortality rates
- A young age structure with a certain degree of built-in momentum for future increases in population size (even if the growth rate were to continue to decline in the immediate future);
- Growing numbers of elderly people;
- High dependency ratio
- High rates of immigration
- High levels of urbanization relative to the provision of infrastructure and services; and large rural populations in areas without adequate productive basis, infrastructure or services.

AIDS is changing the face of the South African population. It has a significant impact on the life expectancy of South Africans. The State of the Population Report (2000:61) indicates that persons born with the virus can expect to live for an average of 2.5 years, whilst the life expectancy of those who contract it during their youth or early adulthood is about 25 years. This is contrast to the life expectancy of in the high sixties of South Africans who do not contract the virus during their lives.

Smart et al., (2000:94,95) indicate that the death rate among AIDS orphans is 2.5 to 3.5 times higher than for non-orphans.

The South African HIV/AIDS Clinicians society (2005:6) is of the opinion that the epidemic has grave social and economic repercussions for developing countries, amongst others:

- Reduced child survival;
- Reduced life expectancy;
- Increased orphan hood;
- Increased demand on formal health care services and communities for care and support;
- Decreased productivity leading to economic losses.



According to Hunter and Williamson (2000:07), the following demographic indicators will change as a result of the HIV/AIDS pandemic:

- Percentage of population loss
- Population growth rates
- Crude death rates
- Fertility rates
- Life expectancy
- Age distribution
- Infant and child mortality
- Dependency ratios
- Gender ratios
- Widow(er)hood
- Household composition and/or co-residence

Hunter and Williamson (2002:17) also add that HIV/AIDS often also causes urban-to-rural migration, the opposite of regular patterns. Illness forces some people to seek care or support from extended families in rural areas. In addition, orphaned children are often sent to live with relatives in a parent's home village. Other people leave cities because they are afraid of contracting HIV/AIDS in urban settings.

Natrass (2004:160) indicates that the pandemic increases morbidity (sickness) and mortality (death) in populations at precisely those ages where normal levels of morbidity and mortality are low.

The State of the SA Population Report (2000:62) summarizes the impact of HIV/AIDS on the long-term demographics of the South African population as follows:

Table 2.2 : The Actual Demographic impact of HIV/AIDS on the South African Population.

<b>Indicator</b>	<b>End 1990</b>	<b>Beginning 2000</b>
Life expectancy	63 years	56,6 years
AIDS deaths	1000	140 000 to 150 000

Child mortality	67 per 1000	91 per 1000
Probability of 15 year old to die before age 60	27 per 1000	40 per 1000
Population infected	< 0.5 %	11.5 %

(Department of Social Development: 200162).

The UNAIDS Report on the Global HIV/AIDS epidemic published in 2004 by the Avert.org website gives more information on the situation in Africa. From this information, it becomes clear that the South Africa is one of the countries worst hit by the illness.

Table 2.3: Comparison between the South African and African HIV/AIDS infection rates.

Country	Adults living with HIV	Adult infection %	Women living with HIV	Children living with HIV	AIDS deaths amongst children and adults	Children orphaned by AIDS
BOTSWANA	330,000	37,3	190,000	25,000	33,000	120,000
LESOTHO	300,000	28,9	170,000	22,000	29,000	100,000
MOZAMBIQUE	1,200,000	12,2	670,000	99,000	110,000	470,000
NAMIBIA	200,000	21,3	110,000	15,000	16,000	57,000
NIGERIA	3,300,000	5,4	1,900,000	290,000	310,000	1,800,000
<b>SOUTH AFRICA</b>	<b>5,100,00</b>	<b>21,5</b>	<b>2,900,000</b>	<b>230,000</b>	<b>370,000</b>	<b>1,100,000</b>
SWAZILAND	200,000	38,8	110,000	16,000	17,000	65,000
ZIMBABWE	1,600,000	24,6	930,000	120,000	170,000	980,000
<b>TOTAL SUB-SAHARAN AFRICA</b>	<b>23,100,000</b>	<b>7,5</b>	<b>13,100,000</b>	<b>1,900,000</b>	<b>2,2 million</b>	<b>12,100,000</b>

(HIV/AIDS Orphan statistics, 2005).

#### **2.4.3.4 ECONOMIC AND MACRO-ECONOMIC IMPACT**

The economic implications of HIV/AIDS will affect all South Africans. The State of the South Africa's Population Report (2000:66) is of the opinion that the projected age structure of the population shows that the number of dependants, both children and the aged, will increase in relation to the potentially economically active population. This means that the dependency rate will increase substantially during the coming years and there will be fewer people to care for the children and the elderly.

HIV/AIDS therefore threatens human development and social and economic security. In developing countries, where 95% of all HIV infections occur, AIDS is already reversing decades of hard-won developmental gains in improving the quality of people's lives and reducing poverty (Hunter & Williamson, 2000:11).

In a typical community affected by HIV/AIDS:

- Economically productive adults leave work due to illness or to attend funerals or to care for sick family members. The local schools lose teachers, health-care workers become sick, husbands and fathers are no longer employed;
- Life expectancy decreases and infant mortality increases;
- Existing under-resourced health services become overwhelmed;
- Disruption of family and community life emerges;
- Children are kept from school to care for adults;
- There are increasing numbers of orphans- most of them have less access to education and adult role models;
- Limited family resources are spent on funerals and care for the sick;
- Food production declines- malnutrition increases;
- Poverty, inequality and crime increase;

- People with HIV become stigmatised and face harm and discrimination (Smart et al., 2000:30).

Smart et al. (2000:93) states that HIV hits poor households dramatically, placing an increased burden on already over-burdened households as it is a fatal disease or results in disability. Adults between 25 and 45 are most affected. People become ill and die in the years when they are potentially economically active. Death of an adult means the loss of a provider, carer and nurturer. Insurance and medical aid benefits are also lost when a person passes away. Burial and medical costs are also an additional strain on families.

Resulting poverty can lead to the sale of assets and land. Children may have to leave school and are possibly forced into a lowly paid work. They may also turn to crime or sex as a survival option. Workplace absenteeism, loss of labour, loss of skilled, trained personnel; rising costs of employer benefits, reduced work performance and lower productivity are also economic effects resulting from the epidemic (Smart et al., 2000:93).

Griesel -Roux (2004:37) quotes Juma (2001) on the variety of strategies households use to cope with the economic shock of losing a breadwinner. The most commonly applied strategy is drawing on family savings or selling assets. The selling of land, livestock, bicycles and radios is quite widespread in rural areas. Many households that suffer an adult's death sell some of the durable goods as part of their coping strategies.

Hunter and Williamson (2000:12) mention that the costs of HIV/AIDS- related illness and death could be enough to send a household into permanent poverty or from poverty to destitution. Higher sero-prevalence in urban areas will aggravate the situation of the urban poor possibly more than the rural poor, who have broader household and community support systems and can fall back, to some extent, on household food production as their income decline. Reverse migration, as urban dwellers become sick and go home, may overwhelm the resources of rural relatives.

Natrass (2004:33) echoes the impact of AIDS on food security. According to her, AIDS in sub-Saharan Africa threatens food security directly through its impact on peasant agriculture. However, by contrast, South Africa's experience of 'de-agriculturation' resulted in a situation where most food is produced by large, capital-intensive commercial farms. According to the February 2002 Labour Force Survey, only seven % of employment in South Africa is subsistence and small-scale agriculture. Given that only a small proportion of household income is generated by subsistence agriculture, the bulk of this 'employment' is in fact large-scale underemployment. The impact of AIDS on the economic security of poor households in South Africa is thus felt primarily through declining income rather than food production.

The market impact is also very clear: there is a growth in certain areas, like money lending, funeral services, health care. There is also a definite decline in areas like consumables (Smart et al., 2000:93).

On a macro-economic level, a reduction in the number of workers available in the economy (human capital) and increased production costs are results of the epidemic. This may reduce investments and drive up the cost of capital (Smart et al., 2000:93). Hunter and Williamson (2000:11) indicate that the growth of per capita GDP (Gross Domestic Product) will decline slowly but steadily in most countries in the sub-Saharan Region as a result of HIV/AIDS.

A decrease in the size of the public sector and less personal and corporate savings because of increasing medical expenses, may reduce investments and drive up the cost of capital. Reduction in direct Government investment in areas such as infrastructure is possible, especially when health care expenditure increases (Smart, Dennis & Pleaner, 2000:93).

The reduced life expectancy may eventually compromise developmental objectives of the country. The impact of HIV/AIDS on households include a decline in productivity, loss of assets from the home, and an increase in

household expenditure which is the direct outcome of meeting bills as well as funeral services (Dorkenoo et al., 2002:11).

The measurement of the impact of AIDS on the workplace is complex. The actual cost of AIDS cases to employers varies greatly. Productivity will be affected as skilled or experienced staff fall ill, stay absent and finally die. Dorkenoo et al. (2002:26) indicates that an increasing number of workplaces have their own clinics where staff can receive free treatment, as it is in the interest of business to prevent and treat HIV/AIDS.

Medical aids schemes will probably suffer first, as their profits are dependant on the assumption of a healthy population. Most working South Africans may first become aware of the impact of the pandemic by increases in their medical aid deductions.

The social impact of HIV infections within households increases certain kinds of long-term expenditure. If infected persons are income earning, their illness and possible death reduce the household income. Special nutrition and medical treatment and the inevitable funeral costs constitute major financial burdens on the household budget. This combination of burdens will lead to a further, immediate degradation in the household economic status, adversely affecting the living standard and quality of life of surviving members (The Department of Social Development, 2000:62).

## **2.5 RESPONSES TO THE HIV/AIDS PANDEMIC**

The actions taken by governments worldwide now will have a serious impact on the future progression of the HIV/AIDS pandemic. "By 2025, depending on the actions taken today, up to 43 million HIV infections could be averted over the next 20 years" (UNAIDS, 2005). Internationally, the initial Government reaction of countries like India and Cuba, was to attempt to curb it by using draconian public health measures, e.g. placing persons living with HIV in isolation, quarantine, forcing them to undergo mandatory testing and disclosure of their status.

In South Africa, only two statutory interventions specifically limiting the rights of persons living with HIV exist. The Admission of Persons to the Republic Act allows immigration officials to detain and deport immigrants, visitors or migrant labourers with HIV (Smart et al., 2001:111). However, legislation to prevent discrimination on the basis of health status does exist. The amended Medical Schemes Act prevents discrimination in enrolment on the basis of health status, meaning that HIV status cannot be used as a basis for refusing enrolment. Furthermore, Employment Equity legislation exists so that no person may be unfairly discriminated against on the basis of HIV status (Dorkenoo et al., 2002:86).

South Africa has a National AIDS Council (SANAC), which has the power to make policies, and advise government on all HIV/AIDS policy making. It is chaired by the country's Deputy President and is composed of 15 government representatives and 16 civil society representatives. There is also an Inter-Ministerial Committee of SANAC that is chaired by the Deputy President. This committee comprises of all Ministers and Deputy Ministers. Its role is to guide the National AIDS Programme. An Inter-departmental Committee on AIDS, which brings together officials responsible for coordination of HIV/AIDS activities for HIV/AIDS, also assists the Ministers. There are also MINMECS, which are meetings of Health Minister and Members of Provincial Councils who meet every six weeks to approve national policies and guidelines (Dorkenoo et al., 2002:84).

South Africa has a National AIDS policy, the principles of which are HIV/AIDS and STI prevention, treatment and care efforts for South Africans. These were adopted as part of the National AIDS plan for South Africa and outlined in the White Paper on the Transformation of the Health Care System.

NGO's view the national policies as not fully comprehensive and the strategies as limiting. There have been several NGO demonstrations that demand the widespread implementation of a programme to prevent transmission of HIV from mother to child. The South African HIV/AIDS policy is

also criticized for not providing care to people living with HIV/AIDS (Dorkenoo et al., 2002:84).

South Africa has a National AIDS Plan entitled "The National HIV/AIDS/STD Strategic Plan for South Africa 2000-2005". This plan has four priorities, namely:

- **Prevention:** Promotion of safe sex, healthy sexual behaviour, management of STI, reduction of mother-to-child transmission, improvement of blood transfusions, post-exposure prophylaxis, access to voluntary counselling and testing.
- **Treatment, care and support** in health facilities, communities and for children affected by HIV/AIDS, including orphans.
- **Research, monitoring and surveillance**, including vaccine development, investigations into treatment and care options, policy research and regular surveillance.
- **Human Rights:** creation of appropriate social, legal and policy environment (Dorkenoo et al., 2002:85).

The Nelson Mandela Children's Fund commissioned a report on the situation and special needs of children in child-headed households in 2001. In this report, (2001:16) the UNAIDS Report of June 2000 was quoted to describe other African countries' responses to the HIV/AIDS crisis' impact on children. The following can be highlighted:

#### **MALAWI**

A national Orphan Care Task Force was established in 1999. Government actively supports community efforts like child-care canters to improve the care of the children. Efforts are also made to improve the children's learning opportunities.

#### **ZAMBIA**

This country has a strong Non Governmental Organization sector that works at filling the gaps in Government provisioning by providing food, clothing and



school fees. This country has enormous challenges, as they proportionately have the second largest orphan population in Africa.

### **UGANDA**

This country has the biggest orphan population in Africa. Uganda Women's Effort to Save Orphans (UWESO) has more than 35 branches and is the strongest provider of support to Uganda's huge orphan population. They assist in funding education and training and they have a micro-finance scheme to assist caretakers.

### **BOTSWANA**

Botswana has a Short Term Plan of Action (STPA) for the care of their orphans. The policy aims to build and strengthen capacity of social welfare and other essential services. They also support community-based initiatives. A part of the policy makes provision for the establishment of Child Welfare Multi-Sectoral Committees at Local Government level.

## **2.6 SUMMARY**

HIV/AIDS affects the South African society in virtually all spheres of life. The disease grew from virtually unknown in the 1980's into a pandemic, unsurpassed by any other illness or natural disaster.

South Africa appears to be particularly vulnerable to the spread of the disease because of a number of social factors, amongst others, poverty, unsafe sexual practices, gender inequality, and social dislocation. The perception of illness and sexuality in Africa also directly contribute to the vulnerability of the South African Society.

HIV/AIDS have serious economic implications. The Health and Social Services and Education sectors are also directly affected by the pandemic.

The most vulnerable part of the community appears to be the affected children. The disease itself and the experiences the patient and affected family members go through are complex and multi-layered.

The next chapter will therefore focus on the orphan phenomenon, in conjunction with a discussion of the actually felt experiences of the infected family members, as the latter directly influence the psychosocial health of the affected children.

## CHAPTER 3

### THE EXPERIENCES OF THE HIV INFECTED PERSON AND THE CONCURRENT INFLUENCE OF THE ILLNESS ON EXTENDED FAMILY MEMBERS

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#### 3.1 INTRODUCTION

“Sometimes, I feel like a spirit. I feel like I can be seen but not heard. Not many people pay attention to me. Like a spirit, I’m always there, but people don’t notice the things I do.” (Geballe & Gruendel, 1998:47).

Dorkenoo et al. (2002:19) is of the opinion that AIDS deaths left an estimated 4,7 million children orphaned in the South African Development Community in 1999. Orphans may grow up deprived of maternal or paternal love and support; they may be discriminated against because of the status of their parents; they may have to discontinue their education because of a lack of money or the need to take care of siblings. Socially speaking, the consequences of raising large numbers of children without love or support from primary caregivers still remain to be seen.

Stefan German researched the psychosocial impact of HIV/AIDS on children (2004:18). He is of the opinion that in the face of visible social and economic hardship due to HIV/AIDS, with children’s basic rights to basic needs constantly violated, the psychosocial burden of the HIV/AIDS epidemic may seem less important, less urgent, less compelling – but not to the children themselves. The emotional demand of HIV/AIDS on children’s lives is heartbreaking. Long before a parent dies, children experience trauma and stress related to caring for terminally ill parents. The impact of HIV/AIDS, linked with fear, economic insecurity and other stress factors frequently results in domestic violence. Children are directly exposed to these factors with little support to make sense or to develop skills to manage such household

situations. One can only begin to understand the psychosocial impact of HIV/AIDS on children by listening to their stories.

Children suffer tremendously when their parents are infected, and the needs of children with infected parents are often neglected. There is no tradition of talking to children as equals and on an intimate basis in many African societies, and caregivers often report seeing 'the suffering of children, who are too often hovering in the shadows of a sick room, seeing and hearing everything but never addressed directly' (UNAIDS, 2000 quoted by Van Dyk, 2003:261). Children are largely excluded from the counselling process in Africa because (amongst other reasons) caregivers often simply do not know how to talk to children.

HIV/AIDS causes serious problems for children. But singling out for assistance those children whose parents have died of AIDS stigmatizes the intended beneficiaries. The needs of individual children are not necessarily greater than those of children orphaned by other causes or vulnerable for other reasons and the problems may begin long before their parents become ill or die from HIV/AIDS. Because of increased economic stress on households, many children who are not orphans will also experience these problems (Dorkenoo et al., 2002:15).

Smart, Dennil and Pleaner (2001:94) mention that the term "Children living with HIV/AIDS" was developed by National AIDS and Children Task Team (NACTT) to embrace all children infected and affected by HIV/AIDS. This includes those who are infected, those vulnerable to infection, those from households with people living with HIV/AIDS, and those adversely affected by the epidemic in their community.

Van Dyk (2003:265) is of the opinion that children are affected by HIV/AIDS in different ways. They may be infected with HIV themselves, they may have one or two parents who are HIV-infected or they may be orphaned because of the AIDS-related deaths of their parents.

## **3.2 HIV/AIDS INFECTION**

Although chronic illness or death of a parent or sibling from any cause clearly exposes children to a variety of major psychological challenges, those who work with children affected by AIDS believe the: “specific constellation and intensity of problems facing families affected by HIV set this disease apart from all other contemporary health problems” (Bauman & Weiner, quoted by Geballe & Gruendel, 1998:50).

### **3.2.1 THE PHYSICAL CONSEQUENCES OF HIV INFECTION**

#### **3.2.1.1. TYPES OF HI VIRUSES**

HIV is a Retro virus, meaning it does the reverse of what other viruses do. HIV uses an enzyme (reverse transcriptase) to transform its viral RNA into DNA in order to produce more viruses (Van Dyk 2003:15).

Reuter (2005:8) explains that there are two types of Human Immuno deficiency viruses isolated, namely HIV1 and HIV2. However, this category is further divided into Major type viruses and Outlier Type viruses. The Major type viruses, which are further divided into 10 subtypes, A to J, categorised into the so-called clades or genotypes, cause most infections. The O-type HIV1 viruses are distinct from the M group and include a number of African isolates.

Five HIV2 subtypes (A to E) have been described so far.

Barnett and Whiteside (2002:125) describe the HIV2 as a form of virus that is less aggressive, has a longer lifecycle and therefore does not kill so rapidly.

The major virus strain causing infections in South Africa is the HIV1 subtype C.

### 3.2.1.2. TRANSMISSION

Smart et al. (2001:35) explains that HIV affects the body by affecting the immune system. The immune system is the body's defence against infection by micro organisms (bacteria and viruses) that cause disease. Amongst the cells that make up the immune system is one called a CD4 lymphocyte. HIV is able, by attaching to the surface of the CD4 lymphocyte, to enter, infect and eventually destroy the cell. Over time this leads to a progressive and finally profound impairment of the immune system, resulting in the infected person becoming susceptible to infections and diseases such as cancer.

Van Dyk (2003:14) indicates that although all viruses live and multiply solely in cells, HIV hijacks the most important defensive cell in the immune system (the CD4 cell) and turns it into an efficient virus factory to manufacture perfect replicas of itself. When this happens, the CD4 cells are unable to do what they would normally do when confronted by an alien virus, i.e. orchestrate and coordinate the body's defences against HI viruses. Instead, they themselves are captured and forcibly turned into small factories to manufacture the very carriers of death against which they are supposed to defend the body.

Although several antibodies are formed during this process, they are completely powerless against the HI virus because it hides (completely undetectable) inside the CD4 cells while they subvert the cell to manufacture copies of itself (Van Dyk, 2003:14).

Smart, et al. (2001:38) mention that HIV is a virus that cannot survive outside the body. Although it is present in all body fluids, HIV is only present in sufficient concentrations to cause infection in blood, semen, vaginal secretions and breast milk.

HIV can be transmitted from an infected person by the following routes:

1. Sexual intercourse (vaginal, anal, oral): the most frequent mode of transmission;

2. Contact with infected blood, semen, vaginal and cervical fluids- in situations where the infected body fluid is able to enter another person's body;
3. From an infected mother to her child- during pregnancy, birth or breastfeeding.

The major route of transmission is unprotected sex. The safest form of prevention is thus abstinence, limiting the number of sexual partners and using barrier methods (e.g. condoms).

Women are four times more vulnerable to HIV. The State of South Africa's Population Report (2000:64) postulates that they are biologically more vulnerable to infection than men, as they have larger mucosal surfaces, and micro-lesions may occur during intercourse, which can serve as an entry point for the virus. Sperm contains a higher count of the virus than vaginal secretions. In addition, the presence of untreated STD's is a risk factor for HIV infection.

Both ulcerative and non-ulcerative Sexually Transmitted Illnesses have been shown to facilitate HIV infection, especially in the early stages of the epidemic (Dorkenoo et al., 2002:37).

Smart, Dennil and Pleaner (2001:37) is of the opinion that HIV infection is the most powerful factor known to increase the risk of developing Tuberculosis. In Sub-Saharan Africa, anyone with Tuberculosis is in a high-risk group for HIV. Treatment of Sexually Transmitted Diseases has become one of the most important strategies for containing the HIV epidemic. Tuberculosis accelerates the progress of HIV, but can be cured effectively in HIV positive or HIV negative people. Using a drug called Isoniazid can decrease the risk for HIV positive persons of contracting TB.

### **3.2.1.3 DEVELOPMENT AND SYMPTOMS OF THE ILLNESS**

HIV infection is commonly divided into several stages, predominantly on the basis of the CD4 cell count and the most common clinical symptoms. Rates of viral replication are also used to determine the stage of the disease (Reuter, 2005:4).

#### **3.2.1.3.1. ADULTS**

In adults, the typical course from HIV infection to AIDS is as follows:

##### **STAGE 1: PRIMARY INFECTION (ACUTE SERO-CONVERSION ILLNESS)**

This stage can either be without symptoms or be characterised by an acute sero conversion syndrome, occurring in about 50% of infections. Six weeks to three months after becoming infected a person will develop antibodies to HIV. At this time, some people will experience a 'flu-like or glandular fever-like illness', possibly coupled with a rash.

Antibodies to HIV first become detectable within one to three weeks after the onset of the symptoms. Antibodies appear initially, reaching a peak two to five weeks after the onset of symptoms but becoming undetectable within three months.

Because of the rapid replication of the virus, the HIV viral load is usually very high during the acute phase. Immediate and aggressive treatment with anti-retroviral treatment (ART) at this stage may be effective in reducing the viral load to undetectable levels, or even in eradicating the virus (Compare Smart et al., 2001:35; Reuter, 2005: 5-9; Van Dyk, 2003:37).

##### **STAGE 2: ASYMPTOMATIC LATENT PHASE**

The a-symptomatic phase is usually associated with a CD4 cell count of between 500 and 800 cells per cubic millimetre of blood. The normal CD4 cell



count in healthy non-infected individuals is approximately 800-1200 cells per cubic millimetre. In this phase the infected person displays no symptoms. Infected individuals are often not even aware that they are carrying the virus in this stage, and may therefore unwittingly infect other persons. The virus stays nevertheless active in the body during this stage and it continues to damage the immune system.

HIV infected people can remain healthy for a long time, show no symptoms and carry on with their work in a normal way. In some cases, the only symptom is persistent swollen glands (Van Dyk, 2003:37).

### **STAGE 3: MINOR SYMPTOMATIC PHASE**

The early stage disease can be defined as a CD4 count of between 500 and 350 cells per cubic millimetre in the blood. Irrespective whether or not antiretroviral therapy is given, most individuals in this stage may present with one or more of the following symptoms:

- Mild to moderate swelling of lymph nodes;
- Occasional fevers;
- Shingles (This is often the first sign of HIV infection. It affects the nerve cells and cause painful blisters on the face or on the body).
- Fungal nail infections;
- Recurrent oral ulcerations;
- Recurrent upper respiratory tract infections;
- Weight loss of up to 10% of the person's usual body weight;
- Malaise, fatigue and lethargy;
- In this period the risk of developing opportunistic infections including pulmonary tuberculosis is considerably higher than amongst those in the Early Stage of the disease. Co-infection with HIV and Pulmonary Tuberculosis is common. This period can last up to eight years (Compare Smart et al., 2001:35; Reuter, 2005: 5-9; Van Dyk, 2003:37).

#### STAGE 4: ADVANCED STAGE DISEASE / MAJOR SYMPTOMATIC PHASE

At this point, the CD4 cell count becomes very low while the viral load becomes very high. The following symptoms are usually an indication of advanced immune deficiency:

- Persistent and recurrent vaginal and oral thrush;
- Recurrent herpes infections such as cold sores;
- Shingles;
- Bacterial skin infections;
- Intermittent or constant fever that lasts for more than a month;
- Night sweats;
- Chronic diarrhoea that lasts for more than a month;
- Weight loss of more than 10% of body weight;
- Swollen glands;
- Abdominal discomfort, headaches;
- Thickened white patches on the sides of the tongue (oral hairy leucoplakia);
- Persistent cough and reactivation of tuberculosis;
- Opportunistic diseases of various kinds.

Advanced stage disease is defined by a CD4 cell count of less than 200 CD4 cells per cubic millimetre in the blood. When this count is so low the risk of developing certain opportunistic infections increases substantially. A key feature of advanced-stage disease is that opportunistic infections that initially respond to therapy tend to relapse unless lifelong maintenance therapy is used. In addition, neurological symptoms become particularly common during advanced stage disease. For example, a progressive decline in mental activity, short-term memory and concentration, loss of spontaneity and motor functioning (for example clumsiness, slowness and tremor) can be caused by direct infection of the central nervous system. This results in HIV-associated dementia.

Personality changes may occur, including apathy, withdrawal, irritability and depression. In the last stage of AIDS the patient may enter a conscious, but vegetative state. Patients may even realize that they are losing cognitive functioning and this may lead to severe depression.

As soon as the brain is infected, it becomes a sanctuary site for ongoing viral replication despite antiviral therapy as the blood brain barrier may limit drug penetration

Many individuals with advanced stage disease develop the typical HIV wasting disease syndrome, losing a substantial proportion of their body weight. This can be attributed to a loss of appetite, gastro-intestinal mal-absorption, and adverse effects of medication. Untreatable opportunistic conditions and cancers begin to manifest. These patients are likely to die within two years. Anti-retroviral therapy and the prevention and treatment of opportunistic infections may prolong this period.

Anxiety and depression are common in terminally ill patients. Physical signs of anxiety like restlessness, insomnia and shortness of breath can be detected. Patients often appear pre-occupied with their death and may wish to hasten it.

In recent years, morbidity and mortality rates among people living with AIDS have decreased and life expectancy for such individuals has increased. This improvement has generally been attributed to the use of more intensive anti-retroviral therapies and advances in the treatment of opportunistic infections (Compare Smart et al., 2001:35; Reuter, 2005: 5-9; Van Dyk, 2003:37).

#### **3.2.1.3.2 CHILDREN**

In children, the majority of HIV infected infants develop disease during the first year of life and there is a high mortality rate. Others may live well into their teenage years. The transfer of antibodies in the mother's blood to the child complicates diagnosis of the virus in babies. The child may falsely test HIV

positive for up to 18 months following birth. The common symptoms identified by the World Health Organization for clinical diagnosis of AIDS in children are:

- An increased frequency of common childhood infections;
- Symptoms such as fever, diarrhoea and dermatitis which tend to be more persistent and severe and do not respond well to treatment;
- Enlarged lymph nodes and liver;
- Failure to thrive;
- Delays in attaining developmental milestones and the loss of those already attained;
- AIDS defining conditions such as Kaposi's sarcoma, Pneumocystis carinii pneumonia (PCP).

Other minor criteria are:

- Chronic cough for longer than 1 month;
- Chronic skin infections;
- Oral thrush;
- Neurological abnormalities such as seizures and reduced head growth;
- The mother of the child is HIV positive. (Compare Smart et al., 2001:35; Reuter, Chapter 5:5-9).

HIV infected children do not respond to medication as well as non-infected children and they are likely to suffer life-threatening complications. The course of the development of the illness differs significantly from that of adults. The time lapse between infection and the onset of full-blown AIDS is usually much shorter in children and most infected children develop the disease within the first year of life. Children who acquire HIV infection during pregnancy, birth or breastfeeding can be divided into two groups, namely *rapid progressors* and *slow progressors*. Rapid progressors usually fail to thrive from birth and die within the first two years of life. Slow progressors develop some symptoms from time to time and often survive to older childhood years and even early teenage years.

The progress of AIDS in children may be accelerated by poor nutrition (Van Dyk, 2003:43).

#### **3.2.1.4. TESTING**

The diagnosis of HIV infection is based mainly on the laboratory testing of blood samples. Two broad classes of tests may be distinguished. These are (1) HIV Antibody tests, which react to antibodies, which have formed in reaction to the virus, and (2) tests which detect the actual virus (HIV) in the blood (Van Dyk, 2003:57).

One test for antibodies is the ELISA test (Enzyme Linked Immuno Sorbent Assay). The period between infection with HIV and when the body develops antibodies is called the 'window period'. In this period the antibody test cannot detect infection, even though the person is infected and infectious (Smart et al., 2001:39).

Rapid HIV antibody tests can be performed outside a laboratory (in places like clinics or even at the bedside of a patient) and the results are usually available within 10 to 30 minutes. Rapid HIV antibody tests are relatively easy to use (they involve a prick of the finger with a lancet), they are relatively cheap and they demonstrate a high rate of reliability if they are correctly used. Positive results should however always be confirmed with a laboratory test or if that is not possible, a second rapid HIV antibody test of another kind.

It is possible that these tests can give a false negative result, if the patient is in the so-called window period. This is the period between the onset of HIV infection and the appearance of detectable antibodies to the virus. In the case of the most sensitive HIV antibody tests currently in use, this period is between three to four weeks. With less sensitive tests, this period can extend to even 12 months (Van Dyk, 2003:59).

HIV virus tests do not rely on the development of antibodies before the yield of a positive test result. These tests detect the actual virus in the blood.

Examples of this, is the HIV P24 antigen test and the PCR technique. Both are laboratory tests, which indicates the presence of the virus and the amount of viral material in the blood (Van Dyk, 2003:60).

### 3.2.1.5. TREATMENT AND CARE

Barnett and Whiteside (2002:185) are of the opinion that the first sign of full-blown AIDS in a family is when the youngest child (infected in vitro) fails to thrive, dying after protracted illness. An infected mother is likely to have been infected by her partner, who then falls ill and dies.

According to Smart, Dennil and Pleaner (2001:41) the objectives of treatment and care are mainly:

- To reduce suffering and improve quality of life;
- To provide appropriate treatment of acute infections, for example:
  1. Treatment for STD's and TB
  2. Treatment of opportunistic infections
  3. Prophylaxis for opportunistic infections
  4. Palliative care
- Anti-retroviral therapy.

Antiretroviral (ARV) drugs are used to treat HIV and in some instances to prevent infection. Different types exist, but all act to prevent replication or reduce the rate of replication of the virus and so slow the progression of the disease and prolong the survival of infected persons.

According to Van Dyk (2003:67), a combination of two or three different anti-retroviral drugs has been shown to produce the best effects and to reduce the possibility of viral resistance. Anti retro-viral drugs act by blocking the action of enzymes that are important for the replication and functioning of HIV.

A vaccine is a substance that teaches the immune system to recognise and protect against a disease caused by an infectious organism or virus. Some experimental AIDS vaccines are in development, but the widespread availability of an effective vaccine is still many years away (Smart et al., 2001:42).

Demmer (2004:40) writes that for those who lost loved ones to AIDS in South Africa, 2004 is a bittersweet moment in the pandemic. As ARV treatments are beginning to be rolled out, survivors may feel anger and a sense of unfairness that their loved ones did not live long enough to benefit from the treatments. Infected individuals who are lucky enough to access ARV treatment and experience improved health, will look around and find that many in their social network are no longer around due to AIDS. These patients are likely to experience loneliness and depression. Survivor guilt is common and some patients may feel that there is no future worth living when they contemplate the many losses they experienced already.

Even though ARV treatment is very effective, some patients still die. The reasons for this include:

- Patients may experience initial benefits but then the treatment is no longer effective;
- Patients may fail to respond to ARV treatment because of severely compromised immune systems or drug resistance;
- Treatment may be disconnected because of intolerable side effects;
- Patients may experience great difficulty following complex medication regimens that require extraordinary high levels of compliance;
- As patients survive longer, their risk of developing various kinds of cancers as well as organ deterioration increases, which could be fatal (Demmer, 2004:40).

### **3.2.2. PSYCHOSOCIAL EXPERIENCES OF THE INFECTED PERSON**

The diagnosis of HIV infection or AIDS evokes severe emotional reactions- not only in the infected person, but also in his or her affected significant others.

Emotional support is a very important part of improving the quality of life of the patient. HIV-infected people often have the following psychosocial experiences:

#### **3.2.2.1 Shock**

Reactions to a positive antibody test are influenced by the person's physical health at the time and the degree of preparation for the news. Perceptions of psychological, social, and material support from family, friends, and community are a factor contributing to the state of mind of the patient. Combined personality attributes and the psychological condition of the patient also determine the initial reaction of the patient. Because of the stigma and discrimination, the person may need assistance in deciding who to tell about his or her HIV status. Attention should be given to the potential psychosocial concerns following a positive test result (National Association for Social Work, 1995:1269).

#### **3.2.2.2 Fear**

Infected persons often fear being isolated, stigmatised and rejected. They fear the uncertainty of the future: will there be pain or disfigurement, and who would look after them? They are afraid of dying- and particularly of dying alone and in pain. Many HIV-infected people have experienced the pain and death of loved ones and friends who have already died of AIDS and they know and fear what awaits them. Fear may also be caused by not knowing enough about what is involved in HIV infections and how the problems can be handled (Van Dyk, 2003:256). Uncertainty about the rate of progression of infection, symptoms and disease as well as anxiety and



depression about health care available may increasingly cause fear (National Association for Work, 1995:1269).

### **3.2.2.3 Loss**

For some people, a process of anticipatory loss begins almost at once. HIV-infected people often feel that they have lost everything that is most important and beautiful to them. They experience loss of control, loss of autonomy, the opportunity to have children and live a full life, loss of their ambitions, their physical attractiveness, sexual relationships, status and respect in the community, financial stability and independence. They fear the loss of their ability to care for themselves and their families and they fear the loss of their jobs, their friends and family. They mourn the loss of life itself. HIV-infected people also feel that they have lost their privacy and their control over their lives once they begin to need constant care. Perhaps the most commonly experienced loss is the loss of confidence and self-worth occasioned by the rejection of people who are important to them – people who were once friends. A reason for possible rejection may be the physical impact of HIV-related diseases that cause, for example, loss of mental competence and dementia or facial disfigurement, physical wasting and loss of strength or bodily control (Van Dyk, 2003:256; National Association for Social Work, 1995:1270).

### **3.2.2.4. Grief**

People with HIV infection often have profound feelings of grief about the losses they have experienced or are anticipating. They grieve for their friends who die from AIDS, and they grieve with and for their loved ones- those who must stay behind and try to cope with life without them (Van Dyk, 2003:257).

Demmer (2004:40[]), writes that ARV treatment results in extended survival for many patients, but a challenge for the patient and their loved ones is that they will have to cope with a longer period of uncertainty and anticipatory

grief. Anticipatory grief is the process of anticipating the loss of the patient with AIDS.

#### **3.2.2.5 Guilt**

Guilt and self-reproach for having contracting HIV and for having also possibly infected others are frequently expressed by HIV-infected individuals. They often feel guilty about the behaviour that may have caused the infection. Feelings of guilt may be associated with a person's unresolved conflicts about homosexuality or about sexuality in general. There is also guilt about the sadness that the illness will inflict on loved ones and families – especially the children. Previous events that may have caused others pain or sadness but which still remain unresolved will often now be remembered and be the cause of even greater feelings of guilt and anguish (Van Dyk, 2003:257). Family and friends also feel loss and sometimes anger toward the person with infection or disease. Such feelings may give rise to feelings of guilt and may affect the quality of important relationships (National Association for Social Work, 1995:1270).

#### **3.2.2.6. Denial**

Most HIV-positive people go through a phase of denial. Denial is an important and protective defence mechanism because it temporarily reduces emotional stress (Van Dyk, 2003:257).

#### **3.2.2.7. Anger**

HIV-infected people are often very angry with themselves and others, and this anger is sometimes directed at the people who are closest to them. They are angry because there is no cure for AIDS and because of the uncertainty of their future. They are often also angry with those who infected them and with society's reaction of hostility and indifference (Van Dyk, 2003:257).

### **3.2.2.8. Anxiety**

The chronic uncertainty associated with the progress of HIV infection often aggravates feelings of anxiety. HIV-infected people often experience anxiety because of the prognosis of the illness, the risk of infection with other diseases, the risk of infecting loved ones with HIV, social, occupational, domestic, and sexual hostility and rejection, abandonment, isolation, and physical pain, fear of dying in pain or without dignity, inability to alter circumstances and consequences of HIV infection, uncertainty about how to keep as healthy as possible in the future, fears about the ability of loved ones and family to cope, worries about the availability of appropriate medical treatment, a loss of privacy and concerns about confidentiality (Van Dyk, 2003:258).

### **3.2.2.9. Low self-esteem**

The self-esteem of HIV-infected people is often severely threatened. Rejection by colleagues, friends and loved ones can cause one to lose confidence and a sense of one's social identity- and thus to experience reduced feelings of self-worth. The inability to continue in a career or to participate in social, sexual and loving relationships also diminishes the client's self-esteem. The physical consequences of HIV infection such as physical wasting and the loss of strength and bodily control contribute even more to a lowering of self-esteem (Van Dyk, 2003:258). HIV is often viewed as evidence of immorality or contamination, affecting self-esteem (National Association for Social Work, 1995:1270).

### **3.2.2.10. Depression**

HIV-infected individuals often experience depression because they feel that they have lost so much in life- and that they themselves are to blame for it. The following factors all serve to increase depression: the absence of any cure and the resulting feeling of powerlessness, knowing others who have died of AIDS, the loss of personal control over their lives, self-blame and feelings of guilt (Van Dyk, 2003:258).

### **3.2.2.11 Suicidal behaviour or thinking**

Inwardly directed anger may manifest as self-blame, self-destructive behaviour or (in its most intense form) suicidal impulses or intention. Suicide may be construed as a way of avoiding pain and discomfort, of lessening the shame and grief of loved ones, and of trying to obtain a measure of control over one's illness (Van Dyk, 2003:258).

### **3.2.2.12. Obsessive conditions and hypochondria**

Some HIV-infected individuals become so preoccupied with their health that even the smallest physical changes or sensations can cause obsessive behaviour or hypochondria. This may be temporary and limited to the time immediately after diagnosis, or it may persist in people who find it difficult to adjust or to accept the disease (Van Dyk, 2003:259).

### **3.2.2.13. Spiritual concerns**

HIV-infected people who are confronted with death, loneliness, and loss of control often ask questions about spiritual matters and they search for religious support. They may want to discuss the concepts of sin, guilt, forgiveness, reconciliation and acceptance (Van Dyk, 2003:259).

It is the opinion of the researcher that the impact of the HIV/AIDS pandemic affects the South African society on different spheres like the economy, health and social services and the demographic profile of the country. However, it also has some psycho-social implications for the infected person and those affected around them.

### **3.3 THE ORPHAN PHENOMENON**

#### **3.3.1 INTRODUCTION**

According to the U.S. Census Bureau, 15,6 million children will have lost their mothers or both of their parents by 2000 in 23 countries heavily affected by HIV/AIDS. That number will increase to 22,9 million by 2010, largely as a result of the HIV/AIDS pandemic. Nineteen of these countries are in sub-Saharan Africa, where by 2010 these orphans will comprise up to 8,9 percent of children under age 15. The sheer size of the population at risk for HIV/AIDS in Asia means that the problem of orphaning there will eventually eclipse that of sub-Saharan Africa. The number of orphans will continue to grow in Latin America and the Caribbean, where the pandemic started later (Hunter and Williamson, 2002:01).

Webb (1997:12) is of the opinion that the AIDS orphan crisis in Africa can be attributed to a number of situations. Firstly, Africans have big families and as AIDS has killed a large number of people of parenting age, it has left behind a large number of orphans. Secondly, the African extended family has traditionally nursed its sick and absorbed its orphans without fuss or legal process. Death of adults at an earlier age leaves no financial support system to cope with the care of these orphans. Thirdly, many African parents no longer live long enough to see their children reach maturity. Fourthly, the death of adults at a parenting age causes some families to collapse. In most desperate cases relatives will steal some orphan's inheritance, leaving some children to struggle alone in their parent's homes to make ends meet.

The loss of a parent has profound significance for a child. The death of a mother, in particular, has dramatic psychosocial consequences. Children lose love and nurturing, and their households may break up, with siblings sent to live with different members of the extended family. Loss of a father often means the loss of income and results in economic deprivation. When a father dies of AIDS, the children often lose their mother as well, to illness or for social reasons like re-marriage (Hunter and Williamson, 2002:02).

Hunter and Williamson (2002:03) are of the opinion that the growing number of orphans will have a profound impact on the societies in which they live. Orphans may suffer the loss of their families, depression, malnutrition, lack of immunizations or health care, increased demands for labor, lack of schooling, loss of inheritance, forced migration, homelessness, vagrancy, starvation, crime, and exposure to HIV infection. With orphans eventually comprising up to third of the population under the age of 15 in some countries, this outgrowth of the HIV/AIDS pandemic may create a lost generation- a large cohort of disadvantaged, under educated, and less-than-healthy youths. The threat to the prospects for economic growth and development in the most seriously affected areas is considerable.

The vulnerabilities of these children are increased by the geographic concentration of the HIV/AIDS pandemic- vulnerable children are cared for by vulnerable families and reside in vulnerable communities. Many of the communities most affected by HIV/AIDS are impoverished and isolated. Hunter and Williamson (2000:03) is of the opinion that some communities devised creative programmes to identify and assist the needy families in their midst, and there are similarities among these community- based responses. These include labour-sharing arrangements for day care and nutrition centers, agricultural work and other income-generating projects, home repair and home care for the ill and for orphans. These support systems appear to be the least visible but most cost-effective ways to help families affected by HIV/AIDS (Levine, 2001:20).

Demmer (2004:40) writes that there is little empirical research on the experiences of children orphaned in sub-Saharan Africa. The researcher concurs with this opinion, as social workers experience a need for more information in practise. The following, however, became clear from the available research:

### 3.3.2. FOOD, FOOD SECURITY AND EDUCATIONAL NEEDS

Hunter (in Levine, 2001:2) is of the opinion that taking in an orphan tends to increase household poverty and food insecurity, as the fostering family must share its resources more widely, increasing the vulnerability of all the children in such a household. Children also suffer from weakened caregivers, increased societal pathologies associated with a high rate of HIV and ADIS, and adverse environmental conditions. Finally, children face the threat of reduced social services and safety nets. This can be confirmed from the practical experiences of the researcher, as the need for sustainable food security is on the increase among families affected by the pandemic.

Smart. et al., (2003:33) indicate that affected children are vulnerable to malnutrition, both due to scarcity of food and to the weak position they occupy within their guardian's homes in the household resource distribution process. This is equally true for educational needs, like books, school fees, uniforms, shoes, school trip funds and after care facilities for younger children. Demmer (2004:40) quotes research that shows that AIDS- affected families have less money to spend on food, clothing and education.

To reduce their food costs, affected households may reduce the frequency and quality of their meals (Foster, 1997:15). AIDS- affected households tend to be poorer, consuming less food and with smaller disposable incomes; it is hardly surprising that children in these households are usually less well nourished and have a greater chance of being stunted (very low height for their age) or wasted (very low weight for their height). Stunting results from poor nutrition over an extended period (Nelson Mandela Children's Fund Report, 2001:14). Orphans may have been deprived of proper nutrition during the period that their parents were sick and dying. Stunting has long-term effects. Foundations for future life are poorly built with poor physical condition, compromised immune systems and mental functioning. This will affect the ability of children to benefit from education and to function socially and economically later in their lives. It can affect a society for a generation or more (Barnett and Whiteside, 2002:202).

The researcher is of the opinion that the HIV/AIDS pandemic creates a number of social problems, but that the poverty resulting from it is devastating for child development.

### **3.3.3. HOUSING, CLOTHING AND BEDDING**

AIDS deaths lead to the redistribution of household assets, often with the disenfranchisement of women and children. Redistribution according to customary law favours the relatives of the male head of the household (Hunter and Williamson, 2002:17).

Elderly grandparents and children can often not repair and maintain their homes. In times of poverty, repairs are neglected. The family's supply of bedding may be reduced because the deceased parent may have been bedridden and incontinent before death; children commonly sleep on sacks on the floor. Many children have no footwear and only one set of clothing (Smart et al., 2003:33).

Barnett and Blaikie (1992:119), say that orphans cared for by grandparents often experience problems due to the lack of financial resources, since grandparents no longer are in full-time employment. They also lack energy to work long and hard. Grandparents with their diminished support capacity and grandchildren may have conflict because of a lack of resources.

### **3.3.4. SCHOOLING**

Orphans are less likely to have proper schooling. The death of a prime-age adult in a household will reduce a child's attendance at school (World Bank, 1997, quoted by Barnett and Whiteside, 2002:202). This household may be less able to pay for schooling. An orphaned child may have to take on household or income-earning work. Sick adults may have reduced expectations of the returns of investing in children's education, as they do not expect to live long enough to recoup the investment. When a child goes to another household after his or her parents' death, the obstacles become greater as the child is not their own.



### **3.3.5. HEALTH CARE**

Immunization and simple medical care may not be reaching these children. Children under five years old are particularly vulnerable (Smart et al., 2003:34). Hunter and Williamson (2002:17) are of the opinion that children under the age of two who lose their mothers are most likely to suffer additional morbidity and mortality .

### **3.3.6. PSYCHOLOGICAL DISTRESS CAUSED BY AN AIDS ILLNESS AND DEATH IN A FAMILY**

Demmer (2004:40) is of the opinion that affected family members are at risk of prolonged grief and psychiatric problems as they mourn an AIDS death. However, there is very limited research conducted in sub-Saharan Africa on psychosocial issues in general and related to HIV/AIDS in particular. In addition, research suggests that existing psychometric tools, mainly developed in Europe or the USA, should not be used in culturally different settings, as results cannot be validated (German, 2004:2, 19).

Children are exposed to a multitude of stressors when their household is exposed to HIV/AIDS. Fear, worry, observing and caring for ill parents in pain, stigmatization, hospital visitations, shattered hope and eventual loss are all experiences shared by these children. 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 (German, 2004:19).

Kaaya and Smith Fawzi (1999) in Griesel-Roux (2004:38) support this line of thought, in terms of the psychological impact of HIV/AIDS. They state that the impact of psychological needs of persons infected and affected by HIV/AIDS are often overshadowed by physical and social needs in a setting with limited resources, and thus often ignored.

The same authors have identified some of the AIDS-specific challenges as:

### 3.3.6.1 DISTURBING CLINICAL COURSE OF HIV/AIDS

Children's psychosocial distress begins with a parent's illness, and they are left emotionally and physically vulnerable by the death of one or both parents. They may suffer lingering emotional problems from attending to dying parents and seeing parents die (Hunter & Williamson, 2002:17).

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. 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).

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. Stress, depression, 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 to discover that a parent "disappeared" to hospital (Geballe & Gruendel, 1998:50).

The illness and death of their parents may have a serious impact on the perception of body, illness, and death for children. Small children have a very primitive concept of contagion. A 'bug' causes illness or a 'germ' that you can 'catch'. How the germ brings about the illness is a mystery to them,

but they nonetheless will have a theory. Five or six year olds can and will ask questions and can understand simple answers. In a household affected by HIV, it might happen that the child's normal questions are not answered or are discouraged. This may give rise to fantasies and fears that are more frightening than the truth itself (Geballe & Gruendal, 1998:55).

### **3.3.6.2. UNCERTAINTY**

There is no relief from the single current certainty of AIDS: the infected individual will eventually die. The rest of the course of AIDS is characterized by tremendous uncertainty for both the infected parent and the affected child. Periods of acute, serious illness punctuate the daily living of families in which a person has AIDS. The infected parent may be in and out of hospital. No one knows when the hospitalization will occur, how long it will last, and whether the parents will return home. During these periods, children are placed informally with neighbours or extended family or may be left to fend for themselves. Living with such uncertainties as these poses great challenges to the secure psychological base essential to a child's development of a healthy and functional personality (Geballe & Gruendel, 1998:51).

The Northern Uganda Psycho-Social Needs Assessment carried out in 1998 (Strode & Grant, 2001:19) found unexpectedly widespread and chronic psycho-social problems after decades of civil unrest, famine, and AIDS.

Pervasive insecurity about physical well-being, provision of basic needs, abductions, lack of social services and displacement manifested in various social ramifications. These included:

- Sleeping problems;
- Depression;
- Anger;
- Alcoholism and drug use;
- Early sexual activity;
- Increased school drop-out rate;
- Domestic violence;

- Suicide;
- Criminality;
- Rape;
- Teenage pregnancy;
- Family breakdown.

In this study, researcher found that 10 to 30 percent of the population experienced psychosocial trauma, while between 80 and 100 percent of the population suffer from sleeplessness, anxiety, flashbacks, or excessive fear.

Strode & Grant (2001: 19) confirm that the most common experiences of children in their study, were:

- Worry about ill parents
- Worry about the future
- Worry about food
- Worry about safety
- Seriously diminished sense of self-worth
- Powerlessness
- Grief

### **3.3.6.3 MULTIPLE LOSSES**

AIDS frequently causes illness and death in more than one family member, and often in more than a single generation of the family. These multiple and multigenerational deaths challenge the very integrity of the child's family in a manner akin to war. They will almost certainly subject children to additional losses (including changes of residence, of school, of parental figures, and separation from siblings) that may result in a "bereavement overload", leaving children vulnerable to loss and disruption in later life. Splitting siblings up after parental death compounds the loss of the parents, especially in families where older siblings had assumed a care giving role to younger siblings and strong feelings of dependency and attachment had developed (Geballe & Gruendel, 1998:52).

In practise, the emotional bond formed between siblings who are living in a child-headed household sometimes are the reason why the children prefer to stay together, even if it means that they have to live on their own. It is also very difficult for children who took on parental responsibilities, to fit into a new household.

Barolsky (2003) and Call et al. (2002) quoted by Griesel- Roux (2004:38) are of the opinion that adolescents of nations devastated by AIDS live in a world of near-constant bereavement, facing the death of family, friends and acquaintances on a daily basis. Another aspect to consider is that the literature shows that parental death reduces children's self-esteem and increases depression, anxiety, conduct disturbance, academic difficulty, somatic complaints and suicidal acts in the long term. (Compare Rotheram-Borus, Lee, Gwadz and Draimin, 2001 quoted by Griesel- Roux, 2004:38.)

However, existing research suggests that the impact of HIV/AIDS at household level, may lead to sequential trauma associated with continuous traumatic stress syndrome. Many children suffer multiple losses – a father, a mother, siblings, grandparents, uncles, aunts, and other relatives. In addition, they may lose friends, familiar surroundings, schooling, and their hope for the future, and their remaining childhoods. Separation of siblings is a major factor contributing to psychological distress; which underlines the importance of providing support to orphans in ways that go beyond traditional support interventions (German, 2004:2, 19).

Demmer (2004:40 ) concludes that AIDS is a disease of loss. Family members experience various losses throughout the course of the patient's illness, including the loss of the person they once knew as he or she declines. Survivors of multiple AIDS- related losses may protect themselves by deadening the pain into denial (psychic numbing). There may be changes in personality and the following emotions may dominate: pessimism, rage, disillusionment, despair and powerlessness. In addition, survivors may experience guilt that they survived while their loved ones died and they may question whether they did enough for their loved one.

#### 3.3.6.4. STIGMA, SILENCE AND FAMILY SECRETS

"The stigma carried by these children is a big problem- the community isolates them and they respond by further isolating themselves from the community; parents discourage their children from playing with kids from affected households because they are believed to also have AIDS; the children who go to school tell us their friends don't want to play with them as they might infect them" (Service Providers' Focus Group quoted by Strode & Grant, 2001:13).

AIDS remain a highly stigmatized disease, causing persons affected as well as persons infected to be victimized by discrimination and to be ostracized by their communities and even by their own families (Geballe & Gruendel, 1998:52). Stigmatization, discrimination and social isolation, dropping out of school, moving away from friends and bearing an increased workload in the home all increase the stress and trauma that accompanies the death of a parent (Medical Research Council AIDS Bulletin, 2004:19).

" As the illness becomes impossible to conceal, caregivers and all household members are likely to experience rejection, fear of contagion and anticipatory grief" (LoveLife, 2000: 9).

Many parents are reluctant to talk openly and honestly about their infection with their children from a sense of shame and self-reproach- both because their children might inquire about parental "risk- behaviours" that occasioned the infection and because they know, they have brought harm to their children, directly (through infection) or indirectly (by leaving them behind at death). Infected parents also resist telling children about their condition because the disclosure forces into common awareness the parent's own illness and potential death. As a result, the disease becomes unnamed, unspoken, and often unspeakable to children who then have no name for what they know is happening to their loved ones and to themselves. Often, if children are told that the parent has HIV, they are also told to keep the

“family secret”, denying them access to social support that could help buffer them from this enormous stress. (Geballe & Gruendel, 1998:53).

Individuals in South Africa who lose a loved one to AIDS are not likely to receive the same amount of support and sympathy that they would receive if their loved one died of more socially accepted causes (e.g. cancer, heart disease). Survivors may be forced to keep the nature of the death secret and hide their own grief. As a result, AIDS survivors have been called “hidden grievers” (Dane & Miller, 1992 quoted by Demmer, 2004:40). Because of their fears of being ostracized by others, survivors may be hesitant to mourn openly in public and to seek support from others.

In addition to the secretiveness of HIV/AIDS, the relationship between the deceased and survivor may not be socially sanctioned (e.g. gay relationships). AIDS survivors are regarded as disenfranchised grievers. This term was coined by Doka (1989) and is used to describe the grief that individuals experience when they are not allowed to mourn publicly and do not receive adequate social support for their grief. The stigmatization of AIDS not only increases the pain and suffering of survivors, but contributes to the social and economic vulnerability of those living in AIDS-affected household. (Demmer, 2004:40).

Strode and Grant (2001: 12) are of the opinion that discrimination in the more rural areas had a lot to do with misconceptions of how the disease is transmitted. The discrimination results in the isolation of the affected family. Children are treated as if they are contagious and parents tell their children not to play with someone whose mother became “thin” as they will also be infected. They are also not allowed to play with the same toys or use the same cutlery.

Teasing at school worries children a lot. It affects their sense of self-worth and it can even drive children away from school. The manner in which they or ill parents may be treated at health facilities is also a source of discrimination and hurt. This creates feelings of powerlessness and anger (Strode & Grant, 2001: 12).

### 3.3.6.5. COMPLICATED GRIEF

Before discussing bereavement due to AIDS deaths, it is important to clarify the terms *bereavement* and *grief*, which are often used interchangeably. *Bereavement* is the long-term adjustment or accommodation of the loss of a loved one. *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 (Goodkin et al. in Demmer, 2004:40). Grief work is the process and work of adjusting to irrevocably lost objects, relationships and dreams. It is a universal and normal response to loss and it affects all aspects of an individual's life – physical, emotional, cognitive, behavioural and spiritual. Grief is a highly individualized experience and is influenced by a variety of factors including its context and concurrent stressors.

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, the HIV status of the bereaved, multiple losses and inadequate support due to the social stigma associated with AIDS( Maasen, 1998 in Demmer, 2004:40 ).

Examples of complicated bereavement are:

- Not being able to let go (keeping the deceased's room intact long after the death; holding on to anger or guilt;
- Feeling chronic intense pain years after the death;
- Not being able to return to normal day-to-day functioning after the death
- Engaging in self-destructive behaviours that mask grief (e.g. impulsiveness, suicidal thoughts, persistent psychosomatic complaints, including the physical symptoms of the deceased;



- Psychiatric disorders, including depression, anxiety, eating disorders (Demmer, 2004:40 [3]).

Smart et al., (2001:93) and Van Dyk (2003:275) also describe the difficulties AIDS orphans may have in the grieving process. Most of the children struggle to come to terms with the reality of being orphaned and feel the loss of parental attention and physical and social security. The normal grieving process is complicated by guilt of children who were unable to save their parents. Behavioural problems may result from this. The following are common amongst smaller children:

- The child may believe that the family member did not really die and will come back from a faraway place;
- Fantasies of re-unification with the parent in heaven;
- Mourning on a piecemeal basis, for example feeling the loss on special days;
- Daydreaming as if the person is still alive;
- Keeping something of the parent as a way of holding on to a memory;
- Fear of sharing memories or fantasies with others;
- Avoiding expression of feelings and opinions in fear of upsetting the remaining living parents;
- Keeping feelings a secret (Geballe & Gruendel, 1998:54).

Because independence of the nuclear family was compromised, they are unable to participate effectively in the kinship network where they are perceived as a liability and many, as a result, show socialization problems (Smart et al., 2001:93). Necessary support for a child's mourning can be lacking, especially when it is the child's mother who died, when the child's surviving caregiver is struggling with grief over losing a spouse or child to AIDS, or when well-established patterns of family secrecy do not allow open communication of the child's feelings of loss (Geballe & Gruendel, 1998:54).

Not surprisingly, children and youth affected by HIV/AIDS in their families exhibit behaviours signalling the need for mental health and social support.

Geballe and Gruendal (1998:54) refer to a study of orphaned adolescents in the USA that found that all experienced significant isolation from their peer and adult social networks. AIDS-affected children and youth universally worry about their futures, and in particular, who will care for them after the parents' death. Among pre-school children, parental depression, unpredictability, and erratic behaviour can result in the child's insecure attachment to caretakers and a limited sense of self-worth.

Geballe and Gruendal (1998:54) also indicate that slightly older children (four to six years) often exhibit excessive dependency, oppositional behaviour, and have problems forming and maintaining peer relationships. Children report fears of contagion and of their own early death. Children before the age of puberty often hold themselves responsible for the illness in the family. They may also feel great anger with the parent at becoming infected and at infecting other family members, compromising their capacity to have a sense of positive identification with a parental figure that is so necessary for their development. Some children even report feeling invisible, a feeling that has profound ramifications for identity formation.

Van Dyk (2003:275) writes that *adjustment disorders* may develop after a period of bereavement or other trauma. These usually develop within three months after the stressful event and they usually disappear within six months. They are characterized by diverse symptoms such as anxiety, depression, a combination of anxiety or depression, behavioural and/or emotional disturbances. Bereavement often causes adjustment disorders. Complicated or prolonged bereavement is often found in situations where there has been an untimely or unexpected death- as is very often the case with AIDS-related deaths. People who feel hostility, resentment, or intense guilt towards the deceased also often experience extreme adjustment disorders (Carson, 1998 in Van Dyk, 2003:275).

*Acute stress disorder and post-traumatic stress disorder* may also present itself in children after the death of a loved one. An acute stress disorder is an anxiety disorder that develops in response to an extreme psychological or

physical trauma. Acute stress disorder is described by Sue et al. (2000) and Carson et al. (1998) quoted by Van Dyk (2003:275) as:

- Severe feelings of anxiety and helplessness;
- Feelings of dissociation, emotional unresponsiveness, numbness and withdrawal;
- Persistent re-experiencing of the traumatic event through intrusive, recurring thoughts, repetitive dreams about the event, illusions and flashbacks;
- Sleep disturbance, irritability, finding it difficult to concentrate or remember things, and restlessness;
- Avoidance of interpersonal involvement.

If the symptoms last for longer than four weeks, a diagnosis of post-traumatic stress disorder can be made.

Not all people who experience a traumatic event develop acute or post-traumatic stress disorders. Factors such as the person's individual characteristics, his or her perception of the event, and the existence of support also influence whether or not a disorder will develop.

While *depression* is a common problem in our society, HIV/AIDS affected family members frequently experience it. The symptoms of depression may be categorized as follows:

- Affective symptoms:  
The most striking symptom of depression is a depressed mood characterized by feelings of sadness, unhappiness, worthlessness, anxiety and apathy.
- Cognitive symptoms: Sufferers report feelings of futility, emptiness and hopelessness. They often have profoundly pessimistic beliefs about the future; they find it difficult to cope with daily life because of a loss of motivation, interest and energy. Suicidal thoughts, guilt, negative

thinking and concentration problems are also common among depressed people.

- Behavioural symptoms:

Low energy levels are one of the most common behavioural symptoms of depression. Other symptoms include neglect of personal appearance (dirty clothing, unkempt hair, lack of personal hygiene); crying, agitation, social withdrawal, slow or reduced speech, and passivity. Depressed people often have dull, mask-like facial expressions. They move slowly and they do not initiate new activities. These symptoms are called *psychomotor retardation*.

A child's mental health depends to a large extent upon the status and well being of his or her primary caregiver. Signs of a mother's depression, guilt, anger or fear may be experienced (though not understood) by the child. This is often reflected in children as changed behaviour. A study in Zambia found that 82% of those caring for children noted changes in children's behaviour during parental illness. Caregivers noted that children became worried and sad, and they tried to help more in the home and stopped playing to be close to their parent (Medical Research Council AIDS Bulletin, 2004:2, 19).

- Physiological symptoms:

Depressed people often describe a loss of appetite and weight (some however have an increased appetite and experience weight gain); sleep disturbances (difficulty in falling asleep, waking up early, waking up during the night, insomnia, nightmares); loss of libido, disrupted menstrual cycle and constipation.

Depression in children and adolescents is often disguised as boredom, restlessness, and feelings of worthlessness or even belligerency (Van Dyk, 2003:277).

### 3.3.6 DEVELOPMENTAL DELAYS

Toddlers in an affected household are often cared for in a context of parental depression, unpredictability, and erratic behaviour. The parent may take refuge in isolation and secrecy. Excessive protection of the baby or toddler often occurs. The child may have difficulty in establishing relationships with peers. Insecure or anxious attachments to the caretaker may occur, accompanied by a lowered sense of self-worth. The toddler may show signs of withdrawal and apathy like food refusal, temper tantrums and in some rare instances the failure-to-thrive syndrome (Geballe & Gruendal, 1998:54).

Between four and six years, excessive dependency and clinging behaviour may occur. Marked oppositional behaviour is another result. Anxious attachments may interfere with the child's ability to form and sustain relationships with peers and adults (Geballe & Gruendal, 1998:54). Increased anxiety may present as regression, like thumb-sucking, baby-speech, wetting, and soiling.

By school-going age, the child in the HIV affected family may also have been exposed to further stress like serious illness of parents or relatives and the death of parents or siblings. This may lead to further erosion of self-esteem, increasing depression, and this may lead to difficulties in keeping up in school. Oppositional and disruptive behaviour may follow the failure to resolve emotions and fears (Geballe & Gruendal, 1998:55).

In adolescence, ambivalent feelings toward the ill or surviving parent or caregiver may manifest in severe behavioural and psychological problems. Acts of destruction, self-destruction and thoughts of suicide may occur. Impulsive "solutions" like uncontrolled defiance and running away may be the result of unresolved emotions and ambivalent feelings. The child's fear of the outcome of the illness of the adult or others may lead to counter-phobic risk taking that includes high-risk sexual encounters or drug abuse (Geballe & Gruendal, 1998:56).

Rejection and acting out may be mechanisms of defence. In this triad of defences, an adolescent may even subconsciously put himself in the place of the dying person, resulting in self-destructive behaviour (Geballe and Gruendal, 1998:56).

### **3.3.8. CHANGED ROLES**

The extended family structure is a primary support mechanism in Africa societies – a social safety net for children that has remained resilient over the years (Strode & Grant, 2001:13). However, AIDS disrupts social roles, rights, and obligations. For the orphaned child there is often a premature entrance to burdens of adulthood, all without the rights and privileges- or the strengths- associated with adult status. Becoming an orphan of the pandemic is rarely a sudden switch in roles. It is slow and painful, and the slowness and pain have to do not only with loss of a parent but also with the long-term care, which that parent's failing health may require. Children who care for adults may experience a world gone seriously awry. Coping with a parent who is weak and requires food to be cooked or water to be brought is one thing. Coping with a parent's severe diarrhoea, declining mental functioning and mood changes is quite another. Children also become uncommonly familiar with death (Barnett & Whiteside, 2002:206).

Hunter and Williamson (2002:17) write that HIV/AIDS affects the nature of households. There is an increase in multigenerational households without the middle (income-generating) generation. There is an increase in female-headed households that have little access to family or external resources. The roles of family members change. Children may care for ill adults and work to produce food and generate income. Children are also marrying at a younger age.

All children have physical and material needs, intellectual and educational requirements and psychosocial wants. Children affected by HIV/AIDS are particularly vulnerable in all these areas, as they take on adult household,

parenting and care responsibilities. The consequences of being affected by the disease are thus manifold. Children are forced to take on roles in their households that they are not ready for. So, for example, a young girl whose parents are infected will have to run the household, cook and see to younger siblings, which in turn has an impact on her performance at school (Giese et al., 2003 and Smart, 1999 in Griesel- Roux, 2004:42).

These children are forced in many ways to be "grown-up" when all they desire is to be able to enjoy their childhood. Hepburn (2001) states that girls are particularly vulnerable among children affected by HIV/AIDS for the reasons stated above (Griesel- Roux, 2004:42).

Significant others often have to fulfil a role for which they are not trained, namely that of caregiver. They have to look after seriously ill loved ones. This can be arduous, disconcerting and all-consuming task that utterly drains all the caregiver's physical, emotional and (often) financial resources. If there are unresolved relationship issues in such circumstances, they can quickly become acutely aggravated (Van Dyk, 2003:261).

Most children report having lost their friends due to their rigid time budgeting which does not allow them time for play (Smart et al., 2000:33). Child heads of households confess to being ill equipped to provide proper parental guidance and discipline for their siblings, let alone the love and care which they themselves need. There are also no moral and ethical guidance for the children, where the only adult attention may be in the form of irregular and inadequate supervision.

Infected parents can place heightened demands (emotional and physical) on the children, reversing normal parent-child roles and leading some children and youth to resist age- and situation-appropriate outbursts of anger or disagreement, lest they become a greater strain on parents. Among adolescents, this relinquishment of the normal impulse toward rebellion coupled with intense feelings of ambivalence toward the ill parent can render the developmentally normal conflicts around separation nearly

impossible to resolve, resulting in developmental delays (Geballe & Gruendal, 1998:54).

### 3.3.9. DISCRIMINATION, ABUSE AND NEGLECT

Adolescents and their families also face the daily threat of stigmatization and discrimination (UNESCO, 2002, in Griesel- Roux, 2004:38). For families with HIV or families living in high HIV seroprevalence areas, stigma and discrimination is a complex issue. The entire family can experience stigma, and therefore HIV can be a source of conflict and shame within families. Discrimination is also the social action whereby abstract stigma becomes visible.

Freedom from discrimination within school, foster families, orphanages, etc. is a need. After the death of a parent who was ostracized or rejected, children may experience some stigma. Children also need legal protection, with respect to inheriting land and other material goods as well as protection from unscrupulous relatives. Some discrimination does take place in South Africa. In some instances health workers obtain consent to test for Hepatitis B, but then test for HIV. Day care centres often refuse to admit HIV positive children and employers refuse persons living with HIV to join medical aid schemes (Smart, Dennil & Pleaner, 2001:111).

The National Household HIV Prevalence and Risk Survey of South African children (Brookes, 2004:51) describes the situation of orphaned children as follows:

- Forty- five of the children who participated in the survey live in a home where there is not enough money for food or clothing;
- 12,7% of the surveyed households with at least one child in the two -14 year age group, ran businesses from home – such as spaza shops and taverns;
- 32% of children are exposed to someone in their home and neighbourhood who is drunk once a month;
- Besides mother-to-child infections of HIV/AIDS, the study identified three components that make children vulnerable to HIV infection; unsafe



environments; a lack of care and protection of children; and a lack of knowledge and communication about sex and HIV/AIDS.

Children from uninfected households living in affected communities are also affected, either directly, for example through day-to-day contact with their peers who have been personally affected, or indirectly by the consequences of the epidemic, such as deteriorating levels of education and health care (Smart, Dennil & Pleaner, 2000:33).

Orphans are victims of a more silent process of neglect and deprivation, namely deprivation of contact and stimulation. Cultural deprivation can be identified amongst children who show an episodic grasp of reality (here and now world), inability to see connections or recognize inconsistencies (anything goes), failure to make comparisons between present and past and impulsiveness and lack of goal-directed control. They may lack experiences, may feel excitement in relation to very few experiences or objects, and associated primarily with the satisfaction of basic physiological needs.

The health, general well-being and development of these children may be neglected as grandparents, extended family, fictive kin, such as social workers and even communities may not be able to carry the burden of so many orphaned children. AIDS orphans have to carry both the trauma of losing their parents and the stigma of the virus. Some studies estimated that death rates among orphans are two and a half to three times higher than for non-orphans (Department of Social Development, 2000:68).

MacLeod (in Levine, 2001:10) discusses the accommodation of orphans in residential care after being removed from the community because of abuse or neglect. For many children, residential care is an option of last resort. Nearly all the children in residential institutions have family who abandoned the children, using the institution as a strategy to cope with poverty or violence. Most institutions provide a relatively higher level of material support, better healthcare, food, and educational and housing conditions.

Macleod (in Levine, 2001:10) continues to discuss the invisible and long-term detrimental costs to children. Children in residential care often lose their connections to their families, clans and friends. This alienation, coupled with inadequate and inconsistent attention to developmental needs, especially of small children, leads to stunting of social and intellectual development.

Barnett and Whiteside (2002:211) mention that the rights of children may be threatened by orphan hood. The International Convention on the Rights of the Child in principle provides a protective framework for children. It accords them the following rights, which are to be protected by signatory governments, like South Africa:

Table 3.1: Convention on the Rights of Children

<b>Convention Article</b>	<b>Rights of children</b>
Article 7	To be cared for by his or her parents
Article 8	To preserve identity, name and family relations
Article 9	To maintain regular contact with parents if separated
Article 13	To freedom of expression
Article 15	To freedom of association
Article 18	To be brought up by parents or guardians whose basic concern is his or her best interests
Article 19	To protection from physical or mental ill-treatment, neglect or exploitation
Article 27	To conditions of living necessary for his or her development
Article 28	To education
Article 31	To rest, leisure, play and recreation
Article 32	To protection from economic exploitation and performing any work that interferes with his or her education or is harmful to his or her mental, spiritual or social development.
Article 34	To be protected from all forms of sexual exploitation and sexual abuse

Article 35	To be protected from abduction, sale or trafficking
Article 37	To be protected from torture or other cruel, inhuman or degrading treatment or punishment.

Barnett and Whiteside (2002:212).

In normal circumstances many of these rights are violated; HIV/AIDS increases the numbers of children at risk. In extreme cases, which are all too often, orphans turn to the street, where their physical needs and financial desperation makes them vulnerable to crime, substance abuse and sexual exploitation (Barnett & Whiteside, 2002:212).

### 3.3.10. CHILD- HEADED HOUSEHOLDS

Foster (1997:5) describes the factors that may predispose the development of a child-headed household, namely:

- **Reluctance of relatives to foster orphans**

Many uncles and aunts of orphaned children are reluctant to foster a relative's children because it would result in their own children's standard of living suffering. If forced by economic circumstances to choose between their own and fostered children, they would tend to show preference towards the former. Relatives may also consider themselves free of responsibility towards orphans, even though they are closely related to the children. This may be because there was little contact between the affected children and the family before the parent's death, especially among relatives who have cut off links with their extended family and adopted western nuclear patterns of living. Relatives may even not recognize the legitimacy of orphaned children in certain circumstances; for example if Lebola (bride price) was never paid (Foster, 1997:5).

Another reason parents may be reluctant to foster children may be because of their concern about caring for orphans when they suspect that the parent died from AIDS. Relatives may fear contracting HIV infection from the

children, or feel that the children will bring the stigma into their home (Foster, 1997:5).

- **Lack of contact of relatives with the children**

Lack of assistance from relatives may sometimes simply be because of distance or a lack of access to communication media. Family sometimes simply does not know about the desperate situations faced by orphaned children living in difficult circumstances. This may be particularly the case when large distances separate households, such as the case is with migrant workers (Foster, 1997:5).

- **Presence of adolescents able to care for younger children.**

Foster (1997:7) writes that it is common for older children to take over parenting roles during prolonged illness of a parent. Adolescents learn responsibility, effective coping mechanisms, and nurturing skills in this situation. Following the death of a parent, this adolescent may be deemed capable of continuing to care for the siblings by members of the extended family who are reluctant to take the responsibility themselves. Relatives often seem reluctant to foster older children compared to younger children.

- **Death of a single mother leaving illegitimate children**

Some of the most vulnerable orphans are children from single mothers, especially if the mother was a commercial sex worker. When a single mother becomes sick or dies, her children may be left in the care of grandparents; because other relatives who refuse to provide any support to the children because they consider the children illegitimate may neglect such orphans. Child-headed households may be particularly likely to result from single-mother households (Foster, 1997:8).

- **Death of a grandparent-caregiver**

Grandparent-headed orphan households are becoming increasingly common because of AIDS. Grandparents are more likely to be older and be more incapacitated than aunts and uncles. When the grandparent passes away, older brothers or sisters may be left to head orphan households (Foster, 1997:5).

- **Children preferring to live in the child-headed household**

Some children may prefer this option, because of inheritance of the residence by the surviving children or because of a death wish of a dying parent. In some case, siblings in a family may choose to form child- or adolescent headed households in order to avoid being separated. The children may desire to stay together as a family group rather than to be split up between various relatives, or wish to stay living at their own residence, in familiar surroundings rather than change school, friends, home and neighbourhood. They may resist attempts of relatives to take them into their household, fearing maltreatment or because the relative actually only wants the younger children.

Orphaned children may also be concerned about losing their inheritance rights to property and land if they live with others. Urban children in particular may be concerned about their schooling being discontinued or deterioration in their standard of living if they have to live with a poor rural relative. Instead, children may actively choose to stay living together in a child- or adolescent-headed household, rather than relocate to a poor, reluctant, or abusive relative's home (Foster, 1997:5).

Sometimes, adolescents have to make a deathbed promise to take care of young children and keep them together. Because of this, adolescents who might otherwise prefer to see the family caring for the children may resist reasonable plans made by family or welfare authorities (Foster, 1997:5).

The following problems are common amongst child-headed households:

- **Lack of supervision and care**

These children lack day-to-day supervision by an adult. This lack of consistent care may manifest as an increased frequency of accidents by young children, difficulties coping with family illness, exploitation, or abuse of children by relatives or community members and discipline problems of children. 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 girl child caregivers may lead to their attachment to older men in the community, which makes them vulnerable to exploitation (Foster, 1997:10; Demmer, 2004:40; Barnett &Whiteside, 2002:212).

- **Poverty**

Orphaned children in child-headed households are more likely than other orphans to suffer from stunting and hunger, especially at times of famine. Orphans often have poor clothing, and their housing is more likely to be of poor quality. Child-headed households in urban communities may have difficulty in maintaining rental for accommodation and may be forced to move to rural areas. During times of stress as when children are sick, poverty is likely to be a serious obstacle since they may struggle to get access to medical care (Demmer, 2004:40; Foster, 1997:11; Barnett &Whiteside, 2002:212).

Some children included in the Nelson Mandela Children's Fund Report (2001:13) reported going days without food. The humiliation of begging for food or money from neighbours or family was deeply felt by all participants. They often experienced ridicule about inadequate school uniforms or because their parents died of AIDS. Mostly, children from child-headed households relied heavily on the goodwill of neighbours to survive. In some

cases, child heads performed small jobs, like washing cars, polishing shoes or sold vegetables to support siblings. Some children make themselves available to run errands for sympathetic neighbours for payment in kind. The most constant source of support, however, was grandparents who would share maize meal with their grandchildren when they replenish their own supply.

- **Psychological reactions**

Multiple death experiences are common amongst children from child-headed households. In addition, they live in households, which are precarious and assume care giving and family support roles whilst they are still passing through child or adolescent development. It is to be expected that they may exhibit a variety of psychological reactions (Foster, 1997:11).

Household heads are likely to experience depression and anxiety, related to the stress of caring for younger children at a time when they still require care and support themselves. They may feel overwhelmed and resentful that they have been forced into an adult life full of responsibilities, especially when their peers are in school or simply having fun (Foster, 1997:11).

Child-headed household members also have to work harder than other children do. Some adolescent household heads 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 (Barnett & Whiteside, 2002:212; Foster, 1997:11).

Evidence exists that neighbours and relatives avoid visiting destitute children, either because of poverty or because of the AIDS-related stigmatization.

Normal childhood and adolescent development may thus be seriously disrupted amongst children living in child-headed households, often with long-term consequences (Foster, 1997:12; Demmer, 2004:40).

### **3.4 IMPACT ON THE ELDERLY**

The physical, economic, and psychological toll of AIDS on the bereaved elderly in South Africa is immense, but there are few interventions to support them. AIDS in Africa has also been called the 'grandmother's disease' because older women are expected to take in grandchildren as they watch their own children die. They are expected to care for these children orphaned by AIDS and to feed, house, clothe and educate them. This situation is even complicated further if the children are HIV infected and they later on have to bury them. They are deprived of the support in their old age that their deceased children would have provided (Demmer, 2004:40).

### **3.5 STRENGTHENING RESILIENCE AS COPING STRATEGY FOR THE ORPHANED CHILD**

The South African experience with orphans as a social problem is limited. Historically, orphaning on a large scale has been a sporadic, short-term problem, caused by war, famine, and disease. HIV/AIDS has transformed orphaning into a long-term, chronic problem that will extend into the next century. The serious social and economic dislocation that will result from the large and growing proportion of children who are orphaned will require comprehensive, creative and long-term solutions (Hunter & Williamson, 2000:04).

In many cases, traditional mechanisms for assisting orphans have been overwhelmed by the scale and scope of the problems (Levine, 2001:i). Communities have coped with children who have lost their parents in past generations, but the expanding scale of the problem and the weakening of community mechanisms and the undermining of social capital make external intervention essential. Many agencies are responding with a range of external



interventions, but as yet there is no clear model of an international intervention strategy to effectively tackle the problem. The combined responses of different agencies need to pay attention to innovation, advocacy and difficult policy trade offs (Levine, 2001: i).

However, specific factors exist that appear to contribute to the resilience of children and adolescents facing difficult psychological, familial and environmental circumstances. These factors are:

- The way the child approaches challenges;
- The child's experience within the family;
- The external supports that exist for the child (Dennis, 2004:29).

Characteristics of the child that promote resilience include an active rather than passive orientation to problems, persistence in problem resolution, access to a range of flexible strategies to respond to problems, development of a broad range of interests and goals, and skills in using peers and adults to receive support and assistance. Family characteristics that contribute to resilience include a consistent nurturing relationship between at least one parent, older sibling, or other adult and the child; consistent parental supervision tempered by predictable rules and balanced discipline; emphatic understanding of the child as an unique individual; an open system of communication in which problems and planning for the future are shared and cohesiveness among family members (Geballe & Gruendel, 1998:56).

Effective social support from outside of the family is the critical third leg of the resiliency triad. For children, effective social support means relationships with caring individuals in whom **they** trust and safe places to expend energies and express emotions. Such support often includes same-age and older friends, parents of friends, church leaders, teachers and sports coaches (Geballe & Gruendel, 1998:56).

Applying recent research on resilience to the situation of AIDS-affected children and youth provides several initial insights concerning key elements of any resiliency- based model of care. Firstly, the quality of care and support

the child receives from whomever assumes the primary caretaker roles during the parent's illness and after the parent's death is especially critical. Early permanency planning is essential to reduce the stresses of the inevitable transition and enhance the likelihood that sibling can remain together (Geballe & Gruendel, 1998:56).

Secondly, open communication about the illness and death is essential. The child affected by AIDS will need to communicate thoughts and fantasies about the death of the parent or siblings and to express feelings of anger, guilt, sadness, and loss. The child will also need to receive accurate information to dispel misconceptions, such as a young child's common fantasy that his own evil thoughts caused the death (Geballe & Gruendel, 1998:57).

Thirdly, children's own internal coping abilities can be strengthened, by providing them both with opportunities to distance themselves from what is going on in the immediate family and with mental health support, problem-solving skills, esteem-building experiences, positive outlets for physical energy and emotional expression, and a chance to be actively involved (in an age-appropriate way) in planning what happens to them.

Promoting consistency and stability in the child's environment at every opportunity is of paramount importance (Geballe & Gruendel, 1998:56).

It describes "the ability to resume personal growth in adverse circumstances" Resilience, according to the International Resilience Project, a research programme that studies factors conducive to resilience in children, is " the universal capacity which allows a person, a group or a community to prevent, reduce or surmount the negative effects of adversity.

Adversity may mean the terminal illness or death of a parent due to AIDS. Illness and death are frequently compounded by the unexplained absence of a father (Medical Research Council AIDS Bulletin, 2004: 29).

In contrast with traditional counselling techniques, approaches based on the concept of resilience use the inner resources of the traumatized subject- in this case, the child affected by AIDS. The traumatized child does not need to be 'taken care of' – that is, by some familial or social authority that makes decisions about children without consulting them. The solution lies within the child himself. It is he, in the final analysis, who has the capacity to overcome adversity.

To do this, children need 'resilience tutors', Boris Cyrulnik's apt phrase to refer to the "availability of emotional support, activities and verbal exchange ... which allow a child to minimize the trauma that has occurred". Although adults cannot do this healing for the child, they nevertheless have an essential role to play in the process (Dennis,2004: 29).

When a child is in mourning- for a deceased parent or for the deteriorating family conditions which the parent's sickness and death entail - one of the means by which he can regain control of the situation is by remembering. The role of memory in mourning has often been discussed in literature on helping children deal with grief and loss (Medical Research Council AIDS Bulletin, 2004: 29).

Phillip Dennis (2004:29) wrote in his article "Enhancing resilience in times of AIDS: The memory box programme of the University of Kwazulu-Natal" about the possible methods that can be used to assist children orphaned by AIDS.

The term 'memory box' must be understood as a metaphor: it is a method that encourages children whose parents are deceased (or will die soon) to preserve their memory of them in a manner allowing them to "grow up despite all". But the term also refers to an object: a box of metal or cardboard that holds photos, identity documents, objects belonging to deceased family members, and the folder containing the text of an interview. The emphasis on the narration (recorded or transcribed) is a characteristic of the project's methodology (2004: 29).

Memory box work rests on the hypothesis that it is good for the child to know his family history, however painful this may be, but only if that history is recounted in a warm, non-judgmental way. If the child knows his parent's history, he is better able to overcome the suffering caused by their illness or death. He accesses this knowledge through memory – his own and that of those close to him (Dennis, 2004: 29 and Demmer, 2004: 40).

While the parent is still alive, the memory facilitator's work consists of helping the child to acquire memories. They create a context in which the sick parent can speak to the child, and the child can listen. In this way, the child is better able to preserve the memory of the parent's voice, face, and words when the parent has died (Dennis, 2004:29).

### **3.6 SUMMARY**

The Human Immuno Deficiency Virus destroys the immune system of the infected person. The first phases of the illness are virtually symptom free, until the commencement of the major symptomatic phase.

HIV/AIDS has a particularly disturbing clinical course and concurrent social implications. The illness creates amongst other, feelings of grief, anger and depression for the infected and affected persons.

HIV/AIDS causes multiple deaths in thousands of households in South Africa, leaving behind the most vulnerable, children and the elderly, to fend for themselves. Social roles change 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 food 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, but the

expanding scale of the problem 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 a household, often cause relatives to shy away from their responsibilities. Children may also choose to live alone to protect an inheritance or because of strained family relationships.

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 because of the role changes, stigma and expectations created by the death of their caregivers. It is in the light of this that the researcher will discuss the adolescent development phase in the next chapter in order to be able to fully understand the complex interplay between "normal adolescent development" and experiences very specific to the adolescent affected by HIV/AIDS related conditions.

## CHAPTER 4

### THE ADOLESCENT DEVELOPMENTAL PHASE

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#### 4.1 INTRODUCTION

The experiences of adolescent orphans, who 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 as described in chapter two and three.

A central factor in adolescents' health and well - being is their interaction with their environment, with the people and settings in their daily lives. Call, Riedel & Hein referred to by Griesel- Roux (2004:51) state further that adolescents play an active role in selecting and interacting 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, like 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 implication for the health and well being of the individual and for society as a whole. 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. Adolescence is the first phase of life requiring mature patterns of functioning. Failure to cope effectively with the challenges of adolescence may have negative consequences for subsequent development (Griesel- Roux, 2004:51).

In this chapter, adolescence will be discussed against the background of 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 understand the normal developmental tasks of the adolescent in full.

## **4.2 ADOLESCENCE IN CONTEXT**

### **4.2.1 DEVELOPMENT DEFINED**

Development is a lifespan process involving physical, behavioural, cognitive and emotional changes over time. Psychological literature is permeated with models of development, representing the varied perspectives of numerous theorists. However, common to the models is the consensus that:

- Development is an interactive, creative, ever changing and dynamic process;
- The parent is not the exclusive (or even the primary) source of the growing child's construction of reality or development of coping strategies; and
- Significant growth and change occur at any stage of life (Dwivedi, 1999: 61).

### **4.2.2 DEVELOPMENTAL STAGES PRECEDING ADOLESCENCE**

Erikson regarded successful psychosocial outcomes in infancy and childhood as paving the way toward a coherent, positive identity (Berk, 2000:456).

A developmental task is a set of skills and competencies that contribute to increased mastery over the environment. These tasks define healthy, normal

development at each age in a particular society (Neuman & Neuman, 1997:5).

Adolescents can be influenced by the quality of the attachments they managed to make in previous developmental phases. Adolescents who were socially deprived or abused as infants are likely to be withdrawn and apathetic and may later display intellectual deficits, behaviour problems and reactive behaviour disorders. Their problems appear to stem more from their lack of responsive social stimulation than from failure to receive care (Shaffer, 2002:416).

The failure of young children to attain secure attachments to a primary caregiver is indicated as significant in the development of psychological problems in adolescence and adult life. These children fail to respond to the normal social stimuli, tend to withhold close bodily contact, and have difficulties forming relationships later in life. Insecurely attached children according to tend to be:

- Less cognitively competent
- Less able to show social proficiency
- Less able to get along well with their peers
- More likely to develop emotional or behavioural problems (1999:65-67)

Dwivedi (1999:65-67) identified the following developmentally important moments in the lives of all people as:

#### **4.2.2.1 Stage 1: Birth to six months**

The young infant's psychological need centres around being cared for, nurturance, warmth, physical closeness and touch. Healthy emotional bonding takes place in contexts in which parents are genuinely pleased at the arrival of the newborn, expressing their joy in gentle confidence, 'giving' as much as needed. When the infant has its needs adequately fulfilled a sense of belonging and security, trust in self and optimism about life (expressed in curiosity and creativity) results (Dwivedi, 1999:63).



#### 4.2.2.2 Stage 2: Six to 18 months

The infant becomes increasingly physically mobile and is therefore able to initiate exploration, starts to feed itself, and may start to identify its own needs during this stage. Most exciting for most parents is the emergence of speech. Environmental provision of consistency and predictability are fundamental to the confirmation for the growing infant that there are people in the world who are trustworthy and caring. This is the stage at which infants will explore and 'do' (Dwivedi, 1999:64; Neuman & Neuman, 1997:84).

Erikson sees autonomy versus shame and doubt as the psychosocial crisis in this phase, as the toddler now encounters rules (Meyer & Van Ede, 1998:52). Imitation is the central adaptive process development to produce the ego quality of will. Fantasy play, language development and self-control development are tasks of this stage (Neuman & Neuman, 1997:86).

The child who is deprived of constructive and positive parenting in this stage of his development may become passive, withdrawn, and dependent. He is unlikely to initiate exploratory activity and his anxious attachment is most frequently seen in his crying easily. An absence of stimulatory experiences may result in developmental delay and slow learning (Dwivedi, 1999:65).

Erikson described this phase Infancy and identified "Basic Trust versus Basic Mistrust" as the psychosocial crisis for this period, resulting after successful adaptation in hope. Mutuality with the caregiver is the central process used to adapt. Withdrawal is a sign of pathology in this phase (Neuman & Neuman, 1997:86).

In later life, individuals whose needs have not been adequately met in the six to eighteen months' period tend to endure extreme discomfort before taking care of themselves. They lack a coherent awareness of their body or feelings. Motivational problems and boredom are common and pleasure is frequently absent from the life of such individuals, who respond to difficulties with either inappropriate frenzied activity or by engaging the fight-flight response (Dwivedi, 1999:65).

#### **4.2.2.3 Stage 3: Eighteen months to three years**

Most commonly referred to in the psychoanalytic literature as the anal stage, this is also the stage of pre-operational thinking in the Piagetian frame. It is the stage during which the toddler develops an acute sense of their separateness and is often characterized by expressions of intense rage (Dwivedi, 1999:65).

The toddler is no longer the centre of all attention, as is most frequently the case in preceding stages. Control is a central issue here and this stage is characterized by the toddler's strong tendency to be oppositional, negative, and resistant to parental requests. The presence of language makes problem solving more easily. The toddler develops a new ability to think, although the characteristic thought process at this early stage is linear cause effect thinking (Dwivedi, 1999:66).

A primary developmental task is that of socialization, the establishment of appropriate independence, and the rudiments of a sexual identity. The primary focus of the parent-child relationship is around setting limits (Meyer & Van Ede, 1997:228).

#### **4.2.2.4. Stage 4: three to six years**

In the Piagetian frame, preoperational thinking is further developed during this stage of development, although in the psychoanalytic frame the central concern is with Oedipal issues. Sexual exploration is a core feature of the child of this age. An awareness of sexual differences emerges and the child characteristically engages in fantasy and imaginative play. The opposition of the preceding stage gives way to co-operation and an ability to understand the rudiments of concepts of time, rules and sharing. An awareness of consequences develops and the child is actively able to effect different outcomes by initiating strategies of changes (Dwivedi, 1999:67).

Experimentation, especially in social relationships takes place as the individual tests out his newly developed sense of control and power, and learns what it means to be male or female in society. Exploration of the larger world takes place as the child is exposed initially to playgroups and later to nursery schools. Support and encouragement of this process ensures the establishment of a core sense of initiative and purpose according to Erikson, inhibition is the core pathology which may develop in this phase if the child is unable to master the tasks of sex-role identification, group play and early moral development (Neuman & Neuman, 1997: 87).

In later life, it is not uncommon for individuals with difficulties at this stage to engage in almost perpetual wishful thinking. Sexual/gender identity issues may occur, as may sexual acting out (Dwivedi, 1999:67).

#### **4.2.2.5. Stage 5: six to twelve years**

This, the psychoanalytical Latency Period, sees the development of concrete operational thought. Children of these ages cluster together in same sex groups and tend to exclude members of the opposite sex from their activities. An orientation to achievement and competitiveness may result in a tendency to be argumentative, particularly in the family context. The child's value system is frequently augmented from sources outside the family, and teachers and peers begin to play an increasingly prominent role (Dwivedi, 1999:67; Turner & Helms, 1995:49).

Accomplishments and achieving a sense of 'industriousness' are the central tasks of this age group of children. They develop a sense of humor, learn to argue constructively and take some responsibility. Unhelpful parental behaviours include situations in which parents become competitive with their offspring, or those in which they are either dogmatic and authoritarian or permissive and overly relaxed (Dwivedi, 1999:67; Louw,1996:325).

Successful negotiation of the developmental tasks results in a sense of pride at accomplishments, with a concomitant sense of the individual's capability and personal adequacy. Difficulties in this stage may lead to lying, cheating

and stealing. Non-completing tasks and 'giving-up', or excessive rebellion is indicators that the child has difficulty in negotiating these developmental tasks (Dwivedi, 1999:68).

Dwivedi (1999:69) is of the opinion that the adult, who suffered difficulties that originate in this stage, presents as rigid and inflexible. They frequently do not complete tasks in spite of a harried, perfectionist style. Performance takes place without forethought, and self-criticism is commonplace. Problems are frequently made overt when there is a necessity to deal with authority figures or when new skills are being learned.

It is clear that three kinds of influences can have a major effect on physical growth and development: nutrition, illnesses and the quality of care children receive (Shaffer, 2002:173).

Diet is perhaps the most potent environmental influence on human growth and development. Children who are inadequately nourished grow very slowly, if at all. Comparing the heights of children before and during wartime periods when food is scarce can see the dramatic effect of malnutrition on physical development. If under nutrition is neither prolonged nor especially severe, children usually recover from any growth deficits by growing much faster than normal once their diet becomes adequate. However, prolonged under nutrition has a more serious impact, especially during the first five years of a child's life: Brain growth can be seriously retarded, and the child may stay relatively small in stature. In many of the developing countries, as many as 85 percent of the children under the age of five years experience some form of under nutrition (Shaffer, 2002:174).

Malnutrition can cause young children to be lethargic, inattentive, irritable, and intolerant of stressful situations- a behavioural profile that places them at risk of alienating their caregivers and thereby receive very little social or intellectual stimulation (Shaffer, 2002:175).

Otherwise, healthy children who experience too much stress and too little affection are likely to flag behind their age mates in physical growth and motor development (Shaffer, 2002:176).

Stress appears to be significant in studying the impact of HIV/AIDS related orphanhood, as many children become adolescents a period in which there is an acute scarcity of food and other means of survival, causing severe stress.

### **4.3 ADOLESCENCE DEFINED**

Adolescence is a dynamic period of change. There are changes not simply within the young person, but within his or her completely social structure (Durkin, 1995:506).

Despite the familiarity of the term adolescent in everyday language, it proves remarkably difficult to define precisely what this stage entails. Chronological criteria fail to take account of the maturational differences among young people. One person of 12 years may be more advanced 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 correlates 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 criterion, 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 that starts between the ages of 11 and 13 years and the end of the stage is between 17 and 21 years. 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 characteristics and legal age of majority. (Louw et al., 1998:388) It is in the light of these differences that authors often describe the stage of adolescence by dividing it into three different phases, namely:

- Early adolescence: Between 11 and 14 years
- Middle adolescence: Between 14 and 18 years
- Late adolescence: Between 18 and 21 years.

Adolescence can thus be defined as beginning at puberty, a physiological transformation that gives boys and girls adult bodies and alter how they are perceived and treated by others, as well as how they view themselves.

#### **4.4 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 (from the Latin word *pubertas*, meaning "to grow hairy"), the point in life when an individual reaches sexual maturity and becomes capable of producing a child (Shaffer, 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 the adolescent growth spurt. Perhaps the most noticeable changes are the appearance of breasts and a widening of the hips for girls, and a 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 (Shaffer, 2002:160).

Huebner (2000:2) identified some psychosocial effects of physical development on adolescents as:

- A need for longer sleep;
- Clumsiness because of growth spurts in different body parts;
- Sensitivity amongst girls about their weight;
- Concerns with the speed of development;
- Feelings of awkwardness in demonstrating affection to the opposite gender parent;
- Interest in sexuality;
- A need for physical space and privacy;
- Excessive grooming habits.

Adolescence is probably experienced as the most embarrassing time in the life cycle. At a time when teenagers are acutely self-conscious and sure, 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 mature. Girls worry about the size of their breasts and about the possibility of getting menstrual blood in their clothes (Gething, ; Papalia & Wendkos Olds, 1999:328).

#### **4.4.1. PHYSICAL CHANGES IN GIRLS**

According to Herbert (2003:168) girls are on a quicker physical developmental timetable than boys are. At puberty, they are developmentally two years ahead of boys. The physical changes of puberty continue for about two years and have a significant impact on the erstwhile child's body image. This ultimately influences the self-image of the adolescent.

The physical changes of adolescence appear to be more stressful for girls, as it is negatively associated with blood and discomfort. There is evidence that the onset of menarche varies as a function of general social conditions, such that girls in more affluent societies (with better nutrition) tend to start earlier. Other social commitments and choices can also affect this transformation:

girls, who train excessively in some physical activity like ballet or sport, tend to start later (Durkin, 1995:509).

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 the developing person's social context. Girls who grow up in conditions of protracted family stress (including parental conflict, marital instability and divorce) 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).

Physical and social changes intertwine. Early maturing girls are more likely to begin dating earlier. As a result, they are drawn into more mature, out-of-home activities at an earlier age than many of their peers. They tend to begin drinking and smoking earlier, which may incur additional stresses (Durkin, 1995:509).

Girls typically enter the growth spurt period by age 10 and a half, reach a peak growth rate by age 12, and return to a slower growth by age 13 to 13 and a half. Because girls mature much earlier than boys, it is not at all uncommon for females to be tallest two or three students in their class group

Maturation of the reproductive system occurs at roughly the same time as the adolescent growth spurt. This maturation begins at about 9 or 10 years as fatty tissue accumulates around their nipples, forming small "breast buds". As a girl enters her height spurt, the breasts grow rapidly and the sex organs begin to mature. Internally, the vagina becomes larger and the walls of the uterus develop a powerful set of muscles that may one day be used to accommodate a fetus during pregnancy and to push it through the cervix and vagina during the birth process (Shaffer, 2002:160).



The average girl in Western societies reaches menarche - the time of her first menstruation at the age of 12. Although it is generally assumed that a girl becomes fertile at menarche, young girls often menstruate without ovulating. In the year following menarche, female sexual development concludes as the breasts complete their development and axillary (underarm) hair appears (Shaffer, 2002:160).

#### **4.4.2. PHYSICAL CHANGES IN BOYS**

The available evidence suggests that there are also similar interactions between biological change and social expectations. In some American based studies, it appears as if early maturing boys tended to be regarded more favorably by their peers and by adults, and tended to develop more positive self-image than later-maturing boys. However, in 1987, Weisfeld found that boys who enjoyed dominant status among their peers in adolescence had actually been dominant since at least six years of age (Durkin, 1995:511).

Boys typically begin their growth spurt by age 13, peak at age 14, and return to a more gradual rate of growth by age 16. For boys, sexual maturation begins at about 11 to 12 with an enlargement of the testes. The growth of the testes is often accompanied or soon followed by the appearance of unpigmented pubic hair. By the time the penis is fully developed at age 14 to 15, most boys will have reached puberty and are now capable of fathering a child (Shaffer, 2002:160).

Somewhat later, boys begin to sprout facial hair, first at the corners of the upper lip and finally on the chin and jaw line. Body hair also grows on the arms and legs although signs of a hairy chest may not appear until the late teens or early twenties, if at all. Another hallmark of male sexual maturity is a deepening of the voice as the larynx grows and the vocal cords lengthen (Shaffer, 2002:160).

Timing of puberty does have some meaningful implications although its impact differs somewhat for boys and girls. Among boys, it is clear that those who mature early enjoy a number of social advantages over boys who mature late. Late matures appears to be more eager, anxious and attention seeking than their more developed counterparts who appear to be more poised and confident in social settings. The early maturers' adult-like appearance may also prompt others to overestimate his competencies and to grant him privileges and responsibilities normally reserved for older individuals. These differences between early and late maturers generally fade away in early adulthood.

#### **4.5 COGNITIVE DEVELOPMENT**

The experiences of adolescents orphaned by HIV/AIDS related circumstances are closely linked to the manner in which they are able to understand the world around them and how they perceive themselves.

The maturation of the nervous system (for example development of senses of sight and hearing - eye-hand co-ordination and balance are particularly important in this regard) and the endocrine glands (for example the sex glands) are prerequisites for cognitive development (Gouws & Kruger, 2004:47).

The development of the thinking and organizing systems of the brain is defined as cognitive development. Some of the main domains of cognitive development are language, problem solving, memory development, and reasoning (Lythgoe, 2004:1).

Herbert (2003:166) is of the opinion that youngsters become capable of propositional thinking by the end of middle childhood. They can propose hypotheses and deduce consequences. Their language is now fast and versatile.

Huebner (2000:4) describes the impact of improved but incomplete reasoning skills as:

- High levels of self-consciousness (feeling that they are continuously performing in front of an imaginary audience);
- The belief that no one else has ever experiences similar feelings and emotions. They may become overly dramatic, thinking, "My life is ruined!"
- The development of a personal fable, in which bad things only happens to other people;
- Cause-orientated or activist orientated thinking like "Save the Whales";
- A Justice-orientation in which they are quick to point out consistencies between adults' word and their actions. They see little room for error.
- "Pseudo stupidity" in which adolescents attribute complicated motives to significant others in their lives by thinking too much (for example seeing a simple request as a manifestation of a parent to intentionally try to hurt them) (Gething et al., 1999:340).

A consequence of cognitive development is the development of the moral orientation of the adolescent. Kohlberg argued that moral development progresses through a number of levels, with different stages at each level. At the lower stages of 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, 2003:294).

#### **4.6 PSYCHOSOCIAL DEVELOPMENT**

Adolescents, who are maturing physically and sexually, not only feel differently about themselves but also come to be viewed and treated differently by other people. In many non - industrialized societies rituals called rites of passage inform the whole community that a child has become and adult (Shaffer, 2002:164).

This aspect appears to be the single most important developmental factor influencing the experiences of adolescents orphaned by HIV/AIDS related

circumstances, 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 tasks. 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).

#### **4.6.1 ESTABLISHMENT OF AN IDENTITY**

The establishment of a clear sense of identity is one of the major tasks of adolescence (Herbert, 2003:172). 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 enable 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 (1967,1985) 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). The researcher is of the opinion that the experiences of adolescents affected by the illness and death of a parent because of HIV/AIDS, may be magnified by the "imaginary audience" phenomenon.

A closely related feature of adolescent thought 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).

Children between the ages of about 14 or 15 not only provide mutually contradictory self- descriptions, but also appear to be oblivious to the conflicts. Adolescents become aware that they are not the same people in all situations- facts that may puzzle or even annoy them. As children develop, they not only understand increasingly about 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; they recognize their strong points, can acknowledge their weaknesses (often hoping to overcome them) and generally feel quite positive about the characteristics and competencies they display. By contrast, children with low self-esteem view the self in a less favorable light, usually choosing to dwell on perceived inadequacies rather than on any strength, they may happen to display (Shaffer, 2002:428).

Cognitive processes are not occurring independently from the social context. Some of the institutional transitions of early adolescence- especially the shift to high school- appear to have unsettling consequences for at least some young people's self-understanding 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. Deciding who one is to become tends to attract a lot of advice, possibly from conflicting sources, and substantial input from reality in the form of school grades, peer feedback and career prospects (Durkin, 1995:513).

The multiple stresses of early adolescence have consequences for how the young person feels about her or himself, and particularly for self-esteem. Self-esteem denotes the individual's sense of worth as measured on dimensions which she or he values. The change to high school is associated with changes in self-concept and self-esteem 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 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).

Four different types of identity status are found amongst adolescents:

***Identity diffusion:*** an identity status characterized by the avoidance of commitment, indecision about major life issues such as vocation, ideology, and religion.

***Identity foreclosure:*** a status of preliminary commitments and value orientation, but values rather than self-determined goals (e.g. selecting school options because an adult says they are worth while).

***Moratorium:*** a status of intense identity crisis characterized by active attention to major decisions, exploration of possibilities for the future (occupational, political, social, sexual) but not yet resolved in firm commitments. Erikson stressed that this period can be intense without being anguished, and he regards it as a psychologically healthy process rather than a potentially catastrophic pathology.

***Identity achievement:*** Individuals with this status have resolved their crises and made firm commitments to ideals and plans (Durkin, 1995:516).

Many parents expect that adolescents will undergo a period of storm and stress, but research findings indicate that only about 15 percent of the adolescent population report severe psychological disturbances- a large number of young people, but by no means a majority (Durkin, 1995:512).

By early adolescents, one's perceptions of self-worth become increasingly centered on interpersonal relationships. Adolescents often begin to perceive their self-worth somewhat differently in different relational contexts (e.g. with parents, teachers, with male classmates and with female classmates). These domains of relational self-worth contribute to one's global self-esteem although the same domain may be much more important for some teenagers than others (Shaffer, 2002:429).

Given the increasing importance of interpersonal relationships, it is hardly surprising that new relationship orientated dimensions such as romantic appeal and quality of close friendships become very important contributors to an adolescent's global self-esteem, although they may influence the self-appraisal of boys and girls in somewhat different ways. Girls who enjoy very high self-esteem are often those who have had supportive relationships with friends whereas boys are more likely to derive high self-esteem from their ability to successfully influence their friends. Low self-esteem in girls is most strongly associated with a failure to win friends' approval whereas a major contributing factor to low self-esteem in adolescent boys is a lack of romantic competence, as reflected by their failure to win or maintain the affection of girls (Shaffer, 2002:429).

A limited and manageable degree of stress motivates a person to perform better. Too much stress in the life of the adolescent may exert a negative influence on the self-esteem (Gouws & Kruger, 2004: 99).

#### 4.6.2 ESTABLISHMENT OF AUTONOMY

Another developmental task is the establishment of autonomy from parents or primary caregivers. Adolescents may be critical of, and even despise, what they now perceive as their hopelessly out-of-date parents. As Mark Twain so aptly put it: 'When I was a boy of fourteen my father was so stupid I could hardly stand to have him around. At twenty-one I was astonished at how much he had learned in the past seven years' (Herbert, 2003:166). Louw et al. (1988:389) adds that guidelines for adolescents were very clear in traditional societies. Now, adolescents find themselves now in a complex, technologically advanced society where behavioural guidelines can often be very vague. Children are economically dependent on their parents for longer. Puberty also starts earlier (e.g. in the 1840's puberty started at 17 and now around 13 years). This leads to a phenomenon in which the adolescent may be psychologically independent, whilst still be economically and legally dependent.

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, 2004:01).

Durkin (1999: 521) is of the opinion that the achievement of autonomy is one of the major developmental tasks of adolescence. There are three distinctive aspects to autonomy, namely:



- o ***Emotional autonomy:*** in which the individual relinquishes childish dependence upon his or her parents;
- o ***Resistance to peer pressure:*** in which the individual becomes able to act upon his or her own ideas, rather than conform to those of peers;
- o ***Subjective sense of self-reliance:*** in which the individual feels free of excessive dependency upon others, takes initiative, and has a feeling of control over his or her life.

Durkin (1999: 521) suggests that the parent-adolescent conflicts reflect the parties' different roles in the family and their attempts to coordinate conflicting social cognitive perspectives. Light (2004:3) concurs that this is a normal process for adolescents, especially when they begin to realize that their parents are not always right. These changes are cognitive, occurring within the brain at puberty.

Parents and adolescents both feel that they are often the victims in confrontations. Adolescents often feel that their rights were being curtailed; parents feel adolescents often defaulted in their moral obligations to the family. Clearly, the young person's felt need to express his or her autonomy and the parent's sense of responsibility for their offspring's development can, and often do, lead to clashes. However, relationships are established and maintained by parties engaging in consistently rewarding exchanges. The amount of emotional investment that both adolescent and parent have in their relationship means that they are both inclined to preserve it. Conflict does arise at times, but it is generally not so intense as to destroy the relationship (Durkin, 1999: 524).

Conflict usually pertains to chores, finances, appearance, and substance abuse. In addition, family relations, school, curfew, dating, friends, and sexual behaviour cause disagreements between parents and their teenagers (Light, 2004:4).

According to the American Academy of Child and Adolescent Psychiatry's website (2004:1), adolescents normally experience these feelings whilst experimenting with independence:

- Moodiness;
- Improved ability to use speech to express one's self;
- Identification of parent's faults and fears that others would notice it;
- Less overt affection shown to parents, with occasional rudeness;
- Complaints that parents interfere with independence;
- Tendency to return to childish behaviour, particularly when stressed.

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 environments. Even though that very person may be the cause of the stress, the need for a soothing response from that attachment figure does not diminish. 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 then 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 too early a 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 is the opinion of the researcher that early, forced independence as in the case of adolescents orphaned by HIV/AIDS related circumstances, may have a severe impact on their psychosocial development.

#### 4.6.3 ESTABLISHMENT OF INTIMACY

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 (Durkin, 1999: 528).

Peers do become increasingly important to adolescents, and they spend more time with them. In some contexts, early to mid-adolescents tend to conform to expectations and values, though these are not invariably in conflict with parental values and, when they are, the differences tend to be over relatively superficial issues such as grooming and entertainment preferences. Overall, adolescents' increasing involvement 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).

Castrogiovanni (2004:1) described a peer group as a small group of similarly aged, fairly close friends, sharing the same activities. Adolescents spend much of their time in these groups- much more time than with parents or other 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 an increased capacity to enter close relationships or peer groups.

The role played by peers in adolescence is very critical. Relationships with peers during the adolescent years come closer to serving as prototypes for adult relationships in social relationships, in work and in interactions with members of the opposite sex. Teenagers who do not learn how to get along with others by the time they reach adulthood are likely to face obstacles in years ahead. The role of the peer group in helping an individual to define his or her own identity becomes very important during adolescence. At no other stage of development is one's sense of identity so unstable. The adolescent

must get ready to meet society's demands for social independence, for relationships with sexes, marriage and adulthood. For these reasons, teens need the support and guidance of their peers (Castogiovanni, 2004:01).

According to Castogiovanni, (2004:01) peer groups provide the following for adolescents:

- o The opportunity to learn how to interact with others;
- o Support in defining identity, interests, abilities and personality;
- o Autonomy without the control of adults and parents;
- o Opportunities for witnessing the strategies others use to cope with similar problems, and for observing how effective they are;
- o Emotional support;
- o Building and maintaining friendships.

Peers are more likely to be the sources 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 (such as careers) (Durkin, 1999: 529).

Chierichella (2004:2) is of the opinion that peer groups can be defined in numerous ways. There are two commonly observed groups during adolescents, namely cliques and crowds.

Cliques are small groups of between two and twelve individuals, and the average clique consists of five or six adolescents. Cliques are small enough so that the members feel that they know each other well and appreciate each other better than do people outside the clique. Members of a clique can be defined by common activities or by friendships. This is important because they provide the main social context in which adolescents interact with each other. They are social settings in which adolescents 'hang out', talk to each other, and form close friendship (Chierichella, 2004:2).

The second type of peer group structure is the crowd. Crowds are larger, reputation based groups of adolescents who may or may not spend a lot of time together. In contrast to cliques, crowds are not based on actual friendships. Crowds serve to locate the adolescent within the social structure of the school. Crowds are seen as having different degrees of status or importance. A membership group is a crowd to which an adolescent belongs. It serves as a guidepost for determining one's values and actions or measuring one's abilities (Chierichella, 2004:3).

The pressure adolescents' feel from their peers is called peer pressure. These peers, whom adolescents look to for approval and support, are inevitable and necessary. Peer groups provide opportunities for practicing new behaviours and developing necessary social skills for future interactions. It can range from positive influences, such as academic and athletic achievement, to negative influences, such as drug and alcohol use (Stanton, 2004:3).

It appears that adolescent conformity is not an absolute condition but a form of social accommodation that varies according to situation and developmental status. Moreover, it is not a blanket covering all aspects of social behaviour (Durkin, 1999: 527). However, Stanton (2004:2) is of the opinion that peer pressure does exist. The need for acceptance is as strong as biological drives. Two factors that help adolescents resist negative peer pressure are high self-esteem and self-confidence. Positive peer values pressurize adolescents not to do drugs or not to engage in sexual activities or to participate and excel in athletics, music and various types of activities (Stanton,2004:2).

Adolescents who are not accepted by the group usually display a lack of social competence. They tend to be reticent, nervous, shy, self-centred and have little self-confidence (Gouws & Kruger, 2004:122).

#### **4.6.3.1 SEXUALITY AS FORM OF INTIMACY**

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 of which is increased production of androgens in boys and girls, which dramatically increases one's sex drive. Although primary school children often play kiss-and-chase games that prepare them for heterosexual relationships later in life, the new urges they feel make adolescents increasingly aware of their own sexuality – 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 (Shaffer, 2002:166).

Huberman (2004:2) is of the opinion that most teens between the ages of 13 to 17 will:

- Understand that they are sexual beings and understand the options and consequences of sexual expression;
- Choose to express their sexuality in ways that may or may not include sexual intercourse;
- Recognize the components of healthy and unhealthy relationships;
- Have a clear understanding of pregnancy and of HIV and other sexually transmitted infections and the consequences of sexual intercourse and have the ability to make reasoned choices about sex.
- Recognize the role media play in propagating views about sex;
- Have the capacity to learn about intimate, loving, long-term relationships;
- Have an understanding of their own sexual orientation.

The Website of the American Academy of Child and Adolescent Psychiatry (2004/8/6), describes the feelings of adolescents about their sexuality as follows:

- Shyness, with blushing and modesty;
- Movement towards heterosexuality and fears of homosexuality;
- Concerns regarding physical and sexual attractiveness to others;

- Fluctuating interest in different members of the opposite sex, leading to frequent changes in relationships;
- Worries about being normal.

Dating can allow the adolescent to explore the process of beginning relationships as well as terminating them. It also contributes to the social status of the individual with his or her peers through dating and can provide companionship. However, dating can also have harmful effects for adolescents. Early dating may lead to early sexual activity, which may occur before the adolescent is emotionally or physically prepared. In order to maintain a dating relationship adolescents can be forced to hide or disguise undesirable traits for their partner. In turn, one may forfeit their self-esteem and morals to achieve higher social status through dating (Fink, 2004:1).

Gouws and Kruger (2004:126) is of the opinion that dates with members of the opposite sex are usually made for one or more of the following reasons:

- **Recreation:** Although formal dating often creates considerable stress for individuals, being together informally with members of the opposite sex can be relaxing for both parties.
- **Experimentation:** During early adolescence informal dating can be seen as experimentation with different techniques of social interaction.
- **Declarations of independence:** Dating gives the adolescent the opportunity to prove his independence.
- **Need for participation:** Loneliness and boredom are relieved by going out.

#### 4.7. ACHIEVEMENT AND CAREER CHOICES

One reason why adolescence is such an important phase in the lifespan is that critical choices are made during this period, which has major implications for the individual's future direction. How well a person performs in the educational system, what he or she aspires to do as an adult, have long-term consequences. Many studies have shown that the educational

attainment and aspirations of adolescents are associated with aspects of the family and school environments that they experience (Durkin, 1999:548).

Choosing a job or career is a developmental task, which depends in part upon the young person's conceptualization of her or his abilities and preferences, and the pursuit of a match between these and job requirements (Durkin, 1999:548).

Adolescents have an urgent need for adult guidance in terms of planning for a future career (Gouws & Kruger, 2004: 159). They need career knowledge, which refers to insight into the world of careers. In order to make a realistic career choice the adolescent must know what the working world comprises. This requires a great deal of time and effort on the adolescent's part.

Unemployment or bleak employment opportunities have negative consequences for the mental health of young people. How the individual interprets his or her situation appears to be critical (Durkin, 1999:553-555). One consequence of adolescent unemployment is that the afflicted individuals feel excluded from the adult world. This has consequences for self-image and orientation toward the social structure. Apathy and a sense of isolation are common reactions or in some instances, these young people can reject the values of the status quo and attack the system directly, through subversive activity.

Orphaned adolescents experience the loss of hopes and dreams for the future, especially because of financial constraints that limit educational opportunities. Some young people are even deprived of schooling, thus reducing their chances of formal employment even further.

#### **4.8 THE GRIEVING ADOLESCENT**

There is substantial evidence that survivors of HIV/AIDS are a risk of prolonged grief and psychiatric problems as they mourn an AIDS death (Demmer, 2004:40).



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: behavioural, emotional and physical, and encompass problems experienced both inside and outside the family. Some reactions of children and adolescents in grief are similar to those of adults: rejection, guilt, shame, anger, blame and so on. Most grief reactions in children are largely dictated by the child's developmental stage and may be carried forward into the next developmental phase as an unresolved issue. Pre-school children often appear to ignore death; they do not understand its finality, thinking that it is just like sleeping. Between five and eight, they become intrigued with death and are concerned with fantasies, ghosts and monsters that can be frightening. This is also the age of magical thinking in where one's wishes can come true – maybe they wished the person would die and they did. At nine plus children, begin to grasp the permanency of death and are more able to express their sorrow as adults do. Some children may become withdrawn, hostile or angry. Some may appear unaffected or callous regarding the death of someone close to them, leaving adults confused and angry (Dwivedi, 1999:185).

Children and 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 or become clinging and tearful. Some children experience physical and health problems following bereavement, for example, they develop asthma, stomach aches, headaches and some may even imitate the symptoms of the person who died. 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 include anorexia nervosa. In later life, these behavioural patterns may be seen to continue, with a concomitant failure to establish intimate relationships by the use of a self-centered type lifestyle (Dwivedi, 1999:70).

At times, some adults responsible for children are unable to appreciate 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 overburdened 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 adolescent household heads 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).

The central developmental task of the young person is emancipation from parents, as well as the development of identity. Isolation is the result of unsuccessful mastering of the tasks of this phase. Issues of identity re-emerge and value structures are refined, as the lifestyle of the individual becomes increasingly established. (Dwivedi, 1999:69; Neuman & Neuman, 1997:84).

#### **4.9 SUMMARY**

Adolescence is a period in which physical, sexual, psychological and cognitive changes, combine with changes 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 changes, which in turn influence the way in which they perceive themselves and the world around them.

The main psychosocial tasks of the adolescent developmental phase are:

- Establishment of an identity;
- Establishment of autonomy;
- Establishment of intimacy.

It is a period in which the young person needs guidance and reassurance. Premature withdrawal or loss of this parental or family support will cause stress in the life of the adolescent.

It became clear from this chapter, that 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 related circumstances.

## CHAPTER FIVE

### RESEARCH FINDINGS

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#### 5.1 INTRODUCTION

This Chapter will focus on the presentation and the analysis of the data obtained from the investigation. The purpose of the study was to explore and describe the experiences of adolescents orphaned by HIV/AIDS related circumstances. This information provided more insight into the manner in which these adolescents deal with their situation and how they make sense of their lives.

In Chapter One of this research report, the researcher explained the relevance of the topic as well as the method in which it was investigated. Chapter Two dealt with the reality of the HIV/AIDS pandemic in South Africa and the rest of the world. The psychosocial impact of the decease on the patient as well as his or her significant others can be found in Chapter Three. Adolescents were identified as a group of children affected significantly by the changed roles and other complications of losing a parent, hence the discussion of Adolescence as a developmental phase in Chapter Four. This was deemed necessary by the researcher in order to improve her understanding of the characteristics of the developmental phase, as all their experiences cannot just be related to being an orphan because of HIV/AIDS related conditions. Being orphaned by HIV/AIDS related conditions appears to be a serious and significant form of stress added to their complex lives.

#### 5.2 GOAL AND OBJECTIVES OF THE STUDY

##### 5.2.1 GOAL OF THE STUDY

The goal of this study was to explore the experiences of adolescents who were orphaned by HIV/AIDS related conditions.

### 5.2.2. OBJECTIVES OF THE STUDY

The following objectives had to be achieved to attain the goal of the research:

#### Objective 1:

To build a knowledge base of existing literature on the impact of HIV/AIDS related conditions on children left behind, orphanhood, deprivation and adolescent development and challenges. The literature study was objective one of this research and was also necessary for the development of the interview schedule.

#### Objective 2:

To conduct an empirical study on the experiences of adolescents in terms of the following themes derived from the Developmental Assessment Framework: Belonging, Mastery, Independence and Generosity. Chapter Five deals with the results of the empirical study.

#### Objective 3:

To produce a qualitative research report about the experiences of adolescents orphaned by HIV/AIDS related conditions.

### 5.3 RESEARCH QUESTION

The researcher endeavoured to answer the following research question:

**What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande Region of Mpumalanga ?**

### 5.4 RESEARCH METHODOLOGY

A Phenomenological strategy was used to conduct the research. Creswell (in De Vos, 2002:273) regards a phenomenological study as one that describes the meaning experiences of a phenomenon, topic or concept have for various individuals. The experiences of the participants were reduced to a

central meaning of the experience. The product of the research is a description of the experiences of adolescents, orphaned by HIV/AIDS related conditions.

#### 5.4 **DATA COLLECTION**

The Developmental Assessment Model was used as a basis for the semi-structured interview schedule. Semi-structured interviews were held with 15 participants. 20 young persons were identified, but one withdrew from the interview because of personal reasons. Four participants identified fell outside of the selection criteria of age (two were too young, one too old and one was not an orphan). Participants were identified by social workers and Home Based Care Co-ordinators, because of their suitability to the following sampling criteria:

- Ability to understand English
- Age: adolescents between 13 and 18 years
- Care status (orphaned or not)
- Person and circumstances of the family known to or nursed by a registered Home Based Care Group.
- Willingness to participate
- Orphaned for a period exceeding six months
- Confirmation of the AIDS-like symptoms of the parent before he/she passed away from a family member or health service provider
- Registered as a client at the Department of Health and Social Services, Gert Sibande Region.

Interviews were conducted in English with five young people, one in Afrikaans and nine in isiZulu. Different interpreters were utilised to ensure the quality of translations. On completion of this, data analysis commenced. Interviews took place in Hendrina, Ermelo, Carolina, Chrissiesmeer and Piet Retief. Interviews were recorded and the data was then transcribed into English.

It is important to note the context in which the interviews took place. The young people who participated in the interviews all received some form of assistance from social workers, home based care groups or the Secure Care Facility. This means that the basic needs of the participants were all met and that that directly influenced the possible repetition of the study. The young persons were reflecting back on their experiences. No young person was interviewed before assistance was given, as this would have been unethical and demeaning.

## 5.5 DATA ANALYSIS

According to De Vos (1998:48), data analysis follows after data collection. Mabutho (2004:28) defines data analysis as a search for a pattern in recurrent behaviours or objects of a body of knowledge. Once a pattern is identified, it is interpreted in terms of social theory or the setting in which it occurred. Data analysis is therefore a process of bringing order, structure and interpretation to the mass of data collected.

According to Apaslan and Mabutho (2005:282) data analysis should include examining, categorising, tabulating or otherwise recombining the evidence to address the research question.

A grounded theory analysis of the data was conducted in the following manner:

- The researcher read through all the transcripts and made notes in the margin of possible categories and themes;
- The researcher then repeated the process to cluster together categories that emerged most prominently;
- The categories emerging from the transcripts were then identified and written down separately.
- Information from the transcripts fitting under each of the categories were recorded under those categories;

- The researcher then searched for commonalities or contradictions in these categories;

The researcher hereafter clustered together the different categories and from this clustering, themes emerged.

## 5.6 PRESENTATION OF RESEARCH FINDINGS

The presentation of the findings of the study will be according to the following outline:

- A biographical profile of the research participants.
- A presentation of the themes and sub-themes that emerged from the process of data analysis. These themes and sub-themes are discussed at the hand of relevant literature or supporting narratives, followed by verbatim quotes from the research interviews.

### 5.7.1 A BIOGRAPHICAL PROFILE OF THE RESEARCH PARTICIPANTS

Table 5.1 provides a biographical profile of the research participants.

**TABLE 5.1: PROFILE OF RESEARCH PARTICIPANTS**

Participant code	Age	Gender	Schooling	Area of origin	Parental situation	Current caregiver	In receipt of foster care grant
NH	17	Male	Grade 11	Urban	Both deceased	Child headed household	No
GU	15	Female	Grade 9	Urban	Both deceased	Maternal uncle	Yes
TB	15	Female	Grade 9	Semi-urban	Both deceased	With maternal aunt	No
MZ	17	Male	Not schooling	Rural	Mother's whereabouts unknown; Father deceased	Step-mother (In Secure Care at time of interview)	No
TH	15	Female	Grade 9	Semi-	Both	Maternal	Yes



				urban	deceased	Grand-mother	
ZA	18	Female	Grade 12	Urban	Both deceased	Maternal aunt	Yes
NOMK	13	Female	Grade 8	Urban	Both deceased	Maternal aunt	Yes
BD	17	Male	Not schooling	Semi urban	Mother deceased; father's whereabouts unknown	Child headed household (In Secure Care at the time of the interview)	No
AY	14	Female	Grade 8	Semi-urban	Both deceased	Maternal grand-mother	Yes
BAWN	17	Female	Grade 11	Urban	Both deceased	Child headed household	No
SF	13	Male	Grade 3	Semi-urban	Mother deceased, father's whereabouts unknown	Children's Home	No, but subsidized in Children's Home
NVA	13	Female	Grade 1	Rural	Both deceased	Place of safety parent	No
BERN	13	Female	Grade 4	Urban	Both deceased	Children's Home	No, but subsidized in Children's Home
SIMP	14	Female	Grade 4	Rural	Both parents whereabouts unknown	Children's Home	No, but subsidized in Children's Home
NJ	14	Male	Grade 6	Urban	Both deceased	Children's Home	No, but subsidized in Children's Home

The following young people participated in the study:

**5.7.1.1. NH**

NH is a 17-year old boy, living in Ermelo. He is the second eldest child in a child headed household. The children are staying alone, even though there are several uncles and aunts living around Ermelo. His elder sister of 19 is the functional head of the household, which consists of six children. NH appeared to be self-confident and participated in an English interview. His mother passed away in 2004 and his father in 2002. He was casually dressed in modern clothes.

**5.7.1.2. ZA**

ZA is an 18-year old girl. She is in the foster care of her maternal aunt in Ermelo, since the death of her mother in 2003. Her father died in 2001 in a non HIV/AIDS related death. ZA participated in an English interview and she was able to express her feelings. She was neatly dressed in her school uniform.

**5.7.1.3. GU**

GU is a 15-year old girl. She is in the foster care of her maternal uncle who is a teacher in Ermelo. She appeared to be self-confident. English is the language in which she is attending school, so she was able to express herself freely. GU was neatly dressed in her school uniform, but a worrying fact is that she is extremely obese. Later on during the interview, she became tearful and she was referred for follow-up counselling. Her twin brother, biological father, stepfather, brother, mother and grandmother passed away during the last five years of her life.

**5.7.1.4. NOMK**

NOMK is ZA's 13-year old younger sister. She was shy during the interview but she tried her best to participate. She is in foster care of her maternal aunt in Ermelo. Her basic needs are adequately met. NOMK appeared to be well adjusted in the foster home. She was about nine years old when her father passed away. Her mother passed away when she was 11.

**5.7.1.5. AY**

AY is a 14-year old girl, living in the small town of Carolina. She was well dressed and groomed at the time of the interview. She participated well in a Zulu interview which was interpreted by Mr. Nelson Mbokane, Assistant Probation Officer of the Carolina area. The researcher noticed that the young person was not really experiencing herself as an orphan, as she lived with her grandmother for her whole life and her mother passed away when she was six years old. She has no memory of her father.

#### **5.7.1.6. MZ**

MZ is a 16 year old young man from Taalbos. This is a rural village approximately 30 km from Piet Retief. MZ is the eldest boy in a family of 15 children. His father had four wives. His father was in Prison for some time for stocktheft. After he was released, his father fetched him and his four siblings from his mother to go and stay with him at the kraal where the other three wives reside. That was the last time he saw his mother, as she disappeared after that. After his father passed away, MZ was left in the care of his stepmother. There are a total of 20 children in the kraal, if the stepmother's own children is counted. MZ was interviewed at Hendrina Secure Care Centre, where he is awaiting trial on a charge of rape. The interview took place in Zulu, interpreted by the Chief Child Care Worker at the Centre, Mr. Thomas Mazibuko.

#### **5.7.1.7. BD**

BD is a 16 year old boy from Carolina. He is the third eldest child in a child headed family of five, in which a 19 year old boy is the functional head of the family. He was interviewed at Hendrina Secure Care where he is awaiting trial on several housebreaking cases. He was very willing to participate in a Swazi interview, translated by Mr. Mazibuko of the Centre.

#### **5.7.1.8. TH**

This is a 15 year old girl from Chrissiesmeer. This is a semi-rural. She is in the care her maternal aunt, but they are not yet receiving a Foster Care Grant. She had to nurse her dying father and experienced some extreme hardships before being found by the Home Based Care Group. She was very eager to

participate in the interview. The interview was conducted in Zulu, with Mr. Mbokane as the interpreter. Her clothes were old, but clean.

#### **5.7.1.9. TB**

TB is a 15 year old girl from Carolina. She is in the foster care of her grandmother and she has always lived there. Her father died in 1992 and her mother in 1996. They are four siblings from that family staying with the grandmother. TB participated in a Zulu interview, with Mr. Mbokane as the interpreter. She appeared bored, but cooperated.

#### **5.7.1.10. BAWN**

BAWN is a 17 year old girl from Ermelo. She is the functional head of a household, as she cares for her 12 year old brother. She has an elder brother who is now in prison for murder. Her mother passed away early in 2005. She welcomed the opportunity to ventilate feelings and to tell her story. She was neatly dressed in her school uniform.

#### **5.7.1.11. SF**

SF is a 13- year old boy, originating from the Carolina area. His father left the family when he was still a baby and his mother passed away in 2004. He and his siblings were left behind in the care of their 22 year old sister. She has some psychiatric problems and the children ended up being left alone for days in horrible conditions, whilst the sister was roaming the streets. The children were then taken by in persons who wanted to start a "foster home" in order to obtain income and food parcels from the Government. When they did not receive immediate assistance, they chased them away. SF and his three younger siblings were then placed in a Children's Home. He participated in a Zulu interview with an interpreter.

#### **5.7.1.12. NVA**

NVA is a 13- year old girl from a very rural area, Warburton, near the Swaziland border. She was reported to the social worker by the Sexual Offences Court. The child was the victim of rape in which she was allegedly sold by the grandmother to uncles in the family for sexual intercourse. The

family was especially hard hit by death, as the grandmother was left with 11 children under 13 to care for, with no source of income. The child experienced a lot of resentment and rejection from her grandmother. She is currently with a place of safety parent.

#### **5.7.1.13 BERN**

This is a 13-year old coloured girl. She was left with a grandmother, together with her three younger siblings after her mother died in 2003. They were placed in a Children's Home after the grandmother became died. She participated in an Afrikaans interview.

#### **5.7.1.14 NJ**

NJ is a 14 -year old who lives in a Children's Home. He was cared for by ailing grandparents after his mother died in 1998. He was not in school until he was placed in the Children's Home in 2003. He was placed in a "fast tracking" pilot programme of the Department Of Education and progressed to Grade six. He participated in a Zulu interview.

#### **5.7.1.15 SIMP**

SIMP is a 14-year old girl, who was left to fend for herself and her two siblings after her grandparents passed away. Both her parents are missing and presumed dead. The children are from a deep rural area, Iswepe. They are presently in a Children's Home. She participated in a Zulu interview.

In Chapter One, the researcher defined the term "orphan" as "...a child between 0 and 18 years, after the death of his or her primary caregivers, or the death of one caregiver and the disappearance of the other". Four of the adolescents interviewed indicated that they still have a biological parent whose whereabouts are unknown. The other young people lost both parents, and were thus "true" orphans. However, all participants were suitable according to the selection criteria and the definition of an orphan, as SIMP lost both her primary caregivers.

Strode and Grant (2001:13) mentioned that the extended family structure is a primary support mechanism in African societies – a social safety net for children. Four participants were in the care of their maternal family and two in the care of the paternal families. When this safety net fails, child headed households emerge. Three of the participants are members of child headed households and one is at 17 years old the functional head of the household.

Two young people were not schooling at the time of the interview. However, this can be not be directly linked to their orphan status, but to the fact that they were in Police custody for some time before being transferred to the Secure Care facility where there is no formal schooling provided. One of the adolescents was schooling before arrest, the other one was allegedly requested to leave school because of behavioural problems.

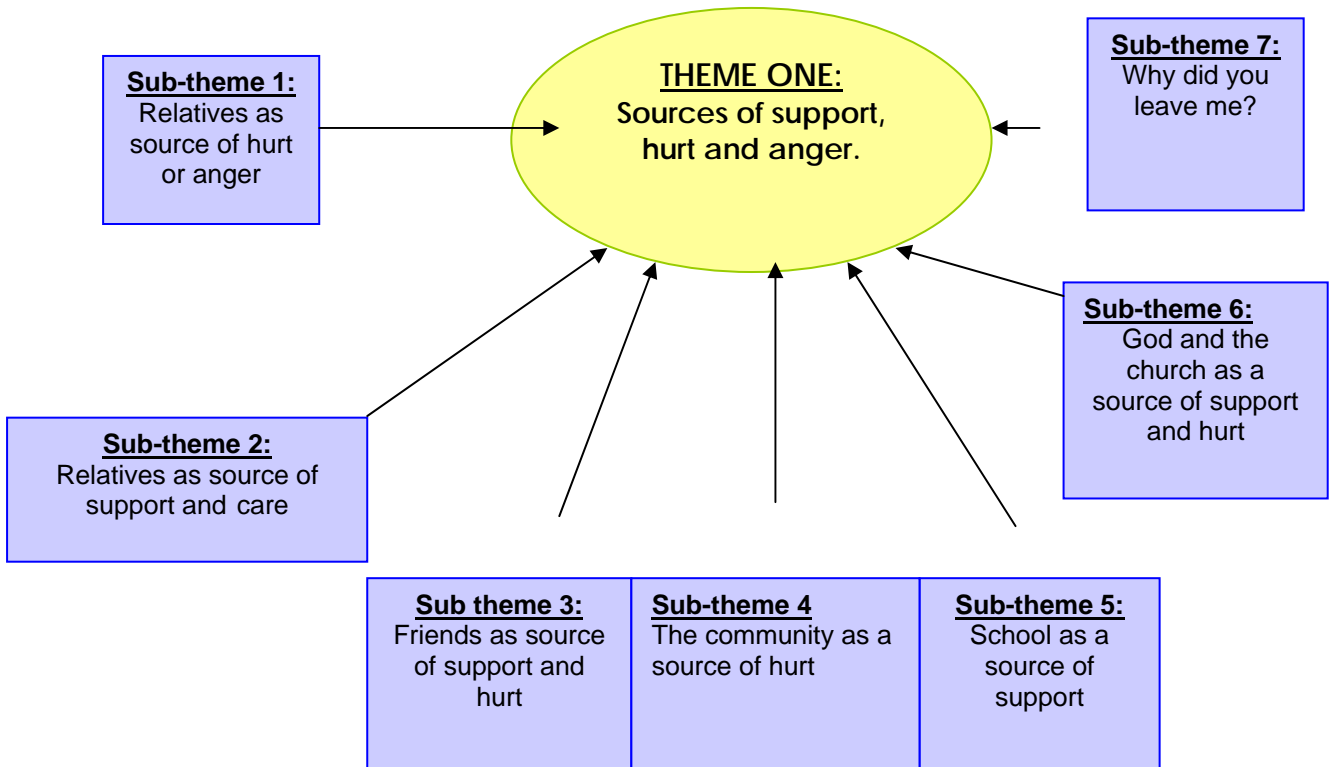
The researcher found it necessary to indicate the different settings from which each participant originated, namely urban (big town like Ermelo), semi-rural (small village like Chrissiesmeer) and rural areas (forest like Iswepe, traditional village or kraal, like Taaibos), in order to indicate the transferability of the study.

#### **5.7.2. THEMES AND SUB-THEMES**

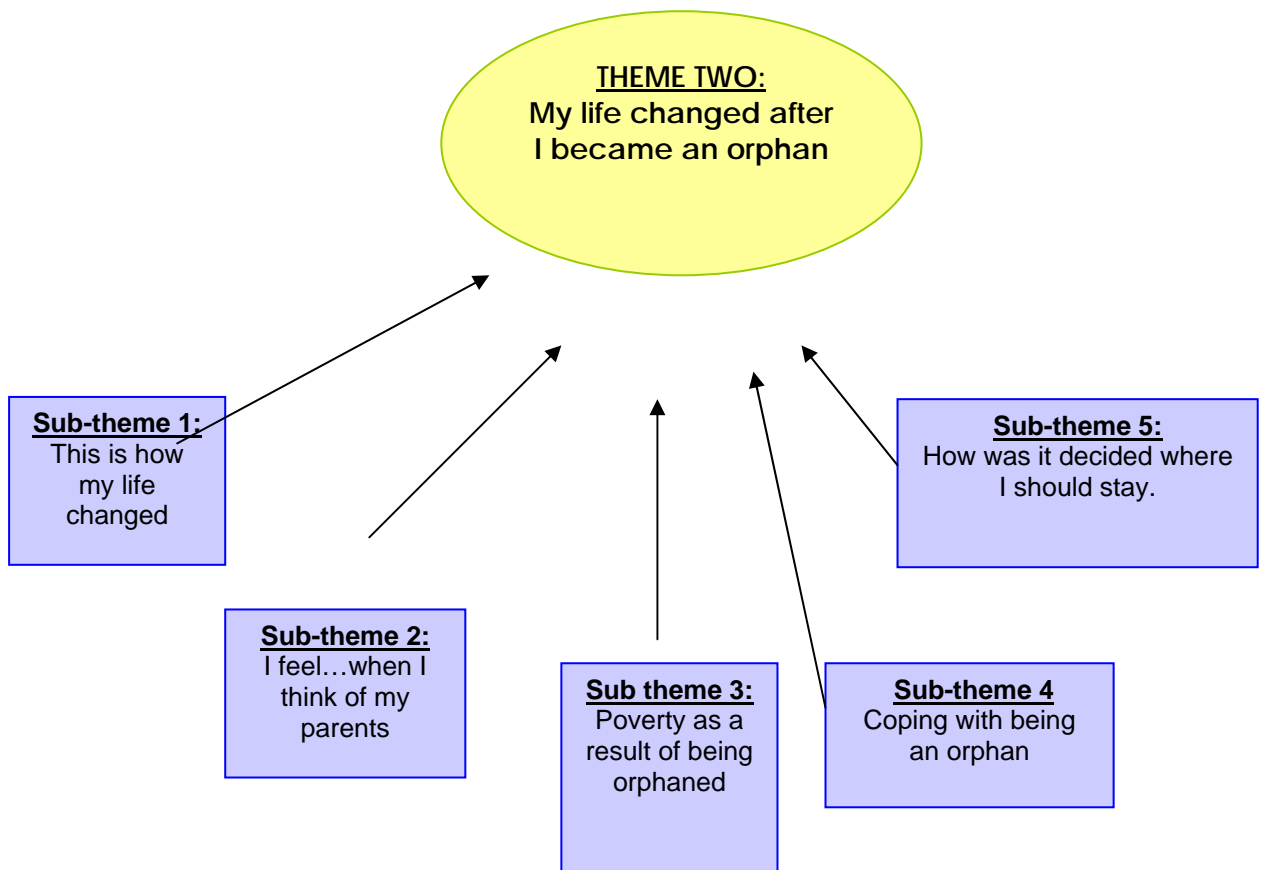
Three main themes emerged from the responses to the semi-structured interview schedule. Several sub-themes formed part of these main themes.

These themes and sub-themes were condensed into the following diagram:

**FIGURE 5.1: THEME ONE AND SUBTHEMES**



**FIGURE 5.2: THEME TWO AND SUBTHEMES**



**FIGURE 5.3: THEME THREE AND SUBTHEMES****5.7.2.1. THEME 1: SOURCES OF SUPPORT, HURT AND ANGER**

This theme was divided into the following sub-themes:

- Relatives as a source of hurt and anger
- Relatives as source of support and care
- Friends as a source of support and hurt
- The community as a source of hurt and anger
- The school as a source of support
- God and the church as a source of support and hurt

This theme and its sub-themes dealt with the young persons' expression of hurt and anger towards family members, missing parents, the church and others they hoped would assist or care for them. The central developmental task of the young adolescent is emancipation from parents, as well as the development of identity (Dwivedi, 1999:69). It appeared as if being dependant on other people, like family members whilst they actually need to move towards guided independence is a source of frustration and pain for the participants. "Instant independence" in the case of child-headed



households appeared to have left the participants with worry, fear and anger, as they are not ready to take on all adult responsibilities.

#### 5.7.2.1.1. SUB-THEME : RELATIVES AS A SOURCE OF HURT OR ANGER

Foster (1997:5) indicated that some uncles and aunts or orphaned children are reluctant to foster a relative's children because it would result in their own children's standard of living suffering. If forced by economic or other circumstances to choose between their own and fostered children, they would show preference towards their own children.

It is in the light of the aforementioned that this sub-theme emerged. Confusion about promises and mixed signals are shown by these comments:

My father's family is not supporting me, I do not know why, because they are not poor... it is not as if they are not friendly- they always invite me to their home when they see me on the street. I do not understand why they do not help me. – TH

My grandmother said to the court- she is tired of me. I am lying, it (rapes) never happened. She wishes I could stand in the road and a truck could drive over me. That is how she feels about me. She made me do bad things and she told everyone I have the sickness (HIV) to that they could give her money for medicine. - NVA

My grandmother loves my elder half brother more than us, when she buys some clothes. She buys for him only. - BD

She (aunt) pretends to like us, but when she goes out to her family and friends, she goes and tells them that we are boring (irritating) her. – GU

Sometimes it is hard, because my other uncle's wife is very talkative. My grandmother's child is also at University so she talks lot about my mother and grandmother, saying 'Why did she have to die, now we have to look after those two...Think of all the money my child could get and now we have provide for those two. – GU

He (aunt's husband) likes to yell all the time. He sometimes drinks too much and then he starts. He says we do not belong there. He says he can throw us away anytime... it hurts. It does not feel good inside. – ZA

It appears as if the recognition and assistance of the paternal family is of great importance to adolescents cared for by maternal families. Those cared for by paternal families are using that surname and they appeared to be very proud to be associated with the surname. They explained this source of belonging as:

I feel I need to keep this surname going... I want to use my father's surname because he really loved me and probably still care for me.-NH

I am proud of it. – MZ

They treat us very well – ZA

My parents were married so now I stay in the same house as my father's mother. -ZA

Unfortunately, the opposite was true for most of the participants:

He left before I could know him. I don't want him (in my life). - SF

I hate my father's family! I hate them! Because when my father passed away in 1993, my father was shot, they said my mother's boyfriend killed my father. Even to my mother's funeral, they did not come. That is why I hate them. – BAWN

He (my father) died of lung cancer. He called for me when he was in his deathbed, but I told him it is no use calling for me when I am in High School while he was not there when me and my mother needed him...they (father's family) know me, but I don't really like them. When he was in his deathbed, he remembered, 'Oh, I have a child' and when I got there he did not even know me. –GU

I do not know them (my father's family). – AY

Child-headed households are often an extreme result of rejection or neglect by extended families. Foster (1997:5) described the factors that may predispose the development of a child-headed household, namely:

- Reluctance of relatives to foster orphans
- Lack of contact of relatives with the children
- Presence of adolescents able to care for younger children
- Death of a single mother leaving illegitimate children
- Death of a grandparent-caregiver
- Children preferring to live in Child-headed households, because of inheritance of the residence by the surviving children or because of a death wish of a dying parent.

The circumstances of the three child-headed households that formed part of the study, all fitted these criteria. BD's circumstances were compounded by the fact that his father left them after a second marriage to their aunt did not work out. In that family, there were adolescents that could take over the care of the smaller children. BAWN and NH chose to live independently, because of their strained relationships with extended family. NH expected the family to assist them, but they were disappointed and vowed never to ask them for anything. It became clear that very serious problems start when grandparents also pass away. Some of the participants were placed in Children's Home after the death of their grandparents, as no possible foster parents were left.

I see my uncles and aunts maybe once or twice a month. Sometimes they say we don't really come to them, because the most of the time we are used to be on our own...they say we think we are better than them...how will I ask something if I know you don't really care. I don't like people who talks too much. – NH

... They were supposed to assist us. – NH

It was very hurtful. They (Family) would give you food because of your mother, but they would say nasty things before they give you that food. Like I am a beggar, always hungry. -BD

I thought we will die of hunger too after my granny died. -BERN

When my grandmother died, I had to do everything. It was so bad. The 'small uncle' nearby buried her. Later they called the social workers because they could see we are starving. - SIMP

My sister became sick (mentally ill) after my mother died. She could do nothing. She was supposed to cook for us but another lady had to take us. She just left sometimes and we could not find her for long- a week maybe. We later did not have a place to stay. People told me they will take care of us, but they wanted money from the social workers. They promised me R50 if I told the social worker I want to stay there. Sis Dudu (the social worker) said they are bad people and took us to Uzwelo (Children's Home). I was so angry because I wanted my R50. It would have been the best if my sister would be healthy. But it is nice here. - SF

Four young persons had missing parents. SIMP, MZ, SF and BD felt confused and angry about this, even though two expressed love for the missing parent:

I would like to ask him why he left us alone without anything to eat... he just left like someone who is going to visit somebody and would come back. He never came back and left us (4 children) alone. – BD

I would like to ask her why she left us when we were so young. - MZ

I won't talk to him. I don't know him. - SF

I wish they could still be alive, but people say they are dead. It must be true, otherwise they would have come for us.- SIMP

Conflict (justified or not), especially about chores and other children of the family where they are currently staying, often make the participants feel that they don't belong to the family. Conflict appears to be inherent to adolescent relationships, especially when they begin to realize that adults are not always right (Light (2004:3). Conflict usually pertains to chores, finances, appearance and substance abuse. In addition, family relationships, school curfews, dating, friends and sexual behaviour cause disagreement between parents (and also alternative caregivers) and their teenagers (Light, 2004:4). It appeared to researcher as if the participants experienced this sometimes normal conflict as rejection and extremely hurtful.

My aunt was abusing us. She wanted me to do everything, I had to do the dishes, clean the yard, everything. My aunt was lazy.- BD

Yes, I have to work harder than them, because if I want something, my cousins say I am lazy – I do not deserve to get it, so now I work extra hard to prove a point so I can get what I want. – AY

My grandmother got money for what the uncle did to me. She said it is time that I earn money. I never could go to school. - NVA

I go to school until 15h00. Then I come home at 15h30. Then I have to chop wood, fetch water and fetch the cattle. I work harder than the other children, because I am the eldest boy. But when I don't get to finish everything, my stepmother's child (a young adult of 20) say that I don't deserve to eat because my work is not done. – MZ

My uncle gives us more jobs than his children. They also get away with things and we get blamed. – ZA

My eldest cousin thinks she is my mother- she is always on my case. She always think I am going to get drunk or pregnant if I try to go somewhere...I really hate her.- AY

They (cousins) broke the TV and I was the one who got blamed... I must just admit. My uncle also does not want them to do anything in the house. -GU

#### **5.7.2.1.2. SUBTHEME 2: RELATIVES AS A SOURCE OF SUPPORT**

Barnett & Blaikie (1992:119) is of the opinion that orphans are mostly cared for by grandparents. Only 20% of the participants in the study were cared for by grandparents. 40% were cared for by maternal aunts or uncles. 30% lived in child-headed households whilst one young person were cared for by one of his father's four wives (stepmother). From this study it became clear that maternal families often take on more responsibility for the care of orphans.

Participants experienced them as supportive, especially in terms of nursing of the ill and funerals.

In the beginning I could do it (nursing father) but later my grandmother on my father's side came to fetch him when it became really worse. My father and my granny looked after my mother. – TH

Granny looked after her, but she was in hospital when she was very sick. – TB

My sister and the nursing people looked after her. When they saw my sister could not, they look my mother to the hospital. - SF

My aunt nursed her at the end. – NH

She was taken to where she grew up. – ZA

My aunt and my granny. (nursed her) – AY

It was so scared. I did not know what to do anymore until my grandmother came - TH

My grandfather sometimes came to us to see how we are doing. He gave us food. I am his special child. I think he spoke to the social worker. - SF

My 'small uncle' (father's younger brother) buried my mother. - SIMP

Older siblings and even a helper at home appeared to be perceived as the trustworthiest source of emotional support and advice. Uncles and aunts are seen as 'caring but too busy to listen'. It became clear that emotions are not discussed openly in the family, especially not about the dead. In most instances, photos of the deceased are not displayed openly, as the deceased can only be approached at the gravesite as an ancestor.

The helper. She is very religious and she understands. She always gives the right advice according to the Bible. She is a Christian and she raised us up according to that

values. She taught us that if things go wrong, just go to God and pray and He would help you.

- GU

My aunt does not have enough time. I speak to my sister.- ZA

I can talk to my friends, but more to my sister who is older.- AY

I talk to my elder sister. – TH

I talk to my sister.- TB

I can talk to Zama (my sister) and my aunt. - NOMK

There is no-one to listen...everyone is doing their own thing. I can only talk to my sister or my friends, but sometimes they give bad advice! – NH

The aunty (place of safety parents) is so nice. I want to stay with her forever. - NVA

I talk to my friends. - SIMP

#### **5.7.2.1.3 SUBTHEME 3: FRIENDS AS SOURCE OF SUPPORT AND HURT**

The role played by peers in adolescence is very critical (Castrogiovanni, 2004:1). The role 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 friendships as would normally have been the case.

This is not always the case. Mabutho (2004:58) quoted McKerrow (1994) about the difficulties orphaned adolescents may experience: "Their anger at the

unfairness of the world often contaminates their peer group relationships 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, except GU who appears to have problems in finding friends to trust. This is congruent with the views expressed in literature.

I used to have one friend, I trusted her, but she used my being an orphan to look better, you know, 'look at me, I am friends with an orphan'. So I decided to stay alone- no friends, no nothing. I can stay alone, I don't need anyone. – GU

I have three friends. I like them and they like playing with me. - SF

I only have classmates, no friends- GU

I have a friend, Lucky. We hang around talk, read and play cards. – BD

I have three good friends. We talk and do hair, maybe walk around a bit. But with problems I would rather talk to my sister. The other girls talk about the way I dress. I don't have enough clothes. They say bad things. –TH

I can only talk to my friends about that (emotions) but sometimes they give bad advice. I have friends from dancing and friends from singing. - NH

I talk to my friends. - SIMP

I have many friends, but I only talk to one. Some of the others gossip about me, because I am in the children's home. They want to know why. -BERN

I have a special friend from the Tshabalala boys next door. He left school because he could not afford the school feed and he wanted me to also leave school. I refused because I like school a lot. He is my best friend. ..We sit around and talk, and sometimes if I have to do too much at home, I call him to help. - MZ



I have five friends. I have a lot of friends. – AY

I have three friends. We do hair and talk, maybe walk around a bit. – TB

I have one friend, I see her everyday at school and maybe over the week-end. - BAWN

#### 5.7.2.1.4. THE COMMUNITY AS A SOURCE OF SUPPORT AND HURT

A perception of 'being different' can clearly be seen in this sub-theme. Young persons participating in the study appeared to be suspicious of community members, except persons associated with the Home Based Care Groups, who served as a regular source of support to some. In some cases, the community isolated the young person and they responded by isolating themselves further from the community. Young participants experienced feelings of being different and being observed. This is the experience of adolescents under normal circumstances (imaginary audience), now complicated by stressful circumstances.

...you get people who feel sympathy for me...I don't really want their sympathy. – NH

They used to treat me as if I have got some or other disease: I don't have parents and they have parents... I can just live my life alone. – GU

Yes, people do (talk)- they always like to say: what is she going to do now, her parents have died- like who is going to stay with her? When you pass them, they look at you in a different manner. I go and buy some bread they want to know – I just say they just died. ..People should understand they must talk to me about other things, not make me start crying again. – GU

They say ...God punished you for being like this...for what you are.- GU

Everyone there is poor, but they tried to help us, especially when we were not having food. - SIMP

People always discuss the way in which I dress...TB

We did not have enough food at that time, because my father was not working. The Home Based Care Group came to give us food...-TH

They (Home Based Care Group) brought food when they found out. If it was not for them...I don't know.- BAWN

(The children's home) took me to school and helped me too much with my brother and sisters. I am so grateful. I don't have to worry anymore. - SIMP

#### 5.7.2.1.5. THE SCHOOL AS A SOURCE OF SUPPORT AND HURT

100% of the participants reported their school and a teacher or teachers as a source of support, even BD was expelled from his school at some point because of rowdy behaviour. None reported discrimination because of unpaid school fees or poor school uniforms. MZ reported that his school demanded school fees for admission, but he was able to pay it. This was contrary to the expectation of the researcher, who expected some discrimination or abuse at school. Most participants reported pride in their ability to continue scholastically, despite their circumstances.

I am happy (at school). I feel it is valuable...if I want to become somebody, I must study. – NH

I feel great at school... They trust me at school.. I have the keys to the gate to unlock it in the mornings. – MZ

When my father was sick I could not go- me and my sister took turns to look after him. I passed last year...it was really a bad year, but I made it. – TB

Good, except if the fat one (bully) is around. – AY

I can go to my teacher. He really understands me and he is a Christian person and not a racist. I talk to him. – GU

I am really good in school. I want to be a Policeman one day. The teacher said I can do it. - SF

I was so sad because I was not in school. Now I am and they really help me.- NVA

I don't see anything (discrimination). I am very happy. – BAWN

It can also be noticed that 100% of the young persons reported the school, teachers, child care workers in the children's home and television as their only sources of sex education. This is clearly is still a taboo in most African households.

#### **5.7.2.1.6. GOD AND THE CHURCH AS A SOURCE OF SUPPORT AND HURT**

The young people 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.

Why? Why does it happen to me? Why does it have to be me?...because there are so many other children who still have their parents until they are 90. My parents died when they were still young. My father was 50 and my mother 48. Why? You know, as a child you grow up thinking, I am still going to do this for my father and that for my mother. So...sometimes I don't believe in God, because I feel He let me down. Maybe it would have been better if I had at least one parent...maybe I would then have believed that there is a God who cares for me. (The church helped) just with the funeral, they also left- just like a dream. – NH

Church is boring. I don't go. – AY

Why did it happen to me? Sometimes I don't believe in God and then I talk to the helper and then she says 'No if God does something, He wants you to learn about life'... I think I have learnt enough now. – GU

They came to pray at my home. I am happy with God. Was angry at God, but not anymore. He helped my sister to get a job. – TH

They collected money and brought it home. It also helps me not to lie and hate people. – BD

My sister lied to the church and stole the irons (corrugated iron) they bought for a shack for us. She sold it. So we had no place to stay, but they tried to help us. The men in the church even said they will build the shack because we are children. - SF

They care about me, because they advice me on what to do if I have problems. - BAWN

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. – MZ

#### 5.7.2.2. **THEME 2: MY LIFE CHANGED AFTER I BECAME AN ORPHAN**

##### 5.7.2.2.1. **SUB-THEME 2.1: THIS IS HOW MY LIFE CHANGED**

Existing research suggests that the impact of HIV/AIDS on household level, may lead to sequential trauma associated with continuous traumatic stress. Many children suffer multiple losses- a father, a mother, siblings, grandparents, uncles, aunts and other relatives. In additions, they may lose friends, familiar surroundings, schooling, and their hope for the future and their remaining childhoods and are subject to surges of loneliness and sadness, triggered by some memory (Medical Research Council AIDS Bulletin, 2004:2,19).

...we miss her a lot. I feel sadness if I think of her. \_ ZA

I definitely don't have happiness in my life. I am happy... or I am pretending to be happy. I don't feel special. I have a girlfriend but she does not make me feel that special like my mother did. I cannot show the young ones that I am hurting because they will break apart. – NH

I just remember I had a father who used to wake me up for school. – MZ

My happiness died with my mother. It is getting better, but I don't feel special.- SF

I would not have been at the Center (Awaiting trial facility). My father would have spoken to the court and would have spoken at the court and may be he could have rescued the situation. My stepmother does do to the court, but she does not say anything. – MZ

Life is tough now. Because she was the one looking after us with clothing and all that. Sometimes I am hungry and have nothing to eat. Then I am tempted to go and steal. – BD

It was sad for a few weeks, but the helper helped me a lot- she became like my mother, but sometimes I remember that she is not my biological mother and she has children of her own.- GU

#### **5.7.2.2.2. SUB-THEME 2.2: I FEEL... IF I THINK OF MY PARENTS**

The emotional demand of HIV/AIDS on children's lives is heartbreaking. Literature shows 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 (Griesel-Roux, 2004:38). It was noticeable to the researcher that the participants have a very limited emotional vocabulary. Discomfort is often described as 'feeling bad' or 'it does not feel good'. This was tested in a peer group discussion with two senior Zulu speaking social workers (Mrs. Mahlangu and Mrs. Mabena on 2005.10.14).

They explained that there are very few words in Zulu to describe emotions and that the discussion of emotions are not deemed appropriate by traditional households. As previously indicated, discussions about the dead are also not seen as appropriate.

The young participants ventilated the following emotions during the interviews:

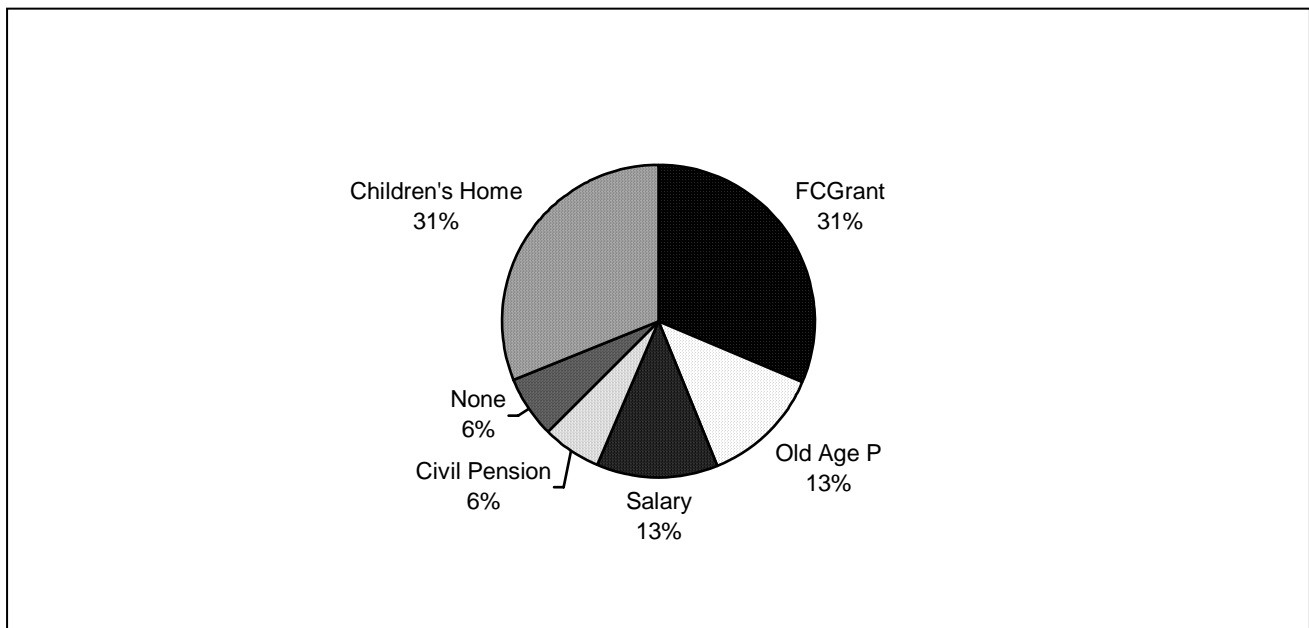
**Table 5.2: Emotions expressed by participants**

EMOTION	CONTEXT	EXPRESSION
<b>Sadness</b>	Remembering parent	'It was so sad..' –GU '... We miss her a lot. I feel sadness if I think of her.' ZA 'Sadness- because I found her' - BAWN 'I cry if I am reminded of her.' -BERN
<b>Guilt</b>	Not being at father's funeral Selling mother's possessions to survive. Not being able to 'unveil the tombstone' Feeling guilty about being a burden.	'I felt very bad, because I was not able to see him for the last time.' MZ 'It felt so bad- she worked so hard for it, but we had no choice.' –ZA 'There is no tombstone. It feels so bad.' ZA 'I am just trouble. My grandmother said that. Where to get food from?' - NOMV "My granny was so old, it was so bad for her to have all of us at home. - SIMP
<b>Loneliness</b>	At night Thinking about his missing father. Talking about her family. Talking about feelings.	' I felt so lonely that I sometimes my mother is calling me.' –NH 'He just left like someone who was going to visit somewhere and he would come back. He just never came back' – BD '...so, I really have no-one left.' – GU 'There is no-one to listen.' BAWN 'I was so lonely and scared' -SIMP
<b>Humiliation</b>	Asking for food or money.	'They talk and talk before they give. It makes me feel not good inside.' BAWN

	About not having clothes.	'It was very hurtful' BD 'They chased us away.' SF 'It was no feeling that good' MZ 'People talk about the way I dress' TH
<b>Anger</b>	Why did it happen to me? Father's family	'I am angry' -NH 'I hate them, I hate them!' - BAWN 'I was so angry. I ran away if someone wanted to help me.' SF
<b>Powerlessness</b>	Unable to cope	'I did not know what to do anymore.' -SIMP 'They did not want to help me.' -MZ 'I am waiting for months now (for foster care grant). - BAWN
<b>Pain</b>	Thinking about parent	'I feel so much pain. I don't want to cry, because the last time I cried was at my mother's funeral.' -NH 'It is so painful' - NJ ' My heart is so sore.' - BERN
<b>Irritation</b>	Not having a variety of food Dealing with younger cousins or siblings	'Pap and eggs- it really irritates me.' NH 'They are noisy' ZA 'I can only do homework when they went to bed.' NH
<b>Fear and Worry</b>	Looking after parents whilst ill  When brother comes from Prison Worry about what will happen if grandparents die.	'I was so scared.' TH 'I was very worried, because he was the only person who was looking after me.' MZ 'I worried when she (grandmother) also passed away'. GU 'Yes (I am scared). He is in jail for murder. He is coming back'. BAWN  'Things became really bad when my grandfather died. It was so terrible when my grandmother also died and we worried because we did not have anybody then.' SIMP

### 5.7.2.2.3. SUB-THEME 3 :POVERTY AS A RESULT OF BEING ORPHANED

The type of income in the family was a point of interest to the researcher as she knew that all participants are known to the social workers of the Department of Health and Social Services. It became clear, however, that less than half of the participants were in foster care, which is the least restrictive, most empowering option. Four children were in Children's Homes, which is subsidised by Government. Figure 5.4. is a summary of the main sources of income reported by the participants. (N=15)



When evaluating Table 5.1 and Figure 5.1, it is noticeable that 62% (N=10) of the participants are in receipt of Government assistance in the form of a Foster Care Grant, Place of Safety Fee or Children's Home subsidy. However, these results cannot be directly transferred to the rest of the orphan population, as all of the participants already received social work attention. The researcher concurs with Demmer (2004: 40) who indicated that the South African Social Welfare system is unable to adequately meet the needs of children orphaned by HIV/AIDS, as there are still thousands of children who are still on waiting for services. The provision of care for orphans when their foster parent grandparents pass away, is also a worrying factor, as it appears from the study that children then depend on children's homes or child headed families for care.



Only nine percent of the participants have access to the civil pension of a deceased parent, whilst the rest depended on the Old Age Pension of a grandparent or the salary of a working caregiver. Two young persons reported no income at home. Foster (1997:15) mentioned food stinting and the selling of furniture and assets as a way in which a severely affected family attempts to cope with food shortages:

We only ate once a day for a long time- we only ate at night... maybe for two months. My granny tries to buy clothes. - BAWN

We did not have enough food at that time, because my father was not working. Sometimes we did not eat for two days. – TH

We did not have money or someone to fix the house. The roof was taken by the wind (blown away). So then we stayed outside most of the time. We only had pap to eat and sometimes maroggo. The uncles sometimes brought a chicken.- NVA

We sometimes had to look in the dustbins in town when we had nothing. We also tried the dumping site. -SF

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. - SIMP

We always has something, even if it was just pap.- NH

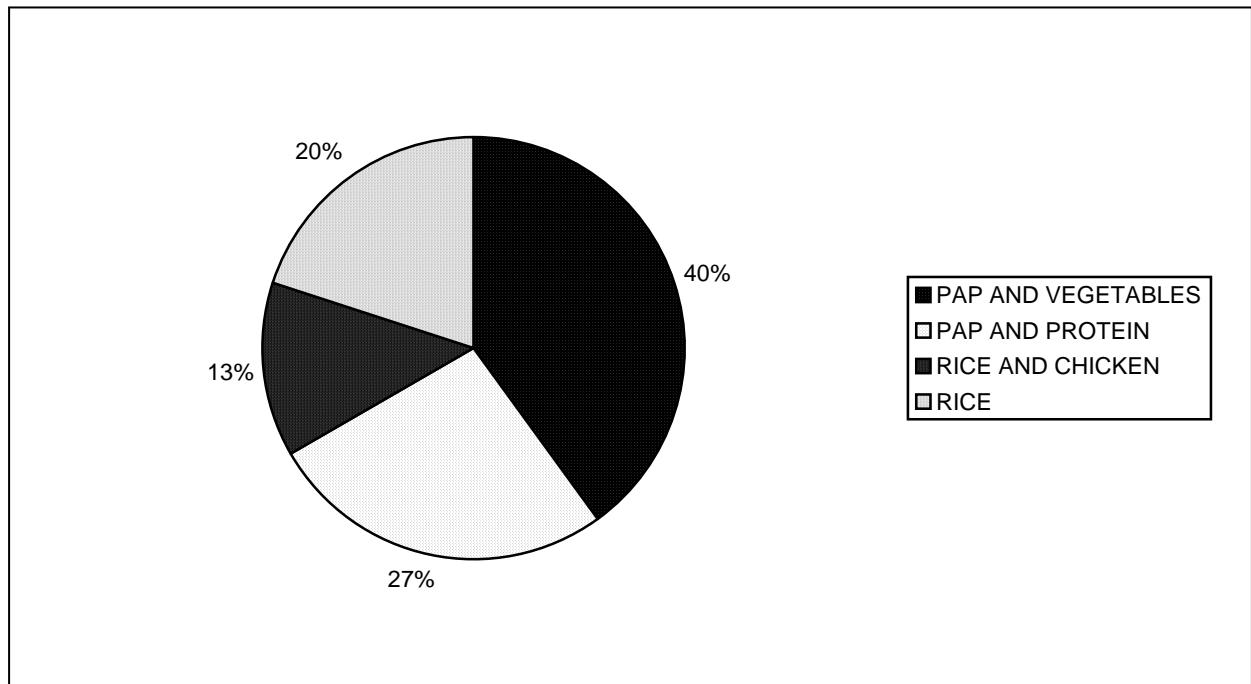
Pap and eggs- it really irritates me! – NH

We only eat pap and beet (Wild beet picked in the veld). We eat with my grandmother maybe twice a month. We were selling sweets and fruit. We had to ask for food from the neighbours...it is then that I get tempted to steal money and food. – BD

We had to sell the furniture of my mother.- ZA

The participants in the study (N=15) indicated their staple food one month after the death of their parents as:

**FIGURE 5.4. STAPLE FOOD OF ADOLESCENTS ORPHANS ONE MONTH AFTER DEATH OF PARENT**



From Figure 5.4 it is clear that 40% of the participants ate very little or no protein during the period before the receipt of some form of assistance, which may have serious consequences for their immune systems and general health. The young people in foster care and children's homes now indicate an improved nutritional status, as well as those having access to a civil pension of a deceased parent. It is therefore clear that the foster care grant does make a significant contribution to the general well-being of orphaned children.

Access to proper clothes and school clothes appears to be a constant source of worry and humiliation for the participants. Only two young people (GU and AY) reported to have enough clothes, even though they would have liked more. Children in children's homes is of the opinion that they have enough now, but had poor clothing at home.

Another manifestation of poverty is the deterioration of living conditions. NVA's grandmother was unable to fix the roof of their mud house and the family ended up living under open skies.

#### 5.7.2.2.4. COPING WITH BEING AN ORPHAN

Poverty resulting from the HIV/AIDS pandemic can lead to the sale of assets or land. Orphans may even have to turn to crime or sex as a survival option (Smart et al., 2000:93). The participants in the study reported the following strategies to cope with the sudden loss of parental income:

We were selling sweets and fruit. - BD

We don't have furniture anymore. It was sold for food. -BD

We had to ask food from the neighbours. - BD

We had to sell the furniture. - ZA

I ask for food once a month from the family. The Home Based Care also helps us. -  
BAWN

The social workers used to provide some, then they stopped. I don't know why they stopped. -BD

My grandmother made me do things (allowed her to be raped by her uncles) for food.-  
NVA

I stole money...even from my grandmother to get food. I was also tempted to do housebreaking when we did not have anything to eat. That is why I am here (Secure Care Centre). -BD

#### 5.7.2.2.5. HOW IT WAS DECIDED WHERE I SHOULD STAY

Living with uncertainty poses a great challenge to the secure psychological base essential to a child's development of 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 death. They were only removed or assisted by family when serious problems arose. In some cases, the young persons remained in the home they knew, mostly with grandparents or maternal family (for example AY, TH, GU).

The absence of a formal family decision about their future, is a constant source of disappointment and humiliation for the adolescents in child headed households:

They (family) did not decide because we stayed in our homes. After the funeral, just immediately when we came back from the graveyard...two hours and we were left all alone. That is when we made the decision to stay away from them, because they showed us that they did not really care. -NH

They did not even come to the funeral all of them. How would they take him (smaller brother) then? - BAWN

They knew my sister became sick and we had to look for food in the dustbins. They just made as if they did not know us. Except my grandfather, but he is old. Other people wanted us, but just for the money. When they saw they will not get it, they chased us away.-SF

They fetched her to go where she grew up and left us with our aunt. - ZA

My father married my mother's sister. But they always were fighting because she was gambling. He was too upset one day and left and never came back. My aunt also abused us - she was so lazy. I am happy she is back on the farm. She is our only family except my grandmother who is old. - BD

I stayed with my uncle after my grandmother died. It is the same house...my mother also stayed there. I think I will grow up in that house, I hope. - GU

My father came out of Prison. Then he fetched us four from my mother after my grandfather (Maternal) died and we stayed with and my stepmother. She takes care of us now. - MZ

My mother lived with my grandparents. She died, then I just stayed there until now (child in children's home). It just worked out that way. -NJ

I always lived with my granny. It is my home. – AY

### 5.7.2.3. **THEME 3: PARENT'S ILLNESS AND DEATH**

Children's psychosocial distress begins with a parent's illness, and they are left emotionally and physically vulnerable by the death of one or both parents. They may suffer lingering emotional problems from attending to dying parents and seeing parents die (Hunter & Williamson, 2002:17).

#### 5.7.2.3.1. **THIS IS WHAT I SAW**

The clinical course of HIV/AIDS is disturbing to the infected person and affected family. Chapter Three dealt with the clinical development of the illness in detail. The participants in the study were not required to reveal the actual illness of their deceased parent or parents, but to describe the symptoms they observed.

She was not really that sick. She was just ...asleep. When I go to school, I come home I find her, she was asleep. I say 'Wake up, wake up!' but she passed away. The shock was so terrible. I could not sleep well for three months, I kept on waking up. – BAWN

The last week before she passed away, she was unable to eat...she could only drink mageu...she could not swallow anything. It was so terrible. – NH

He was coughing and sometimes he could not even walk. I had to make fire for him to keep him warm. He died at home, but I was not there. – MZ

It was terrible. Her face was so swollen, you could actually not see where her eyes were, cause the black thing of her eyes totally disappeared. It was so terrible – she had so much pain

and she could not do anything. She was in a Pretoria hospital but they could no longer help her.- GU

She could not walk or talk. She was just lying there.- ZA

He started coughing and could not eat anymore on his own. I had to feed him. We had to carry him to the toilet and wash him- later on, he was not talking anymore. – TH

She was in bed, but she was strong until the end. She tried to show us that she can do everything by herself. – NH

She was coughing and blood and phlegm came from her mouth. She was screaming sometimes with pain. It was terrible. She died in hospital. – BD

She was so sick. She was talking no sense and she was urinating in bed. My sister ran away, she could not take it. I did not know what to do. They took her to hospital. – SF

I remember that she was coughing and was crying. It was so bad, I do not want to remember. - NVA

#### 5.7.2.3.2. FUNERALS AND ILLNESS OF OTHER PEOPLE

According to the Medical Research Council (2004:19) children affected by HIV/AIDS suffer multiple losses. This may result in “bereavement overload” (Geballe and Gruendal, 1998:52). One participant, GU, lost her biological father, twin brother, stepfather, biological mother, brother, stepbrother and grandmother in a period of four years. SIMP saw the death of both her primary caregivers in a period of six months. From the study, it became clear that funerals and illness of other persons are a source of secondary trauma for them, as it brings repressed memories and emotions to the fore.

I cannot handle funerals. I cannot handle it anymore, it is too painful. I don't want to remember. I don't want to cry. Even now, if you can tell me someone is sick, I would not ... even...the person could rather go. I am scared if people are really sick. – NH

It just came back when my grandmother also died. It brings back memories. You don't really cry for the person who died, but for your mother or grandmother. I prefer not to go to other people's funerals. I don't like dead people- I saw my grandmother also- now I rather stay in the car. – GU

I can't stand funerals.- ZA

I run away.- AY

I had enough - SIMP

I feel so bad. It brings memories of my father being ill. I also feel for the person who is ill. - MZ

I have been to so many, I cannot even tell you how many.- BAWN

No, I cannot stand sick people. I want to vomit. - TB

## 5.8. CONCLUSIONS

### 5.8.1. THEME ONE: SOURCES OF SUPPORT, HURT AND ANGER

The data contained in Theme One is a clear indication of the feelings of disappointment and anger, experienced by the participants.

These emotional experiences complicated the life of the orphaned adolescent, as they also struggle to find their way through the normal adolescent development tasks.

Anger and sadness were the two prevailing emotions noted by the researcher. Anger was directed at relatives and friends who could not live up to expectations, parents who abandoned them, community members who humiliated them and God who chose to 'punish' them. Some of the young persons endured terrible trauma (like NVA who was raped for payment by uncles with the permission of the grandmother), whilst others experienced normal adolescent conflicts.

All the participants reported that they are happy and treated well at school. This was contrary to the expectation from the researcher and reports of stigmatisation and discrimination found in literature. A possible explanation of this disparity may be the efforts of the Department of Education in the Region to reduce stigmatisation and discrimination against children affected by HIV/AIDS. It should also be noted that four of the participants were not in school prior to social work intervention.

The following sub-themes were identified:

- Sub-theme 1: Relatives as a source of hurt or anger
- Sub-theme 2: Relatives as a source of support and care
- Sub-theme 3: Friend as source of support and hurt
- Sub-theme 4: The community as a source of hurt
- Sub-theme 5: School as a source of support
- Sub-theme 6: God and the church as a source of support and hurt
- Sub-theme 7: Why did you leave me?

#### **5.8.2 THEME TWO : MY LIFE CHANGED AFTER I BECAME AN ORPHAN**

SF's comment that " my happiness died with my mother..." summarised the sadness and loneliness experienced by the participants. The researcher often found that the participants struggled to find words for what they feel and that most participants had a limited emotional vocabulary. This can be directly related to the fact that Zulu, the mother tongue of most participants, does not have a vocabulary of feeling words.

The lack of permanency planning by the extended family as well as social workers was a source of worry for the young persons, as no contingency plans were made for them in case their current placement could continue. Uncertainty has serious implications for the emotional basis of the orphaned child (Geballe & Gruendel, 1998:51).



Twelve of the 15 participants experienced a reduction in food security as a result of their parents' death. The humiliation to beg for food was an experience common to most participants. The intensity of their feelings should be seen in the light of their developmental phase, in which they may already be very self-conscious.

The following sub-themes emerged:

- Sub-theme 1: This is how my life changed
- Sub-theme 2: I feel ... when I think of my parents
- Sub-theme 3: Poverty as a result of being orphaned
- Sub-theme 4: Coping with being an orphan
- Sub-theme 5: How it was decided where I should stay

### **5.8.3 THEME THREE : ILLNESS, DEATH AND FUNERALS**

The clinical course of HIV/AIDS can be upsetting to the affected family members (Hunter & Williamson, 2002:17). The findings of the study concur with this statement, as most participants responded in horror about what they have witnessed. It appeared as if they dealt with the trauma by suppressing the memories. They appeared fearful of any occasion (funerals and sick people) that may trigger the recollection of those memories. "Bereavement overload" is a term used by Geballe and Gruendal (1998:52) to describe the multiple losses suffered by most of the participants.

The following sub-themes became apparent:

- Sub-theme 1: This is what I saw
- Sub-theme 2: Funerals

### **5.9. SUMMARY**

In this chapter the research findings were presented and subjected to literature verification. A biographical profile of the participants was followed

by a discussion of the various themes obtained from the data analysis process.

The following themes could be identified:

- Sources of support, hurt and anger
- My life changed after I became an orphan
- Parent's illness and death

## CHAPTER SIX

### SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

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#### 6.1 INTRODUCTION

The purpose of this chapter is to summarize the content of the research report and to make conclusions and recommendations about the study of the experiences of adolescents orphaned by HIV/AIDS related circumstances. The researcher would also make recommendations to social workers for improved services to the affected adolescent orphan.

In Chapter One of this research report, the researcher explained the relevance of the topic as well as the method in which it was investigated.

Chapter Two dealt with the reality of the HIV/AIDS pandemic in South Africa and the rest of the world.

The psychosocial impact of the decease on the patient as well as his or her significant others can be found in Chapter Three. Adolescents were identified as a group of children significantly affected by the changed roles and other complications of losing a parent, hence the discussion of Adolescence as a developmental phase in Chapter Four. The researcher deemed this necessary in order to improve her understanding of the characteristics of the developmental phase, as all their experiences cannot be indiscriminately related to being an orphan because of HIV/AIDS related conditions. Being orphaned by HIV/AIDS related conditions appears, however, to be a serious and significant form of stress added to their complex lives.

The results of the data analysis process were discussed in Chapter Five. Three main themes were identified, namely:

THEME ONE: Sources of hurt or anger

THEME TWO: My life changed after I became an orphan

THEME THREE: Parents' illness and death

The purpose of this chapter is therefore to provide a brief summary of the preceding chapters. Secondly, conclusions and recommendations derived from these chapters will be made. The chapter would also evaluate each objective and the overall goal of the study.

This chapter will consist of:

- Evaluation of the research goal and objectives
- Research methodology
- Findings regarding the experiences of adolescents orphaned by HIV/AIDS related conditions
- Conclusions
- Recommendations

## **6.2 EVALUATION OF GOAL AND OBJECTIVES OF THE RESEARCH**

### **6.2.1 EVALUATION OF THE GOAL OF THE STUDY**

The goal of this study was to explore the experiences of adolescents who were orphaned by HIV/AIDS related conditions, thereby improving the knowledge base and insight of social workers that will enable them to render more effective services.

The goal was achieved as the study provided information on the experiences of the adolescent orphaned by HIV/AIDS related conditions. This information can also be utilized in the improvement of services to these affected children, as it indicated some of their actual felt needs.

### **6.2.2. OBJECTIVES OF THE STUDY**

This study had three objectives, namely:

**6.2.2.1. OBJECTIVE ONE:**

*To build a knowledge base of existing literature on the impact of HIV/AIDS related conditions on children left behind, orphanhood, deprivation and adolescent development and challenges.*

This objective was achieved as literature study was undertaken as reflected in Chapter Two, Three and Four. HIV/AIDS and its impact on the children left behind, orphanhood, deprivation and adolescent development were studied.

**6.2.2.2. OBJECTIVE TWO**

*To conduct an empirical study on the experiences of adolescents in terms of the following themes derived from the Developmental Assessment Framework: Belonging, Mastery, Independence and Generosity.*

This objective was achieved as 15 adolescents participated in the empirical investigation. They were part of a group of 20 children identified through purposive non-probability sampling. A semi-structured interview schedule was used as data collection tool. This schedule was based on the Developmental Assessment Framework, according to the themes of Belonging, Mastery, Independence and Generosity.

**6.2.2.3 OBJECTIVE THREE**

*To produce a qualitative research report about the experiences of adolescents orphaned by HIV/AIDS related conditions*

This objective was achieved with the compilation of this research report.

### 6.3 EVALUATION OF THE RESEARCH QUESTION

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

**What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande Region of Mpumalanga ?**

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

- THEME ONE: SOURCES OF SUPPORT, HURT AND ANGER
- THEME TWO: MY LIFE CHANGED AFTER I BECAME AN ORPHAN
- THEME THREE: PARENTS' ILLNESS AND DEATH

It can be concluded that the HIV/AIDS pandemic has a damaging impact on the emotional, social and physical status of the orphaned adolescent in the Gert Sibande Region.

### 6.4 RESEARCH METHODOLOGY

The research process utilized by in this study was derived from the five phases of the qualitative research framework outlined by De Vos (2002:84-85).

#### 6.4.1. PHASE 1: SELECTION OF A RESEARCHABLE TOPIC

The identified research problem formed the basis of this study. This research problem was identified from literature, personal experience and a felt need within the Department of Health and Social Services. The researcher is of the opinion that the topic was researchable and the strategy could address the research problem.

## 6.4.2 FORMAL FORMULATIONS

The qualitative research approach was chosen, as the study intended to explore and describe the experiences of adolescents orphaned by HIV/AIDS related conditions. This approach was appropriate as the data collected could answer the research question.

## 6.2.5 PHASE 2: PLANNING

### *Research strategy:*

The researcher decided on phenomenological study as the most appropriate strategy to conduct the research, in order to describe the meaning experiences of the phenomenon (HIV/AIDS related conditions) have for various adolescents who were orphaned because of these conditions. This proved to be appropriate as their experiences could be described in order to create better understanding of their world.

### *Preparation for data collection and analysis:*

The preparation for data collection involved decisions about the sites of data collection, the population as well as sampling procedures. The researcher's decision to focus on the Gert Sibande Region in Mpumalanga proved suitable, as this area was the most accessible to her. Purposive non-probability sampling was decided upon as the sampling procedure and this proved to be appropriate as suitable participants could be identified. Some problems were experienced with social workers or Home Based Care Coordinators who did not understand the criteria and five young people identified could not be included in the study. The definition of 'orphan' proved to be interpreted differently by different persons.

Some sampling criteria used were:

- Ability to understand English
- Age: adolescents between 13 and 18 years
- Care status (orphaned or not)

- Person and circumstances of the family known to or nursed by a registered Home Based Care Group.
- Willingness to participate
- Orphaned for a period exceeding six months
- Confirmation of the AIDS-like symptoms of the parent before he/she passed away from a family member or health service provider
- Registered as a client at the Department of Health and Social Services, Gert Sibande Region.

The researcher found the criteria to be suitable, even though English proficiency was not a factor because of the availability of interpreters.

### **6.5.3 IMPLEMENTATION**

The researcher conducted a literature study as first part objective of the study of the implementation process in order to assess the research findings against the background of existing literature (De Vos, 2002:91).

Semi-structured interviews were held with 15 participants. 20 young persons were identified, but one withdrew from the interview because of personal reasons. Four participants identified fell outside of the selection criteria of age (two were too young, one too old and one was not an orphan).

The Developmental Assessment Model was used as a basis for the semi-structured interview schedule. Interviews were conducted in English with five young people, one in Afrikaans and nine in isiZulu. The data was then transcribed into English.

The researcher is of the opinion that the data collection method was appropriate, though the use of focus group interviews could also have proved to be valuable. This was initially shied away from, as the young person in the Pilot Study interview indicated that she will be too ashamed to talk in a focus group interview. The researcher later on experienced that the young



persons would have benefited from the sharing of experiences in such focus group interviews.

#### **6.5.4. ANALYSIS, INTERPRETATION AND PRESENTATION**

The researcher is of the opinion that the findings of the study would be transferable to a similar setting with a similar population. Analysis was done according to qualitative processes.

#### **6.5.5. CONCLUSIONS AND RECOMMENDATIONS**

The qualitative approach proved as appropriate as the information gathered was in the form of words and descriptions to give meaning to the social reality as experienced by the orphaned adolescents. The researcher was able to obtain first-hand information at the hand of the semi-structured interview schedule (Appendix 1), as it allowed some freedom to explore some topics further in some cases. It can therefore be concluded that the semi-structured interview as a method of data collection worked effectively in answering the research question.

The choice of the Developmental Assessment Model (See Chapter One) as a basis for the schedule was suitable as it allowed the interviewer to get a general picture of the life experiences of the participants in a relatively short time. However, the researcher found it not to be practical to structure the themes that came from the research results, according to the main headings, namely: Belonging, Mastery, Independence and Generosity.

Guba and Lincoln's method of evaluation of the trustworthiness of the information assisted the researcher by providing criteria and strategies that could be implemented in the research process. It became clear from the process and results that the findings can be transferred successfully to a similar population. It should be noted that the population in this study all received some social work assistance and their basic needs were met prior to the study.

The researcher can therefore recommend these methods to future researchers who are aiming to explore experiences of adolescents. The phenomenological design is appropriate when experiences and the meaning they have for individuals are condensed into central themes.

#### **6.6. FINDINGS REGARDING THE EXPERIENCES OF ADOLESCENTS ORPHANED BY HIV/AIDS RELATED CONDITIONS**

The themes and sub-themes that emerged during data analysis were:

<b>THEME</b>	<b>SUB-THEMES</b>
<b>SOURCES OF SUPPORT, HURT AND ANGER</b>	Relatives as a source of hurt and anger
	Relatives as a source of support and care
	Friends as source of support and hurt
	The community as a source of hurt
	School as a source of support
	God and the church as a source of support and hurt
	Why did you leave me?
<b>MY LIFE CHANGED AFTER I BECAME AN ORPHAN</b>	This is how my life changed
	I feel...when I think of my parents
	Poverty as a result of being orphaned
	Coping with being an orphan
	How it was decided where I should stay
<b>ILLNESS, DEATH AND FUNERALS</b>	This is what I saw
	Funerals

##### **6.6.1. THEME ONE : SOURCES OF SUPPORT, HURT AND ANGER**

The researcher is of the opinion that orphaned adolescents experience their environment both as supportive and hostile. Social workers featured nowhere as a source of support, but rather as inconsistent providers of material needs and broken promises. Friends and siblings are the most trusted sources of support, together with Home Based Care Groups. Hurt and anger are mostly the result of being betrayed, gossiped about or being rejected by family members or those in helping professions.

### **6.6.2. THEME TWO : MY LIFE CHANGED AFTER I BECAME AN ORPHAN**

All the participants reported some form of significant change in their life as a result of the death of a parent. Some experiences extreme poverty as a result of the loss of income. Deprivation and shame because of food shortages were some of the experiences related by the participants. Most of the young people reported feeling sad or depressed most of the time, struggling to understand what has happened to them.

### **6.6.3 THEME THREE : ILLNESS, DEATH AND FUNERALS**

The researcher is of the opinion that a number of the participants in the study suffered from Post-traumatic Stress Syndrome at the time of the interview. The clinical course of HIV/AIDS can be upsetting to the affected family members and the findings of the study concur with this statement, as most participants responded in horror about what they have witnessed. It appeared as if they dealt with the trauma by suppressing the memories. Cultural boundaries, for example that it is inappropriate for Zulus to display photos of the dead or talk about the dead, stall the natural grieving process. This leaves the orphaned children with unresolved grief.

Some participants in the study also suffer from "bereavement overload" as they have experienced too many deaths in their short lives.

### **6.6.4 CONCLUSIONS**

The above research findings provided the following answers to the research question, namely: "What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande Region of Mpumalanga?"

The participants experienced the following:

- A lack of emotional and physical support from their extended families.

- Paternal families of unmarried parents are often not involved in the care of orphans.
- Poverty often is a result of being orphaned by HIV/AIDS related circumstances, led to food stinting, poor clothing and shelter as well as acts of desperation like theft.
- The community and church are not perceived as supportive by adolescent orphans.
- Schools are seen as a source of support by most orphaned adolescents.
- Sadness and fear are the two most common emotions experienced by the orphaned adolescent.
- Home Based Care groups are seen as the most constant source of assistance.
- The adolescent in a Child Headed Household has no legal protection against family members who want some of the deceased parents' possessions.
- Orphaned adolescents have insufficient opportunity to mourn their parents because of cultural norms.
- Traumatic memories are suppressed.
- Orphaned adolescents living with grandparents have a significant risk of being displaced for a second time, if grandparents become ill or pass away.
- Caregivers are not always capable or suitable to care for orphans.
- Awareness and prevention campaigns do not take cultural beliefs and practices into consideration.

#### 6.5. **RECOMMENDATIONS**

Based on these conclusions, the following are proposed to Government and other Social Work Service Providers:

### 6.5.1. RECOMMENDATIONS FOR THE IMPROVEMENT OF SERVICES ON A MICRO-LEVEL

- **Improved Foster Parent Screening**

The researcher is of the opinion that some family members are not suitable as foster parents and that it is not always in the interest of children to be placed with an extended family member. Four participants (NVA, ZA, NOMK and BD) reported serious forms of abuse within their extended families.

- **Improved Awareness and Prevention campaigns**

Assistance of traditional leaders should be considered when prevention campaigns are planned. The distribution of condoms alone cannot create understanding and behaviour changes.

- **Establishment of Support Groups**

The adolescent experience their siblings and friends as most reliable sources of support and support groups can therefore assist them to feel less isolated. Group assistance will enhance resilience.

- **Life Skills Camps and Programmes**

Young persons in Child Headed Households need training in some of the basic life skills, like cooking, personal hygiene and household chores. Camps held in school holidays can also address issues like self-awareness, emotional development and grief.

- **After-school centres as respite care**

Most of the participants indicated that they have very little assistance when it comes to homework and studying. They have to look after younger siblings, cook for them and wait until they go to bed before they can study themselves. The provision of after-school centres, where younger children can eat, play and be assisted with homework, will provide more free time to the adolescent who has care giving responsibilities.

## 6.5.2. RECOMMENDATIONS FOR IMPROVEMENT OF SERVICES ON A MACRO-LEVEL

- **Strengthening of Home Based Care organizations**

Home Based Care Organizations are perceived in a positive light by adolescent orphans and therefore these organizations can be strengthened by Government and Civil Society into fully fledged Social Welfare Organizations that can provide the following services:

- ◆ Support groups
- ◆ Bereavement counselling
- ◆ Consistent food security and economic support
- ◆ Nursing of ill family members
- ◆ After school care
- ◆ Provision of fun activities
- ◆ Education of foster parents
- ◆ Foster care supervision
- ◆ Marketable skills training.

- **Increased Children's Home capacity as last resort caregiver**

Several orphaned adolescents will eventually need institutional care, even though care within the community would be the preferred option. Mpumalanga Government should consider the increasing of this capacity in order to provide for the escalating number of children orphaned by HIV/AIDS. This can prevent some children from living in child-headed households or falling prey to unscrupulous community members who take in children in order to obtain the Foster Care Grant.

- **Assisted Living for child-headed households**

Child-headed households appear to be a phenomenon that is here to stay. Some models of assisted living, like the Isibindi Model does exist,

but on a small scale. It is recommended that Government should make provision for specific funding for this kind of project, including the employment of community childcare workers or auxiliary social workers.

### **6.5.3. RECOMMENDATIONS FOR IMPROVEMENT OF SERVICES ON A MESO-LEVEL**

- **Legislative changes**

It is recommended that legislation be provided to protect the property of children orphaned by HIV/AIDS, as the appointment of a guardian from the family often leads to the assets of the children being distributed amongst family members. Changes to the Social Assistance Act to enable orphaned children to access financial assistance without the Foster Care process would also increase the quality of life of thousands of South African children.

- **Provision of affordable Anti-Retroviral Medication**

The improvement of the life expectancy and quality of life of HIV positive parents is the most logical manner in which to assist their children. It is recommended that suitable, affordable medication be made available as far as possible in order to increase life expectancy.

- **National Youth Service**

The National Youth Service may be a possible manner in which the unemployed late adolescent can be utilised in some community development, whilst earning a stipend. This will increase their own standard of and motivation for living, as unemployment was identified as a source of serious stress for the late adolescent. This will also increase the employability of these young adults, as they will be exposed to the working world.

- **Future research**

The following questions are suggested for future research:

- How is the self-image of the child orphaned by HIV/AIDS related conditions affected?
- What support programmes for the foster parent of a child orphaned by HIV/AIDS can be developed?
- What are the experiences of the biological children of the foster parent who is caring for an HIV/AIDS orphan?
- What are the experiences of young adults who were brought up in a child-headed household?

#### 6.6. **SUMMARY**

This Chapter provided an overview of the research report. A summary was provided of the research methodology and its effectiveness. The qualitative process was employed successfully to answer the research question, "What are the experiences of adolescents orphaned by HIV/AIDS related conditions in the Gert Sibande District of Mpumalanga?"

The experiences of the orphaned adolescents showed that an intensified effort is needed from social welfare service providers, in order to address their needs for counselling, food security and permanent care. It became clear from their experiences that the placement of orphaned children with extended family members are not always the best option and that different options should be made available.

Recommendations were made in this Chapter in order to address some of the needs of the orphaned child in South Africa. On a Micro-level, this includes improved foster parent screening, life skills camps, improved awareness campaigns and the establishment of support groups.

On Macro-level, the researcher is of the opinion that the strengthening of Home Based Care Groups should be seen as a source of diversified service rendering, combined with After School Care and increased Children's Home capacity to provide a whole range of suitable services to affected children.



On a Meso-Level, the researcher suggested legislation changes in order to improve access to Social Assistance, as well as increased access to suitable medication in order to improve the life expectancy of the affected parent.

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## ANNEXURE A: CONSENT FORM

## CONSENT FORM

I, .....(participant), declare herewith that...

<p>I will participate out of my own free will in the interview that had been explained to me and that I will cooperate by sharing my experiences and be honest at all times. I know that I will not be disadvantaged in any way if I choose not to participate.</p>	<p>VOLUNTARY PARTICIPATION</p> <p>You are not forced to participate!</p>
<p>I understand that the interview is part of a research project and that my information will be published anonymously for research purposes, but that it may also be recorded by way of an assessment report in my file at my social worker's office.</p>	<p>PUBLICATION OF RESULTS</p> <p>The results of the research will be used, but without using your name and embarrassing you!</p>
<p>If I know that if I do not want specific information to be recorded in my personal file, I will tell the researcher and I expect her to keep that information private.</p> <p>I agree to the presence of an interpreter to assist the researcher and me to understand each other better, if I struggle to express myself in English.</p> <p>I know that information will be treated as confidential and issues that are recorded shall only be used by the social worker to assist me further. The Department of Health and Social Services may also use the information anonymously in order for them to be able to improve their work.</p>	<p>CONFIDENTIALITY</p> <p>Your name will never be used, except in the report that will be given to your social worker.</p> <p>An interpreter will help you if you struggle with English. The interpreter will also keep</p>

	your information private.
I agree to an interview session of no longer than 4 (four) hours. I will be available for follow up interviews if necessary.	PERIOD OF PARTICIPATION How much time will it take?
I understand that I will not receive any form of payment, gift or other forms of compensation for my participation in the interview. I am also aware that I will not be penalized in any way if I choose to withdraw my participation. The researcher is responsible for my transport, if necessary.	COMPENSATION, GIFTS OR PAYMENT  Unfortunately, participation will not mean that you will be paid.
I am aware that topics discussed will be about how the death of my parent/s affected my life. It may upset me. I am free to tell the researcher at any time that I am unable to continue, or that I need a break.	IMPACT OF THE INTERVIEW The interview may upset you a bit,.
I am aware that the researcher has the responsibility to arrange follow-up counseling for me at no cost to me, if it is required.	FOLLOW-UP COUNSELING If you are feeling upset after the interview, follow-up counselling will be arranged for you.

Signed at ..... on this ..... day of 2005.
Signature : participant
Signature : guardian
Particulars of the guardian
Surname: _____

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Contact telephone number: \_\_\_\_\_

**APPENDIX B: SEMI-STRUCTURED INTERVIEW SCHEDULE****The experiences of adolescents living as orphans because of HIV/AIDS related conditions****THEME 1: BELONGING**

A	RELATIONSHIPS, IDENTITY AND WELL-BEING
1.	Tell me about your family. Can we draw a family tree?
2	Who was part of your family when you were born? How did it change since you were born?
3	Who cared for you when you were a baby?
4	Who looks after you now?

5	Who cares about you the most in your family?
6	Who encourages you?
7.	Who helps you at home when you are sick?
8.	Who listens to you when you are angry or sad?
9	What does this person say when you are angry or sad?
10	Who lives in the same house than you do?
11	Tell me about the house you are living in now? Is it safe?
12	Tell me about the space where you sleep.
13	Tell me about the space where you keep your own things and do your homework.
14	Is there someone at home who is troubling you or who makes you feel uncomfortable?
15	Is there someone at home who hurts your feelings sometimes? Can you tell me about it?

16	Do you have electricity at home?
17	Where do you bath and use the toilet?
18	Is there someone at home who can protect you against intruders?
19	Who is the person at home who takes the decisions?
20	Who cooks breakfast?
21	Who cooks supper?
22	Who shops for food?
23	Who baths younger children who need assistance?
24	Who fetches water or coal?
25	Do you think you have to work harder than the other children in the family? Why do you think so?
26	Who is responsible to find money for food?
27	Who washes clothes and irons them?
28	Who ensures that homework is done?



29	Tell me about the things you do together as a family to have some fun.
30	Do you feel respected at home?
31	Did you have to look after your mother/father when they were ill? Tell me about it. What do you remember?
32	Does your father's family recognize you? If not, why?
33	<i>In cases where the whereabouts of the father is unknown.</i> If your father could be here today, what would you have liked to say to him?
34	Do you have a photo and other valuables of your father and mother?
35	Tell me about the manner in which your family supported you in the following situations.
	Before your mother became ill

	During your mother's illness	
	The day when your mother died	
	During the arrangements for the funeral	
	The unveiling of the tombstone	
	Rituals at the ancestral graves, if your family believes in them	
	3 months after the funeral	
	6 months after the funeral	
	12 months after the funeral	
	When you needed food	
	When you needed school clothes and school fees	
<b>B</b>	<b>FRIENDS AND PEERS</b>	
1	Tell me about your friends.	
2	Who is your best friend?	

3	What do you do when you are together?
4	Do you have a friend who you can trust with your secrets?
5	Does someone in your class or neighbourhood gossip about you?
6	Do you have time to spend with your friends?
7	Did your friends change towards you when your parent became ill and died?
8	Who teases or bullies you?
<b>C</b>	<b>RELIGION, CULTURE AND ETHNICITY</b>
1	Tell me about your church.
2	Do you know your pastor or priest?
3	How does the church support you?
4	What do you participate in at church?
5	Does God play a role in your life?
6	Do you stay with a family that belongs to the same culture and

	church as you are?
<b>D</b>	<b>LANGUAGE</b>
1	What language do you use most often?
2	Did you have to change to a new language at some point?
3	How did it affect you when you had to change to a new language?
4	Do you still have the opportunity to speak your own language?
<b>E</b>	<b>HEALTH AND WELL-BEING</b>
1	What is your favourite food?
2	How often do you get the opportunity to eat your favourite food?
3	What food do you eat most often?
4	How many times per week do you have less than enough food to eat?
5	Where do you get food from?
6	Who cooks for you?
7	Do you sleep well? Do you sometimes have dreams that upset you?
8	Where do you get medicine if you are ill?
9	How well are you treated at the hospital or clinic?

10	Do you have problems with your  a) Eyes b) Ears c) Feet d) Teeth e) Stomach f) Lungs g) Menstruation
11	Do you use alcohol to make you feel better?
12	Do you use cigarettes to make you feel better?
13	Do you use dagga to make you feel better?
14	Has someone told you about the changes that will take place in your body when you grow up?
15	Has someone told you about contraceptives and how to prevent HIV/AIDS
16	Do you have enough school clothes? Who provides them for you?
17	Do you have enough casual clothes? Who provides them for you?

	<b>THEME 2: MASTERY</b>
<b>A</b>	<b>GENERAL COMPETENCY</b>
1	What does your family see as your special talent?
2	What do you see as your special talent?
3	Is there something you want to be good at?
4	What do you want to become when you are a grown-up?
5	Do other people see your special talents?
6	Who encourages you when you want to give up?
7	What are your special interests and hobbies?
8	Do you need special assistance with some school subjects, like reading or mathematics?
9	Tell me about times when you had to do grown-up things and had to cope on your own.

10	How do you cope when everything goes wrong and you do not know what to do anymore/
<b>B</b>	<b>SOCIAL, EMOTIONAL AND LIFE SKILLS</b>
1	Have you ever been in trouble with the law? Tell me about it.
2	Is there a difference in the manner you speak when you talk to your friends, grandmother and your little brother or sister?
3	Who taught you these differences?
4	What do you do when someone wants you to do something and you do not feel comfortable with it?
5	Can you do shopping?
6	Can you count money?
7	Tell me about the last time someone made you angry. What did you do and say?
8	Did this reaction of yours improved the situation and made you feel better?
9	You do not understand what the teacher in class wants you to do. How do you handle this situation?

10	Do you give other people compliments? How do they react on it?
11	Do you know how to use a phone?
12	Do you know how to: <ul style="list-style-type: none"> <li>• cook a meal</li> <li>• wash the dishes</li> <li>• mend clothes</li> <li>• iron clothes</li> <li>• basic first aid</li> </ul>
<b>C</b>	<b>EDUCATION AND EMPLOYMENT</b>
1	What Grade are you in now? What was the last Grade you attended if you already left school?
2	Do you go to school every day? What are the reasons for you sometimes missing school? How often do you miss school?
3	How far do you have to walk to go to school?
5	Does God play a role in your life?
6	Do you stay with a family that belongs to the same culture and church as you are?
<b>D</b>	<b>LANGUAGE</b>
1	What language do you use most often?



2	Did you have to change to a new language at some point?
3	How did it affect you when you had to change to a new language?
4	Do you still have the opportunity to speak your own language?
E	<b>HEALTH AND WELL-BEING</b>
1	What is your favourite food?
2	How often do you get the opportunity to eat your favourite food?
3	What food do you eat most often?
4	How many times per week do you have less than enough food to eat?
5	Where do you get food from?
6	Who cooks for you?
7	Do you sleep well? Do you sometimes have dreams that upset you?
8	Where do you get medicine if you are ill?
9	How well are you treated at the hospital or clinic?
10	Do you have problems with your <ul style="list-style-type: none"> <li>h) Eyes</li> <li>i) Ears</li> <li>j) Feet</li> <li>k) Teeth</li> <li>l) Stomach</li> <li>m) Lungs</li> <li>n) Menstruation</li> </ul>

11	Do you use alcohol to make you feel better?
12	Do you use cigarettes to make you feel better?
13	Do you use dagga to make you feel better?
14	Has someone told you about the changes that will take place in your body when you grow up?
15	Has someone told you about contraceptives and how to prevent HIV/AIDS
16	Do you have enough school clothes? Who provides them for you?
17	Do you have enough casual clothes? Who provides them for you?
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<b>A</b>	<b>GENERAL COMPETENCY</b>
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2	What do you see as your special talent?

3	Is there something you want to be good at?
4	What do you want to become when you are a grown-up?
5	Do other people see your special talents?
6	Who encourages you when you want to give up?
7	What are your special interests and hobbies?
8	Do you need special assistance with some school subjects, like reading or mathematics?
9	Tell me about times when you had to do grown-up things and had to cope on your own.
10	How do you cope when everything goes wrong and you do not know what to do anymore/
<b>B</b>	<b>SOCIAL, EMOTIONAL AND LIFE SKILLS</b>
1	Have you ever been in trouble with the law? Tell me about it.

2	Is there a difference in the manner you speak when you talk to your friends, grandmother and your little brother or sister?
3	Who taught you these differences?
4	What do you do when someone wants you to do something and you do not feel comfortable with it?
5	Can you do shopping?
6	Can you count money?
7	Tell me about the last time someone made you angry. What did you do and say?
8	Did this reaction of yours improved the situation and made you feel better?
9	You do not understand what the teacher in class wants you to do. How do you handle this situation?
10	Do you give other people compliments? How do they react on it?
11	Do you know how to use a phone?

12	Do you know how to: <ul style="list-style-type: none"> <li>• cook a meal</li> <li>• wash the dishes</li> <li>• mend clothes</li> <li>• iron clothes</li> <li>• basic first aid</li> </ul>
<b>C</b>	<b>EDUCATION AND EMPLOYMENT</b>
1	What Grade are you in now? What was the last Grade you attended if you already left school?
2	Do you go to school every day? What are the reasons for you sometimes missing school? How often do you miss school?
3	How far do you have to walk to go to school?
4	What is your relationship with your teachers?
5	How do you feel when you are at school?
6	What career would you like to follow?
7	What is the main challenge standing between you and your dreams?
	<b>MAIN THEME 3: INDEPENDENCE</b>
<b>A</b>	<b>INNER CONTROL AND DISCIPLINE</b>
1	When was the last time you were really angry?
2	How did you react?
3	Did this action make you feel better? Did it solve the situation?

4	How do you react when you do not get your way?
5	How do you get other people to do things you want them to do?
6	How long can you concentrate in class or when you study at home?
7	Do you feel restless sometimes? How do you react then?
8	Do you give up easily when you struggle?
9	Do you ask other people for advice? Do you take their advice?
10	Tell me about problems you sometimes face. How do you solve them?
11	Have you experienced happiness lately? How did you show happiness?
12	How do you react when someone tells you how to behave?
13	Do you have an ID or birth certificate?

14	When was the last time you were really in trouble? What happened? How was the situation resolved?
<b>THEME 4: GENEROSITY</b>	
A	<b>CARING AND SHARING</b>
1	How do you handle it if someone you care for is crying?
2	Do you sometimes give away or share things. Tell me about this.
3	Do your family members allow you to express emotions freely?
4	Do your friends come to you for advice or comfort? Why?
5	How does helping other people make you feel?
6	Do you like animals? Do you have a pet?
7	Do you feel needed?
8	Who makes you feel needed?

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## APPENDIX C: APPLICATION OF THE DEVELOPMENTAL ASSESSMENT APPROACH

1

### THE APPLICATION OF THE DEVELOPMENTAL APPROACH WITH RESPECT TO ASSESSMENT AND PROGRAMMES FOR CHILDREN AND YOUTH

By André Viviers  
2001

#### Introduction

The developmental approach is contextualised within the post-modernistic era of human sciences, that places reflects human sciences as a non-exact sciences influence by nature of human development as well as the environment. It captures the notion that the human scientist operates within an arena that is characterised by unpredictability and constant change due to the complexity of the aforementioned factors. It is a deliberate move away from the medical approach that was applied by human scientists in the late 1800's until the mid 1900's, which attempted to explain human behaviour and development as an exact science.

#### Development

In understanding the developmental approach, one needs to understand the theories of development. Though within the scope of this assignment, it cannot be discussed in full, it need to be understood that most personality psychologists and behaviour scientist such as Freud, Adler, Erikson, Murray, Bandura, Maslow, Allport, etc (Hjelle and Ziegler: 1985) developed theories on human development and how it impact on the human nature. A developmental theory focuses on change over time and describes changes in behaviour with one or more areas of behaviour; in the relationships among several areas of behaviour and explains the course of development. The theories of development represent frameworks for the understanding of what is normal or average for a person in a particular stage of life. Development can, within these contexts can be defined as change over time (ACY101CE). Development can be understood (ACY101CE) as being:

Progressive – the change and growth in the person from conception until death throughout life

Sequential – development occurs in a specific order i.e. different kinds of behaviour characterise different stages of development.

Affected by the environment – the external events and other experiences that impact on growth and change in the individual.

The latter is most significant that perpetuate the element of risk that impacts on the psychological, emotional, physical, social and cognitive development of the individual. In understanding children and working with children, including assessment as well as programmes, the child and youth care worker needs to understand the theory of child development that is based on progressive and sequential development capturing the different stages of development through childhood with the context of the ecological perspective. According to the Interim Policy Recommendations on the Transformation of the Child and Youth Care System (1996) the **Ecological perspective** refers to “the practice of understanding and viewing each person within the context of, and connected to, their family and community”. Hence, child development should not be merely be seen as a chronology of development events, but need to be understood and interpreted within the context of the individual

2

**Working towards an approach.**

In understanding the developmental approach, one needs to capture that it refers, as an approach, to the application of different theories and models within the human science field. The following schematic outline with the subsequent explanatory notes attempts to capture this.

Psychoanalytic  
Theory  
Existentialism  
Psychosocial  
Theory  
Need Theory  
Behaviouristic  
Theory  
Humanistic  
Theory  
Cognitive  
Theory  
Social  
Learning  
Theory  
Phenomenolog  
ical Theory

## **Approach**

### **Medical**

### **Model**

### **Development**

### **al Model**

Assessment  
Programmes  
Therapy/Counseling

A number of theories have been developed within the human and social science over the past century and a half, which to a large extent form the basis of the social sciences. These theories capture different perceptions on humanity and social sciences.

3

The developmental approach, to a large extent is captured in the application of the theories within practice. This choice usually rests with the practitioner and his or her worldview. Hence, an approach to be followed is the choice that is made and this approach has a fundamental impact on the practice of the professional. It captures the application of knowledge and skills and directly influences the attitude of the practitioners. In following and applying the developmental approach, it is guided by fundamental principles and requires a worldview and level of personal commitment towards the approach.

The latter perhaps indicates the complexity of the developmental approach as it is based on the individual's belief system and perceptions, whereas the medical model is largely clinical and impersonal. It impacts on how assessment is conducted, how programmes are designed and implemented and the methodology followed in therapy and counselling.

Within the developmental approach and the key principles underlying it (see assignment 1) there are key aspects that are present namely, the importance of development in the moment i.e. the needs of the person in the immediate, both in assessment and programmes and the role of influencing.

Influencing is fundamental in the developmental approach and can be regarded as it deals with the child and youth care worker understanding that development cannot be forced, but that it can be influenced through what we model (thus the requirement to internalise the developmental approach), the resources that we avail to child, youth or family and how the environment are changed that is most conducive for their growth and development.

In applying influencing with assessment and programmes, we need to always consider the context where in the child and the family exists or function. We need for example understand aspects such as poverty, different lifestyles, social values with cultures, diversity, perceptions of childhood (both that of the children, their families and communities), etc. No child or family operates in isolation from his or her ecology and they are in constant interaction with their ecology. This has a profound impact when we assess children and with the subsequent

development of programmes, as it need to be done within a context that is identifiable for the child and the family.

### **Labels**

The principles that form the foundation of the developmental approach clearly state the labelling is not helpful with this approach. Labelling is inherent to the medical model and contradicts the outcomes that are envisaged with the application of the developmental approach. Labelling creates a system of categorising people and their behaviour, and it is usually the purpose of an assessment done from a medical perspective to find a category for the person to "fit" so that a subsequent programme can recommended and followed, for example, if a child is assessed or diagnosed as having a conduct disorder, there is usually a certain approach towards the therapy or programme that needs to be followed, with often recommendations towards this in the DSM IV classification system for disorders. It then focuses on the problem and making the child and/or family "problem free". It is usually the task of the expert, being the practitioner, to identify the problem and lead the child through the programme. This in essence goes against the nature of human development and problem free are often interpreted as perfect, which is impossible within the context of development. The latter is characterised by a range of normative challenges that can be often interpreted as "problems" from the medical perspective.

As stated, the developmental approach, does not work on the concept of labels or categorising people, which creates an environment within the approach to be nonjudgemental and open. It focuses within the assessment on the strengths and potential as well as the developmental needs of the child as a whole within his ecological context.. A proper assessment within the developmental approach should always result in a programme

4

that reflects the unique needs of the child and should be implemented taking into account the strengths and potential of the child enabling the child to experience himself or herself differently. It also goes from the premise that the child is a partner in both the assessment and the programme.

### **Therapy**

Therapy is a component within the programmatic design of the developmental approach that is aimed at influencing the child and the family through counselling, guidance, resources, modelling, etc. towards growth and well being. Therapy, within the developmental approach, refers to the application of knowledge and skill within the principles of the developmental approach. The developmental assessment process can also be the start of therapeutic work with the child and the family and should not be seen as isolated from the programme. The manner in which we assess can contribute in itself to the growth and development of the child and the family.

As have been mentioned, therapy may form part of the programme for the individual child, which results from the developmental assessment.

### **Specialisation**

Specialisation within the developmental approach refers to the knowledge and skills require to address the NEEDS of a certain target group in an holistic manner. For example, a child and youth care worker works in a specialised field focussing on the needs of children in a holistic manner within the context of their family and community life. Hence, there is certain amount of knowledge and skill that are required to, for example assess children and engage in programmes with children.

It also further requires that the different resources that are available need to be acknowledged and utilised, particularly towards professions that has certain specialised knowledge for example occupational therapist, psychologists, social workers, medical practitioners, etc. In engaging other professions in working with a child, a high level of teamwork is required (which is fundamental to the developmental approach).

### **Closure**

The developmental approach is a highly complex approach in child and youth care and requires personal commitment and a deep understanding of the nature of human development. The approach is also fundamentally supported within international human rights treaties such as the United Nations Convention on the Rights of the Child and the OAU Charter on the Rights and Welfare of the African Child as well as the South African Constitution. In working developmental, from assessment to programmes, the basic premise of departure are the rights of the person (young person/child) that you work with and the

developmental approach captures the essence of people/children as rights holders.

**REFERENCE:**

South Africa. Inter-Ministerial Committee on Young People at Risk: 1996. Interim Policy Recommendations on the Transformation of the Child and Youth Care System. Pretoria: Department of Welfare

Technikon SA. 1999. Applied Development for Child and Youth Care/ Youth Work I: Study Guide for ACY101CE. Florida

## **ANNEXURE D: DEPARTMENTAL CONSENT**