

**AN EXPLORATIVE STUDY OF THE EXPERIENCE OF  
ADOLESCENTS WHO HAVE LOST THEIR PARENTS THROUGH  
HIV/AIDS**

**NOMSA WINNIEFRED SOMTSEWU**

**(9625074)**

**The degree MA in Child and Family Studies in the faculty of  
Community Health and Sciences, Department of Social Work.**

**University of Western Cape**

**Supervisor: Dr. N. Roman**

**Date: 2010**

## **ABSTRACT**

AIDS related deaths of parents have resulted in children being orphaned, in large numbers. Adolescence is a particularly vulnerable period in a child's developmental life. It is a period characterised by uncertainties, role confusion and identity crises. This stage becomes even more complex when adolescents lose their parents through AIDS. This thesis is an explorative study to understand the experience of adolescent who have lost their parents through HIV/AIDS. This study was theoretically located within a phenomenological framework. The participants were recruited from the foster care project of Ikamva Labantu in Gugulethu. The participants were adolescents aged from 14 - 17 years old. They were purposively selected to participate in this study. The study was conducted within a qualitative research design, and underpinned by an interpretative framework. Data was collected by means of in-depth interviews with the aid of an interview guide, and observations. This study identified seven themes. Three themes share the experience prior to parental death and the four express the experience after parental death. The research findings led to the conclusion that adolescents struggle with a myriad challenges such as discrimination, stigmatisation, caring for siblings and having to deal with the death of parents often without the necessary support. The conclusions drawn and the recommendations made will contribute to knowledge that will support social workers and other professionals working with AIDS orphaned adolescents, in understanding their experiences.

## CANDIDATE DECLARATION

I hereby declare that the thesis entitled, *an explorative study of the experience of the adolescents who have lost their parents through HIV/AIDS*, is a result of my own research. I declare that all sources have been acknowledged and that this work has not been submitted for any other degree at any other university.



Name: Nomsa Winniefred Somtsewu

Signed:

Date:

## ACKNOWLEDGEMENTS

This work is dedicated to the memory of my late parents especially my mother who left me when I started my journey of post graduate studies. To those colleagues who found the journey too long and fell along the road

I am sincerely grateful to the following people for their different contributions towards the completion of this dissertation.

- The HIV/AIDS orphans who contributed towards the development of this document, their approval in allowing me to listen to their life experiences is appreciated.
- Professor Rose September who took me through the first journey of writing this work.
- Dr. Sam Muyanga and his team who gave me the courage to persevere when I wanted to give up.
- Most importantly my supervisor Dr. Nicolette Roman, a woman of steel who has the courage to motivate people whose self esteem was broken down by the system. Her guidance and support allowed me to think out of the box and better understand the experiences of the adolescents who have lost their parents through HIV/AIDS.
- My colleagues and friends for their motivation and support when I had lost hope. Florence Nkgudi you have been my pillar of strength.
- The Erica Theron Fund and VLIR for their financial contribution towards my research.
- My family, especially my husband and children for their continuous support and encouragement.
- To God almighty who has given me the strength and the courage to persevere, I give You all the glory.

## TABLE OF CONTENTS

Abstract	i
Acknowledgement	ii
Declarations	iii
Table of Content	iv
Chapter One: Context	
1.1. Introduction	1
1.2 Theoretical Framework	4
1.3 Problem Statement	5
1.4 Research questions	6
1.5 Research aim and objectives	6
1.6. Methodology	6
1.7 Clarification of concepts	7
1.8 Significance of study	8
1.9 Outline of the thesis	9
Chapter Two: Conceptual Framework	10
2.1 Introduction	10
2.2 A phenomenological understanding	10
2.3 Understanding HIV/AIDS	15
2.4 The effects of HIV/AIDS on the family	19
2.5 Understanding adolescence	25



2.6 Adolescents as AIDS Orphans	36
2.7 Adolescents and bereavement	42
2.8 Effects of HIV/AIDS on culture	50
2.9 The coping strategies of HIV/AIDS orphans	52
2.10 Relevant support systems for HIV/AIDS orphans	53
2.11 Conclusion	54
Chapter Three: Methodology	56
3.1 Introduction	56
3.2 Research design	56
3.3 Study site	58
3.4 Access to the study site	59
3.5 Participants	61
3.6 Instruments	62
3.7 Data collection	64
3.8 Data analysis	65
3.9 Ethical considerations	68
3.10 Trustworthiness	70
3.11 Reflexivity	72
3.12 Conclusion	73
Chapter Four: Findings and discussion	74
4.1 Introduction	74



4.2 Biographical profile of research participants	74
4.3 Discussion of Themes and Sub-themes	78
4.4 Conclusion	132
Chapter Five: Conclusion and recommendations	133
5.1 Introduction	133
5.2 Central issues	133
5.3 Experience of caregivers after parental loss	134
5.4 Challenges	134
5.5 Coping strategies	135
5.6 Recommendations	135
5.7 Limitations of the study	137
5.8 Summary	137
5.9 Conclusion	138
References	139
Appendixes	161



# CHAPTER ONE

## CONTEXT

### 1.1 Introduction

Acquired Immune Deficiency Syndrome (AIDS) is responsible for leaving vast numbers of children across Africa without one or both parents. A larger portion of orphans have lost their parents to AIDS than any other cause of death (UNAIDS, 2002; Dorrington, Bradshaw & Budlender, 2002). Smart (2003) highlights, that orphaning caused by HIV/AIDS is an increasing and chronic problem affecting developing countries throughout the world. Adolescents, who have lost their parents to HIV/AIDS, are challenged in many aspects. A child whose mother or father has AIDS begins to experience grief before the death of the parent (Department of Social Development report, 2003).

Steffenson, (2004) and Smart (2000) note that one of the realities of the AIDS pandemic is that many children find themselves thrust in the role of a parent(s) assuming adult responsibilities. They find themselves doing household chores, looking after siblings caring for the ill and dying parents resulting in stress that would exhaust them. For example, children often leave school earlier, enter the labour force market earlier and are frequently exploited. In some instances when parents die, children are often left in the care of grandparents or other family members. The death of adults not only denies children their parents or guardian or somebody they love and cared for, but inevitably also deny them a primary or sole breadwinner (Marcus, 1999).

AIDS has emerged as one of the largest threats to humanity worldwide. Van Dyk (2001, 2008) reported that HIV/AIDS was first discovered during 1979 /80, when doctors in the United States observed clusters of diseases that had been extremely rare. In South Africa, the first two cases were reported in 1982 (Van Dyk, 2001). Whiteside and Sunter (2000) and Walker, Reid and Cornel (2004) suggest that few could have imagined the loss of life and the suffering South Africa faces today. Van Dyk (2008) and Walker *et al.*, (2004) noted that this epidemic first had its greatest impact among minority groups, intravenous drug users, prostitutes and gay men. Van Dyk (2008) and Walker *et al.*, (2004) pointed out that warning lights started to flash in the mid 1980's when several migrant workers tested positive. By 1988 it was clear that the HIV/AIDS epidemic in the Southern African region was mainly heterosexually transmitted (Walker *et al.*, 2004). Van Dyk (2001) reported that by the end of 1991, this disease had infected 1095 people in South Africa.

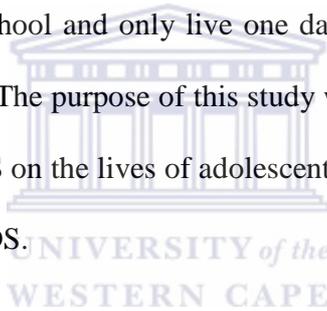
UNICEF (2003) reported that 13 million children were orphaned because of HV/AIDS globally and predicted that up to 25 million children will be orphaned by 2010. South Africa is known to have the highest number of people living with the HIV worldwide (UNAIDS 2000; Dorrington, Bradshaw & Budlender, 2002). According to statistics released by the National Department of Health, 4.7 million people in South Africa alone were estimated to be HIV-positive in 2001. This meant that one out of nine South Africans were infected with HIV (Department of Health, 2006). The current statistics indicated that approximately 5.7 million people in South Africa are living with the HI Virus, 1800 are infected daily and almost 1000 HIV/AIDS related death are occurring daily (De Jong, 2003). Van Dyk (2008) and Shisana *et al.*, (2005), however state that

results from a household survey the number of HIV positive persons has decreased to 4.8 million in South Africa.

Shisana and Simbayi (2002) indicated that the prevalence of HIV/AIDS among the different racial groups in South Africa varied from 18.4% among blacks to 6.6% among coloureds and the lowest was 6.2% among whites. Frederickson and Kanabus (2008) state that South Africa had a total of 1 200 000 AIDS orphans during 2005. This number has grown to 1 400 000 by 2007 (Pennington, Kanabus & Pembrey, 2009). Bradshaw and Dorrington (2005) highlighted that in 2004, 13 % of the total population of the Western Province was HIV positive. A City of Cape Town report (2002) noted that the bulk of the AIDS burden was among the Xhosa speaking areas of the City of Cape Town. Similarly, Bradshaw *et al.*, (2005) found that Gugulethu had a total of 28.1% HIV positive people followed by Khayelitsha with 27%. This report further states that the City of Cape Town alone had a total of 34 299 AIDS related deaths. The City of Cape Town (2002) highlighted that from a total of 48,683 orphans, 9,958 were AIDS orphans. The Western Cape Province and the City Council's Integrated Developmental Plan (2004) reported that this number grew so high that in 2003 alone there were 21 000 AIDS orphans in the Cape Town area.

Van Dyk (2008), Aspaas, (1999) and SAHARA (2004) state that most orphans are cared for by their grandparents, extended family and even communities, many who are unable to carry the burden of so many orphaned children. Shisana *et al.*, (2002), and SAHARA, (2004) reported that there are clear indications that the integrity, cohesion and efficiency of the extended family as a social support network are being distorted by a number of factors such as social upheavals, rapid urbanization, and poverty and overstretched

resources. Sloth-Nielsen (2004) highlights that adolescents are often called upon to become functional heads of households, whilst being mere children themselves. Giese, Meintjies, Croke and Chamberlain (2003) reported that others have to rely on already poverty stricken extended family members for support and nurturing. Some adolescents are nursing terminally ill parents or siblings (Sloth-Nielsen; 2004). Simbayi *et al.*, (2002) and Sloth-Nielsen (2004) concur that adolescents in this situation often have to cope with the deprivation of childhood as they have to cope with the need to be a child and the vital need to assume adult responsibilities as household providers. Adolescents may become angry, depressed, and desperate to be loved and seek attention (Sloth-Nielsen, 2004). Some are unable to cope in school and only live one day at a time without dreams and future plans (Van Dyk, 2008) The purpose of this study was to offer an understanding of the consequences of HIV/AIDS on the lives of adolescents, aged 14 to 16 years, who have lost their parent(s) through AIDS.



## **1.2 Theoretical framework**

This study is rooted within a phenomenological framework. Cerbone (2006) states that Heidegger believed that phenomenology is having a capacity to interpret meaning, and that meaning is within interpretation. Cerbone (2006) argued that understanding death in Heidegger's sense meant self-understanding. The study clarifies the experiences of the adolescents who have lost their parents through HIV and AIDS. Phenomenology in essence is about finding human world and all its aspects.

### **1.3 Problem Statement**

Worldwide, much of the research done so far has focused on the effects of HIV/AIDS (Deacon & Stephney, 2007). Other studies have also focused mostly on how it has affected and infected people (Van Dyk; 2008). Research has indicated that very little is known about the experiences of adolescents who lost their parents through AIDS (Louw, 2007). Social workers within the Department of Social Development and Welfare Organisations within the Western Cape have experienced a growing number of orphaned children in need of urgent statutory intervention, due to the economic burden brought about by their orphaned status (National Strategic Plan, 2007). The National Strategic Plan (2007) reveals that very little time can be spent on the socio-emotional care of these children as the emphasis is on the provision of the basic needs.

The literature that is available on the experiences of adolescents in South Africa and Africa is minimal. Most of the literature available is international and in most cases defines orphans as a collective from birth to young adulthood and does not divide them according to their different developmental stages and needs (Robertson & Donaldson, 2003). Harber (1998) reported that social welfare interventions should not only focus on survival, however also on the psychosocial, educational and moral aspects of deprivation. It was then clear that there is a gap in understanding the experiences of adolescents who have lost their parents through HIV/AIDS. The purpose of this study then was to offer an understanding of the consequences of HIV/AIDS on the lives of adolescents.

### **1.4 Research question**

The following research questions were constructed to guide the study:

- How do the adolescents experience the loss of their parents from HIV/AIDS?
- What are the challenges of losing a parent(s) to AIDS?
- What coping mechanisms do adolescents use to deal with the loss of a parent(s)?

## **1.5 Research aim and objectives**

The aim formulated for this research study is to explore the experiences of adolescents who have lost their parents through HIV and AIDS.

### **1.5.1 The study has the following objectives:**

- To understand and describe the experiences of adolescents who have lost their parents through HIV/AIDS.
- To explore the challenges of adolescents who have lost their parents through HIV/AIDS
- To understand the coping mechanisms of adolescents who have lost parents through HIV/AIDS

## **1.6 Methodology**

In order to be able to respond to the research questions the researcher had to look at a suitable method that would be able to give substance to this study. The most suitable method for this study was qualitative methodology. Denzin and Lincoln (2008) state that qualitative research is difficult to clearly define as it has no theory or paradigm that is distinctly its own. Mouton (2001) states that one of the major distinguishing

characteristics of qualitative research is the fact that the researcher attempts to understand people in terms of their own definition of their world. May (1993) states that qualitative research is best used in unexplored areas where it would be premature to define and measure patterns and variables. A detailed presentation of the methodology is presented in chapter Three. An individual semi-structured interview guide was designed to collect data. One interview was conducted with each participant. A thematic analysis was used to analyse the data.

## **1.7 Clarification of concepts**

### **Adolescence**

It is the transitional stage of physical and mental human development that occurs between childhood and adulthood. The transition involves biological, social and psychological changes. This period covers the ages between 12 and 18 years. (Colman, 2001; Papalia, Olds & Feldman, 2008)

### **AIDS orphan**

An AIDS orphan is defined as a child either HIV-negative or HIV-positive who has lost a mother, a father or both parents to AIDS. The definition of AIDS orphan in South Africa includes children up to the age of 18 years (UNICEF, 2007; Department of Social Development, 2003). The age group selected in the study ranges from 14 – 17 years of age.

### **Caregiver**

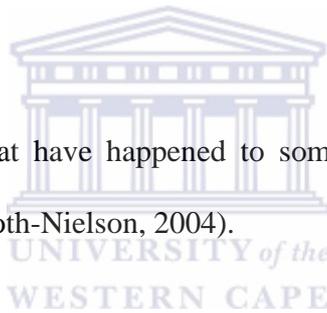
The word/ term Caregiver is normally used to refer to unpaid relatives or friends who are at times HIV positive themselves though caring for terminally ill and orphaned children (Sloth-Nielson, 2004).

### **Child headed household**

The children heading households after the death of their parents and teenagers taking an adult role to care, and financial support, in an effort to cope with the loss of their caregivers. Children maybe themselves infected and possibly caring for ill parents or other family members (Sloth-Nielson, 2004).

### **Experiences**

The experiences are things that have happened to someone and only that person has knowledge and skill over it (Sloth-Nielson, 2004).



### **1.8 Significance of the study**

The findings of this study will contribute to a better understanding of the problems that adolescents affected by HIV/AIDS face in their everyday lives. It will, for example, provide a better understanding as to how they feel about assuming adult responsibilities while they are themselves children. It will also enhance understanding of the support systems that they have. It is hoped that the study findings will guide policy and service delivery programme makers in designing policies and interventions and meet the needs of adolescents. Furthermore policies to protect the rights of adolescents who are affected by HIV/AIDS?

## 1.9 Outline of the thesis

The chapter outline for this thesis is as follows:

**Chapter one** presents the introduction and background of the study

**Chapter two** A theoretical review and conceptual framework about HIV. The psychological and psychosocial effect of HIV/AIDS on both the parents and the children is discussed, as well as highlighting the importance of allowing children to grieve. Furthermore understanding adolescents as a developmental stage is explored.

**Chapter three** details the methodology used in the study. This includes the study design, data collection and data analysis.

**Chapter four** presents the analysis of the results from the interview guide. Common themes that were extracted from the data are discussed as a means to illustrate the experience of the adolescents who have lost their parents through AIDS.

**Chapter five** presents the results and findings. It also presents the conclusions drawn from the study and presents recommendations.

## CHAPTER TWO

### CONCEPTUAL FRAMEWORK

#### 2.1 Introduction

This chapter offers a conceptualization of the theoretical underpinnings of key concepts in this study. The chapter starts with a phenomenological understanding of loss of parents and HIV/AIDS during the developmental phase of adolescence as well as the challenges this poses for the adolescent. This chapter also includes key concepts which address the focus of this study.

#### 2.2 A phenomenological understanding

Phenomenology has its origins in the thinking of a German philosopher Edmund Husserl (1859 – 1938) who is regarded as the principal founder of phenomenology, and thus one of the most influential philosophers of the twentieth century, (Spiegelberg, 1976; Spiegelberg 1989, Cerbone, 2006; Grossmann, 1984). Koch (1995) cited in Paley (1997) stated that Husserl is known to be the founder of the phenomenological movement. Edmund Husserl (Spiegelberg, 1989) viewed phenomenology as the foundational science of all the sciences, and sought to clarify through the use of critical reflection and description, the foundation and constitution of knowledge in consciousness. Husserl defined phenomenology as a discipline that attempts to describe what is given to humans in experience, without obscuring preconceptions or hypothetical speculations but rather to the things themselves. Husserl is known to have made an important contribution to

almost all areas of philosophy, and anticipated central ideas of its neighbouring disciplines such as linguistics, sociology and cognitive psychology (Spiegelberg, 1976).

Grossmann (1984) highlighted that Husserl believed that there is more to phenomenology than the reflection of essence. Husserl viewed experience as consisting of both concrete particulars and the categories of meaning to which they belonged (Hein & Austin, 2001).

Van Manen, 1990; Todres and Holloway, 2005 state that the goal of phenomenology is to fully describe lived experiences. Phenomenology emphasises that only people who have experienced phenomena can communicate them to the outside world, and answer questions as an exploration of the essence of lived experiences (Grossmann, 1984).

Jennings (1986) highlighted that essences were eminent, meaning that they were grasped in an act of reflective consciousness. Phenomenology consists of a reflection on the consciousness, which is on ordinary mental acts of perception, experience, desires and fear. Thus consciousness commanded the fundamental position as the special medium that constituted all forms of “being” in the world (Grossmann, 1984; Spiegelberg, 1989).

Ray (1994) claims that while Husserl was purely descriptive in his exploration of a phenomenon, Heidegger moved phenomenology more into the interpretative area, trying to gain more understanding of the connectedness of a phenomenon.

Spiegelberg (1989) notes that Heidegger continued Husserl’s phenomenological method of exploring consciousness and knowledge by undertaking a broader explanation of being and time. Cerbone (2006) highlighted that for Heidegger phenomenology is subservient to what he calls fundamental ontology, which is centered on the question of being. Heidegger is known to have lost the sight of the meaning of being and focused rather on human beings (Grossmann, 1984). Heidegger believed that the nature of the kind of being

which humans have is the nature of existence and these are the body and mind. Grossmann (1984) continues by saying that Heidegger argued that in order to answer the question of being we must first look at that phenomenon through which the being becomes accessible to us, namely our understanding or comprehension of being. Spiegelberg (1989) and Grossman (1984) shared that the nature of the being which human beings have is the nature of existence. This has resulted in Heidegger's work to be cited as the first union of existentialism and phenomenology.

The phenomenological viewpoint is known to be based on two premises. The first is that there is the basic unit of interest as a person rather than a mind. Secondly, phenomenology tries to discover the eternal laws which govern essence and pays no attention to whether or not these essences are instantiated. Becker (1992) states that phenomenologists assume that experience are a valid source of knowledge and that people's everyday experiences contain rich insights into phenomena. Through a phenomenological method, the essence of orphanhood, as a lived experience by the adolescents who have lost parents through HIV/AIDS, could be unfolded. Grossmann (1984) shares that the mind is always related to something, thus always coming with objects.

Cerbone (2006) states that Heidegger believed that to make the transition to authenticity, to the state or condition of being self-owned, something must occur that disrupts the patterns and routines of everyday life. Heidegger called this moment of disruption anxiety. The experience of anxiety threatens everyday concerns as it manifests about one's existence. Cerbone (2006) argued that understanding death in Heidegger's sense meant self-understanding. The current study explored the experiences of adolescents who

had lost their parents through HIV and AIDS. This then means understanding and refers to the unique human capacity to make sense of the world. Patton (2002) states that the value of empathy is emphasised in the phenomenological doctrine of Verstehen, which means understanding. Becker (1992) states that the goal of phenomenological research is to illuminate the phenomenon's structural qualities.

Nord (1997) highlights that a survivor's sense of self is forever altered by multiple AIDS-related losses. Additionally, Cerbone (2006) states that identity is challenged by an experience that disrupts interpersonal connections and sometimes alters personality. This can result into normal developmental issues and tasks being scrambled. Nord (1997) reports that AIDS provokes existential issues, including questions of being versus non-being, desires for relationships versus ultimate isolation. Furthermore, he argues that one of the most astonishing outcomes of this disease is the tendency of those most likely to be affected by HIV to assume the identifying label of HIV status, to use a variation of a verb, to be, to describe themselves. It is normal to hear one saying, "I am HIV positive" or "I am negative" and yet these labels are not applied to other diseases like cancer, high blood pressure and others. Phenomenology argues that disease is something one has, and not something one is (Munro, 2002). Nord (1997) argues that due to isolation and stigma related to HIV/AIDS it is easier to identify with the disease. Research demonstrates that from the beginning people with AIDS were divided according to their HIV/AIDS status thus resulting in relations among families and communities being affected (Poku, 2005; Walker *et al.*, 2005). Similarly, Bradshaw and Dorrington (2005) suggest that this matches with underlying shame prevalent in communities affected by AIDS, and this shame becomes a state of being taking over one's whole identity. Nord (1997) argued

that people who have lost a loved one to HIV/AIDS, instead of identifying with the loved one, has a tendency of identifying with HIV.

Van Dyk (2008) believes that grief is a narcissistic injury that Freud identified as damaging the self-esteem of the aggrieved. Similarly Nord (1997) indicates that survivors of HIV/AIDS sometimes reported significant distress about self-perceptions that their personalities have changed. One of the most striking features about surviving AIDS-related loss is the potential in survivors, for normal developmental stage progression to be confused or replayed. Erikson (1959; 1980 cited in Nord 1997) supports this statement by saying conceptualisation of the development offers a valuable framework for understanding this aspect of the survivor's experience. Erikson (1959; 1980) called basic trust the first component and cornerstone of a healthy personality. This is not only in terms of its chronological development, but also in terms of its importance for all of the remaining of the psychosocial stages of development. In cases where adolescents are in the process of trying to understand the world, one may start identifying withdrawal symptoms as they try to reflect whether the world is a safe place.

According to Erikson (1959; 1980) autonomy develops as opposed to shame and doubt, after trust is established. Erikson asserts that shame is characterised by feeling completely exposed to the consciousness of being looked at. Nord (1997) noted that bereavement overload results in the sense of being inappropriately and regularly exposed to the public. The identity formation characteristic of adolescence is often recycled in the survivor of AIDS-related loss. Nord (1997) states that fundamental issues related to one's choices about relationships, spirituality, belief systems and careers may be re-thought, and thus affecting the survivor's ego identity. The survivor has a chance to choose an identity that

may be more synchronous with the values and insights brought about by his or her survivor's experience (Nord, 1997). Dworkin and Kaufer (1995, cited in Nord, 1997) concludes that grief reactivates emotions related to the developmental experiences involved in establishing one's identity. In experiencing such loss, one's identity, self-esteem and body image are challenged. Nord (1997) shared that when a survivor loses a loved one, he or she loses a part of the self. Heidegger (1962) distinguished between two modes of existence, an inauthentic life characterised by forgetfulness of being and an authentic life characterised by mindfulness of being and self-awareness. Nord (1997) observed that this distinction is remarkably clear in survivors of AIDS-related loss in whom this attitudinal and intentional difference is at times stunning.

### **2.3 Understanding HIV& AIDS**

Acquired Immune Deficiency Syndrome (AIDS) is a disease that is not inherited but caused by a virus called Human Immunodeficiency Virus (HIV) which poses a health threat to society. According to Van Dyk (2003; 2008) the human immunodeficiency virus is characterised by a deterioration of the immune system, while AIDS is a condition in which the individual is susceptible to opportunistic infections. Most of which would have been cleared by a normal functional immune system. It has different ways of infecting people, such as bodily contact where there are open wounds; misuse of needles in health institutions; misuse of needles during the abuse of narcotic drugs; unsafe sexual practices, such as to engage in sexual activities without the use of a condom or any other form of protection; and mother-to-child transmission (MTCT), during the gestation period through mother and fetus as well as during breast-feeding. Walker *et al.*, (2004) states that the HIV epidemic also has a devastating impact on the youngest members of society, as one

third of infants born to HIV-positive mothers are infected and very few live to the age of six. Children, especially those children orphaned by HIV/AIDS, are vulnerable to HIV infection through sexual abuse in South Africa (Meintjies, Hall, Marera and Boulle, 2010).

AIDS (Acquired Immune Deficiency Syndrome) has emerged as one of the largest threats to humanity worldwide. Van Dyk (2001; 2008) reported that HIV/AIDS was first discovered during 1979/80, when doctors in the United States observed clusters of diseases that had been extremely rare. In South Africa the first two cases were reported in 1982 (Van Dyk, 2001). Few could have imagined the loss of life and the suffering South Africa faces today (Whiteside and Sunter, 2000; Walker, Reid & Cornel, 2004). Van Dyk (2008) and Walker *et al.*, (2004) note that this epidemic first had its greatest impact among minority groups, intravenous drug users, prostitutes and homosexual men. Van Dyk (2008) and Walker *et al.*, (2004) suggest that warning lights started to flash in the mid-1980's when several migrant workers tested positive. By 1988 it was clear that the HIV/AIDS epidemic in the Southern African region was mainly heterosexually transmitted (Walker *et al.*, 2004). Van Dyk (2001) reported that by the end of 1991, this disease had infected 1095 people in South Africa.

According to Smart, (2000) the AIDS pandemic has claimed more than 13 million adults and more than three and a half million children worldwide. UNAIDS (2008) reported that since the beginning of HIV positive diagnoses, more than 60 million people globally have been infected. Furthermore, by the end of 2001, an estimated 40 million people globally were living with the virus. In the year 1999 alone an estimated 5.6 million people were infected with HIV, and there were about 2.6 million deaths resulting from AIDS

(UNAIDS, 1999). UNICEF (2003) reported that 13 million children were orphaned because of HIV/AIDS globally and predicted that up to 25 million children will be orphaned by 2010.

Sub-Saharan Africa continues to bear the brunt of HIV /AIDS, with close to 70% of the global total of HIV infected people (UNAIDS, 1999). HIV/AIDS is noted to be the leading cause of death in Sub-Saharan Africa (UNAIDS, 1999). According to UNAIDS (2005), in 2003 an estimated 3 million people in the region became newly infected and of these 2.2 million had already died. Walker *et al.*, (2004) reports that a total of 25 million of the 38 million people infected globally by the end of 2003 were Africans. This number has grown to an extent that the total number of people living with AIDS within this region is currently 42 million, which is 74% of the total population of the Sub-Sahara (UNICEF, 2007). Although Sub-Sahara is known to be home to just over 10% of the world's population, it is among the most highly infected regions, with almost two thirds of the people living with HIV.

South Africa is known to have the highest number of people living with the HIV worldwide (UNAIDS, 2000; Dorrington, Bradshaw and Budlender, 2002). The responsibility is laid on the South African Government for their lack of a nationwide response to the AIDS pandemic. UNAIDS (2007) reports that a study conducted by Harvard University indicates that 365 000 deaths could have been prevented in South Africa should its government have availed antiretroviral medication. Van Dyk (2008) and Shisana *et al.*, (2005), however state the findings of a household survey they conducted showed that the number of HIV positive persons has decreased to 4.8 million in South Africa.

Ewing (2000) reports that one out of four women between the ages of 20 to 29 years is infected with HIV, direct significance for children was the fact that an estimated 3.2 million women of childbearing age, 15-49, were living with HIV/AIDS during July 2002. As of July 2002 an estimated total of 885 000 children under the age of 18 years in South Africa had lost a mother. Dorrington, Bradshaw and Budlender, (2002) predicted that this number is expected to reach over 2 million by 2010.

Van Dyk (2008) further indicates that AIDS develops after HIV has spread all over the body. Parker and Aggleton (2002) emphasise that this is the most damaging stage as it involves an illness of social, cultural and political dimensions, including stigmatisation, discrimination and denial. Perkel (1992) notes that from the time AIDS was first discovered as a distinct syndrome, it became increasingly evident that it was spreading at an alarming rate. The AIDS pandemic is described as the world's deadliest undeclared war. It is often claimed that Africa bears the brunt of this disease (UNAIDS, 2000). The rich and poor socio-economic conditions have accelerated the flourishing of HIV/AIDS, particularly in the marginalised communities (UNAIDS, 2000). Walker *et al.*, (2004) indicate that the emotional cost and economic burden resulting from this epidemic on families and communities is vast. Walker *et al.*, (2004) commented that parents and grandparents bury children, and at times, die prematurely themselves. This results in children and older people battling to keep their families together in the absence of biological parents. Foster and Williamson (2000) note that children are directly affected by HIV/AIDS when they are orphaned in addition to that many are affected indirectly when they lose a close relative, an extended family member and mostly their community. Family members often respond to the news that a close relative has HIV by imposing

severe restrictions on their contact with other members of the household (Walker *et al.*, 2004).

## **2.4 The Effects of HIV/AIDS on the family**

Deacon and Stephney (2007) state that in order to understand the impact of stigma and discrimination on children one needs to understand its impact on caregivers, whether these are biological parents or not, whether caregivers are positive or not. Households experience the immediate impact of HIV/AIDS because families are the main caregivers of for the sick and thus suffer AIDS –related financial hardships. If a person is diagnosed as HIV positive, it does not only affect that person but also poses significant problems to others, which is the family, children and friends. According to Kelly and Lawrence (1991), a person diagnosed with HIV/AIDS faces enormous challenges that can be identified as effects of HIV/AIDS. These include psychological, social and physical factors. The patient's status, attributes, familiarity with the disease and the available environmental support are identified as the psychological effects (Kelly *et al.*, 1991). Some of the psychological effects are accompanied with depression and anger.

### **2.4.1 Socio-behavioural effects of HIV/AIDS on the family**

According to Poku (2005) the socio-behavioural factors has been regarded as having a major impact on the transmittion of HIV/AIDS in Africa. Hope (2001) cited in Poku (2005) reported that 30% to 50% of married women in Africa are currently in polygamous marriages, meaning that these women are at greatest risk of being infected by their husbands. Poku (2005) continues by saying that in most African communities there is a general feeling that men may have multiple relationships irrespective of their

marital status, whereas women are not allowed similar relationships. Walker *et al.*, (2004); Ross *et al.*, (2004) and Poku (2005) indicated that research has shown that mobile workers, or partners working away from home and engages in sexual behaviours, while away from their partners may increase vulnerability to HIV/AIDS. Poku (2005) states that research conducted in KwaZulu-Natal demonstrated that 13% of women whose husbands worked away from home had increased vulnerability to HIV/AIDS, while two thirds who stayed with their husbands all the time were found to be negative.

#### **2.4.2 The socio-economic effects of HIV/AIDS on the family**

Ross and Deverell (2004) highlighted that HIV/AIDS affects the economic well-being of families, business and societies. Poku (2005) and Ross *et al.*, (2004) informs that when people die or become ill society does not only lose those people but also their productive potential. Meintjies and Giese (2004) concur by saying that HIV/AIDS causes labour shortages for farm and domestic work by reducing the household workforce. Van Dyk (2008) reported that when families are destroyed by HIV/AIDS livestock are lost as remaining family members may not know how to care for livestock, or plant to produce crops and fodder. In trying to link HIV/AIDS with poverty, Poku (2005) states that the relationship between HIV/AIDS and poverty is not that simple. However, it is possible that all factors predisposing Africans, particularly women and girls, to increased risks of HIV/AIDS infections, are aggravated by poverty. Foster *et al.*, (1997) reported that in a study conducted in Zimbabwe, it was observed that the main reason for extended family refusal to take in orphans was poverty and that poverty was responsible for the emergence of child headed households. It is widely acknowledged that poverty plays a

pivotal role in increasing vulnerability to HIV infection sub-Saharan African countries including South Africa (Milton, 2000 and Shisana *et al.*, 2002).

According to Poku (2005) there is a large socio-economic gap between men and women in Africa. However, research indicated that when women have significant opportunities for remaining financially independent and access to education they are less vulnerable to HIV/AIDS. Poku (2005) continues by saying that a strong feature of HIV/AIDS infections clusters within families, thus resulting in both parents being infected and at times falling sick and dying. As families use their time and money to care for ill family members their energies are diverted from working to provide income or farming to provide food (Ross *et al.*, 2004). Poku (2005) states that there is an enormous strain on the capacity of the families to cope with the psychosocial and economic consequences of illness, such that many families experience great distress due to the high cost of drugs to treat opportunistic infections and cost of transport to health centers. AIDS has challenged medicine; Maj (1991) suggests that AIDS places medicine 50 years back when doctors could only provide psychosocial support and no cure to the disease. Poku (2005) emphasises that reduced household productivity through illness, diversion of labour to caring roles, loss of employment through illness and job discrimination, funeral costs are just as high. Drawing the attention to children living with HIV-infected parents, Foster *et al.*, (2000) highlight that the future dimensions of the epidemic social, developmental and health problems on orphan children prior to the death of their parents. Deacon *et al.*, (2007) report that children become orphans while their parents are dying. Ross *et al.*, (2004) mentioned that the effects of the AIDS pandemic will be felt for generations,

because so many children are being deprived of adequate nurturing, nutrition, education and good role models.

#### **2.4.3 The socio-political and historical effects of HIV/AIDS on the family**

Poku (2005) states that there are a number of reasons why the socio political and historical factors play a role in the spread of HIV/AIDS. The lack of adequate investment in health infrastructure has made it difficult to provide adequate medical care to prevent the spread of HIV/AIDS. The African borders have been drawn by the colonial powers on the basis of various political objectives rather than that of national identities which has resulted in a number of wars. The World Health Organisation (WHO) (2004) reported that soldiers have been found to have the high rates of HIV infections and low access to HIV prevention interventions. Poku (2005) sees incarceration as another factor of spreading HIV/AIDS. Croyer (2001) cited in Poku (2005) states that a study that was conducted in South Africa found that HIV prevalence in prisons is twice as high as that of the population at large. Furthermore, Poku (2005) emphasises that some countries have been able to maintain an effective response to HIV/AIDS epidemic due to the commitment of their government to the broader majority of the population, rather than to the narrow urban-based elite. Africa, in this perspective, has been seen as lagging in its priorities which have been seen as lagging, and has made it more difficult for AIDS related issues to be translated into budgetary allocations and decisions.

#### **2.4.4 The effects of care on the family**

According to Walker *et al.*, (2004), Ross *et al.*, (2004) and Poku (2005) women and girls tend to provide most of the care for sick individuals, but men do play an important role in

the care of other men. A household survey that was conducted in South Africa found that in more than two thirds of households primary caregivers were women. Kelly (2001) concurs by saying that in a study conducted in urban and rural households in South Africa's Free State Province; found that women caregivers devoted four hours of their time daily in caring for the sick relatives. Poku (2005) shared that most of the people caring for children orphaned by HIV/AIDS were over 50 years of age. Van Dyk (2008), Walker *et al.*, (2004) and Poku (2005) care giving involves opportunity costs. In South Africa research has shown that 40% of care givers take time off from work or income generating activities so as to care for the sick (Steinberg *et al.*, 2002) cited in Poku (2005). Children have also been identified as taking time off from school or studying so as to provide care.

AIDS patients are said to experience anxiety, depression and anger after being diagnosed with the disease (Marcus, 1999). This is due to the fact that the victims experience difficulties in coping with the disease and in the process influence the severity of the disease. Harvey (2001) confirms that persons with HIV/AIDS may be caused to see themselves as undesirable by others who view them as contagious. This situation may cause infected people to withdraw and not to disclose their feelings resulting in them being socially isolated (Poku, 2005). Kelly *et al.*, (1991) and Marcus, (1999) indicate that a person's attributions regarding the disease influence the extent to which the AIDS patients will experience emotional distress. This is due to the fact that many of the HIV infected people believe that they acquired the disease through their unfaithful behaviour. Ross *et al.*, (2004) state that HIV is an illness that affects the whole family not only the

infected individual. Poku (2005) noted that when HIV infects one partner in a relationship both partners are affected.

Ng'weshemi, Boerma, Bennet and Schapink (1997) noted that the psychosocial implications of AIDS, such as social withdrawal, are similarly found in other chronic and fatal diseases. Witchcraft is believed to be the causal agent in the transmission of HIV, and AIDS death mostly among the rural poor or people with less education (Van Dyk, 2003; 2008). Beliefs have negative implications for AIDS Counseling and education. Nord (1997) states that stigmatisation can take forms that are far hurtful to the bereaved and harmful to the grieving process. Nord (1997) continues by saying it is then very important for religious institutions to be involved in supporting the victims and survivors of HIV and AIDS.

UNICEF (1999) indicated that close relatives of HIV/AIDS patients are also affected in the same way as the patient. This is because the disease poses multiple stresses over them. Families have to provide support and offer home care for the patient. Ng'weshemi *et al.*, (1997) reported that irrational fears of becoming infected through social contact or through caring for a sick person might also lead to ostracism and isolation of the infected person by the family members and the community. Van Praag (1995) reported that individuals often fear disclosing their HIV status either because of a general medical diagnosis as one clings to hopes that the process might have been wrong, or the fact that there is no cure available. Van Dyk (2008) noted that the stages of grief identified by Kubler-Ross (1985) including denial, anger, bargaining, depression and acceptance can all be experienced by the person with HIV/AIDS. According to Smart (2003), people with HIV/AIDS face multiple losses throughout their illness, including the loss of

intimate relationships, changes in employment patterns and loss of self-esteem. These multiple losses may leave individuals living with HIV feeling disempowered and lacking control of their lives. HIV/AIDS has an enormous impact on communities that are already poor. Kelly *et al.*, (1991) indicated that this causes stress for the HIV/AIDS people and their families. A large part of the family income is spent on healthcare and eventually funeral costs as a result of AIDS. In many families' breadwinners, mostly women, leave their paid employment to look after the sick (UNAIDS 2001).

## **2.5 Understanding adolescence**

Colman (2001) and Ng'weshemi *et al.* (1997) define adolescence as a transition between childhood and adulthood. This period covers the ages between 12 and 18 years. Deacon *et al.*, (2007) state that the definition of adolescence seems to be extended beyond most of the standard end points for childhood. The American Centre for Diseases Control (CDC) defines adolescence from age 10 -24 years while the WHO defines adolescence from 10-19 years. The South African context presented in Section (38) of 2005 in the Children's Act states that legally adolescence ends at the age of 18 years. Durkin (1995) and Louw, Van Ede and Louw (1998) state that, it is difficult to determine when adolescence ends. Societal and economic criterion, like financial independence, achieving academic qualifications and age of maturity can be seen as some form of boundary, but this is not applicable in every society. Louw *et al.*, (1998) state that the difference in age definition can be attributed to differences in cultural perceptions, rather than the use of chronological age. It is then more accurate to say that adolescence starts at puberty and ends when a child reaches his/her cultural appropriate social roles, psychological characteristics and legal age of maturity.

Papalia *et al.*, (2008) highlighted that adolescence offers opportunities for growth, not only in the physical dimensions but also in the cognitive and social competence, autonomy, self esteem and intimacy. Chatto and Windus (2007) state that adolescence is a time of dramatic change and this can be seen in the way adolescents express their feelings and in the way they interact with their families. Van Dyk (2008) states that during this stage adolescence are very self absorbed and are at times not able to decentre from their own ideas. Adolescents become more aware of the environment its possibilities and constraints (Bezuidenhout, 2004). Van Dyk (2008) state that many adolescents fall into a trap of mind reading, innocent actions of others may be taken as personal criticisms as they jump into conclusions. Adolescents who have lost their parents through HIV/AIDS should be understood within the context of the developmental phase they are in. Bezuidenhout (2004) states that during this stage adolescents learn how to think, act and experiment with new behaviours that can encourage them to take risks and increase their confidence. Papalia *et al.*, (2008) state that adolescence is no longer solely a western phenomenon but globalisation and modernisation has added to societal change. Adolescence is a phase in which the young person has partially matured physically and cognitively but still needs the involvement of parents or caregivers. Jackson and Rodriguez-Tome (1993) and Bezuidenhout (2004) indicated that the nature of relationships with parents changes as adolescents move towards greater independence. The researcher then feels that the impact of HIV/AIDS related conditions may have a long-term effect on the development of South African adolescents.

### 2.5.1 Physical changes in adolescence

Adolescence portrays the period between childhood and adulthood. This period is known as puberty. Puberty involves spectacular biological changes. During this stage the sex organs of the females begins to enlarge including the appearance of the breast buds. Puberty brings more restrictions on girls as their virginity must be protected so as to uphold their family status. Puberty in boys is distinguished by the development of sex organs such as the enlargement of the testes, facial hair and others. During this stage unlike the girls' boys gain more freedom and mobility and their sexual exploits are more tolerated by parents and admired by peers (Papalia *et al.*, 2008)

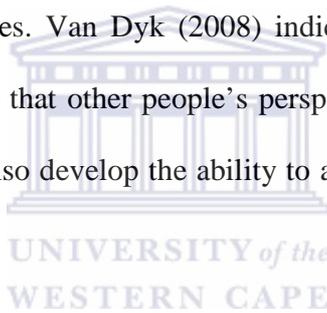
During the adolescent stage the brain of the adolescent is not fully developed. Papalia *et al.*, (2008) state that dramatic changes in the brain structures are involved in emotions, judgment, organization of behaviour and self control all takes place during puberty. Van Dyk (2008) states that because of the accelerated development during puberty, adolescents become more aware of their sexuality. This may play a large role in their interpersonal relationships. Papalia *et al.*, (2008) and Van Dyk (2008) agree that during this stage adolescents discover their sexual orientation; they are often confused and worried about the changes in their bodies. Although they may have many questions about sex, adolescents do not always wish to ask these questions as they do not want to be seen as uninformed. This all explains some of the emotional outbursts and unsafe behaviours of some of the teenagers (Papalia *et al.*, 2008). Richter *et al.*, (2004) argued that adolescents affected by HIV/AIDS are themselves often highly vulnerable to HIV infection. Adolescents need parental support to deal with changes of puberty and sexual and aggressive impulses, at the same time trying to become independent and self

supporting (Smart, 2003). Foster *et al.*, (2000) state that there is a need to understand the circumstances of HIV/AIDS orphans so that targeted interventions can be established so as to minimize their vulnerability. This is resulted by the early onset of sexual activity, commercial sex pressure, and sexual abuse all which might be precipitated by economic need, peer pressure, lack of supervision, exploitation and rape. Van Dyk (2008) indicates that this is the best time to convey information about sex, for instilling values, and encouraging critical thinking. This can become a difficult transition for those adolescents who might find themselves in a situation of not having a parent with whom he/she may share fears and concerns about the changes and challenges they are experiencing.

### **2.5.2 Cognitive changes in adolescence**

Wyse (2004) states that cognitive development is the development of thinking and reasoning, during this stage adolescents do not only look different from their younger siblings however also think and talk different. Piaget (1950) cited in Papalia *et al.*, (2008) describes the shift from childhood to adolescence as a movement from concrete thinking to formal thinking. Van Dyk (2008) states that during this stage adolescents have developed a value system about what is wrong and right. Piaget (1950) called this stage the formal operations meaning the highest level of cognitive development. Adolescents are seen to be able to manipulate information. Adolescents are more likely to use emotional focused coping and thus try to avoid negative thoughts, this strategy has been associated with greater distress than problem-focused coping (Deacon *et al.*, 2007). Van Dyk (2008) states that some of the main domains of cognitive development are language, problem solving, memory development and reasoning. Piaget (1950) believed that adolescents' value systems are influenced by the ability to formulate hypothesis,

investigate and test them to make certain deductions. Wong and Jevne (1997) state that the development of a child before adolescence is like pieces of puzzle scattered around the table. Children affected by HIV/AIDS tend to worry a lot as they are afraid that one day they will find their parents dead when they come home from school Foster *et al.*, (2000). Van Dyk (2008) states that both cognitive development and social situations encountered push individuals to combine the puzzle pieces. Adolescents who have lost their parents through HIV/AIDS can closely link their circumstances to how they perceive and understand the world around them. Papalia *et al.*, (2008) states that adolescents at this stage of formal operations can integrate what they have learnt in the past with the present challenges. Van Dyk (2008) indicates that once adolescents can think in abstract terms and see that other people's perspectives and opinions may differ from theirs, adolescents then also develop the ability to approach moral issues in a more mature manner.



Changes in the way adolescents' process information reflect the maturation of the brain's frontal lobe and may help explain the cognitive advances described by Piaget, (1772), cited in Papalia *et al.*, (2008). Piaget (1972) cited in Papalia *et al.*, (2008) reported that culture and schooling plays an important role in the development of an adolescent these are then seen as tools that they can use in problem solving including trying to understand complex situations that affect their development such as the loss of a parent. Foster & Potgieter (1995) reported that in many non-industrialised societies' rituals called rite of passage inform the whole community that the child has become an adult. Wyse (2004) reported that Vygotsky (1896–1934) was concerned with the historical and social aspects of human nature and the importance of social and cultural factors in the development of

intelligence. Vygotsky argues that there is a close link between language and thought and that children acquire their cultural values, beliefs and problem-solving strategies through collaborative dialogues with more knowledgeable members of the society. The cultural aspect appears to be an important developmental factor influencing the experiences of adolescents who have lost their parents through HIV/AIDS, as it closely relates to the manner in which they perceive the world and themselves. Kohlberg (1978) cited in Van Dyk (2008) states that once adolescents acquire capacity for principle moral reasoning, they then begin to see that rules can be questioned as they are based on someone else's reasoning; and therefore they will adhere to rules that are useful that support individual and social rights. Adolescents, who are maturing physically and sexually, not only feel different about them but also come to be viewed and treated differently by other people.

### **2.5.3 Psychosocial changes in adolescence**

Adolescence is known to be a time of both opportunities and risks. During this time the adolescents' cognitive development helps them to construct a "theory of the self" (Papalia *et al.*, 2008). Lynch (2000) states that adolescence is seen as a psychosocial and physical stage of development. According to Erikson (1963) cited in Lynch (2000) identity formation is at its primary developmental task. Erikson (1959/ 1980) adds that the effort to make sense of the self is part of a healthy process that builds on the achievements of the earlier stages of development. Erikson calls these stages trust, autonomy, initiative and industry. Erikson (1963) believed that the chief task of adolescence is to confront the crises of identity versus identity confusion so as to become a unique adult with coherent sense of self and a valued role in society. Lynch (2000) states that this stage is also associated with a broad range of social problems brought

about by adolescents taking risks, and feelings of invincibility regardless of their actions. Adolescents become aware that they are not the same people in all situation-facts that may puzzle or annoy them. Deacon *et al.*, (2007) state that during this stage peer support becomes increasingly important as adolescents may suffer more than younger siblings should they be isolated from these sources of support. Foster *et al.*, (2000) state that during this stage, adolescents who have lost a parent(s) to AIDS could experience anxiety about re-starting life in unfamiliar surroundings in a new location, often a new school and having to make new friends. Deacon *et al.*, (2007) state that adolescents are in a state of transition, embarking on their sexual careers, developing their adult identity and very sensitive to peer norms and are likely to both express and experience stigma more deeply than both adults and their younger siblings.

During this stage adolescents 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). Van Dyk (2008) states that during this stage the peer group plays a very important role in the adolescent's development as they serve as a source of information. According to Erikson (1963) identity forms as a young person tries to resolve three major issues in their lives namely the choice of an occupation, the adoption of values to live by and the development of a satisfying sexual identity. Lynch (2000) and Papalia *et al.*, (2008) agree that during this stage adolescents begin to withdraw from their parents as they become more self-preoccupied and self-absorbed. Durkin (1995) states that multiple stressors of adolescence have consequences for how a young person feels about her or himself and particularly the self-esteem. Foster *et al.* (2000) note that parents who are HIV infected may show less interest on their children

due to mood swings associated with the pressure of being infected. Gouws and Kruger (2004) reported that too much stress in the life of an adolescent may exert a depressing influence on the young person's self-esteem. Deacon *et al.*, (2007) note that during this stage, adolescents tend to personalize experiences such as insults against their parents. The researcher feels that adolescents who are forced to independence as in the case of adolescents who have lost their parents to HIV/AIDS, this may have a severe impact on their self-esteem. Peer support become increasingly important to children as they grow older. Adolescents may suffer more than younger children if they are isolated from sources of support and might be at higher risk of low self-esteem if peers stigmatise them (Deacon *et al.*, 2007).

Lynch (2000) states that narcissism is at times not what these children want but a need to have a strong attachment to a caring and trustworthy adult. In the absence of a caring parent to adolescent HIV/AIDS orphans these children may seek comfort through engaging in sexual behaviours so as to try to gain affection. This can result into danger as Lynch (2000) informs that using sex to cope with unmet needs can result in depression, low self-esteem and increased boredom and loneliness. Erikson (1982) cited in Papalia *et al.*, (2008) states that adolescents who resolve the identity crisis satisfactorily develop the virtue of fidelity. Fidelity can mean identification with a set of values, ideology, religion, political movement, a creative exercise or an ethnical group. Richter *et al.* (2004) then informs that children who grow up without the love and care of adults devoted to their wellbeing are at risk of developing psychological problems.

#### **2.5.4 Parent-adolescent interactions**

Adolescence ranges between twelve and eighteen years as prescribed by the Children's Act Section 38 (2005), however the sample age group used by the researcher ranges from 14-17 years of age. Van Dyk (2008) reported that the relationship between the adolescent and his or her parents plays an important role in whether or not the adolescent will internalize moral values. Van Dyk (2008) adds by saying that parents who are warm and loving, who are consistent models of commendable moral behaviour and who apply disciplinary techniques that promote, calm discussion with their children promote the development of moral maturity in their children. Adolescence is stages where by children whose parents die of HIV/AIDS undergo a particularly traumatising experience that encompasses stigma, secrecy, denial and emotional distress as they witness their parents' physical and often mental deterioration (Lynch, 2000). Deacon *et al.*, (2007) indicate that the process of disclosing HIV parental status to children is similar to disclosure of other sensitive information.

Wyse (2004) highlighted that for many people a family is an image of two married biological parents with their children. This is known as the nuclear family. Bezuidenhout (2004) informed that the disadvantage of a nuclear family is that they become isolated from the extended family. While this can be true and can make nuclear families more vulnerable during times of crises, it is also true that these families can strengthen their emotional support that is needed during crisis times as they need each other (Bezuidenhout, 2004). Thus, it is important not to separate siblings from one another during death of parents as they can be a good support for each other (Richter *et al.* 2004). Wyse (2004) and Nord (1997) reported that many people affected by AIDS related deaths

belong to the nontraditional families. Thus families may include the traditional nuclear family, extended family, relatives, lovers, friends and sexual partners. Papalia *et al.* (2008) shared that both parents and adolescents usually have mixed feelings during crisis times.

Many parents are reluctant to communicate 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. Foster *et al.*, (1995) reported that many adolescents view morality as an important part of their identity, and because adolescents are more sensitive than children, they are more motivated to portray and view themselves as honest, fair and caring individuals. Nord (1997) states that the challenge of HIV/AIDS is that children may have to be forced to take care of their parents, and in other instances parents who thought that they have finished taking care of their children's physical needs, find themselves having to do so again. Being an orphan might impact on some adolescents who might themselves be struggling with this transitional stage while having to care for their siblings and caregivers thus forcing them to take a parental role while children themselves. Richter *et al.*, (2004) state that it is during this time that parents need to improve parent-child communication about different issues including their illness, death, and sex education. Lynch (2000) adds love guidance, support and consistent modeling of appropriate behaviour by parents towards adolescents.

Kiragu (2001) states that young people are more vulnerable to HIV/AIDS than older people because their social, emotional and psychological development is incomplete. They assume that they are invincible and nothing bad can happen to them hence experimenting with at risk behaviour, often with little awareness. Many adolescents are at

risk because no one including their parents, educators, counselors, health care workers, religious or the media has taught them about HIV/ AIDS or how to protect themselves and others (Jogunosimi, 2001; Gitelson *et al.*, 1989). Steffernson (2002) reported that despite over 15 years of international education and communication to prevent HIV/AIDS, young people today still have only limited opportunities to learn about the virus and the disease. While the importance of the education about HIV/AIDS is widely recognised, Kiragu (2001) notes that 44% of 107 countries studied did not include AIDS education in their school curricula. In interviews with 277 secondary school principals in South Africa, Kiragu found that 60 % acknowledged that their students were at moderate or high risk of HIV, but only 18% of the schools offered comprehensive sex education curriculum (Kiragu, 2001).

Kiragu (2001) highlighted that young women are far less knowledgeable about HIV than young men and when they know something about HIV/AIDS their knowledge is often limited. Kiragu (2001) continues to say that students in Papua New Guinea were asked how to protect themselves against HIV, 27% said that it was enough to get to know their partner first or to make sure that he had not had sex for the past six months. In countries where HIV is wide spread such as Lesotho and South Africa 50% to 75% of women aged 15-19 do not know that a person with HIV may look healthy (Steffernson, 2002). It is then clear that in order for the nation to succeed in the fight against AIDS, adolescents will have to be part of the solution.

Richter *et al.* (2004) informed that all children need stability and security and for this reason it is crucial for ill parents to plan for the future of their children. Bonsire (2001) concurs by saying that there are different issues that need to be considered for discussion

with children, including adolescents such as being open about their status so as to allow the children to cope more effectively, compiling memory boxes with family history, and ensuring legal protection of assets and inheritance due and intended for the children concerned. Durkin (1995) adds by saying that adolescents have an urgent need for adult guidance in-terms of planning for their future.

## **2.6 Adolescents as AIDS orphans**

Poku (2005) reported that young and middle aged adults are dying of HIV/AIDS thus leaving hundreds of children orphaned by HIV/AIDS. Van Dyk (2008) reported that the AIDS epidemic has created more than 15 million orphans' worldwide and these are children under the age of eighteen years. Van Dyk (2008) continues by saying 80% who are 12.3 million are in Sub-Saharan Africa. UNAIDS (2004) highlighted that this number is expected to climb to 18 million by 2010. Van Dyk (2008) reported that in South Africa alone an estimated 2.2 million children which is 12% of all the children under 18 years in South Africa have lost both parents to HIV/AIDS. Dorrington *et al.*, (2002) commented that without the interventions such as antiretroviral therapy there will be approximately 3.1 million AIDS orphans in South Africa alone by 2015.

Poku (2005) reported that children experience the stress of parental illness; the emotional upheaval of seeing a dying parent may leave children feeling abandoned and increase their susceptibility to abuse. Poku (2005) continues by saying that a study conducted in South Africa indicated about 12% of children where there was an ill or dying parent being sent away to live elsewhere. The death of a parent is devastating, mostly when there are children who still need to be taken care of, are left behind. Nord (1997) reported

that illness and death within the family draw the attention and energy away from the needs of the children. Deacon *et al.*, (2007) concur by saying when one parent dies the surviving parent's grief can interfere with the ability to care for the emotional or even physical needs of the children. Williamson (2002) and Richter *et al.*, (2004) reported that caregivers first experience financial pressures, as they will be expected to clothe, educate, feed, love and support orphaned children. This can be difficult if the caregiver is unemployed. This can be even more difficult in some instances whereby the health of caregivers and guardians is just as well not so good. Richter *et al.*, (2004) reported that the impact of HIV/AIDS on families and households are visible as families attempt to adjust to the stress of economic decline and depression. Nord (1997) concur by saying that children who lose their parents inherently face multiple losses including the loss of their homes, safety, security and income. Some of the challenges facing children who are orphaned by AIDS are poverty, child labour, sexual abuse and child headed households.

Walker *et al.*, (2004) and Richter *et al.*, (2004) argues that an increasing number of AIDS orphans who grow up without parental support and supervision become victims of poverty, school drop outs and subsequently engage in crime, and or prostitution so as to earn a living. Richter *et al.*, (2004) reported that the Convention on the Rights of the Child places the obligation on Government to protect the rights of the children. The African Charter on the Rights and Welfare of the Child concur that States shall ensure that any child who is temporarily or permanently deprived of his or her family environment shall be provided with alternative care including foster placement or placement suitable for children by the government (Article25(2). Simbayi *et al.*, (2002) and Marcus (1999) noted that the death of parents deprive children of love, support and

care that they need. Children who have lost a parent(s) or have a parent who has HIV/AIDS undergo a great deal of stress Richter *et al.* (2004) and (Francis, 2001). In a study conducted with Zimbabwean youth orphaned by HIV/AIDS reported that their experience of orphanhood begins with the illness of a parent and not the death of the parent (Harms, Jack., and Ssebunnya, 2010). According to Williamson (2000) the psychosocial effects of losing a parent to an unbearable illness are severe and can have long-term effects on the child's behavioural development. Similarly, Smart (2003) and Williamson (2000) found that as these orphans endure the loss of parental support and nurturing, many experience anxiety, depression and despair. Foster and German (2002); Meintjies and Giese (2006) further reported that complicating these emotions, siblings are divided among several households within the extended family.

Poku (2005) indicated that the extended family system is overwhelmed by the magnitude of the burden of caring for so many orphaned children. Meintjies *et al.*, (2006) and Poku (2005) informed that the extended family may be absent or find it difficult to meet the material needs of the orphaned children. Poor women and elderly relatives may inherit several dependants. Van Dyk (2008) reported that the extended family system is greatly over extended in those communities affected by HIV/AIDS thus can often no longer take care of its orphaned children. Van Dyk (2008) continues by saying that children themselves lacking knowledge, skills and means find themselves having to care for their siblings. Their vulnerable caregivers might have to force some of these children to leave school and go and work or marry to secure more child labour and generate more income needed to support the family. UNICEF (2003) adds that these children are more likely to fall behind at school, or drop out thus compromising their abilities and prospects. Van

Dyk (2008) reported that AIDS orphans suffer more frequently from malnutrition, illness, abuse and sexual exploitation. Foster and German (2002) adds that relatives and neighbours who have agreed to take care of the orphans sometimes contribute to their despair by taking their properties or inheritance and leaving them more vulnerable to exploitation. Nord (1997) states that orphans from AIDS often face a future of multiple personal loss arising from developmental and behavioural problems resulting from lack of consistency in their lives, including difficulty in trusting and bonding with adults. Richter *et al.*, (2004) state that in order to for caregivers to gain the trust of orphans it is imperative for caregivers to generate more income on the assets and inheritance of these children so as to support and improve their lives. This can result in more trust built between the orphans and their caregivers. Van Dyk (2008) highlighted that families who do not have contact with their extended family have greater likelihood of orphans being abandoned should the current caregiver die. Walker *et al.*, (2004) reported that South Africa is seeing a number of children in distress due to the collapse of family care models such as extended families. Walker *et al.*, (2004) reported that women bare the brunt of HIV/AIDS in South Africa, not only are they more vulnerable to infection but they also carrying the burden to care for their families. Poku (2005) indicated that a study conducted in KwaZulu-Natal in South Africa reported that 57% of households caring for orphaned children were headed by women who on average were 59 years old. Walker *et al.*, (2004) reported that the impact of HIV/AIDS put a strain on grandparents who have become the primary caregivers of these children.

Van Dyk (2008) highlighted that community caregivers are familiar with the actual living conditions of AIDS orphans and other vulnerable children in their communities therefore

have the right to be the guardians of the children's rights and can integrate these rights into their intervention models. Smart (2003) and Van Dyk (2008) reported the following most important rights of the child. The rights to adequate food, shelter, clean water, sanitation and primary health care. Van Dyk (2008) adds that children have the right to the highest level of health and medical care possible. Children have a right to be protected from abuse, neglect, and exploitation. Additionally, special protection should be provided to children deprived of their family environment. Children should be awarded the right to privacy and not always be question about their family for discriminatory reasons. Smart (2003) commented that an appropriate, alternative family care or placement should be considered however that culture of the child should always be considered. Smart (2003) and Van Dyk (2008) agrees that caregivers need to ensure tat the moral, physical, emotional and psychological development of a child through formal education, constructive play art and culture and a nurturing and caring environment. The last important right highlighted by these researchers is the right to be part of the social environment and having some say in and access to information about issues that concern them such as civil, economic, cultural and religious issues.

Richter *et al.*, (2004) reported that orphans are disadvantaged by their pre-existing low socio-economic status at the time of their parents' death. According to Smart (2003), Walker *et al.*, (2004); Van Dyk (2008) and UNAIDS (2003) children orphaned by AIDS faces a high risk of malnutrition and stunting due to their poverty status. UNICEF (2003) indicates that research conducted in Zimbabwe in 2003 (with 42 000 children including 1760 orphans) demonstrated that a higher percentage of orphans were malnourished compared to non-orphans. Smart (2003) concluded that the nutritional health and survival

prospects of orphans are also worsened by the increasing weakened state of health care services which have been overwhelmed by HIV/AIDS onslaught in many Sub-Saharan African countries. Van Dyk (2008) reported that HIV/AIDS orphans don't always know how to protect themselves and at times have no access to doctors, nurses and other health care workers and facilities. Van Dyk (2008) reports that some studies have indicated that death rates among AIDS orphans are between 2.5 and 3.5 times higher than those of children with parents. It has also been noted that children who lose their parents due to AIDS are socially ostracised and marginalised by adult friends and their schoolmates.

Van Dyk (2008) reported that many children live in communities that have been wrecked by the effects of the HIV/AIDS pandemic. Poku (2005) and Van Dyk (2008) reported that as the parents of these children become ill they become more dependent on their children for care. These children become primary caregivers as they have to care for their parents and siblings. Gannon (1994) states that children, who have lost their parents, become the heads of their families and have to care for their siblings who are younger than themselves. Children, especially girls, face more general house duties, care of the sick and younger children. The National Programme of Children in South Africa (2001) reported that South Africa is experiencing a growing number of child/adolescent headed households due to HIV/AIDS. The studies conducted in the midlands of KwaZulu-Natal found that child/adolescent headed households were growing with the average child heading a household aged eleven years (Department of Health, 1998; Smart, 2000). The National survey that was conducted by Shisana and Simbayi (2002) found that 3% of households were reported as being headed by persons aged between 12 and 18 years. Sloth-Nielsen (2004) emphasises that children living in child-headed households may

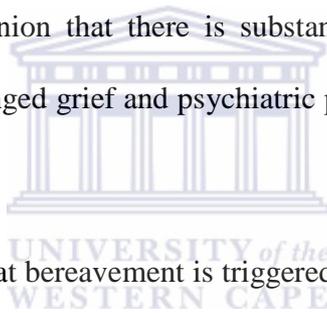
struggle to get births registered, health treatment, social security and other state mechanisms that can help them. Van Dyk (2008) indicated that many children infected by HIV/AIDS have dropped out of school due to financial problems or their new responsibility as caregivers. In addition Van Dyk (2008) reported that children made vulnerable by HIV/AIDS, who do not receive psychosocial support to fulfill their basic needs, may suffer long-term social and emotional impairment and may be at risk of developing depression, anxiety and suicidal thinking.

The reality of AIDS in the family is that children are caring for the sick and assuming adult responsibilities before they are ready to do so (Steffenson, 2002; Smart, 2000). Van Dyk (2008) reported that children who take care of their sick parents are faced with the trauma of nursing and watching their parents die of AIDS. Van Dyk (2008) adds by saying that even with external help to assist children are not emotionally equipped to deal with the role of being a care giver. Children affected by AIDS start grieving in anticipation long before the death of a parent. They often experience multiple losses after the death of their parents, and find themselves caught up in inheritance squabbles. This then minimises the time for the child to grieve the loss of a parent. Van Dyk (2001) reported that if these children cannot be accommodated into foster care programmes, community and governmental support should be offered to help these children cope with their plight in their own homes.

## **2.7 Adolescence and bereavement**

Many children in the African Region are going to be separated from their parents, caregivers and breadwinners on whom they depend. Richter *et al.*, (2004) indicated that

the loss of parent and loved one is associated with internalizing psychological conditions including anxiety, rumination, depression, social isolation survivor's guilt and low self-esteem. Children affected by HIV/AIDS may be subjected to impersonal and abusive child care through exploitative family and community care and poorly chosen and supervised foster care. Richter *et al.*, (2004) informed that currently it is unclear how many children are exposed to unmitigated poverty, multiple losses, and bereavement, cruel and impersonal care. Van Dyk (2008) reported that children affected by HIV/AIDS may at times be infected with the HIV virus themselves, may have a parent or parents who are HIV positive or they may be orphans due to AIDS-related deaths of parent(s) Demmer (2004) is of the opinion that there is substantial evidence that survivors of HIV/AIDS are at risk of prolonged grief and psychiatric problems as they mourn the loss of their parents.



Van Dyk (2008) highlighted that bereavement is triggered by the sense of loss that occurs when one loses something or someone to which we have become attached. This separation or loss initiates a process of grief. Nord (1997) and Parry (1989) define grief as a peculiar amalgam of anxiety, anger, pain and despair following the experience of what is feared to be irretrievable loss of a loved one. Nord (1997) indicated that the definition of grief acknowledges that grieving arises from not only the loss of a loved one but it can also result from the loss of communities, dreams, material goods and expectations. Van Dyk (2008) reported that the bereavement explained by a person who has lost a loved one and the bereavement experienced by a terminally ill or dying person are similar. Louw and Louw (2007) state that some of the factors that have been found to play a role in children's understanding of death include age, the level of cognitive

development, cultural influences, and the way parents communicate about death. Louw *et al.*, (2007) states that children suffer tremendously when their parents are infected and needs of children with infected parents are often neglected. There is no tradition of talking to infected and affected children as equals and on an intimate basis in many African societies. Caregivers often report seeing the suffering of children who are hovering in the shadows of a sick room, seeing and hearing everything regarding their sick and dying parent but never addressed directly (Van Dyk, 2003). Children are largely excluded from counseling processes in Africa because in most cases caregivers do not know how to talk to children.

HIV has swept the world at a unique time in history. Nord (1997) states that for the first time a disease like HIV/AIDS seemed in control and the denial of death was at a high point. (Kubler- Ross 1973) mentioned that death is still a fearful, frightening happening and the fear of death is universal. In many instances a person who is severely ill is often treated like a person with no right to an opinion (Kubler-Ross, 1973; Nord, 1997). Van Dyk (2008) indicated that mourning is similar to the process of healing from an illness, and grief makes people experience emotional pain and this may sometimes manifests its self as physical pain. Van Dyk (2003; 2008) state that children are affected by HIV/AIDS in different ways. They may be infected themselves, may have a parent(s) or caregiver who maybe infected with HIV or who has died because of AIDS – related deaths.

Kubler-Ross was concerned about the way Western Culture and western medicine alienated death. Kubler- Ross (1973) in her book *On the death and dying*, reported that death was no longer seen as part of natural life, but the dying were left to die alone without close relatives to comfort them. Kubler-Ross (1973) reported that Individuals proceed

through a five-stage model of bereavement. Van Dyk (2008) highlighted that the stages of bereavement highlighted by Kubler-Ross are also useful in response to the experience of bereaved as HIV/AIDS is a life threatening disease. The five stages of bereavement are shock and denial, anger, bargaining, depression and acceptance.

One of the first reactions to a loss as highlighted by Kubler-Ross (1973) is that one experience a feeling of numbness and disbelief. Van Dyk (2008) indicates that a client at this stage cannot cry or show any emotion at all. Denial and isolation are usually a temporary defense which will soon be replaced by partial acceptance (Kubler-Ross, 1973, Nord, 1997). Nord (1997) indicated that AIDS-related losses and grief are often treated as urgent problems for families only until their familial loss has passed, then the subject of AIDS is avoided. Van Dyk (2008) reported that anxiety and feelings of helplessness are very common in people who have lost a loved one to a threatening disease such as AIDS. The problem with denial is that it leaves survivors most vulnerable to that very perils against which they have tried to defend themselves. Poku (2005) state that many orphan adolescents tend to deny their feelings of grief as they consider the need for consolation as childish. Furthermore, adolescents show grief through anger and rebelliousness. Demmer (2004) concurs that adolescents may feel angry and may express this through violence and aggression towards other children or adults.

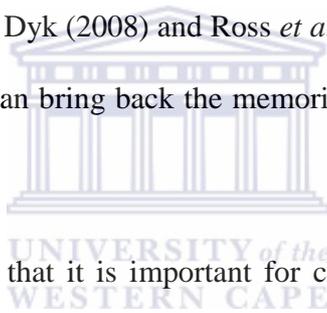
Van Dyk (2008) and Ross *et al.*, (2004) similarly highlight that although anger may seem inappropriate and in many cases come unexpected to the grieving person, bereaved people are often angry at God for letting this person die and at times are angry at the diseased person who has left them. Kubler-Ross (1973) concur that when the first stage of denial cannot be maintained any longer it is then replaced with feelings of anger, rage,

envy and resentment. Parry (1989) highlighted that in most families' denial and anger normally suggest that the doctor might have made a mistake. Poku (2005) reports that some of the adolescents due to their developmental stage may find bad company, have multiple partners and abuse substances such as drugs and alcohol. Kubler-Ross (1987) continues by saying that in contrast to that stage of denial the stage of anger is very difficult to cope with from the point of view of the family and friends. Demmer (2004) indicated that some of the adolescent orphans may feel inferior, become withdrawn, anxious and bad about the changes that are occurring around them and may develop eating problems, clinging and fearful and at times talk about suicide. Poku (2005) states that this results in some children experiencing health problems following bereavement, such as asthma, stomach aches, head aches and some may even imitate the symptoms of the person who have died. Ross *et al.*, (2004) reported that people with HIV/AIDS are aware of the stigma associated with HIV/AIDS and may be uncertain and apprehensive about how to react. Van Dyk (2008) reported that fear of stigmatisation and ostracism are real factors after being diagnosed HIV positive. The fear of rejection and isolation is what causes AIDS patients real pain. Nord (1997) states that in America the fury of angry and confused AIDS-affected persons was embodied in the ACT-UP, which was very active during the Reagan and Bush years. During the Presidency's there was a widespread perception that the highest levels of government were inattentive and hostile towards persons with AIDS. Van Dyk (2008) highlighted that when the bereaved blames themselves or the deceased they make it difficult for themselves to accept the pain of loss. It is then important that the person should face the pain and all the emotions that go with it.

The *third stage* is bargaining and facing reality. Kubler-Ross (1987) highlighted that during this stage the grieving people often bargain with God themselves or with the virus in the case of HIV. Van Dyk (2008) reported that this bargaining usually involves promises and the expectation of rewards, such as curing the person or keeping him/her healthy for indefinite. Nord (1997) and Van Dyk (2008) reported that research has shown that bargaining give the bereaved people the feeling of being in control of what is happening to them. This is the stage whereby the affected realises that the loss has happened, and it will not be reversed (Nord, 1997).

The *fourth stage* as highlighted by Kubler-Ross (1987) is sadness and depression. Van Dyk (2008) reported that the person who experienced a loss often goes through a stage of severe sadness and shows symptoms of depression such as withdrawal depressed mood, loss of interest in sexual and activities, apathy, tearfulness, irritability, lack of concentration and changes in eating patterns. Parry (1989) informs that as the reality of the news sets in, many losses occur including jobs, planned vacations, future events, loss of freedom caused by frequent hospitalisation or constant medical treatment and financial worries. Nord (1997) and Parry (1989) reported that during this stage a person is about to lose everything and everyone he /she loves and it is natural that such a threat should evoke sadness. Demmer (2004) highlights that during this stage children are overburdened with responsibilities beyond one's emotional capacity and the experience of neglect and abuse by caregivers on whom they depend for emotional growth can have seriously emotional damaging consequences. This may be especially true in the case of adolescents faced with the illness and death of parents because of HIV/AIDS.

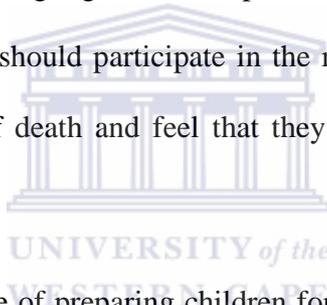
The *final stage* as highlighted by Kubler-Ross (1987) is resolution and acceptance, Nord (1997) calls it reinvestment and recovery. Nord (1997) indicates that this stage is associated with acceptance of the loss. Kubler-Ross (1987) concurs by saying that this stage should not be mistaken for a happy stage. It is almost void of feelings as the person comes to terms with his or her loss. Van Dyk (2008) indicated that this does not mean that the person has forgotten his or her loss but that he or she can move on with his or her life. Nord (1997) states that for some survivors of AIDS-related losses this stage is closed with a Serenity prayer. Nord (1997) reported that cultural outpouring has been seen as an adjustment to the reality of AIDS which is still continuing to be unprecedented by any other disease in the world. Van Dyk (2008) and Ross *et al.*, (2004) agree that special days such as birthdays or holidays can bring back the memories of the lost person reopen old wounds.



Kubler-Ross (1985) suggested that it is important for children to be allowed to grieve without being labeled. Kubler-Ross (1985) continued by saying that if children of both sexes are not allowed to express their natural emotions in childhood, they will have problems later on in the form of self pity and many psychosomatic symptoms. Marcus (1999) states that in her research conducted in Pietermaritzburg, KwaZulu-Natal several participants in the study felt that it was only appropriate to tell children in their late teens and young adulthood about death. Kubler-Ross (1985) reported that grief and fear when allowed to be expressed and shared in childhood could prevent much future heartache. Kubler-Ross (1987), Nord (1997) and Stedeford (1984) agree that adolescence naturally is a difficult time of development and an added loss of a parent is often too much for such

a youngster to endure. Hence, it would be appropriate to listen to them and allow them to express their feelings, whether it is guilt, anger or plain or sadness.

Van Dyk (2001) states that these children are often burdened with a legacy of confusion and grief because many parents remain silent about their HIV status until they die. Van Dyk (2008) reported that children older than 10 years understand that death is final, irreversible, personal and universal. This age group start to realise that death may also apply to them. Kluckow (2004) cited in Van Dyk (2008) highlighted that children older than twelve years who have suffered a loss often have trouble concentrating on their school work. Van Dyk (2008) highlighted the importance of children being involved in the mourning rituals, children should participate in the rituals of death so that they can experience the concreteness of death and feel that they are not alone in their grieving (Kubler-Ross, 1985).



Commenting on the importance of preparing children for the death of a parent, Cullinan (2000) indicated that it is important for parents to start talking about their HIV status with their children as it hurt most when they must hear it from somebody other than their parents. Cullinan (2000) and Van Dyk (2008) also highlighted that one of the ways of expressing themselves is through starting memory boxes. Van Dyk (2003) noted that the memory boxes take the children on a step-by-step journey through different aspects of their own identity, their family history, their lifestyle, culture and beliefs. Van Dyk (2003) and Van Dyk (2008) maintains that it is important for the parents and children to start the memory boxes together as it embodies a treasure of childhood memories and family history for both the parents and children. This will give them a keen sense of

belonging when orphaned and provide them with answers to questions that they would have asked their parents.

## **2.8 Effects of HIV/AIDS on culture**

Culture as defined by Dube (2001) refers to the material production of a society which becomes the central system of practices, meanings, and values which we can properly call dominant and effective. Practices which occur among some African cultural groups include live rite whereby if one of the two partners in marriage dies, a brother or sister of the deceased inherits the remaining spouse (Shisana *et al.*, 2002; Dube, 2001). Dube (2001) reported that culture tolerates a man's unfaithfulness. Nord (1997) states that the death of a family member to AIDS- related death poses a cultural social arrangement, as the bereaved are forced to recognize the social loss, while communities simultaneously deny the presence of the HIV / AIDS pandemic. The belief systems impact directly on how we understand health and respond to illness. Some of the indigenous healing practices may contribute to the spread of HIV/AIDS in Southern African countries as some indigenous healers use unsterilised sharp instruments (Shisana *et al.*, 2002). Van Dyk (2008) highlighted that there is no indication in literature that traditional Africans attribute AIDS to the anger of ancestors or to God's punishment. Some African Christians believe that AIDS is God's punishment for immorality. Walker *et al.*, (2004) reported that some religious groups in Botswana believe that AIDS is God's punishment as he did with Gomorrah and Sodom. Vika (2006) reported that the Methodist Church response to HIV/AIDS is to encourage the aspects of culture that promote healing and wholeness. Vika (2006) continues by saying that the Methodist Church ethics commits them to identify and challenge harmful rituals and practices where culturally supported

rituals and practices makes people more vulnerable to HIV/AIDS including AIDS orphans .

Van Dyk (2008) and Walker *et al.*, (2004) reported that some traditional individuals and communities understand the cause of disease to regulated and controlled by magical and spiritual forces. Walker *et al.*, (2004) reported that South African society is characterised by cultural complexity and difference, this is reflected in many ways that health and disease are understood. Van Dyk (2008) highlights that a person with AIDS may fully understand the immediate cause of his/her illness as the virus, but will still seek traditional healers opinion as he/she may believe that he/she may be bewitched. Witchcraft in many traditional communities is believed to be the cause of AIDS. Van Dyk (2008) and Walker *et al.*, (2004) state that professionals such as social workers and counselor should stress the immediate cause of HIV/AIDS as a germ which is sexually transmitted.

Children should be informed and involved when there is someone ill so as to help you share your sorrow, ignoring them may leave them with feelings of sorrow and guilt (Kubler-Ross, 1985). Credo Mutwa a traditional healer known to have cared for AIDS orphans in Children First (2000) notes that children are more intelligent than credit that adults want to give them, hence they can be told about HIV/AIDS. Children First (2000) reported that if a death occurs in a family and it is hidden from children, they can come and confront you for it. It needs to be understood that funerals are for the family. Kubler-Ross (1985) informs that cultural, religious and local customs needs to be respected; in addition Kubler-Ross (1985) is of the opinion that families and communities should grant

children and mostly adolescence the opportunity to pay their last respect to their loved ones in a dignified manner.

Culture is one of the areas that have either played a positive or a negative role in the lives of the AIDS orphans and their family relations. Within the African culture, death is a topic that is not discussed with children. Deacon *et al.*, (2007) states that the reluctance of caregivers to discuss death and illness with minors in fear of stigmatization and discrimination can result in parents not preparing their children for their death. Deng *et al.*, (2007) reports that lack of knowledge, existing culture, social and religious norms, values and beliefs may impact on families and communities. Kubler-Ross (1985) states that families have a tendency to avoid sharing the truth about the death of a loved one and rationalize that telling them will upset them or that they are too young to be able to cope with the crises. Kubler-Ross (1985) adds that losing a loved one is so much of a tragedy hence it is important to allow people to express their emotions rather than suppressing them.

## **2.9 The coping strategies of HIV/AIDS orphans**

Foster *et al.*, (2000) state that in many AIDS affected communities, the mechanism that keeps families and households together from destitution is comprised of material, labour and emotional support. Foster *et al.*, (1997) reported that orphans may put pressure on older relatives who become primary caregivers; they continue by saying that these children may have to relocate from their familiar neighbourhood and siblings may have to be split apart and this may harm their development. Foster and Williamson (2001) noted that children prefer to stay together in their original residence than being separated

from each other. Foster *et al.*, (1997) noted that some family members fear taking in a child whose parent has died of AIDS because they suspect that orphan is also HIV positive and hence fear for them and their own children; thus the AIDS orphans are often isolated within the family. Alpaslan and Mabutho (2005) discrimination can result in a family being isolated, and children being treated as contagious. Teasing of children can be worrisome and can result in the self-esteem of these children being affected. Foster (2000) highlighted that the extended family has become one of the greatest exploiters of poor children. Ms. Mdaka a South African grandmother caring for seven grandchildren, who are AIDS orphans, attended the 16<sup>th</sup> International AIDS conference and reports that she counsels orphans about bereavement and advises teachers to understand the mood swings of the orphans as they might be thinking of their parents. Ms Mdaka also relates to other grandparents and caregivers in preparing the future of these children, the development of wills and fundraising so as to save for the future of the orphans. Van Dyk (2008) shares the importance of Parents developing memory boxes with their children so as to remind them of who they are. Deacon *et al.*, (2007) and Bezuidenhout (2004) highlight the importance of parents informing their children of the relevant extended family members they will stay with when parents are deceased. During the time of the death of a loved one Kubler-Ross (1985) state that friends can be a good source of support to the bereaved.

## **2.10 Relevant support systems for HIV/AIDS orphans**

Van Dyk (2001) also believes that religious organisations, schools, Health and welfare organisations should play a very important role in supporting these children and should continuously visit them. Van Dyk (2008) highlighted that the experience with existing

models of care has shown that family and community-based are the best ways of meeting the child's physical, psychological, emotional, educational and spiritual needs. Youth groups should also get involved in supporting, educating and caring for these children in innovative ways to equip them with skills to cope under difficult circumstances (Van Dyk, 2008). Smart (2003) reported that a Salvation Army youth project in Zimbabwe has capacitated youth on how to deal with the parental role that they carry and the following life skills are rendered namely teenage parenting so as to help them in caring for their siblings, children's rights, hygiene, nutrition and First Aid.

Rau (2002) states that in a study done in South Africa research has discovered that 90% of South African children are attending primary school leaving over 1.5 million out of primary school and 10% of South African children attending pre-school. Smart (2003) reported that discrimination at school, in health services and other institutions compromises their rights and frequently limits access to opportunities and benefits. Children aged 15-17 years of age are the least to likely access clinics for sexually transmitted infections (STI), by their own choice or most likely because of procedures and attitudes at local clinics (Rau, 2002). Research has shown that children whose parents died of HIV/AIDS are more prone to discrimination than children whose parents die of other diseases.

## **2.11 Conclusion**

The theoretical framework used in this study was presented. The researcher has attempted to obtain an understanding of the development of an adolescent in conjunction with the developmental challenges experienced by adolescents. The guidance towards dealing

with grief is explored. The following chapter discusses methodology that was applied in conducting this study.

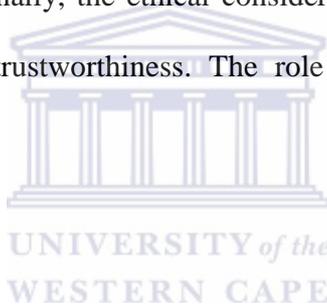


## CHAPTER THREE

### METHODOLOGY

#### 3.1 Introduction

This chapter outlines the methodological procedures used to explore the experiences of adolescents who had lost their parents to HIV/AIDS. The study starts with a description of the research design, which is followed by the description of the study site, the participants, and the sampling procedure. The data collection procedures and data analysis are also discussed. Finally, the ethical considerations are presented, as well as mechanisms used to ensure trustworthiness. The role of the researcher in-terms of reflexivity is also presented.



#### 3.2 Research Design

Patton (1990) states that qualitative methods are orientated towards exploration, discovery and inductive logic. Patton (1990), Skinner (1990) and Rubin and Babbie (1997) state that this method is designed to reveal the respondent's in-depth emotions, thoughts, experiences and perceptions. Denzin and Lincoln (2001) state that emotions are important to understand and theorise relationships. Leedy (1997) states that qualitative research is a broad term that encompasses a variety of approaches to interpretative research. Furthermore, Leedy (1997) states that centuries ago, when reading and writing were not yet developed, people shared their observations and experiences through detailed oral descriptions that were later combined into a series of stories. These stories helped others to understand what was previously observed and experienced.

Denzin and Lincoln (2001) state that qualitative research is difficult to clearly define as it has no theory or paradigm that is distinctly its own. Mouton (2001) states that one of the major distinguishing characteristics of qualitative research is the fact that the researcher attempts to understand people in-terms of their own definition of their world. This study explored the experiences of adolescents who had lost their parents through HIV/AIDS which included the challenges of being stigmatised and ostracised by their community. Kirk and Miller (1986) and Williamson (2004) state that qualitative research is best used in unexplored areas where it would be premature to define and measure patterns and variables. Strauss and Corbin (1998) state that qualitative research means any type of research procedure that produces findings not arrived at by statistical procedures or other means of quantification. Similarly, Silverman (2001) states that methods used by qualitative researchers exemplify a common belief that they can provide a deeper understanding of social phenomena than would be obtained from purely quantitative data. Leedy (1997) states that qualitative methods might be considered warm in approach while quantitative might be considered cold as and an impersonal experience. According to Shank (2006) trying to mix qualitative and quantitative methods is like mixing oil and water. Shank (2006) states that qualitative research enhances our understanding and insights into a situation. According to Patton (1990) critics of qualitative inquiry have argued that the approach is too subjective due to the fact that the researcher is instrumental in both data collection and interpretation. The qualitative approach used in this study focuses on is the interpretivists approach. Strauss and Corbin (1998) cited in Neill (2006) state that interpretivism or qualitative approach is the way to gain insights through discovering meaning by improving our comprehension of the whole. Husserl

(1965) cited in Kelliher (2005) states that interpretivists believe that reality is not objectively determined but socially constructed. Williams (1998) states that interpretivists views the world as a socio-psychological construct where there are multiple realities forming in the interconnected whole. Kelliher (2005) informs that interpretivism in its nature promotes the value of qualitative data. Similarly, Myers (1997) corroborates that this research paradigm is concerned with the uniqueness of a particular situation. This methodological approach was relevant to this study, as it aimed to understand the in-depth experiences of the adolescents who have lost their parents through HIV/AIDS.

This method has been identified as it requires the researcher to ask the extent of the problems experienced by the orphaned adolescents, as well as their feelings towards their experience. The strength of qualitative research is that it is unique and exploratory. It focuses on the deeper understanding of the experiences of the participants.

### **3.3 Study Site**

The area of Gugulethu falls under Wards 40, 41, 42 and 44 in the Wynberg Magisterial District of Cape Town Municipality. Gugulethu is situated 8km north East of Cape Town's CBD and is bordered by Nyanga, New Crossroads, Manenberg, Heideveld, Montana, Charlesville and the Airport Industries area. It is split into four principal urban areas – 1, 2, 3, and 4, that enclose the nine suburbs of Tambo Square, Barcelona, Europe, Kanana, New Rest, Phola Park, Kick Hostels and the Waterfront. Most of the houses are owner built from wood, sheet metal and plastic and some are made of expensive brick and tile construction. Gugulethu's day hospital was built in 1964 at NY3. There is an infant clinic on the corner of NY3 and NY 1 that is also used for physiotherapy, family

planning and X-rays. There is also a TB clinic that is operating at the Uluntu Centre. There is one in NY133, which is attended by TB and HIV/AIDS patients. There are 33 registered social Development NGOs operating in the Gugulethu area (Children's Institute of UCT).

### **3.4 Access to the study site**

De Vos *et al.*, (2007) state that it is very important to gain permission to enter the field that has been decided on. They continue by saying that it is important that all people that will be involved in the study be consulted. Moris (2007) and De Vos *et al.*, (2007) state that gaining entrée to the research site goes beyond formal agreements and arrangements to gather data. Moris (2007) continues by saying that gaining entry to the site begins with engaging gatekeepers. The participants of this study were the clients of Ikamva Labantu. Ikamva Labantu is an organisation that is rendering foster care and therapeutic services to HIV and AIDS orphans within the Gugulethu community. In conjunction with the Trauma Centre they offer psychotherapy training for the foster parents so as to assist them to deal with the behaviour of the orphans as well as therapy for the AIDS orphans, so as to help them deal with their loss. At the time of the study this organisation was rendering foster care services to a total of forty-three orphans. A telephone request to conduct the research with the participants was sent to manager of Ikamva Labantu. The researcher was then requested to put her request in writing which she did and the application was approved. Permission to conduct this study was granted in writing.

The researcher then met with the foster parents as well as the participants. Even though permission to conduct the study was granted by Ikamva Labantu this was only the

beginning of the journey, the researcher had to gain permission from the caregivers to first consult with the adolescents, as they were still under age and their consent was very important. It was critically important to build a positive relationship with the caregivers, and the adolescents from the onset, as I knew if this was not done correctly; it could result to resistance from these caregivers. This could further impact on the influence they might have on the participants. The researcher requested permission to meet the foster parents and address the request at their regular meeting. The foster parents granted permission. The purpose of the study was presented to the caregivers. A number of questions were asked such as (why I had chosen this group of children) specifically, (were there no other children in my area) which is Langa that I have decided to come to Gugulethu? Whether their grandchildren's names and their family identity will be used in the study had to be clearly explained as well as the reason for choosing Gugulethu was due to the fact that the researcher worked in the area as a social worker before.

The researcher also highlighted that should they allow their grandchildren to participate in this study, all their personal information will be treated with outmost confidentiality and none of their names will be used in the study. The caregivers were informed that a copy of the report will be granted to Ikamva Labantu meaning that they will have access to the report. The caregivers were pleased and some felt that they did not know much how these adolescents felt as some never spoke to them about their feelings. The next step of entry was to gain consent from the children themselves. The researcher decided to make individual appointments with each child. Each adolescent was given the purpose of the study and the fact that they were not obliged to participate in the study. It was explained that their participation will make a difference in improving the lives of other

adolescents in the same situation. Some of the adolescents were prepared to participate in the study. A few were not comfortable in participating and the researcher did not force them to do so. This helped the researcher in the selection of the participants based on these children agreeing to participate in the study.

### **3.5 Participants**

Patton (1990) states that sampling is the act of selecting a suitable sample, or part of a population for the purpose of determining parameters of the whole population. De Vos, *et al.*, (2005) and Williams (1998) state that the sample that is used should compose of the elements that contain the most characteristics, representatives or typical attributes of the population. A total of twelve participants were purposively selected. According to Bailey (1982) and Welman, Kruger and Mitchel (2007) purposive sampling is the most important type of non-probability sampling. Similarly Dolores and Tongco (2007) concur by saying that it is a technique that does not need underlying theories or a set of number of informants. The researcher felt that purposive sampling will give the most in-depth data about this study. Patton (1990) states that purposeful sampling is the strategy of selecting a smaller section of the population that will accurately represent the patterns of the target population. In the case of this study it was to explore the experiences of adolescents who have lost their parents through HIV/AIDS. Welman, *et al.*, (2007) corroborate that the advantage of purposive sampling is that the researcher can use his or her research skill and prior knowledge to choose respondent. Patton (1990) states that when selecting a sample the researcher sets a criterion and picks all the cases that meet that criterion. The criteria which were used in selecting the participants were as follows, they had to be on the foster care database of Ikamva Labantu, they had to reside in

Gugulethu, they had to be HIV/AIDS orphans and they were both boys and girls. The participants had to be adolescents ranging from age 12 to 18 years old that had lost their parents through HIV/AIDS and were in foster care, either under the supervision of maternal or paternal grandparents, aunts and even family friends. Lastly willingness to participate was important. A total of twelve orphans were willing to participate and their ages ranged from 14-17 years of age. Of the twelve participants, eleven were still at school and one was out of school.

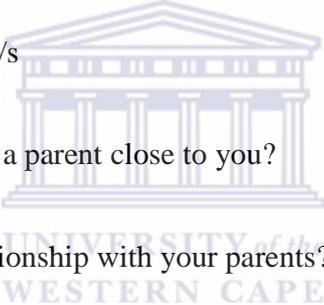
All the participants in the study were informed that participation is voluntary and at any given time should they want to withdraw from the study permission will be granted. A total of twelve participants were selected. However, three of the participants decided to withdraw during the interview process, thus a final sample of the adolescents participated were nine. The researcher respected their choice as they were informed from the start that no one would be forced to participate, (see Appendix 1).

### **3.6 Instruments**

An interview guide was designed to collect data (see Appendix 4). One interview was conducted with each child. This interview guide was divided into two sections. The first section covered the background and demographic information, knowledge of HIV/AIDS and family relationships. Background and demographic information are very important for every study providing an understanding of with the participants and the context of the participants and the study, for example factors such as age, gender, race, level of education, socioeconomic status and geographical area all play a role in describing the participants. Family background information was administered through the use of a

family tree. Though family can be a very diverse concept, in this study the focus was based on the extended family, as it is crucial among black South Africans.

The second section contained in-depth information, for example loss of parents, educational, health and religious experience, economic pressure and support systems. The interview guide was translated into isiXhosa, which is the language spoken by the participants. The interview guide was only issued for those participants who consented to participate in the study (with the permission of their caregivers). The interview sessions were approximately one hour in duration. The interview questions were structured in such a way that they could respond to questions relating to parent child, prior to the death and after the death of the parent/s

- 
- Whom do you regard as a parent close to you?
  - Tell me about your relationship with your parents?
  - What type of activities did you use to do with your parents?
  - How did you find out about your mother or father's HIV/AIDS status?
  - How did you react when you were told that your mother or father has died?
  - How was your education affected by your parent's illness and death?
  - How are children who have lost their parents to HIV/AIDS treated at the local clinics?
  - Are there any programmes or projects run at your church for children orphaned by HIV/AIDS?

- How did the illness or death of your parents affect your financial situation?
- Who are the people who helped you deal with the illness and death of your parents?
- Are there any organisations in your community that supports children who have lost parents through HIV/AIDS?

### **3.7 Data collection**

Permission to conduct the interviews were requested from the office manager at the Social Development office and was granted. Interviews were then held at the local office of Social Development, in a child friendly interview room. The purpose of the interview was once again explained to the participants so as to ensure that they were willing to participate in this study. The researcher then informed the participants that she would like to record their conversation using the audiotape and take notes for the purpose of accuracy. All of the participants accepted this request. Strauss (1990) states that the key informants of interviews can be tape recorded to ensure accuracy of the information. The conversations were also recorded by means of hand written notes. Bogdan and Biklen (1992) state that the purpose of interviews is to gather data in the participants' own words so that the researcher can develop insight into how the participant interprets some of the pieces in their own world. Patton (1990) states that unstructured interviews allow the interview process to be more conversational between the researcher and the participant.

### 3.8 Data analysis

Alpaslan *et al.*, (2005) states that qualitative data analysis is all about sifting and sorting the masses of information acquired during the process of data collection. Thematic data analysis is the method that has been used to analyse this data. According to Braun and Clarke (2006) thematic analysis is a method for identifying and reporting themes within data. Braun *et al.*, (2006) continues by saying that thematic analysis is widely used but there is no clear agreement about what thematic analysis is and how you can go about doing it. Patton (1990) states that a qualitative inquiry strategy emphasises and builds on several interconnected themes. Patton (1990) continues by saying that qualitative designs are naturalistic, in that the researcher does not attempt to manipulate the research setting, rather the point of using qualitative methods is to understand naturally occurring phenomena in their natural occurring states. There are six phases of analysing thematic data (Braun *et al.*, 2006). The first phase is called familiarising yourself with data, the second, phase is called generating initial codes. The third phase is called searching for themes, the fourth phase is reviewing themes the fifth phase is defining and naming themes and the last phase is producing a report.

During this phase the researcher is transcribing the data, reading and re-reading the data, noting down initial ideas (Braun *et al.*, 2006). During this phase the researcher goes over to read the data in that process generating themes. After the interviews the researcher listened to all the tapes several times so as to start identifying possible themes that were emerging. All recordings were transcribed verbatim, from the tapes into notes. The researcher did all the transcriptions. Pauses, hesitations, unclear speech as well as the researcher's input were indicated. Being involved with the interviews and the process of

transcribing was an advantage as the researcher could include non-verbal information and impressions from field notes in the analysis. The initial stage of the analysis involved the immersion of the data (Strebel, 1994). The purpose for this was to acquaint the researcher with the material and identifying themes and patterns (Potter and Wetherhall, 1987). All the interviews were conducted in Xhosa. They were then translated into English by a language expert.

The second phase is called “generating initial codes”. Braun *et al.*, (2006) states that during this stage the researcher would have familiarised him or herself with the data, and have generated an initial list of ideas about what is in the data and what is interesting about them. Welman *et al.*, (2007) state that theme identification is one of the fundamental tasks of qualitative research. Themes can be described as “umbrella” constructs which are usually identified by the researcher before and after data collection (Welman *et al.*, 2007). After the researcher had read and typed all the transcriptions; the different themes that were emerging. This information was then converted into different codes. According to Marshal and Rossman (1999) cited in De Vos *et al.*, (2005) thematic process is the most complex, ambiguous, creative and enjoyable phase. Welman *et al.* (2007) concur that coding is a process of analyzing and making sense of data that have been collected. According to Miles and Heburman (1984) finding the patterns is easy and rather a relatively natural process for researchers. Brenner (1985) states that due to the richness of material gained through the qualitative methods there is a danger of trying to cover too many topics in too much depth.

The third phase which is searching for themes. Braun *et al.*, (2006) state that during this phase the researcher refocuses the analyses to a broader level of themes. According to

Braun *et al.*, (2006) this phase commences when all the data has been initially coded and collated, and the researcher has a long list of different codes which has been identified across the data set. The groups of coded themes were read on numerous occasions. Similarities, differences, and contradictions emerged in which resulted into sub-themes. The sub-themes were created for sections which indicated a relationship or overlap between different themes. The original text was studied continuously so as to ensure that the themes corresponded with the data.

The fourth phase is called reviewing themes. During this phase the researcher identifies real themes and those themes that might be dissolved. Braun *et al.*, (2006) call this phase a phase of reviewing and refining your themes. Because of the wealth of data generated in this study the researcher was not able to make use of all this information hence a lot of it was omitted. The themes and the possible interconnections were mapped and quotes were selected. Braun *et al.*, (2006) state that a thematic map assists the researcher to start thinking about the relationship between the themes and the different levels of themes e.g. main overarching themes and sub-themes, this was done so as to give meaning to the responses of the participants.

The fifth phase which is defining and naming of themes last phase is called defining and naming themes begins when the researcher is satisfied with her thematic map (Braun *et al.*, 2006). Braun *et al.*, (2006) suggest that sub-themes are themes within themes, it is important thou not to over load your themes. During this phase it was important for the researcher to merge some of the themes and make sub-themes of the others so as to accommodate as much data as possible. The different name given to the themes and sub-themes were at this stage refined.

The final phase is to produce a report (Braun *et al.*, 2006). During this phase the researcher has a fully worked out set of themes that involves the analysis and the write up of the report. Braun *et al.*, (2006) state that during this phase the researcher must be able to tell his/her complicated story. The story must contain sufficient evidence of the themes within the data. The researcher tried to highlight the different extracts as they were telling the story of the participant and this was in relation to the research question.

### **3.9 Ethical considerations**

De Vos *et al.*, (1998) define ethics as a set of moral principles, which is suggested by an individual or a group. Mouton *et al.*, (2001) concur by saying that the intention is to confirm standards required in service provision and to ensure that social workers know and understands the standards to conduct clients, as the public expect of them. Gray (2005) agrees that ethics of research concern the researcher's appropriate of the behaviour in relation to the participants or those who are affected by it. In engaging with this research project it was important for the researcher to consider the importance of this study. Consent to conduct this study was first granted by the higher degrees committee at the University of the Western Cape. The researcher then found the following ethical conditions relevant when conducting this study.

#### **3.9.1 Confidentiality**

De Vos *et al.*, (1998) states that strategies to maintain confidentiality are critical when conducting a study, if not this could harm those that are being studied. William (2004) states that it is important to assure the participants that no one who is not directly involved in the study will have access to this information. Gray (2005) concur that it is

important to protect all forms of communications and client records. It was important to store all the relevant information about the participants in a safe place and keep all the information about the participants as confidential as possible. The transcripts and recordings were kept in locked up cupboards at all times and were only available to the supervisor, the colleague who assisted with the translations from isiXhosa to English and the researcher. In order to promote the principle of confidentiality the names of the participants were not used in the study. Participants were each requested to provide a name that they would like the researcher to refer to them.

### **3.9.2 Voluntary participation**

William (2004) states that it is important that people not be coerced to participate in a research. Gray (2005) concurs with William that the researcher needs to inform the participants that they have the right to be contacted at reasonable times and to withdraw at any given time. Voluntary participation for all the participants was important to the researcher as this gave the participants the opinion to be as honest as possible. They were informed that participation is voluntary and under no conditions were they obligated to participate if they were not comfortable. Hence, three of the participants who later withdrew from the study were respected for their decision. De Vos *et al.*, (1998) states that the emphasis should be placed on accurate and complete information so that the respondents will be able to make voluntary decisions about their possible participation.

### **3.9.3 Informed consent**

William (2004) states that prospective participants must be fully informed about the procedures and risks involved in research and must give their consent to participate in the

study. The purpose of the study was explained to the participants so as to ensure that they were willing to participate in this study. Verbal consent was granted by both the foster parents and the adolescents. The participants were made aware that they are not obliged to participate in this study. Hence, should they feel uncomfortable their request to withdraw will be respected. The researcher felt that as the adolescents were young it was important to gain permission from the foster parents. It was also important to respect the adolescents as people who have rights, hence it was important to confer with these adolescents who had lost their parents through AIDS.

Consent forms were given to participants once they had been provided with all the information pertaining to the study and had expressed their willingness to voluntarily participate. The caregivers were also requested to sign consent forms (see Appendix).

#### **3.9.4 Debriefing**

HIV/AIDS is a very sensitive topic. It was critically important for the researcher to be aware that the interviews could have touched on very sensitive topics. This could have resulted in the participants having difficulty dealing with issues, for example they could have recently lost their loved ones and were still struggling with the loss. The researcher then had to ensure that arrangements for debriefing for those who might need this service were available. This was then arranged with the social workers of Ikamva Labantu.

#### **3.10 Trustworthiness**

According to Patton (2002), validity and reliability are two factors which any qualitative researcher should be concerned about, while designing a study, analyzing results and

judging the quality of the study. Validity and reliability are often known as trustworthiness (De Vos *et al.*, 2005). Lincon and Guba (1985) cited in De Vos *et al.*, (2005) propose four alternative constructs that more accurately reflect the assumptions of the qualitative paradigm. Gray (2005) informs that researchers from the naturalistic tradition argue that trustworthiness is more important than concerns over validity and reliability. Gray (2005) continues by saying that trustworthiness focuses on credibility, transferability, dependability and conformability.

The first alternative is called credibility. De Vos *et al.*, (2005) state that this is the alternative to internal validity in which the goal is to demonstrate that the inquiry was conducted in such a manner so as to ensure that the participants were accurately identified and described. The participants identified within this study were orphans who had lost parents through HIV and AIDS. They all resided in Gugulethu. The second alternative is called transferability. Transferability is an alternative to external validity or generalisability. De Vos *et al.*, (2005) state that in qualitative study transferability and generalisability to other settings may be problematic hence recommending triangulation as a multiple source of data. Additionally, designing a study in which more than one data gathering methods are used can greatly strengthen the study's usefulness for other settings. In this study an interviewing method was used. This was further enhanced by observation regarding the participants' behaviour during the interviews. Evidence was done by means of reviewing the captured data of the transcriptions. Lastly, the experience of the researcher of working with orphans and vulnerable children in the field of social work also enhanced her authority during the study. De Vos *et al.*, (2005) state that conformability captures the traditional concept of objectivity. Lincon *et al.*, (1985) cited

in De Vos *et al.*, (2005) stresses the need to ask whether the findings of the study could be confirmed.

### **3.11 Reflexivity**

Reflexivity is an approach that is derived from a humanistic approach, as a researcher this then meant that the researcher had to become self conscious and reflect on her actions during the interviews. Banister, Burman, Parker, Taylor and Tindali (1994) state that reflexivity is one of the important characteristics of qualitative research through which knowledge is produced and constructed. Miles and Huberman (1984) state that flexibility provides the researcher with means of collecting rich and complex data regarding different topics. Flexibility was useful in this study as I made use of a pattern that suited me and this helped me to gain rich data from the engagements. The experience in the field of social work and working with orphans and vulnerable children helped in the way the researcher conducted herself as the researcher is guided by professional ethics. The selection of the participants was also conducted at an organisation that worked within the study's required criteria. The interviews gave the researcher an opportunity to collect the most extensive data on each participant interviewed. They allowed the researcher to explore the meaning of central themes in the life of the participants. The interviews provided the necessary flexibility to adapt methods to the needs of each individual research situation. Any misunderstanding on behalf of both parties was immediately checked. Flexibility enables the interviewee to answer the questions as fully as he or she chooses and motivate their responses when required (Brenner, 1985; Mouton and Marais, 1991). Interviews were facilitated at a neutral and user friendly venue, where participants felt free to participate without fear of intimidation.

### **3.12 Conclusion**

This chapter focused on the methodology, of the study. The following areas were discussed, namely: sampling, instruments, data collection, data analysis, trustworthiness and reflexivity. The following chapter will present the findings and discussion that emerged from the data collection strategies.



## CHAPTER FOUR

### FINDINGS AND DISCUSSION

#### 4.1 Introduction

The aim for this study is to explore the experiences of adolescents who have lost their parents through HIV/AIDS. This aim was supported by the following objectives, to understand and describe the experiences of adolescents who have lost their parents through HIV/AIDS; to explore the challenges of adolescents who have lost their parents through HIV/AIDS; and to understand the coping strategies of adolescents who have lost parents through HIV/AIDS. A phenomenological theoretical approach was used so as to gain a deeper understanding of the experience of the adolescents who have lost their parents through HIV/AIDS. Van Manen (1990) and Todres and Halloway (2005) highlighted that the goal of phenomenology is to fully describe lived experiences. Its emphasises is that only people who have experienced phenomena can communicate them to the outside world and answer questions as an exploration of the essence of lived experiences. This chapter discusses the results of the study. The themes are presented in three parts. Section (A) deals with the experiences before and after parental death and Section (B) deals with challenges before and after death finally section (C) deals with coping strategies adopted by adolescents who have lost their parents through HIV/AIDS.

#### 4.2 Biographical profile of participants

All participants provided pseudonyms for the purpose of anonymity. Background and demographic information is critically important for every study as it gives a solid

understanding of the participants involved in the study and how their unique circumstances will impact the study, e.g. age, gender, race, level of education, and geographical area. All the names used to present the participants are pseudonyms. Some of the participants used were residing with their maternal family members while others were residing with their paternal family members and there was one participant who stayed with her older siblings. Their individual profiles are as follows:-

**Thembile** is a 15 year old boy, in grade 10. He has one older brother. His home language is isiXhosa. Thembile belongs to the Anglican Church. Thembile is a child of a single parent and has been staying with his maternal grandparents since he was born. He was born in Gugulethu. Thembile has had no relationship with his father since the death of his mother. Some of Thembile's responsibilities are house chores such as cleaning the yard, washing his school uniform and taking his grandmother (who has endured a stroke) for walks. Thembile depends financially on his grandparents.

**Mbali** is 16 years old. She has a brother who is 24 years old. Mbali's home language is isiXhosa. She is a member of the St Paul's Pentecostal Church. Mbali is currently staying with her maternal aunt who is HIV positive, her uncle, her brother and three cousins. Mbali stays at the formal settlements of Gugulethu. Mbali has never met her father. She had been informed by her mother that he was a student from Namibia who studied at the University of the Western Cape. Mbali grew up at her maternal house since she was born.

**Noluthando** is 17 years old. She has a brother who is fourteen years old and a sister who is eight years old. She informs that the father of her younger sister is HIV positive. Noluthando is a member of the Presbyterian Church. She has left school as she was (tired

of suffering and depending on friends for food) and is currently looking for work. Noluthando is currently responsible for all the house chores, as well as caring for her siblings. Noluthando states that they are children of different fathers and she had a poor relationship with her biological father, since her parents broke up.

**Yoliswa** is 15 years old. She is the only child of her mother. She was born HIV positive. She currently lives with her maternal grandmother, her maternal aunt, uncle and three cousins. Yoliswa belongs to the Old Apostolic Church. She attends the Red Cross Children's Hospital for her treatment. Her doctor informed her about her HIV status, when she wanted to know why she is the only child taking medication in the house. Confident Yoliswa does not think much about her status, as she feels she (is normal like any child in the house).

**Prude** is 15 years old. She likes this name as it reminds her of a friend she used to have that was called Prudence that used to attend at her previous school. Her home language is IsiXhosa. She has one brother who could not walk until he was about five years. She believes this has affected him as he is a slow learner. Her father used to visit occasionally and she last saw him after the death of her mother. She is currently in grade 10, does house chores. She stays with her maternal family. She calls her grandmother Mama (mother) as long as she can remember. She stays with her cousins, her three aunts and grandmother. Prude belongs to the Old Apostolic church.

**Felicia** is 17 years old. Felicia believes that HIV is a bad disease that takes parents away from their children. She has only stayed with her mother who was a librarian all her life. She knew her maternal family but her relationship grew stronger after her mother got ill

as they had to relocate to her maternal home. Felicia was forced to go and get money for food in whatever way by her aunt who felt that she was not contributing towards food. Little did she know that her aunt was in receipt of the funds left by her mother. She was at one stage suicidal until rescued by her mother's friend Vicky (not real name) who decided to take her in to her home. She calls Vicky mummy, and Vicky's children her sister and brother. Felicia does the house chores willingly with her sister and brother. She belongs to the Methodist Church.

**Thando** is 15 years old. They were born triplets. Thando's one sister died when she was about six months old. When they were about three years old their mother also died. His maternal rand mother went to throw them by the river as she believed that they were a curse. They were rescued from their paternal grandmother's abuse when their maternal aunt came to fetch them and brought them to Cape Town. He is currently staying with his maternal grandmother, aunt, uncle, nieces and nephews as well as his surviving twin sister.

**Linda-** is 15 years old. She is currently living with her siblings. Her eldest sister, who is practicing Rastafarian, is currently looking after her and her other siblings. Her sister left school to take care of them through selling fruit and veggies. Linda stated that her mother was married to her father, and they used to stay in Khayelitsha, while her older siblings used to stay in Gugulethu with her maternal family. Her father used to drink excessive amounts of alcohol and become abusive. Due to the abuse that used to happen in the house her mother decided that she go and live with her siblings in Gugulethu, as they were staying in Khayelitsha at the time. After the death of her father who was HIV positive her mother came to live with her children.

**Sinoxolo** is 16 year old. Sinoxolo is currently living with his paternal uncle and aunt, and their two children. Sinoxolo has two siblings who are currently staying in the Eastern Cape with his paternal aunt. Sinoxolo acknowledges that his current caregivers are his mother and father, but informs that his biological mother and father are his real parents. He hates HIV/AIDS as he states that he does not have parents due to this disease. His parents never told him of their status but overheard his uncle and aunt talking about this disease that has (destroyed their family within a short space of time). Sinoxolo is very close to his siblings though separated by geographical distance. Sinoxolo has been living with his paternal family since the death of his parents. He is religiously affiliated to the Methodist Church.

#### **4.3 Discussion of Themes and Sub- Themes**

The results of this study resulted in seven themes with accompanying sub-themes. These emerged from the semi- structured interviews carried out with the adolescents who have lost their parents through HIV/AIDS. These themes presented challenges experienced by these orphans in terms of their culture, their socio-economic status, and the fact that while they had the right to be children thus becoming caregivers themselves. This includes positive and negative experiences with their caregivers post-parental loss. The emotive reactions of the adolescent AIDS orphans due to losing a support system and the impact of the deteriorating health of the caregivers to these orphans are explored.

##### **4.3.1 SECTION A: Experience before and after parental loss**

- Parent-child relations

- Parental activities with children
- Being told of parental HIV status
- Experience of care
  - Deteriorating health of caregivers
  - Positive care
  - Negative care
- Loss of a support system
- Emotive reactions



#### **4.3.1.1 Parent-child relations**

An illness like HIV/AIDS can be difficult due to the complexity of the related problems that accompanies it. These are problems such as opportunistic infections, stigmatisation and isolation that affect people living with HIV/AIDS. Norman *et al.*, (2005) reported that research has found that HIV-positive women are described as isolated, unsupported, powerless and invisible primarily because of their status as women and the fact that the majority of HIV-positive women are black and poor. Murphy *et al.*, (2003) cited in Norman *et al.*, (2005) highlighted that parenting with HIV is imbued with a variety of dilemmas and challenges. Some of the orphans were never told by their parents about their status. What they know is that while their parents were ill they loved them. The participants shared the affection that their parents had for them as they expressed it all the

time some sharing even during their last days of life parents would express their love to them. Bezuidenhout (2004) notes that nuclear family are more vulnerable in times of crises, however its smaller size may increase the bonds of affection between its members and strengthen the foundation of emotional support that is also needed in times of crises.

The following excerpts share this experience,

Linda shares her relationship with her mother

*My mother always used to tell me that she loves me. Even when she had brought me to Gugulethu she told me that it is better to be in a stable environment where there is no fighting.*

She adds

*Even when she lay sick in hospital she always told me that she loves me I must never forget that. I would always sleep next to her and she would cuddle me.*

Mbali shared the following:

*My mother loved me very much*

Prude in expressing the love she had for her mother shares the following

*I used to rub her when she felt that her legs were feeling cold and when she was in pain*

Noluthando shared the following:

*I had a good relationship with my mother and my mother used to tell me that she loves me all the time.*

Thando, who lost his mother at a younger age, even though did not have the physical experience where his mother verbally expressed her love for him and his siblings believes through the inputs given by other people who knew what a loving person his mother was that she loved him and his siblings very dearly. The following excerpt shares this information.

*I never had the opportunity of knowing my mother that way but I know that she loved us very much as people are saying she was a very caring person.*

#### **4.3.1.2 Parent activities with children**

Children expressed positive relationships they had with their parents, and memories that keep them going, even during difficult times. Some of the children shared the material goods that their parents would buy them as a token of love, and that alone made them feel loved by their parents. The activities and house chores they did together kept them close as a family. The following excerpts presented by the participants present some of these inputs

Thembile who is currently living with his maternal grandparents shares the following:

*She [mother] used to buy me clothes and bring me luxuries like sweets when she comes from work.*

Sinoxolo, whose father was the breadwinner while his mother was a house executive shared:

*My father used to bring us [participant and siblings] fruit and when he is not tired used to play football with us.*

Yoliswa, who was born HIV positive, shares the following:

*What I remember the most about my mother is that she used to go to hospital with me for my checkups on our way back she would buy me Kentucky and take me to the movies.*

Mbali, a young girl who never knew her father as he came from Namibia to study in South Africa shares the following when she relates to the positive times she used to have with her mother.

*My mother used to take me out to the beach and we used to go and do shopping together every month end.*



Education was highlighted as one of the things that were seen as priority by their parents. This was shared by the participants as their parents would assist with their school work.

Some of the participants shared the following:

Thembile shared the following:

*Yoh! I remember she used to ask me to bring my books she wants to see them and help me with my homework*

Sinoxolo shared the following:

*My mother used to help me with my school work and I used to help her with the house chores like emptying the dirt bin and to put water in the bedroom was my duty.*

Felicity who was the only child to her mother and used to stay only with her shares the following

*I used to assist her with the unpacking of the groceries and the cleaning of the house.*

Prude shares the following as she remembers her mother

*One of the things that I miss that we used to do together as a family was to go to church together every Sunday and Wednesday evenings.*

#### **4.3.1.3 Being told of parental HIV status**

Research has indicated that one of the first and most difficult questions an individual struggles with after learning that he or she is HIV-positive is, with whom to share this news. Similarly, Lynch (2000) states that often parents find difficulty telling their children that they have a disease that could cause them (parents) to become sick and die during their children's early years. In engaging with the participants regarding who conveyed the news to them regarding the status of their parents, it was clear that some of the children were informed by their infected parents while others were informed by relatives. Parents had their own way of disclosing this information to their children even though in many instances it was clear that they did not (call HIV by name). Van Dyk (2008) emphasises that children themselves lacking knowledge, skills and means find themselves having to care for their siblings. The following excerpts were presented by the participants:

Seventeen year old Noluthando reports:

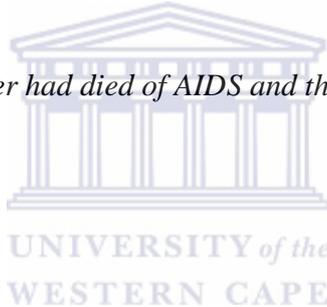
*She told us she was going to die and requested me to promise her that I will look after my siblings.*

It was evident that Noluthando had a positive relationship with her mother, hence she could engage with her regarding her status. This also shows the responsibility that some of these children had to carry inspite their age. HIV/AIDS is associated with domestic violence. In particular women who find themselves vulnerable to the abuse of their partners and spouses. Fifteen year old Linda, who had to be relocated from her parental home to go and live with her other siblings at the maternal house, due to the violent behaviour of her late father. Linda shares the following;

*My mother told us that my father had died of AIDS and that she was HIV-positive.*

Prude shares the following:

*I did not know until she died.*



When asked what she meant by (until she died) Prude shared that the red ribbons that were worn by some of the women and family members symbolised that she had died of AIDS. As she shared:

*I knew it when I saw her friends and my aunts wearing the red ribbons and there was someone talking about HIV.*

Thembile shared the following:

*I was worried to see her sick and in pain but I never knew it was HIV.*

Even though the parents were trying to protect their children by not revealing their status. They underestimated their understanding of HIV/AIDS. The fact that symbols such as the red ribbon was worn as a symbol of awareness could do more harm to these children. Lynch (2000) reported that there are numerous reasons why HIV-infected parents are reluctant to disclose their HIV status to their children such as protecting them from stigma that continues to surround HIV, the fear that the children will tell the secret to other children and that if it is revealed the child and family may experience rejection, ostracism and threats. Gilborn *et al.*, (2001) cited in Norman, Kadiyala & Chopra (2005) reported that in a study conducted in Uganda with HIV-positive parents 91.3% parents felt that it was good to talk to older children about their HIV/AIDS status. Norman *et al.*, (2005) found that in their study conducted in South Africa that some of the responses of the woman indicated that although they had the desire to be open with their children, the process seemed difficult to carry out. UNAIDS (2000) notes that a child whose mother or father has HIV begins to experience loss, sorrow and suffering long before the parents death, and since HIV can be spread sexually once it has claimed a mother or a father ; children find themselves thrust in the role of mother or father or both.

You need to provide a flow between all the literature and your findings. There are only blobs of information from the researchers. How do these link and then to your results as well.

#### **4.3.2.2 Experience of adolescents post parental loss**

Phenomenology emphasises that only people who have experienced phenomena can communicate them to the outside world, and answer questions as an exploration of the

essence of lived experiences (Grossmann, 1984). Jennings (1986) highlighted that essences were eminent, meaning that they were grasped in an act of reflective consciousness. Phenomenology consists of a reflection on the consciousness, which is on ordinary mental acts of perception, experience, desires and fear, thus consciousness commanded the fundamental position as the special medium that constituted all forms of “being” in the world (Grossmann, 1984 and Spiegelberg, 1989). Felicia due to the bad experience she had with her maternal aunt resulted in her being panicky even when reprimanded, she tells her story

*After I was evicted from my maternal home I by my aunt, I went to stay with Aunt Vicky my mother’s friend. I and Aunt Vicky’s daughter went to play until it was late. When we got home that night she told us to go back where we came from, I panicked and ran away. When I reached the NY1 Bridge, I decided to throw myself down for the cars on the N2 to knock me off. I had no one my mother was dead, my aunt did not want me and Aunt Vicky did not like me anymore. As I jumped off the wall, a voice of a man called me from behind, he caught me and asked me what I was up to, as I was crying he asked where I stayed I gave him aunt Vicky’s address. He took me home and told them what had happened. Aunt Vicky took me to church and the Pastor prayed for me. She said I must never scare her again*

Noluthando who had three siblings to care for while staying with an uncle who used to starve her and her siblings shares the following

*When my uncle is under the influence of alcohol, he starves my siblings and I, when he had eaten something let me say a bunny chow he does not mind starving even my baby sister [who was born HIV positive].*

Poverty is linked to poor nutrition, which in turn results in weakened immune systems leaving food-deprived people susceptible to opportunistic infections. Children First (2000) reported that malnourished children are more likely to suffer from infectious diseases because they need proteins and other nutrients in the body to fight diseases. In explaining her experience with her HIV positive baby sister's father she explains

Because we were struggling I gave him [father of baby sister] permission to look after her, at least she was going to be well cared for.

Amoateng & Heaton (2007) reported that even though sociologists for decades have written about two family structures namely the nuclear and the extended family system. Amoateng *et al.*, (2007) continues by saying despite the devastating effects of death due to HIV/AIDS most people still find family living arrangements usually with family members still the best. The findings of this research found that most of the participants were living with family members and most of them had been residing at these residents since their birth. However it was clear that after the death of their parents these children viewed their caregivers in different ways. According to Deacon *at al.*, (2007) and Van Dyk (2008) there are distinct developmental changes in how children viewed their caregivers. Pre-school children view them as nurturers; school age children see them as wizards and mentors and for the youth they become family role models. The nurturing that is highlighted by Deacon *at al.*, (2007) and Van Dyk (2008) was evident in the

positive inputs given by some of the participants. However more negative experiences were also highlighted.

#### **4.4.3.1 Loss of support system**

It is evident that these children lost a support system that had a significant role in their lives. The impact of orphan-hood on a child can begin long before the death of the parents. HIV/AIDS is associated with a long painful death, and children of HIV sufferers are forced to witness this. Deacon *et al.*, (2007) states that there are a number of stressors affecting orphaned children such as going to bed without food, not attending school, not rewarding rewards and praises, lack of an adult to confide in lack of material resources and fear to be infected with HIV/AIDS. Some of the participants spoke about how hurtful it was to watch their parents suffer and being unable to help them. The following excerpts captured the experience and the emotions of the participants.

Noluthando shared the following:

*She [mother] suffered a lot and she was in and out of hospital.*

She continues by confirming that it was painful to see her mother suffering by stating that:

*I used to cry when I saw her in pain.*

Sinoxolo shares his experience by stating:

*My father suffered a lot. I used to see him in pain.*

He continues:

*I was very heartbroken as I saw both my parents' health deteriorating in front of me and I could not help them.*

Linda shared that:

*She could not assist me with my homework anymore she was not even asking for my books to see my school work.*

This experience affected her and as a result she failed her midyear exams. This is illustrated in the following excerpt

*I never failed a class but after the death of my mother I failed the June exams.*

Deacon *et al.* (2007) states that parental illness can be disruptive and distressing for children. It seems that the above participant then developed a coping mechanism in dealing with the death of her mother as she continues by saying:

*I then realised that I will never stop thinking of my mother and it was best to move on and read my books.*

The above excerpt shows that the support that Linda got from her sisters who promised to support her encouraged her. In supporting this Richter *et al.*, (2004) suggested that it is important not to separate siblings after the death of a parent as they can be a good support for each other.

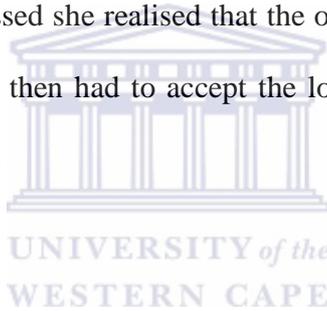
In sharing her experience after she was told the sad news Felicia reports the following:

*I did not cry I was just shocked and the tears could not come out. I only cried after a month that she was buried.*

When asked what the reason for her reaction was, she stated that

*I do not know. The only thing that came to my mind was how she could leave me alone.*

Kubler-Ross (1973) reported that one of the first reactions to a loss of a loved one is the feeling of numbness and disbelief. Van Dyk (2008) indicates that at this stage a person cannot cry or show any emotion at all. Kubler-Ross (1973) and Nord (1997) highlighted that anger; denial and isolation are usually a temporary defense which will soon be replaced by acceptance. Felicia used to live with her mother away from the extended family even though they did have that contact as a family. In the case of Felicia, it could be viewed that as the time progressed she realised that the only person she grew to know as a mother and friend dead. She then had to accept the loss. Hence she could only cry a month after her mother's death.



### **Positive care**

Amoateng & Heaton (2007) reported that even though sociologists for decades have written about two family structures namely the nuclear and the extended family system. Amoateng *et al.*, (2007) continues by saying despite the devastating effects of death due to HIV/AIDS most people still find family living arrangements usually with family members still the best. The findings of this research found that most of the participants were living with family members and most of them had been residing at these residents since their birth. However it was clear that after the death of their parents these children viewed their caregivers in different ways. Poku (2005) indicated that the extended family system is overwhelmed by the magnitude of the burden of caring for so many orphaned children. Meintjies *et al.*, (2003) and Poku (2005) informed that the extended family may

be absent or find it difficult to meet the material needs of the orphaned children. Poor women and elderly relatives may inherit several dependants. Van Dyk (2008) reported that the extended family system is greatly over extended in those communities affected by HIV/AIDS thus can often no longer take care of its orphaned children. Van Dyk (2008) continues by saying that children themselves lacking knowledge, skills and means find themselves having to care for their siblings. Their vulnerable caregivers might have to force some of these children to leave school and go and work or marry to secure more child labour and generate more income needed to support the family.

This study has shown that most of the participants were cared for by grandparents. Maternal grandparents were the caregivers that were identified as the most loving and kind caregivers by the participants. Aunts, siblings, mother's friends and lastly followed by the paternal family were also identified by the participants. This study showed that maternal families played the most important role in supporting these orphans. According to the African Charter on the Rights and Welfare of the Child (1990) as well as the South African Bill of Rights (1996), food, shelter, and clothing are some of the children's basic rights that need to be met if not by the individual's family, then by Government. The positive support that the participants experienced with their caregivers is highlighted in the following excerpts:

Thembile shares:

*I regard my [maternal] grandmother and grandfather as my parents.*

He continues by saying:

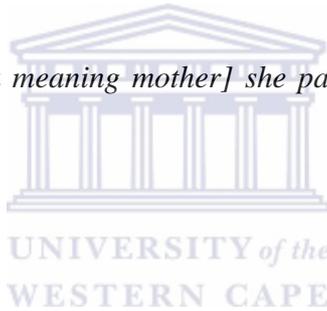
*They are the ones who buy me anything that I want. They pay my school fees and clothes like these Takies I am wearing.*

Thando shared this:

*She [maternal] grandmother reprimands us if we have done something wrong.*

The above excerpt indicates that these children were aware that they had to be reprimanded when they had done something wrong as their parents would. The material support that these children received from their caregivers strengthened the parent child relations with them. Hence, Yoliswa conveys the following:

*I call my grandmother [Mama meaning mother] she pays my school fees and buys me clothes.*



Thando highlighted:

*I call my maternal aunt mother because she is the one who went to fetch us from the Eastern Cape away from the abuse of my paternal grandmother.*

Thando highlighted the parental instinct that was within their caregivers by saying

*When there is not enough food in the house my grandmother will rather give my sister and I the food and stay without than to starve us.*

Yoliswa shared:

*When my mother vomited my aunt used to take me to her friend's house or to the shop while my grandmother was cleaning her [participant's mother]*

Yoliswa, who was born HIV positive, highlighted the following regarding the care and support she receives from her maternal family:

*They treat me well I don't even feel that I am HIV positive; I am treated like any other child here at home.*

Prude said:

*My maternal grandparents treat me well and they always try to make me happy*

Felicia shared that:

*My maternal grandmother and aunt buy my sister and I clothes, food, they pay our school fees, and give us money for excursions and school camps.*

Thando reported:

*The lady from next door used to give us food when we were hungry and comfort us when we were crying.*

Sinoxolo shared the following regarding the care of their caregivers:

*They buy me anything I want and can talk to them about anything they are very nice people.*

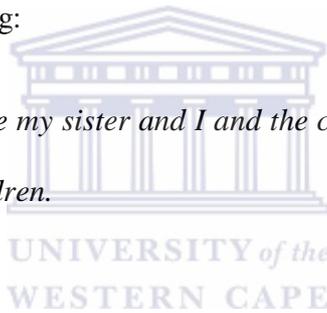
The above expert shows that older siblings were also seen as a source of both financial and emotional support

## Negative care

Phenomenology argues that disease is something one has, and not something one is (Munro, 2002). Nord (1997) argues that due to isolation and stigma related to HIV/AIDS it is easier to identify with the disease. Research demonstrates that from the beginning people with AIDS were divided according to their HIV/AIDS status thus resulting in relations among families and communities being affected (Poku, 2005; Walker *et al.*, 2005). Nord (1997) argued that people who have lost a loved one to HIV/AIDS, instead of identifying with the loved one, has a tendency of identifying with HIV.

Thando shared the following:

*She [stepmother] used to starve my sister and I and the clothes that my father bought us, she would give to her own children.*



Thando adds:

*My [paternal] grandmother and my stepmother treated my sister and me very badly. After the death of my mother and my other twin my grandmother decided to take my remaining twin and I and go and throw us by the riverside.*

In sharing his experience Thando continues by saying,

*She [paternal grandmother] said that my mother, my two twin sisters and I had brought a curse to the family. She even insulted her own daughter who was also HIV positive.*

According to Deng *et al.*, (1997) children affected by the HIV/AIDS epidemic experience exclusion, isolation, loneliness, stigma and discrimination. They continue by saying that

these children are looked down upon or ignored by adults and other children in the community. The negative experiences that were encountered by some of these orphans were so bad that some were even traumatised. This is illustrated by the inputs that were made by the above excerpts, the denial of not wanting to identify with the infected daughter and grand children clearly states the damage that stigma and discrimination has done to society and what these children had to endure.

Themobile reported the following:

*My aunt likes to hit me for anything sometimes without asking what has happened.*

Mbali illustrates:



*My brother treats me bad. He likes to hit me even if I've done something tiny.*

The Child Care Act, the Constitution and the United Nations Convention are strong in protecting children from any form of physical punishment. However, it is clear from both the above statements that these children are victims of this circumstance. The abuse that these children experienced, from being starved or evicted from the homes left these children with scars that they will never forget. The following participants reported:

The abuse that some of these children experienced as the result of some of the caregivers behaviours after abusing substances informs that:

Felicia shares her story:

*My second eldest aunt is the one who evicted me from my maternal home. When under the influence of alcohol she used to say that I am not contributing towards food so she will not dish me food. I never knew when she is going to dish me hence I decided not to eat her food.*

She continues:

*I have not been aware that she was receiving my pension grant until aunt Vicky [mother's friend] said she was going to follow up what happened to my mother's pension as she [mother] was a librarian.*

Deng *et al.*, (2007), in supporting the above statement, state that one of the common forms of stigma is gossip verbal abuse and name-calling. It seems that children realise more clearly the form of abuse when their parents are no longer around to protect them. This could be that the discrimination is done in a subtle way and due to the stress of having to deal with a sick parent his or her energies are focused on the sick parent and hence realises the bad treatment when the parent is no more. Deng *et al.*, (2007) states that discrimination manifests in three major ways namely overt, subtle, and insidious and in all these stigmas adolescents may realise that they have been labeled and have lost their social status. The following excerpt highlights this:

Mbali shares:

*The treatment did not change while my mother was still alive until after her [mother] death that my aunt started treating me badly.*

Thando highlights this:

*We had to fetch the wood from the field and the water from the river but we were not allowed to cook the food, maybe we were going to contaminate it with AIDS.*

Based on narratives given by the participants it was evident that the loss of their parents had affected them negatively, and in different ways. Some were still emotional and angry about their loss even though the incident had taken place a couple of years ago. What is evident from some of these participants is that they did not only lose a parent, but also a support system. The losses they experienced affected them in numerous.

### **Emotive reactions**

Cleiren (1993) reported that the impact of parental loss seems to be more severe in younger children than in adult children. Wolfet (1987) adds by saying that a young child's feelings are being tied and this is causing the child to be sensitive to the feelings of significant others. When a child experience a loss of a parent or a significant other a change occurs in the emotional atmosphere resulting in a threat of the child's security and his or her ability to bond. Attachment is described as a bond or a tie that an infant forms with the mother. It figures provision of feelings, security, protection soothing comfort and help. Faced with the death of a parent the adolescent may deny its reality by engaging in death defying, risk-taking activities such as substance (McKerrow, 1994). McKerrow (1994) continues by saying that," their anger at the unfairness of the world often contaminates their peer group relationships as they are likely to feel bitter that their friends has not had to cope with what they have had to cope with. The emotional demand on these children's lives is of great concern. Literature has shown that parental death reduces the child's self-esteem, and increases depression, anxiety, conduct disturbance

academic difficulty and suicidal acts. The following experts highlight some of the emotive experiences encountered by some of these children:

Noluthando shared the following:

*I did not believe that she had left me I still had hope that she was going to come back from hospital.*

Prude shared her feelings:

*I was hurt and cross, I heard that she was in hospital she does not eat that's all.*

Yoliswa reported

*I did not believe that she had left me I still had hope that she was going to come back from hospital, until the wake and my mother was the only one not in the house.*

Linda, in sharing her shock, highlighted:

*I thought it was a joke.*

She continues

*She was very ill when I left for school. I could not concentrate at school that day. I was thinking of her so much.*

In expressing his concern with regards to how HIV positive people are treated, Thando share the following:

*It breaks my heart to see how people with HIV/AIDS are suffering, and I know from that, that my mother also suffered a lot.*

It appears that the shock and anger or denial of losing a parent was so severe that these participants reacted in different ways to their loss. Parry (1989) reported that the advent of terminal illness is an unplanned and unexpected experience. Parry (1989) continues by saying it is important to understand the concept of denial as it is necessary for both the patient and its family so as to help with the multifaceted problems arising when the family go through the pain and loss. The following statements highlight this:

Thembile related the following:

*I started crying as I realised that I do not have a mother anymore.*

Felicia shares her shock:

*I did not cry I was just shocked and the tears could not come out. I only cried a month after she had died.*

Thando related:

*I think of my mother when the other children boast that their mothers are going to help them with their homework.*

When engaging with the participants regarding their level of knowledge about HIV/AIDS, there was anger and pain expressed by some of the participants regarding this subject. Sinxolo, who had lost both his parents to HIV/AIDS, was not factual and defined it as follows:

*I don't want to talk about that disease [meaning HIV/AIDS].*

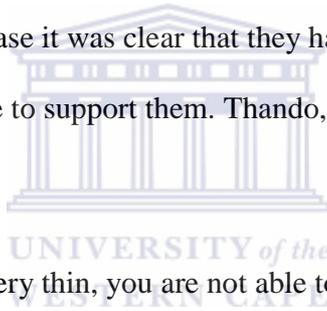
When asked to substantiate on his response he said:

*Today I do not have a mother or a father all because of it [AIDS].*

Yoliswa who was born with the HIV virus regarded it as a disease that children get from their pregnant mothers. The following excerpt illustrates this:

*You see if a woman is pregnant and does not take ARVs [Antiretroviral tablets] while pregnant she will give birth to a HIV positive child.*

As they were defining this disease it was clear that they had observed their parents health deteriorating and not being able to support them. Thando, who had an aunt who died of AIDS, shares the following



It is a disease that makes you very thin, you are not able to breath, and other people must clean you and feed you just like my father's late sister.

#### **4.3.2 Section B: Challenges before and after parental loss**

- Socio-cultural effects of culture to AIDS orphans
- Socio economic status of orphaned children
- The right to be a child and thus become transformed into caregivers.

#### **4.3.2.1 Challenges**

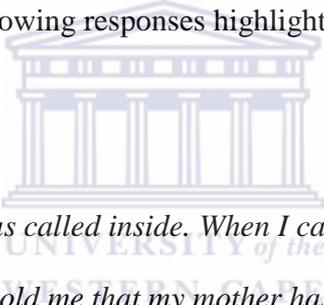
AIDS affects individuals and families in their most productive years and leads to poor economic performance. The AIDS pandemic has caused the loss of productive and often well educated adults, a loss not only for the country but especially for families that lose economically productive breadwinners (Aspaas, 1999). Research reports that many AIDS orphans experience orphan hood way before the death of their parents due to the different challenges that they face,(UNAIDS,2000). Cross (2001) reported that the death of a parent meant the loss of the household's only cash income stream and hits to the point of cash-flow crisis resulted from extended illness ending in death and funeral needs. The following sub-themes in supporting this theme are presented as follows:

##### **Socio – cultural effects of culture on AIDS orphans**

Nord (1997) reported that the death of a family member to AIDS–related death poses a cultural social arrangement as the bereaved are forced to recognise the social loss, while communities simultaneously deny the presence of the HIV/AIDS pandemic. Children should be informed and involved when there is someone ill so as to help you share your sorrow, ignoring them may leave them with feelings of sorrow and guilt (Kubler-Ross, 1985). Credo Mutwa a traditional healer known to have cared for AIDS orphans in Children First (2000) notes that children are more intelligent than credit that adults want to give them, hence they can be told about HIV/AIDS. Children First (2000) reported that if a death occurs in a family and it is hidden from children, they can come and confront you for it. It needs to be understood that funerals are for the family. Kubler-Ross (1985) informs that cultural, religious and local customs need to be respected; in addition

Kubler-Ross (1985) believes that families and communities should grant children and mostly adolescence the opportunity to pay their last respect to their loved ones in a dignified manner. Culture is one of the areas that have either played a positive or a negative role in the lives of the AIDS orphans and their family relations. Within the African culture, death is a topic that is not discussed with children. Deacon *et al.* (2007) states that the reluctance of caregivers to discuss death and illness with minors in fear of stigmatization and discrimination can result in parents not preparing their children for their death. From the responses of the participants it was apparent that some of the children were never granted the opportunity to hear from their own parents regarding their HIV/AIDS status. The following responses highlight this:

Thembile states that:



*I was playing outside when I was called inside. When I came in, there were people from next door and the one old man told me that my mother has passed away and from now I must stay in the house until after the funeral.*

When asked who helped him to deal with the news Thembile, responded by saying:

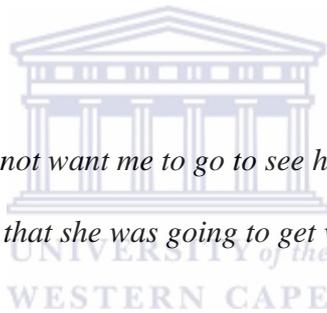
*Nobody helped me after I was told the news I was told [people in the house] to take the news as a man after that I was told that I can go and play in the yard.*

Kubler-Ross (1985) states that families have a tendency to avoid sharing the truth about the death of a loved one and rationalize that telling them will upset them or that they are too young to be able to cope with the crises. Kubler-Ross (1985) adds that losing a loved one is so much of a tragedy hence it is important to allow people to express their

emotions rather than suppressing them. Culture also played a negative part in this case because as shown in this excerpt the child was not prepared for the news. According to the African custom Xhosa to be precise, death is not something that is discussed with children as they are perceived not to understand it. Hence this child was just told as news he heard to hear and accept at face value. Deng *et al.*, (2007) reports that lack of knowledge, existing culture, social and religious norms, values and beliefs may impact on families and communities. In so doing society suppressed the child's feelings and concluded that they were irrelevant and under the circumstances they were not to be considered. This occurs even when the parent is terminally ill.

Mbali says:

*They [family members] did not want me to go to see her at the hospital when she was very ill they always told me that she was going to get well.*



Noluthando, in supporting Mbali, reported:

*My aunt told me not to go and visit my mother at the hospital, I must see to my siblings.*

Even though this made her feel on the other hand reasonable as she thought she was going to make her mother proud when she returns from hospital. She was not aware that the next news was to inform her of her mother's death. Kubler-Ross (1985) highlighted that grief and fear when allowed to be expressed and shared in childhood can prevent much future heartache. Nord (1997), Kubler-Ross and Stedeford (1984) concur that adolescence naturally is a difficult time of development and an added loss of a parent is often too much for such a youngster to endure hence it would be appropriate to listen to

them and allow them to express their feelings whether it is guilt, anger or plain sadness. The excerpt below highlights the pain that was experienced by Noluthando. She longed to visit her terminally ill mother but at the same time had to consider the well being of her siblings in order to make her mother happy.

*I was heartbroken, I always wished if I could see her but my siblings had to be important so that when she comes back [from hospital] she can see that I have looked well after them.*

The cultural rituals in some families are complex that children sometimes have to guess for themselves that there is a crisis in the family. Kubler-Ross (1985) states that families have a tendency to avoid sharing the truth about the death of a loved one and rationalize that telling them will upset them or that they are too young to be able to cope with the crises. This is presented by Yoliswa in the following excerpt:

*When I got back from school the furniture was put outside and immediately I knew that she had passed away [crying].*

Mbali who has a similar experience reports the following:

*She was very sick; my grandmother decided that my brother and I are not going to the hospital again until my mother was better. She convinced us that the ward sister has informed her that children are not allowed in the ward where my mother was in.*

Prude continues,

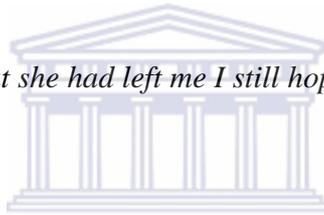
*The following day she told us that the hospital has phoned to report that my mother had passed away.*

Thembile adds:

*I thought it was a joke (shaking his head). I was playing outside with my friends, and then called inside. When I came in there were people from next door and the one old man told me that my mother has passed away and from now I must stay in the house until after the funeral.*

When asked how he responded to the news Thembile reports:

*I cried, I did not believe that she had left me I still hoped that she was going to come back*



When asked who helped him to deal with the loss of his/her parent Thembile reports:

*Nobody helped me after I was told the news I was told to take the news as a man and go and play in the yard.*

Family friends that share their condolences tend to focus on the adults without realising the pain the children are undergoing. When Mbali was asked how she reacted then when the news was conveyed to her:

*I cried and they [the people in the house] told me don't be ridiculous, you have seen your mother suffering now the Lord has taken her to her home.*

Van Dyk (2008) highlighted that bereavement is triggered by the sense of loss that occurs when one loses something or someone to which one has become attached to.

This separation or loss initiates a process of grief. Nord (1997) defines grief as a peculiar amalgam of anxiety, anger, pain and despair following the experience of what is feared to be irretrievable loss of a loved one the responses of the above participants highlights this experience

Sinoxolo in addition to this reported the following,

*I was angry because they did not want me to go to hospital with them and yet my mother used to go with my siblings and me.*

Some of these children have experienced negative treatment from some of their family members who believed that HIV positive parents had brought a curse to their family. Walker *et al.*, (2004) state that South African society is characterized by cultural complexity and difference, this can be reflected in many ways that health and disease are understood. Van Dyk (2008) in supporting Walker *et al.*, (2004) reflects that a person with AIDS may fully understand the immediate cause for his/her illness as the virus but will still seek traditional healers opinion. Witchcraft is believed to be the causal factor in HIV transmission, however van Dyk (2008) notes that while people may believe that the cause of AIDS is witchcraft, counselors, social workers and health care workers should stress the immediate cause of HIV/AIDS as a germ which is sexually transmitted

Thando shares the following

*She [paternal grandmother] said that my mother, my two twin sisters and I had brought a curse to the family.*

Walker *et al.*, (2004) reported that belief systems impact directly on how we understand and respond to illness. Thando, one of the participants whose sibling died very young, believes that the health condition of his mother resulted in the death of his sibling as his mother was not able to care for them due to her own ill health. He explains this as follows:

*She [meaning mother] was not able to care for us hence my one sibling [twin] died [frown].*

In the case of Thando, Kubler-Ross (1987) states that when the stage of denial cannot be maintained any longer it is then replaced with feelings of anger, rage, envy and resentment. The researcher agrees with this author as it was clear that there was an element of (blaming his mother) for the death of his one sibling. His facial expression showed the anger towards the loss.

Kubler- Ross (1985) states that many families especially in the areas where old customs are still alive friends, family, grandparents and neighbours will come together and give the family support. Kubler-Ross (1985) continues by saying, this gives that family and friends a chance to actively participate in the healing of the pain, however the challenge with the bereaved starts when all the family and friends are gone as one have to face the reality. One of the African customs is to support family members during the bereavement this lasts until the day of the funeral. Thereafter all family members go back to their destinations and you are left alone to start grieving with no one realising what this loss has done to you as a person. It was clear that some of these children had experienced that gap in their lives as they highlighted the loneliness that was in the house after the funeral

an. All the participants' highlight the support of the family members during this period the following excerpt has highlighted what Prude shared:

*Everyone was supportive during that week [before the funeral], that made me not to feel her absence much but as weeks goes I realised that she was gone.*

Thando, who has experienced all forms of abuse from his paternal family, shared some of his experience:

*My [paternal] grandmother and my stepmother treated my sister and me very badly. After the death of my mother and my other twin my grandmother decided to take my remaining twin and I and go and throw us by the riverside.*

Deng *et al.* (2007), in supporting the above statement, state, that one of the common forms of stigma are gossip verbal abuse and name-calling. Walker *et al.*, (2004) highlighted that AIDS is greatly feared and popular beliefs can result in stigma and discrimination. Walker *et al.*, (2004) continues by saying that in some communities the transition of HIV is associated with the transgression of sexual taboos, health is associated with cleanliness and moral hygiene and disease is seen as the outcome of forbidden exchanges and even witchcraft. It is then not surprising that these children, together with their mother were seen as a curse for the family. What was also surprising is the fact that this mother was just as cruel to her own daughter as well, as Thando conveys on the following excerpt:

*My paternal grandmother treated her only daughter my paternal aunt bad. She used to swear at her and never assisted her when she was sick.*

When asked how he felt when he saw his aunt encountering the same experience they endured:

*I used to be hurt as she was the only person who cared for us and treated us well.*

The participants expressed their pain and suffering at seeing their parents who were at one stage their support system being broken down by the HIV virus and they were unable to assist them. Erikson (1980) defines adolescence as role confusion developmental stage meaning at this stage parental support is of outmost importance. This was not so with these children as they had to count on each other or other family members Deng *et al.*, (2007) states that in South Africa social isolation is a major manifestation of stigma. People refuse to discuss their disease and children who are affected with HIV are often ostracised by their peers and society.

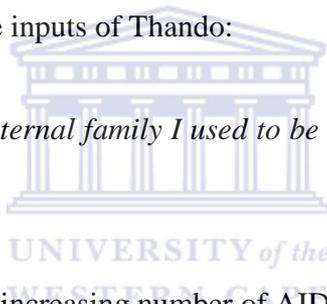
### **Socio-economic status of orphaned children**

South Africa is known to have the highest number of people infected with the HIV virus. This has resulted in the country losing many economic active citizens at a young age that could still be a good resource to the country's economy. This costs the government via the administration of different state grants. Heymann and Kidman (2008) states that families who are already economically marginalised prior to the AIDS related crisis are at the risk of not being able to meet the basic needs of the AIDS orphans.

Most of the participants currently live with their maternal grandparents, siblings, family friends and paternal family. Most of the caregivers depended either on Old Aged pension or Disability Grants. Both are received from the Government of South Africa, which is

R1010 per grant per month. Amoateng and Heaton (2007) states that, in South Africa social assistance is provided in the form of different grants namely the old aged grant, disability grant, care dependency grant, a foster child grant, a child support grant and grants in aid and social relief of stress. As stated in the previous discussion, AIDS is removing the breadwinners and caregivers in large numbers from families, and resulting in the elderly and minors fending for them. Although section (29) (1) (a) of the Bill of Rights (1996) states that every child has a right to education, the lack of income has resulted in some of these children being deprived of education. In most cases this is due to the fact that caregivers often do not have funds to send these children to school. The following excerpt illustrates the inputs of Thando:

*When I was staying with my paternal family I used to be sent home for not paying school fees.*



Van Dyk (2008) argues that an increasing number of AIDS orphans who grow up without parental support and supervision becomes victims of poverty and subsequently engage in criminal activities and prostitution so as to earn a living. Noluthando highlighted that due to her level of poverty she decided to leave school.

*This year I decided not to go back to school as my school shoes were torn and there was no one to buy me school shoes.*

This does not mean that the problem was solved. It could have been the beginning of the problem. Noluthando could get a nutritious meal at school and now that it's not there, she had to look for alternative ways of surviving. Research has indicated that the girl child during this stage is more vulnerable to many forms of sexual abuse as their sex organs

begin to enlarge Papalia *et al.*, (2008). This can result in unsafe behaviours of some of the teenagers (Papalia *et al.*, 2008)

Williams (2000) reported that caregivers experience financial pressure as they are expected to clothe, feed, educate, love and support AIDS orphans. This can be difficult as in most cases caregivers are unemployed and dependent on state grants. The limited income from the caregivers thus prevents them from providing what the participants would need, despite the fact that the caregivers will be trying their best with their limited funds and resources. In most cases this often means that the lifestyles of the participants will change.

Thembile reported this:

*When I asked her [his mother] something she never used to say it is expensive like the “Nike Takies” unlike my grandparents when I ask something expensive they say they cannot afford it however will buy me something cheaper.*

Amoateng *et al.*, (2007) state that information available on the social and economic impact of HIV/AIDS on families and children in South Africa is very little, this epidemic represents a major challenge to the state given the alarming rate in which individuals are infected. The participants reported that biological parents and (mostly mothers) have played a significant role in ensuring that their basic needs are met, even though their health was deteriorating. The following excerpts highlight what Yoliswa presented:

*It was my mother as she was working and when she lost her job due to ill health she got a [disability] grant.*

In supporting this statement Mbali added the following inputs:

*When my father got ill my mother continued to work until her health deteriorated.*

According to Cross (2001) many poor families are sliding deeper into poverty due to HIV/AIDS. She continues by saying that some of the most regular financial needs of the households with unsupported dependants are food, clothing for the children, school expenses, and medical expenses. At times parents had to jeopardise their values and dignity and start doing businesses that can put the lives of their children in danger, and mostly the girl child, for their survival. Noluthando reports the following in supporting this view:

*My mother started a shebeen, as she was unemployed and struggling in order to be able to buy us food and clothes. When her health deteriorated she stopped the shebeen and this meant that we had to struggle again however the [disability] grant helped her to buy us food.*

Mbali who has had the experience of staying with another HIV positive family member reported the following,

*My aunt who is HIV positive is the one who buys us food and pays the electricity and water*

Prude added that:

*My aunt died in 2003 because of AIDS, she used to buy us food and clothes.*

Yoliswa pointed out that:

*My grandmother buys us food mostly on ALPAY [pension] days.*

It was clear that maternal grandmothers were the primary caregivers to the AIDS orphans. This view is also supported by Aspaas (1999) who states that:

Owing to the loss of adults between the economically productive ages of 15 – 45 [due to AIDS –related deaths], an increasing number of orphans are relying on elderly relatives who may lack sufficient resources both mental and physical to provide for them.

In supporting Aspaas (1999), Kelso (1994) reported that elderly women regularly assume the role of caregivers following the death of their children and their spouses. These are left to look after the children that are left behind hence AIDS is known as the “Grandmothers” Disease in most of the African countries. It has been clear that if the grandmother does not inherit these children. It then becomes the role of an aunt and in most cases maternal aunts and family friends as it has been highlighted in the above excerpts.

### **The right to be children: Transforming into caregivers and breadwinners**

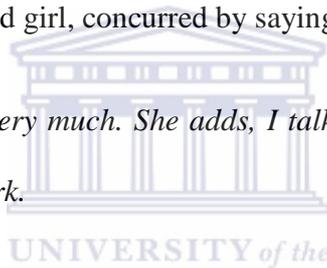
UNICEF (2003) reported that the newest number of children orphaned by HIV/AIDS is alarming and they represent a segment of those affected by HIV and AIDS. The newest phenomenon emerging in Southern Africa is that of child-headed households, in which the eldest orphan becomes the parent as no relative, can or will (Kelso, 1994). Amoateng and Heaton (2007) state that information available on social and economic impact of AIDS on families and children is scanty. Deng *et al.*, (2007) states that marginalised

groups such as the poor, ethnic and racial minorities and particularly single woman are more vulnerable to HIV/AIDS-related stigma and discrimination. Gannon (1994) reported that children who have lost their parents through HIV/AIDS become heads of their families and have to care for their younger siblings. Children especially girls face more general house chores, care for the sick and younger children. The following excerpt highlights the response of Linda in support of this statement:

*I regard my eldest sister as my parent as she is the person who buys me food, clothes, pays my school fees and buys me anything I want when she can.*

Noluthando a seventeen year old girl, concurred by saying:

*I love my brother and sister very much. She adds, I talk to them, do their washing and assist them with their home work.*



The death of a parent is devastating, especially when there are children who still need to be taken care of and are left behind. Nord (1997) reported that illness and death within the family draw attention and energy away from the needs of children. One of the participants Linda concurs by saying:

*I think my mother's illness did impact on her parenting role as she was not able to cook for us as her children.*

This theme also highlights the parental role taken by these children in caring for their own parents, mostly because no one else supported them. In responding to this Linda reported the following:

*Let me say she was not able to care for us instead we had to care for her.*

Steffenson (2002), Nord (1997) and Smart (2000) agree that the reality of AIDS in a family is that children are caring for the sick resuming adult responsibilities before they are ready to do so. Nord (1997) continues by saying being an AIDS orphan or having a parent dying of AIDS might impact on some adolescents who might be themselves struggling with this transitional stage while having to care for parents and siblings. The following quotation from Noluthando who is 17 years old reports:

We later decided to do the house chores ourselves as she was getting tired quickly.

#### **4.3.2.3 Section C: - Coping strategies adopted by adolescents who have lost their parents through HIV/AIDS**

- Available support resources
  - Family and community support
  - HIV and education
  - Health care systems
  - Private welfare organisations
  - Religious institutions

#### **Coping strategies**

Deng *et al.*, (2007) states that in some cultures it is customary to throw away the belongings of the dead however in some families' people still kept some valuable

mementos as keepsakes. These children highlighted family bonds as a strong coping mechanism and celebrations brought their family and extended family closer. The family values that were built among these children help them to cope with the loss of their parents strong. Sinxolo in this excerpt:

*Every night before we go to bed my father used to ask us to gather for the evening prayer and every morning early my father used to wake us up for prayer.*

He adds

*At times you would be half asleep but you had no choice but to wake up for the prayers (He smiles)*

The separation of siblings result in children blaming themselves for the illness and death of a parent and for their misfortune (Smart, 2003) Gouws and Kruger (2004) reported that too much stress in the life of an adolescent may exert a depressing influence on the young person's self-esteem. While this can be true and can make nuclear families more vulnerable during times of crises, it is also true that these families can strengthen their emotional support that is needed during crisis times as they need each other (Bezuidenhout, 2004). Thus, it is important not to separate siblings from one another during death of parents as they can be a good support for each other (Richter *et al.* 2004). Sinxolo who is separated by distance with his siblings relates

*I see them every December holiday. You know what, at the time when I went to my mothers funeral [ Eastern Cape] he [baby brother] would cry and ask for my mother (he keeps quiet looks as if he is going to cry) I did not know what to say I would just cuddle*

*him and try to comfort him. I must say though now that he is growing he is not asking her any more but he just gets excited to see me and want to sleep with me.*

He continues:

*My other brother is very quiet he does not talk much but when I am at home [Eastern Cape] I accompany him to the fields to fetch the cattle. He gets so excited when he sees me. You know when I go to the homelands I bring them something nice like the “Yogetta”.*

Amoateng *et al.*, (2007) reports that taking care of an AIDS-sick person is not only an emotional strain but also a major strain on households. The love and care that some of the families have for each other kept some of the families strong and close to each other even though they were affected by the strain of having to cope with a sick family member this love was at times carried over to the children. The following statement supports this:

*My uncle used to come and chat with my mother and I when he comes from work mostly on Fridays and weekends when he had a drink;*

She continues

I think he was worried about losing his sister. He used to say; “Is jy all right my ma se kind” meanings are you all right my sister.

Mbali, in relating part of her traditional family customs that helped her to cope with the loss of her mother, highlights the following:

*During Xmas and Easter my maternal uncles and aunts, my nieces and nephews let me say the whole family we wake up early in the morning and we visit the graves of our grandparents including my mother’s grave.*

Yoliswa adds that her grandmother wanted them to celebrate every birthday at their house. During these occasions all the family members come together at their home (maternal house).

Prude who had a very close relationship with her mother shares the following

*When I remember the good things we used to do together sometimes when I watch the family videos I get happy*

Thembile shares the following

*I have my mother's photo that I hang in my bedroom; I look at it every day mostly when my aunt has hit me*

Linda shares

*My sister [who is a Rastafarian] would go with me to her stall to sell veggies and keep me busy.*

Linda adds that when asked what she did then when it dawned that her mother was gone:

*I decided not to think about her but it is not easy.*

### **Available support resources**

UNICEF (2003) states that HIV and AIDS on children raises the risk that more children will fall through the cracks and face barriers in accessing education, health care and other basic services. The emotional pressure on children affected by HIV and AIDS can be devastating as they at times suffer from isolation, loss of self-esteem, depression and

anxiety. UNICEF (2003) recommends that the best way to protect children orphaned by HIV and AIDS is through placing them in the care of relatives and extended family members in their own community. Most of the Government Departments are strengthening their policies and strategies aimed at addressing the issue of HIV and AIDS. The following sub-themes will illustrate the different support systems highlighted under the theme support systems available to assist AIDS orphans.

### **Family and community support**

Family is very important in all cultures and is no difference in this study. Hence the researcher had to explore the support systems that participants have. Social support, which is rooted in family and community members, is defined by Amoateng *et al.*, (2007) as the instrumental, educational social and psychological assistance actually provided to a person. The support that these children received from the different family members made them to feel more secure in their community. Amoateng *et al.*, (2007) reported that taking care of an AIDS-sick person is not only an emotional strain but also a major strain on households. The love and care that some of the families have for each other kept some of the families strong and close to each other, even though they were affected by the stress of having to cope with a sick family member. This love was at times carried over to the children concerned. The following statement supports this:

Linda shares:

*My uncle used to come and chat with my mother when he comes from work mostly on Fridays and weekends when he had a drink;*

She continues:

*I think he was worried about losing his sister. He used to say; “Is jy all right my ma se kind” meanings are you okay my sister.*

Sinoxolo who is geographically separated from his siblings appeared to be a great trustworthy support for his sibling relates the following

*I see them every December holiday. You know what, at the time when I went to my mothers funeral [Eastern Cape] he would cry and ask for my mother ( Sinoxolo, keeps quiet looks as if he is going to cry) I did not know what to say I would just cuddle him and try to comfort him. I must say though now that he is growing he is not asking her any more but he just gets excited to see me and want to sleep with me.*

He continues:

*My other brother is very quiet he does not talk much but when I am at home [Eastern Cape] I accompany him to the fields to fetch the cattle. He gets so excited when he sees me. You know when I go to the homelands I bring them something nice like the “Yougetta”.*

Friends were identified as a support. However, it was evident that these children were not comfortable in discussing their parent’s status with them. The following excerpts illustrate this:

Mbali, who also had an experience of being raised by an aunt who was HIV positive, shares the following:

*I have friends they know that my mother has died but I have never shared the cause of her death with them.*

Prude said:

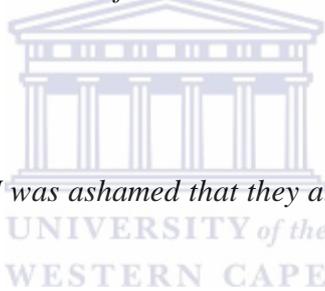
*I told her that my mother was ill. I did not tell her that she had HIV. She then came with her mother to visit my mother. My mother told her mother about my mother's status. We are still friends.*

Noluthando highlights:

*My friends at school would share some of their lunch with me.*

She continues:

*I left school this year because I was ashamed that they always shared their food with me and I had nothing to offer them.*



Thembile said:

*I do not have best friends but the friends that I have did not treat me bad maybe it is because they did not know.*

Thando reports

*I have friends whom I attend with the aftercare classes at Siyaphambili, we play together but we never speak about our parents.*

Yoliswa who was born HIV positive shares

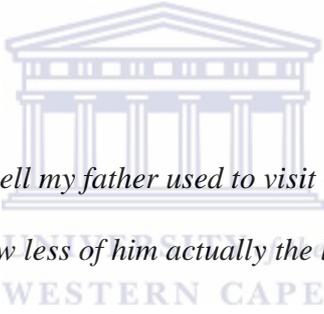
*My friends are nice, we play together but I have never shared with them my HIV status*

Felicia shares her experience

*My classmate called me names and I was angry and I hit her badly*

The Bill of Rights section 28 (1)(b) states that every child has a right to family care or parental care, However, AIDS orphans have reported that they are often faced with lack of support from their biological father's, either before they were even born, or after the death of their mothers. This support can be material, affectionate or financial. The following excerpts illustrate this:

Felicia shared this:



*When my mother was still well my father used to visit us and buy me anything I want.*

*When my mother got ill I saw less of him actually the last time I saw him was on the day of my mother's funeral.*

This statement is supported by one of the participants Thando, who related the following ordeal regarding his father. His father deserted him and his twin sister and went to live with his new family in Gauteng:

*He has never come to visit us; we do not even know if he is still alive as he went to stay in Gauteng with his new wife (frowns).*

It was evident through the frowning that even although he had no power over the desertion, he was not happy. It could be he was missing his father as the only parent

that was alive, or wanted to know whether he was still alive. The case of this participant was interesting and sad as his father deserted them.

Mbali reported that:

*She [my mother] told me that he [my father] was a student from Namibia who came to study here in South Africa, at the end of the year went back. I don't know whether he knew that she was pregnant when he left, as I do not know him and his siblings.*

To which Noluthando, whose younger sister was born HIV positive, reported that:

*Because we were struggling I gave him [father of baby sister] permission to look after her, at least she was going to be well cared for. When my aunt came to stay with us she decided to go and fetch her. They [him and his family] took back everything that they [had] bought [for] her including her school uniform.*

Participants related strong bonds with their mothers. However it was clear that the gap between them and their fathers was bigger than one had envisaged. The inputs from these participants illustrate this:

Thando shared this:

*There were no activities that we did with my father although he was the one alive.*

Linda, who was removed from her paternal home to live with her siblings at her maternal home due to her father's misuse of alcohol, conveyed the following

*I used to be hurt by the fact that he did not come to visit me but my mother used to say he is under the influence of alcohol.*

The extended family throughout the Sub-Saharan Africa is traditionally known to create a safety net to orphaned relatives. Museveni (cited in Aspaas reports of 1999) states that, traditionally at the death of parents, children are sent to live with another member of the extended family. This is, however, changing as the challenge of absorbing the ever-increasing number of children in households with limited resources suppresses in many instances the material ability of these households, regardless of the willingness or desire to help (Aspaas, 1999). Kaseke & Gumbo (2001) suggests that the harsh economic environment makes it difficult for members of the extended family to support their needy relatives. This, at times, could be one of the reasons why some extended families desert their traditional responsibilities. The following excerpts highlight some of these concerns:

*My father had two sisters, the last time I saw them was in 1999 at my father's funeral.*

In some cases caregivers, who were very supportive in their own way, however now being unemployed they could not assist financially. This is stated in the following excerpt,

Mbali shares:

*Most of my uncles [maternal] do not work, so they are not able to assist my aunt financially.*

In other cases in spite of the minimal financial resources, caregivers did not show as much affection as they could, as illustrated below:

Noluthando shares:

*We are struggling there are some days that my siblings and I would go to bed with out food. Sometimes my uncle would come with a bun chow and will eat it in front of us, sometimes when he has had enough will give my brother a left over piece.*

## **HIV and Education**

The Commonwealth Secretariat (2001) reported that schools are one of the most important ways of reaching out to youth before they begin sexual activities. The constitution of South Africa says that no child should be discriminated against, treated unfairly or harassed at school because of their HIV status or because somebody in their family is HIV positive. The life-skills programmes that are taught at the different local schools are seen as an effective resource by the adolescents. These also strengthen the relationships of the teachers with the adolescents. Hence educators are reflected as an effective support system by some of the participants, while others see them as (rude and unkind). The following statements support this:

Thembile shared this:

*Some teachers are kind some swear at you and call you stupid dog (frowning).*

The facial expression of this participant was clear that he was not happy with the behaviour of some of the teachers. It could be that the teacher was not aware of this child's experience i.e. why he was not coping and regarded as a problem child who is misbehaving, and yet he could be crying out for love. The following excerpts highlights a different picture regarding the behaviour of the teachers and this is presented in the following excerpts:

Thando shared:

*Teachers at my school treat children well, they are the ones who identified my sister and me and referred us to the aftercare.*

Mbali adds:

*Teachers at my school treats children well I haven't heard of any child treated badly at my school.*

Felicia highlighted this:

*Teachers do listen to the problems of children but I don't think children talk to teachers about their problems.*

She continues:

*My class mate called me names and I was angry I hit her badly that my class teacher reprimanded me and told me to come with my parent the next day. My maternal aunt came with me and she explained my teacher my problem. My teacher was very sympathetic. He arranged that I see a school psychologist so as to receive counseling.*

There seems to be more support in terms of nutritious foods at primary school level, compared to high school level. This was highlighted by some of the responses of the participants:

Thembile says:

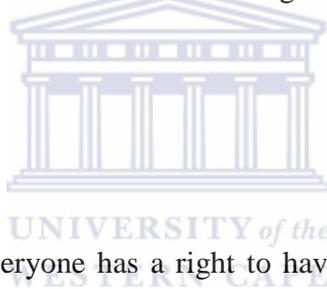
At primary we used to get bread and milk shake but here at high school we getting nothing.

Children also appear to treat each other with respect and dignity as highlighted by excerpt:

Noluthando shares:

*Children treat each other well; maybe it is because in our life orientation class we are thought of HIV/AIDS and how to treat people infected and affected by HIV/AIDS.*

The above excerpt also shows that the school is regarded as a place that educates the participants of HIV/AIDS.



### **Health Care Systems**

The Constitution states that everyone has a right to have access to health care services including reproductive health. The United Nations Convention on the Rights of the Child says every child has a right to enjoyment of the highest attainable standard of health and to facilities for treatment of illness and rehabilitation of health. It is then the Government's role to ensure that no child is deprived of his/ her right to access health care services. The treatment received from nurses is seen as both negative and positive by the participants. This has been reflected in some of the statements made:

Thando shared:

*Some of the nurses listen to you and some shouts at you.*

He continued by saying:

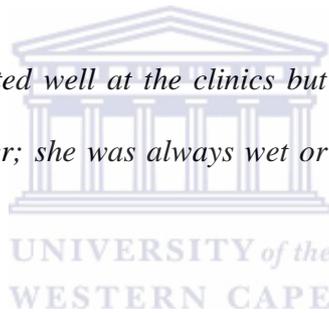
*When I first came to Cape Town because the clinics are at a walking distance compared to the rural areas, I wanted to know more about the disease that killed my mother and my twin sister, the nurse at the local clinic shouted me asking what I am going to do with the information, because I am too young.*

Prude highlighted the following:

*Kind nurses always help me when I require information for my HIV/AIDS school projects.*

Yoliswa simply said:

*I think she [mother] was treated well at the clinics but at the hospital [-----] I don't think they looked well after her; she was always wet or crying in pain when we visited her.*



### **Welfare Services**

The Department of Social Development and the funded welfare organisation such as Ikamva Labantu, Cape Town Child Welfare Society and Siyaphambili Orphan Village within the Western Cape are reflected as systems that support the orphans and their families in assisting them with the different grants and other material goods: This is reflected in the following experts':

Thando shared:

*Our teacher wrote us a letter that we had to take to the social worker together with my grandmother for her to assist us with a [foster care] grant.*

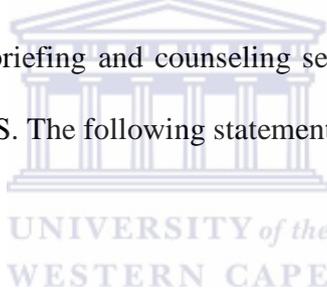
Linda shared:

*She depended on the [disability] grant so I would just not tell her about the school excursions.*

She continues by saying that:

*The little grant money she received was for food, her medication and hiring a taxi when she goes to the doctor.*

In supporting the above statement, Amoateng *et al.*, (2007) states that HIV/AIDS affected households spend a third of their income on medical care. Social workers were seen as a support system in offering debriefing and counseling services to children who had lost their parents through HIV/AIDS. The following statement highlights this:



Linda shared the following:

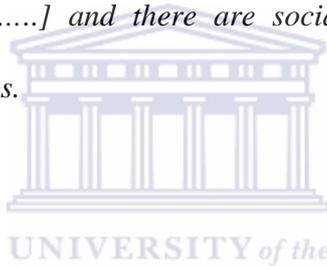
*I used to cry mostly when I think of my mother. My sister then took me to the social worker at the local welfare offices and explained her [social worker] about the death of our parents. She [social worker] used to sit with me and talk comforting words and say I could cry as much as I like I am going to be fine. She [social worker] also helped me to get a school fees discount at my school. She explained to my school principal that I depend financially on my sister.*

De Jong (2003) states that there is a growing determination among communities, NGOs, government departments and other stakeholders that more must be done in supporting families of victims HIV/AIDS. De Jong continues by saying that in 2001 the UN General

Assembly Special Session included the signing of a Declaration of commitment by Governments in empowering stakeholders, global and National. There are also Private Welfare organisations (PWOs) that appear to assist these orphans by providing the much needed support systems for example, Cape Town Child Welfare Society, Ikamva Labantu and Siyaphambili Orphan Village. These are identified as organisations that the Department of Social Development is buying services from as illustrated in the following excerpts,

Thando shares:

*I attend the aftercare at [.....] and there are social workers that assist us with homework and take us on camps.*



He continues:

*They give us clothes and vegetables that are donated to the village.*

Thembile just said:

*She [social worker] invites me to workshops and outings organised for orphan children.*

Yoliswa simply said:

*At [.....] they teach us life skills and educational talks on HIV/AIDS.*

Mbali added:

*If you are feeling down [.....] (social worker) talks to you and most of the time you feel better*

## **Religious Institutions**

According to the Commonwealth Secretariat (2001) religious groups, particularly the Christian churches, have led the way in caring for the individuals infected and affected with HIV/AIDS. In 1997 a religious group called inter-faith was developed in Lusaka. These groups put their faith and doctrines aside and promoted a united front against HIV/AIDS. The Methodist Church of Southern Africa in their Revised HIV and AIDS Strategy and Implementation Plan (2006) states that to respond to the challenge of HIV and AIDS, the churches must be transformed in the face of HIV and AIDS crisis in order that they may become a force for bringing healing and hope to all affected by HIV/AIDS. The children had mixed feelings regarding the support they were receiving from their churches. In some of the churches ministers are not open about the HIV pandemic, while in some churches they were communicating openly about it. The following experts are the example of these:

Thando shares:

*In my church I only know about my sister and me. One never hears about any talks regarding HIV/AIDS or other people who have had this experience.*

Felicia highlighted:

*Every Sunday there is a speaker who talks about HIV and AIDS, she continues to say we have a candle light day and children are also given a slot to share the good memories about their parents if you are strong enough.*

The Methodist Church of Southern Africa in their Revised Strategy and Implementation plan (2006) notes that a support programme for people living with AIDS must include the provision for basic needs, as the body needs certain food substances to remain healthy and to be able to successfully fight against HIV. One of the participants who were asked about the kind of support he receives from his church reported that his church (Anglican Church) supports his family with food parcels. The following expert highlights this:

Thembile shared:

*I do not know but our church brings us food parcels regularly.*

#### **4.4 Conclusion**

This chapter has attempted to explain the findings of this study. This was presented in seven themes. These themes are divided in two sections whereby the first section is presenting the experience prior to parental death. The last section is each theme had sub themes that accompanied it. The following chapter will be focusing on the summary, recommendations and conclusion

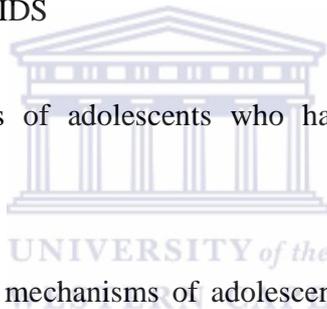
## **Chapter Five: Conclusion and Recommendations**

### **5.1 Introduction**

In this final chapter central issues of the findings are presented, followed by the recommendations.

This study aimed at exploring the subjective experiences of adolescents who had lost their parents through HIV/AIDS. Furthermore, the study's objectives were to:

- Understand and Describe the experiences of adolescents who have lost their parents, through HIV/AIDS
- Explore the challenges of adolescents who have lost their parents through, HIV/AIDS
- Understand the coping mechanisms of adolescents who have lost their parents, through HIV/AIDS



### **5.2 Central issues**

The participants in this study were clients of the Ikamva Labantu project that renders foster care services within the Gugulethu community. The participants provided information regarding their experiences of losing a parent to HIV/AIDS, before and after the death of the parent. Different themes emerged during the analysis of the data, as was discussed in the previous chapter. Central and overarching issues are considered to be challenges, experiences of post-parental loss and available support resources.

### **5.3 Experience of participants after parental loss**

Paternal families were perceived by these adolescents as mostly negative. The treatment they received was regarded as brutal by most of the participants. The participants did highlight elements of abuse within the maternal family but they were more dominant at the paternal side. The maternal grandparents were seen as the most suitable support, even though at times they experienced their own ill health. When asked whom do they regard as a parent in the absence of their biological parents, it was easy for the participants to identify with their maternal grandparents as mother and father compared to the paternal grandparents. Based on the inputs of the participants, this then concerns the researcher as it looks like paternal grandparents are not very much involved when it comes to the care of their sons children. Most of the participants highlighted minimal or no interest by their fathers in their well being after the death of their mothers.

It appears that shock, anger and denial of losing a parent was so severe that participants reacted in differing ways. Some still cried when they shared their experience about their parents. There was a significant level of anger shared as the participants described HIV/AIDS. There was a significant feeling of emptiness highlighted by the participants when other children share current activities they do with their parents, while they are not able to. This resulted in them missing them dearly.

### **5.4 Challenges**

In looking at this theme it was clear that some of these children had to grow up quickly, so as to engage in parental roles before they were at the appropriate age. It was evident that there are cultural rituals that impeded their understanding of death. The fact that they

were used to having access to different material support, e.g. attending good schools and suddenly finding themselves in a situation which was unbearable for some of them to understand. This resulted in them having to compromise so as to understand their new life style. It was clear that there was significant, pain as some of the participants shared their experience. Research concurs that children who lose parents due to HIV/AIDS undergoes a significant level of stress and pain.

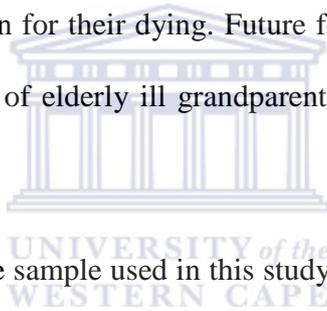
### **5.5 Coping strategies**

It was clear that even though there was an element of negativity when it came to some of the family members such as fathers, uncles and aunts, but still the family and friends at large stood out as a very good support system. The extended family at large is still regarded as the most suitable institution to take the care of these children. The school, the health services, welfare services and the churches were perceived in different ways however in overall the feedback regarding these institutions was satisfactory. Participants in some of the areas made recommendations mostly in the health sector that the health workers be more sympathetic to the victims of HIV/AIDS and their families. It was also clear that the religious sector need to be more open and vigilant about responding to HIV/AIDS as the children did not know much about what the church was doing in-terms of awareness.

### **5.6 Recommendations**

Based on the findings the following recommendations are made. The capability of the grandmothers to take care of these children must be continuously assessed by social workers. It is important that Welfare organisations continue to capacitate the caregivers,

as it seems the most available caregivers are elderly people. When placing these children into foster care it is important to consider close relatives or members of the community that these children are familiar with (compared to strangers). Awareness programmes should be initiated by Welfare organisations. Men to be educated and sensitised regarding the trauma caused by them, abandoning their children. Trauma counseling should be afforded to all the adolescents who lost their parents, due to HIV/AIDS. Health care workers and social workers should encourage parents to disclose their status to their children as this may minimise the trauma that they go under. Parents should be educated in order to make children knowledgeable about their extended family and their possible future caregivers, in preparation for their dying. Future foster care placement in the case where children are in the care of elderly ill grandparents. The establishment of support groups for adolescent orphans.



The researcher is aware that the sample used in this study does not represent the diversity of the Western Cape. The area does not represent the demographics of the entire province. However it is intended that this study, though a tip of the iceberg will be able to contribute to the work of social workers and all those who work in the field of children and families. It is then recommended:

- That research focusing on the experiences of the adolescents be placed on the agenda for future research, and may be replicated on a larger scale.
- A research on the relationship of HIV/AIDS adolescent orphans and Welfare professional can also be a topic to be considered.

- A topic on the experience of caregivers caring for adolescent HIV/AIDS orphans can also be considered for future research.
- The role of paternal family in caring for adolescent orphans

### **5.7 Limitations of the Study**

The researcher viewed the following as limitations in this study. The topic is sensitive and the interview guide contained questions that were sensitive for the participants. The total sample of participants was twelve however only nine finally agreed to participate in the study. Some of the participants might have felt intimidated by the topic, and hence three withdrew from the study. As permission was requested from the caregivers they might also have been intimidated by the study. This could have influenced the feelings for some of the participants. Due to stigma relating to HIV and AIDS and experiences by HIV positive people, their families could have influenced some of the participants not disclosing their full experiences. Gugulethu is vast with the highest HIV/AIDS cases in the Western Province. The small sample size does not represent the whole of Gugulethu. Although the researcher attempted to select the participants from most of the settlements in the area, this was not possible. Therefore, the findings are not able to be generalised to all orphans living in Gugulethu.

### **5.8 Summary**

In summary, there is partial commitment from the biological fathers to take responsibility of caring for their children (mostly after the death of the partners). Orphan children miss their parents and the activities they used to do together. The extended family is still seen

as the most suitable institution to be able to care for AIDS orphans. Culture as an institution is seen as impacting, both positively and negatively in the lives of the orphaned adolescents to HIV/AIDS. Most of the orphans were not prepared for the death of their parents thus leaving them with a lot of unanswered questions. The elderly grandparents are committed to the care of the orphaned children, despite their financial challenges and their health status. The school is seen as an institution that provides support to the orphaned adolescents. The health sector is seen as an institution that needs to be more child-friendly. There needs to be more openness and transparency at churches, regarding HIV/AIDS.

## **5.9 Conclusion**

This chapter presented a summary of the findings, conclusion and recommendations. A public presentation will be made to the Department of Social Development, Welfare Organisations rendering services to Children and Families as well as interested parties such as community leaders, church leaders and Health professionals so as to share the findings. The researcher hopes that this report will bring value to the Gugulethu community.

## REFERENCES

Amoateng, A.Y. & Heaton, T.B. (2007). Families and households in post –apartheid South Africa: Socio- demographic perspectives. Child, Youth, Family and Social Development Research Programme. HSRC.

Alpaslan, N. & Mabutho, S.L. (2005). The Experience of elderly grandmother caregivers and AIDS orphans. *Social Work / Maatskaplike Werk*. 41(3)276 – 295.

Altschuler, J. & Dale, B. (1999). *On Being an III Parent*. The Tavistock Clinic, London. Sage Publications

Arkava, M.I & Lane, T.A. (1983). *Beginning Social Work Research*. Boston

Aspaas, H.R. (1999). AIDS orphans in Uganda; Geographical and gender interpretations of household resources. *Social Science Journal* (On line), Vol. 36, No. 2, p.22 Available: (Accessed 04 November 2003).

AVERT (2008) HIV/AIDS in South Africa.

<http://www.avert.org/aidssouthafrica.htm> (Accessed 25 October 2008)

Babbie, E. & Mouton, J. (2001). *The practice of social research*. Oxford, New York, Oxford University Press.

Bannister, P., Burman, E., Parker, I., & Tindali, C. (1994). *Qualitative methods in Psychology: A research guide*. Buckingham: Open University Press.

Baylies. C., (2000) AIDS Sexuality and Gender in Africa. Perspectives on gender and AIDS in Africa. Chapter 1 p1-24.

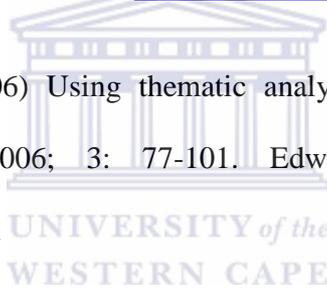
Becker, C. (1992). Living. An Introduction to phenomenology. USA: Sage

Bezuidenhout, F.J. (2004). A Reader on Selected Social Issues. Fourth Ed. Van Schaik Publishers S.A.

Bogdan, R.C. & Biklen, S.K. (1992). Qualitative Research for Education: an introduction theory and methods. Boston, London, Sydney and Toronto: Allyn & Bacon, Inc.

Bonsire, L. (2001). Youth Against AIDS: [www.worldvoices.org/aids/](http://www.worldvoices.org/aids/)

Braun, V. & Clarke V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 2006; 3: 77-101. Edward Arnold Publishers Ltd: [www.QualResearchPsych.com](http://www.QualResearchPsych.com)



Brenner, M. (1985) Intensive Interviewing. in M. Brenner, J. Brown and D. Canter (Eds), The Research Interview: Uses and approaches (pp.147-161). London: Academic

Cerbone, D.R. (2006) Understanding Phenomenology. Series Editor Jack Reynolds

City of Cape Town, (2002). Socio Economic Profile of the Western Cape. Cape Town

Children's ACT, 2005 (ACT (38 of 2005) Government Printers. S.A

Child Care ACT, 1983(ACT 74 OF 1983) Government Printers. South Africa

Cleiren, M.P.H.D., (1993). Bereavement and Adaptation: A comparative study of the aftermath of death. Washington: Hemisphere

Collins Concise Dictionary, (1999) Glasgow: Harper Collins

Colman, O.A. (2001). Dictionary of Psychology. New York: Oxford University Press.

Common Wealth Secretariat (2001). A Commonwealth Response to a global Health Challenge. Marlborough House: London.

Constitution of the Republic of South Africa, (1996) Act 108 of 1996. Pretoria, S.A. : Government Printers.

Creswell, J. W. (1994). Research Design: Qualitative and Quantitative Approaches. Thousand Oaks, London: Sage Publications.

Cross, C. (2001). Sinking Deeper Down: HIV/AIDS as an economic shock to rival households. *Society in Transition*, Vol. 32 (1) p 133-147.

Crotty, M. (1996). Phenomenology and Nursing Research, Churchill Livingstone, Melbourne, Australia.

Croyer, (2001) cited in Poku, N.K. (2005) AIDS in Africa. How the Poor are Dying, Malden, USA

Cullinan, K., (2000). Memory Boxes. South African Memory Box Association. [Joko@pvas.co.za](mailto:Joko@pvas.co.za) . <http://www.health-e.org.za/view.php3?id=20000927> (accessed on 10/17/00)

Cluver, L. & Gardner, F. (2006). The psychological well being of children orphaned by AIDS in Cape Town, South Africa. *Annals of General Hospital. Psychiatry* v.1-3. Published on line 2006 July 19.doi: 10.1186/1744-859x-5-8. BioMed Central Ltd.

Dawes, A. (2002). *Sexual Offences against Children in South Africa*. Children's Institute. University of Cape Town.

Deacon, H. & Stephney, I. (2007). *HIV/AIDS, Stigma and children. A literature review*. HSRC Press. South Africa

De Jong, J., (2003). *Making an Impact in HIV/AIDS: NGO Experiences of scaling up*. ITDG Publishing. Southampton Row, London.

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

Dempsey, P. (2000). *Using Nursing Research*. New York, Philadelphia.

Deng, R., L. J., Sringeriyuang, L., and Zhang K., (2007). Drug abuse, HIV/AIDS and Stigma in a Dai community in Yunnan, China. Vol. (64) p1560-1571.

Denzin, F. & Lincoln, S. (2008). *Handbook of Qualitative Research Method*. London Sage Publications.

Denzin, N.K., & Lincoln, Y.S. (2000). *Hand book of Qualitative Research*. Second Edition. London Sage Publications. Thousand Oaks

Department of Health (1998). *Youth in South Africa Bear A Terrible Burden-HIV/AIDS*.

Department of Health (2006). *Republic of South Africa: Progress Report on Declaration of Commitment on HIV and AIDS*

Department of Social Development, (2003). National Guidelines for Social Services to Children Infected and Affected by HIV/AIDS. Pretoria National Department of Social Development.

De Vos, A.S.; Strydom, H., Fouché, C.B., Poggenpoel, M., & Schurink, E. W. (1998). Research at Grassroots: A premier for the Caring Professions. 2<sup>nd</sup> Ed Pretoria: Van Schiack Publishers.

De Vos, A.S, Strydom, H., Fouché C.B., & Delpont C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3<sup>rd</sup> Ed. Van Schiack Pub.

Dolores, C., & Tongco, D. C. (2007). Purposive Sampling as a tool for informant selection. Ethobotany Research and Applications 5: 147-158

Dorrington, R., Bradshaw, D. & Budlender, D. (2002). HIV/AIDS profile in the provinces of South Africa. Indicators for 2002. Centre for Actuarial Research, Medical Research Council and the Actuarial Society of South Africa.

Dube, M. W., (2001) HIV/AIDS and the curriculum methods of interpreting HIV/AIDS in Theological Programmes. World Council of Churches. S.A.

Durkin, K., (1995). Developmental Social Psychology -From Infancy to Old Age. Cambridge: Blackwell Publishers Inc.

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

Dworkin, S. H., & Kaufer, D. (1995). Social services and bereavement in the lesbian and gay community. *Journal of Gay and Lesbian Social Services*, 2(3/4), 41 -60 Cited in Nord (1997)

Edelston, K. (1988) *Countdown to Doomsday AIDS*. Media House Publications

Everatt, D. (1994) *Creating a future, Youth policy for South Africa*. CASE and JEP, Ravan Press S.A..

Ewing, D. (2000). Where love is the only therapy. *Children First*. Volume4, number 31, June-July.1998

Erikson, E. H. (1968). *Identify Youth Crisis*. New York: W.W. Norton.

Erikson, E.H. (1959). Nord, D. (1997). *Multiple AIDS- related loss. A handbook for understanding and surviving a perpetual fall*. Taylor and Francis, Washington D.C.

Erikson, E. H. (1980). *Identify and life cycle*. New York: W.W. Norton

Filliher, F., (2005) *Interpretivism and the Pursuit Research Legitimation: An Integrated Approach to Single Case Design*. *The Electronic Journal of Business Research Methodology* Volume 3 Issue 2, (123-132).

Foster, G. & Williamson, J., (2000) *A review of the current literature of the impact of HIV/AIDS on children in sub-Saharan Africa*. *AIDS*, 14(Suppl.3): S275 – S284)

Foster, G., (1997). *Children rearing children: A study of child-headed households*. Paper presented at the conference on the socio-demographic impact of AIDS in Africa, held 3-6 February 1997. International Union for the Scientific Study of population: Durban.

Foster, G., & German, S., (2000). The orphans Crisis (Draft). In Essex (Ed) AIDS in Africa.

Francis, E., (2001) Humanitarian Action. Sub-Saharan African Region information on HIV/AIDS. UNDP.

Frederickson, S., & Kanabus, A., (2004). Children on the Brink. A joint report of new orphan estimates and Framework for Actions. UNAIDS, UNICEF/ USAID.

Gannon, G. (1994). Children and Youth at risk of HIV/AIDS. Issues of Residential Care Community Perspectives. National Association of Child Care Workers NACCWCT.S.A.

Giese, S., Meintjies, H., Croke, R., & Chamberlain, R.(2003).Health and Social Services to Address the Needs of Orphans and Other Vulnerable Children in the context of HIV/AIDS. Children's Institute. University of Cape Town

Gilborn, L., Nyonyiton, R., Kabumbuli, R., & Jagwe-Wadda, G. (2001). Making a difference for children affected by AIDS: Baseline findings from operations research in Uganda, The population Council.

Golafshani, N., (2003) Understanding Reliability and Validity in Qualitative Research. The Qualitative Report Volume 8 no(4), 597 – 603.

Gouws, E., & Kruger (1994).Adolescent Development. An educational perspective. Pretoria: Butterworths

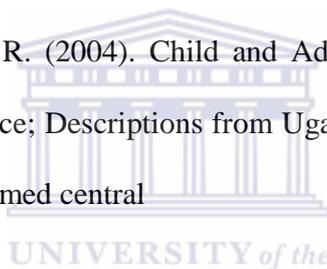
Gray, D.E., (2005) Doing Research in the real world. London. Sage Publications

Gregory, D., and Longman, A. (1992), Mothers suffering: Sons who died of AIDS. Qualitative Health Research, Vol2 no3, pp.334-357

Grossmann, R. (1984) Phenomenology and Existentialism. An introduction. Edmund Husserl, Martin Heidegger, Jean –Paul Sartre. Routledge and Kegan Paul. Mass.02108, USA

Harber, M. (1998) Developing a community- based AIDS orphan project: A South African Case study. ATTIC. Conference on raising the Orphan Generation. Paper No1. Pietermaritzburg.

Harms, S., Jack, S. & Kizza, R. (2004). Child and Adolescent psychiatry and mental health. The orphaning experience; Descriptions from Ugandan adolescents who have lost parents to HIV/AIDS. UK Pub med central



Harvey, R.D. (2001). Individual differences in the phenomenological impact of social stigma , journal of social psychology 141(2): 174 – 189)

Heidegger, M. (1962). Being and time, a translation of Seinund Zet by John Macquire and Edward Robinson. New York: Harper Publishers

Hein, S. F. & Austin, W. J., (2001). Empirical and Hermeneutic approaches to phenomenological research in psychology: A comparison. Psychological methods, 6, 3-17

Heymann, J. & Kidman, R. (2008) Weaving a tighter safety net: How communities can support families in the context of the AIDS pandemic. Institute for Health and Social Policy. Issue Brief 111.

Hope, (2001). Cited in Poku, N.K. (2005). AIDS in Africa. How the Poor are dying. Malden, MA 02148, USA

Hunter, S. & Williamson, J. (2000). Children on the Brink. Executive Summary. Updated Estimates and Recommendations for Interventions. United States Agency for International Development

Husserl, E. in Spiegelberg, H. (1976). The Phenomenological Movement: A Historical introduction. Vol. 2, Martinus Nijhoff, The Hague

Intergrated Development Plan, (2004). City of Cape Town. Cape Town

Jackson, S., Rodriguez-Tome, H. (1993). Adolescence and its social worlds. Lawrence Erlbaum Associates Publishers

Jaffe, M. L. (1998). Adolescence John Wiley and Sons, Inc.

Jennings, J.L. (1986). Husserl revisited: The forgotten distinction between psychology and phenomenology. American Psychologist, 41, 1231 - 1240

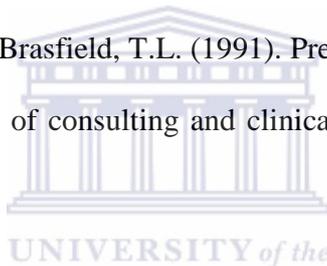
Jogunosimi, J. (2001). Advocates for the Youth: The HIV/AIDS Pandemic among youth in Sub-Sahara Africa .200m Street, NW. Suite 750, and Washington DC.E-mail: [questions@advocatesforyouth.org](mailto:questions@advocatesforyouth.org).

Kaseke, E. & Gumbo, P., (2001). The AIDS Crisis and Orphan Care in Zimbabwe. *Social Work*, Vol. 37 (1) p 53-58.

Kelliher, F. (2005). Interpretivism and the Pursuit of Research Legitimation: An Intergrated Approach to single Case Design. *The Electronic Journal of Business Research Methodology*. Volume 3 Issue 2, pp 123 -132.

Kelso, B. J. (1994). Orphans of the storm, *Africa Report*, Vol. 39, no.1 p5 Available: Ebscohost: Academic search premier Item: AN9406080336 [accessed 04 November 2003].

Kelly, J. A., Lawrence, J. S. & Brasfield, T.L. (1991). Predictors of vulnerability to AIDS risk behaviour relapse. *Journal of consulting and clinical Psychology*. Vol 59 no 1, pp. 163 – 166.



Kelly J.A., (2001). The Impact of HIV/AIDS on the Rights of children to education: Paper presented at the SADC/EU Seminar on the rights of children in a world with HIV/AIDS. Harare

Kersten, F. (1982). Edmund Husserl. Ideas pertaining to a pure phenomenology and to a phenomenological philosophy. Martinus Nijhoff publishers

Kiragu, D. (2002). Addressing the susceptibility of Youth to HIV/AIDS infection. Paper presented at the International Policymakers Conference on HIV/AIDS. Track 1A: knowledge and behaviour change. New Delhi, India 11 – 12 May 2002. [www.csakenya.org/pdfs/vct-report- PageMaker. PDF](http://www.csakenya.org/pdfs/vct-report- PageMaker. PDF). [Accessed on 20 October 2007]

Kirk, J. & Miller, M. (1986). Reliability and Validity in qualitative research. Sage University paper series on qualitative research methods, No.1. Newbury Park, California: Sage Publications.

Kluckow, (2004) cited in Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4<sup>th</sup> edition. Maskew Miller Longman Ltd Cape Town

Kock, (1995), cited in Paley, J. (1997), Husserl, phenomenology and nursing, Journal of Advanced Nursing, Vol 26, pp.187 – 193.

Kohlberg (1978). cited in Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4<sup>th</sup> edition. Maskew Miller Longman Ltd Cape Town

Kubler-Ross, E. (1985). On Children and Death. A touching and inspired work about how children and their parents can and do cope with death. Macmillan Publishing Company, New York.

Kubler-Ross, E. (1987) On death and dying. Macmillan Publishing Company, New York.

Lacity, M.C. & Johnson, M.A. (1994). Understanding Qualitative Data: a framework of text analysis methods. Journal of Management Information Systems/Fall1994. pp.137 – 155.

Leclerc-Madlala, S. (1997). Infect one, infect all: Zulu youth response to the HIV/AIDS epidemic in South Africa.

Leedy, P.D., (1997) Practical Research: Planning and design. 6<sup>th</sup> Ed Columbus, Ohio: Prentice Hall

Lincon & Gumba (1985) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delport C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3<sup>rd</sup> Ed. Van Schiack Pub.

Lynch, V.J. (2000) HIV/AIDS at year 2000.A Source Book for Social Workers. Boston Collage

### **Louw**

Louw, D.R. Darleen, D.R., & Orr, M., (2001). HIV/AIDS: Care and Support of Affected and Infected Learners. A guide for Educators. Department of Health South Africa.

Louw, D. A., Van Ede, D. M. & Louw, A.E., (1998). Human Development 3<sup>rd</sup> Ed. Pretoria: Kagiso Press

Maj, M. (1991) Psychological problems of families and health workers dealing with people infected with Human Immunodeficiency Virus 1, Act Psychiatric Scandinavia, vol. 83, no 3 pp.161 - 168

Mapp, T. (2008) Understanding phenomenology the lived experience. Research and Education. British Journal of Midwifery, May 2008. Vol. 16 no 5 (308 – 311)

Marcus, T. (1999). Wo! Zaphela Izingane. Living and Dying with AIDS. Blesston Printing Johannesburg.

Marshall & Rossman (1999) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delport C.S.L., (2005). Research at Grassroots, For the Social Science and Human Professions 3<sup>rd</sup> Ed. Van Schiack Pub.

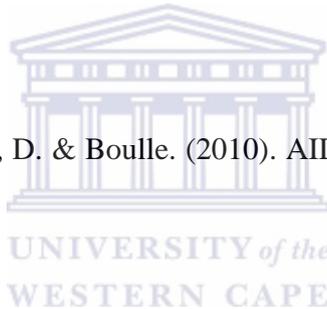
May, L. (1993). *Qualitative Research*, London Sage Publications.

McKerrow, N. (1994). When children are orphaned by AIDS. *Positive Outlook* Vol. 1(4), pp. 8-9.

Meintjies, H. & Giese, S. (2003) Addressing the impact of HIV/AIDS on children in South Africa. *Priorities for funders and Development Agencies*. Children's Institute. UCT. Rondebosch

Meintjies, H., & Giese, S. (2004) Addressing the impact of HIV/AIDS on children in South Africa. *Priorities for Funders and Development Agencies*: Children Institute. U.C.T. S.A.

Meintjies, H., Hall, K., Marera, D. & Boule. (2010). *AIDS Care* 01, 10 Vol.22; (1): 40 - 49.



Metcalf, L. (2001). Youth and HIV/AIDS: [www.stopglobalaids.org](http://www.stopglobalaids.org)

Miles, M. B. & Huberman, A.M. (1994). *Qualitative data analysis: an expanded sourcebook*, second edition. Sage Publications

Milton, J., (2000). The Social spread of HIV/AIDS in South Africa. *Journal of association of nurses in AIDS Care*, 11(4): 17-26

Morris, A.L. (1995). *Listening to older adult learners: the experience of using assistive technology in task performance and home modification*. Blacksburg, VA: Virginia Tech

Myers, M.D. (1997). *Qualitative Research in Information Systems*. *MIS Quarterly*, 21(2), 241 -242.

Mouton, J. (2001). How to succeed in your Master's & Doctoral Studies. A South African Guide and Research Book. Van Dyk Publishers.

Munro, I. (2002). The Lived experience of Gay Men caring for others with HIV/AIDS: living, loving and dying in the era of HIV/AIDS. Submitted in fulfillment of the requirements for the degree of Doctor of Philosophy. School of Nursing Deakin University.

Murphy, D., Johnston-Roberts, K. & Hoffman, D. (2003). Regrets and advice from mothers who have disclosed their HIV+ serostatus to their young children. *Journal of child and Family Studies* 12(3): 307-318.

Museveni cited in Aspaas, H.R., (1999). AIDS orphans in Uganda; Geographical and gender interpretations of household resources. *Social Science Journal (On line)*, Vol. 36, No. 2, p.22. [Accessed 04 November 2003].

National Programme of Action for Children in South Africa. The Presidency, (2001). *Children in 2001 .A Report on the state of the nation's children*. Office on the rights of children .The door communications.

Newman, W. L. (1997). *Social Research Methods: Qualitative and Quantitative Approaches*. Boston: Allyn and Bacon.

Ng'weshemi, J.; Boerman T. & Schapink D. (1997). *HIV prevention AIDS care in Africa. A district level approach*. Royal Tropical Institute, Nederland.

Neill, J., (2006). Analysis of Professional literature Class 6: Qualitative Research  
Accessed on 2009/06/09 from:

Nord, D. (1997). Multiple AIDS- related loss. A handbook for understanding and  
surviving a perpetual fall. Taylor and Francis, Washington D.C.

Norman, A., Kadiyala, S. & Chopra, M. (2005). Placing HIV-positive Mothers at the  
Centre of planning for Orphans and Vulnerable Children: A Case Study of South Africa.  
MRC. S.A.

Paley, J. (1997). Husserl, Phenomenology and nursing. A journal of advanced nursing,  
vol. 26. pp.187 - 193

Papalia, D. E., Olds, S. W. & Feldman R.D. (2008) A child's world. Infancy through  
adolescence Eleventh Edition McGraw-Hill International Edition

Parker, W. & Aggleton S. (2002). On the move: The response of public transport  
commuters to HIV/AIDS in South Africa, Department of Health: S.A.

Parkes, C. M. (1970). The first year of bereavement: A longitudinal study of the reactions  
of London widows to the death of their husbands, Psychiatry, vol.33, pp. 444 – 467

Parry, J.K. (1989) Social Work Practice with Terminally Ill. Haworth Press

Patton, M. Q. (1990). Qualitative evaluation and research methods 2<sup>nd</sup> Ed. London: Sage  
Publications.

Patton, M. Q. (2002). Qualitative evaluation and research methods 3<sup>rd</sup> Ed. Thousand  
Oaks, California: Sage Publications.

Perkel, A.K. (1992). *The mindscape of AIDS: Dynamics of transmission*. Cape Town:

Piaget (1950) cited in Papalia, D. E., Olds, S. W. & Feldman R.D. (2008) *A child's world. Infancy through adolescence Eleventh Edition McGraw-Hill International Edition*

Poku, N.K. (2005) *AIDS in Africa. How the Poor are Dying*. Malden, MA 02148, USA

Potter, J. & Wetherell, M. (1987). *Discourse and social psychology: beyond attitudes and behaviour*. London: Sage Publications.

Pretorius, H.G., Goldstein, N. & Stuart, A.D. (2005). *Meaning-Making of a group of South Africans in their experience of living with HIV: A Phenomenological Study*. *Health S.A.* Vol. 10 No.1

Rau, A. (2002). *combating child labour and HIV/AIDS in Sub-Sahara Africa. A review of policies, Programs, and projects in South Africa, The United Republic of Tanzania, and Zambia to identify good practice*. Printed in France.

Ray, M. A. (1994) in Morse, J.M. eds. (1994). *Critical issues in Qualitative research methods*. Sage Publications, Thousand Oaks

Richter, L. Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town : HSRC Press.

Robertson, M., & Donaldson, M., (2003). *Family murder, the child victims*. <http://www.csvr.org.za/articles/artfamur.htm>. [Accessed on 2003.10.15]

Ross, E., & Deverell, A. (2004). *Psychosocial approaches to health, illness and disability: a reader for health care professionals*. Pretoria: Van Schaik Publishers.

Rossmann (1999) cited in De Vos, A.S, Strydom, H., Fouché C.B., and Delpont C.S.L., (2005). *Research at Grassroots, For the Social Science and Human Professions* 3<sup>rd</sup> Ed. Van Schiack Pub.

Rubin, H. J. & Rubin, I. S. (1995). *Qualitative Interviewing: The art of hearing data*. London .

Rubin, A. & Babbie, E., (1997). *Research Methods for Social Work*. USA: Brooks/Cole Publishers

SAHARA, (2004). *Journal of Social Aspects of HIV/AIDS*. Vol. 1 NO.2 August 2004

Seaberg, J.R. (1998). Utilising sampling procedures. In Grinnell, R. M. *Social Work Research and Evaluation*. Third Edition, Itasca, IL: Peacock

Shaffer, A., Johns, D., Kotchick, B., Foreland, R., & The Family Health Project Research Group. (2001). Telling the children: Disclosure of maternal HIV Infection and its effects on child psychosocial adjustment. *Journal of Child and Family studies*. 10 (3): 301-313.

Shank, G. (2006) Six alternatives to mixed methods in qualitative research. *Qualitative Research in Psychology*; Vol.3: 346 – 356.

Shisana, O., and Simbayi, L., (2002). *Nelson Mandela / HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media. Household Survey*. Cape Town: HSRC Press.

Shisana, O., Rehle, T., Simbayi, L.C. & Parker, W. (2005). South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey. Cape Town. HSRC Press.

Shisana, O., Rehle, T. Simbayi, L.C. & Zuma, K. (2009). AIDS among older children and adolescents in Southern Africa. United Nations Plaza, New York. USA

Simon –Meyer, J. (1998). Children in distress best practice response to children affected by the HIV/AIDS epidemic.

Slot-Nielson, J. (2004). Realising the rights of children growing up in child-headed households. A guide to laws, policies, and social advocacy. Creda Communications

Smart, R. (2000). Children living with HIV/AIDS in South Africa. A Rapid Appraisal. A NACTT Project. Save the children.

Smart, R. (2003). Policies for orphan and vulnerable children: A framework for moving ahead. Policy project, USAID. Washington DC.

Silverman, D. (2001) Interpreting Qualitative Data. Methods for analysing talk Text and Interactions. Second Ed. Sage Publications

Spiegelberg, H. (1978). Doing Phenomenology: Essays on and in Phenomenology. Martinus Nijhoff. Hague

Spiegelberg, H. (1976). The Phenomenological Movement: A Historical introduction. Vol. No.1. Martinus Nijhoff, The Hague

National Strategic Action Plan (2007) HIV/AIDS and STI Strategic Action Plan for South Africa 2007 – 2011. Pretoria.

Straus, A. and Corbin, J., (1998) Basics of Qualitative Research, London: Sage Publishers

Stedeford, A. (1988). Facing Death. Patients, families and professionals. Heinemann Professional Publishing Ltd.

Steinberg et al., (2002) cited in Poku, N.K. (2005). AIDS in Africa. How the Poor are dying. Malden, USA

Steffenson, E.A. MPH. (2002). South African youth's knowledge, attitudes and practices: Potential implications for the AIDS epidemic.<http://www.kff.org/>

Terminology Committee for Social Work, (1995). New Dictionary of Social Work Cape Town: Bookbinders.

Todres, L. (2005). Clarifying the life-world: descriptive phenomenology. Qualitative research in health care journal (104 -145) England: Open University Press.

Tongo, D. C. (2007). Purposive Sampling as a tool for informant selection. Ethobotany Research and Applications 5: 147-158

UNAIDS, (1998). Force for Change: World AIDS Campaign with young people: World AIDS Campaign Brief Paper. Geneva.

UNAIDS, (1999). Listen, Learn, Live! World AIDS Campaign with Children and Young People: Geneva. AIDS Epidemic update. UNAIDS (2000). *Report on global HIV/AIDS epidemic 1211 Geneva 27 Switzerland.*

UNAIDS, (2000). A matter of life and death. South African Journal, 4(12), 3. Robertson AIDS Action Group.

UNAIDS, (2002). A conceptual framework and basics for Action: HIV/AIDS Stigma and Discrimination. Geneva: UNAIDS

UNAIDS, (2005). New Report presents three scenarios for AIDS in Africa by 2025. UNAIDS

UNAIDS, (2008). Report on the Global AIDS epidemic. Geneva: UNAIDS

UNICEF (2003) The Impact of HIV/AIDS on children. A paper presented at 3<sup>rd</sup> meeting of the African Committee of Experts on the rights and Welfare of the Child. Ethiopia: Addis Ababa

UNICEF (2007) Africa's Orphaned Generations. For Every Child Health, Education, Equality, Protection. Advanced Humanity

Van Dyk, A. (2001). HIV/AIDS Care and Counseling a Multidisciplinary Approach 2nd Ed., Maskew Miller Longman Group.

Van Dyk, A. (2003). HIV/AIDS Care and Counseling: A Multidisciplinary Approach 2<sup>nd</sup> Edition Pretoria: Pearson Education South Africa

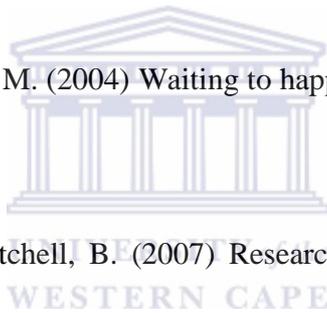
Van Dyk, A. (2008) HIV/AIDS Care and Counseling. A multidisciplinary approach 4<sup>th</sup> Ed. Pearson Education S.A.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. The Althouse press, Canada

Van Praag, E. (1995). The Continuum of care: Lessons from developing countries. *International AIDS Society Newsletter*, 3, 11-13.

Vika, G. M. (2006) Revised HIV and AIDS Strategy and Implementation Plan. The Methodist Church of Southern Africa.

Walker, L., Reid, G. & Cornel, M. (2004) Waiting to happen. HIV/AIDS in South Africa. University of Witwatersrand



Welman, C. Kruger, F. & Mitchell, B. (2007) Research Methodology 3<sup>rd</sup> Ed. Oxford University Press S.A.

Whiteside, A. & Sunter, C. (2000). AIDS: The challenge for South Africa. Cape Town

Williams, M. J. (1988). Gay men as Buddies to persons living with AIDS and ARC, *Smith College studies in Social Work*, vol.59, no1, pp.38 – 52

Williamson, J. (2004). What can we do to make a difference? Situation Analysis concerning children and Families affected by AIDS. Displaced children and orphans. Funds of USAID.

Williamson, J. (2002). Strategic Action for Children and Families Affected by AIDS: USAID.

Wolfet, A., (1987). Helping children cope with grief. Indiana: Accelerated Development Inc.

World Health Organisation (WHO) (2004). The Weekly Epidemiological Records No 47 and 48, November – December; UNDP: Human Development Report.

Wong, G. & Jevne, R. E. (1997) Patient hope: Exploring the interactions between physicians and HIV seropositive individuals', *Qualitative Health Research* vol.7, no1, pp.32-56.

Wyse, D. (2004) *Childhood Studies: An introduction* Blackwell Publishing



## **Appendix 1: Request for permission to conduct a Study**

### **Request for permission to conduct a Study**

The Director Ikamva Labantu  
Woodstock  
Cape Town

Dear Sir/ Madam

**RE: Requesting permission to conduct a Research Study with the clients of your organisation.**

I am currently a Master's student, in the Child and Family Studies Programme, Social Work Department at the University of the Western Cape. My thesis is, **An Explorative Study on the Experiences of Adolescents who have lost their parents to HIV/AIDS.**

The study will focus on adolescents who have lost parents through the HIV/AIDS pandemic. They will have to reside in Gugulethu, and will have to be part of your foster care programme; they will have to be willing to participate in the interviews. Should you grant me permission, a follow up meeting will be arranged with the foster parents so as to arrange a meeting with them and explain the purpose of the study. The results of the study will be made available to you before any information is published.

I shall appreciate if you and your management will favourably consider my request.

Thanking you in advance

N. W. Somtsewu (Mrs.)  
MA. Child & Family Studies Student  
University of the Western Cape

## APPENDIX 2: Consent form

### Consent form

I..... (Caregiver) hereby give consent that my (grandchild, niece, nephew, sister, brother, or friend's child ..... Participate in the research study entitled: **An explorative Study on the Experience of adolescents who have lost their parents through HIV/AIDS.**

It has been explained to me that a mini-thesis in partial fulfillment of requirements for a Master's degree in Child and Family Studies will be submitted to the Social Work Department at the University of the Western Cape.

The purpose of the research was explained to me as the caregiver. I am informed that all the information regarding my child will be kept anonymous. I was informed that under no condition will the participant be forced to participate, and the caregiver has the right not to allow his/her child to participate in the exercise. However the contribution that the participation of my child will make for the development of future policies regarding orphaned adolescents was also explained.

The researcher has informed me that should there be a need for my child to be sent for counseling due to him/her feeling distressed, such service will be arranged at no cost.

Signature of Guardian: ..... Date: .....

Signature of Researcher: ..... Date: .....

**Appendix 3: Assent form**

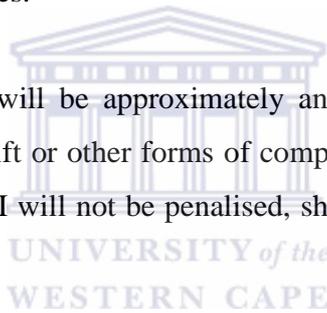
**Assent form**

I ..... (Participant), hereby declare that

I shall participate out of my own free will in the interview, as the purpose of the study has been explained to me. I am prepared to cooperate by sharing my life experience and be honest at all times.

I understand that my identity will be kept anonymous at all times. I understand that after the mini-theses have been compiled all the tapes and transcripts will be erased so as to ensure confidentiality at all times.

I agree to the interview that will be approximately an hour. I understand that I will receive no form of payment, gift or other forms of compensation for my participation in the interview. I am aware that I will not be penalised, should I choose to withdraw from the interview.



I am aware that the topics to be discussed are about how the experience of losing my parents has affected me. I am aware that due to the nature of the sensitivity of this topic that I might be upset and emotional. I am aware that the Researcher will arrange counseling for me should I should I require it at no cost.

Signed at .....on this .....

Signature of participant.....

Signature of researcher .....

## **Appendix 4: Interview guide:**

### **Interview guide:**

#### **1. BACKGROUND INFORMATION:**

Ukulungiselela le-ngxoxo ndicela undixelele igama lakho kunye negama ongathanda ndikubize ngalo kwesi sicatshulwa.

For the perpose of this study can you please give me a name that you would like me to call you?

Mingaphi Iminyaka yakho yobudala?

How old are you?

Ukweliphi ibanga esikolweni?

In which grade are you at school?

Unexesha elingakanani ufunda kweli-banga?

How long are you in this grade?

Unexesha elingakanani uhlala kwelikhaya uhlala kulo ngoku?

How long are you residing at your current home?

Misebenzi mini oyenzayo akhaya?

What type of chores are you doing at home?

Ungena kweliphi ibandla/inkozo/icawa?

To which congregation do you belong?

#### **2. FAMILY RELATIONS:**

##### **Ubuhlobo ngokweFemeli**

2.1. I would like us now to do what I call a family tree. Do you know what a family tree is? If not I explain.

Ndifuna senze lento kuthwa ngumNombo wefemeli, uyawazi umnombo wefeli? ukuba akundiva ndizakukuchazela banzi.

2.2. Who do you regard as a parent close to you in the family? Why is it so? Ngowuphi uMzali ocinga ukuba nguyena osondele kuwe efemelini yakho? kutheni kunjalo?

- 2.3. Tell me about your relationship with your mother and father?  
Khawundixelele bunjani ubuhlobo phakathi kwakho noMama kwakunye noTata wakho?
- 2.4. What kind of activities did you use to do with your parent(s)? (probe)  
Misebenzi mini obuthi uyenze nabazali bakho?
- 2.5. Can you please share who your father's siblings and your mother's siblings are?  
Ndicela ukhe undichazele ukuba ngobani abantakwabo Tata kwakunye noMama wakho?
- 2.6. Can you talk about the relationship between you and your aunt and uncles you have told me about?  
Ungakhe undixelele ngokuba bunjani ubuhlobo phakathi kwakho noMakazi bakho kwakunye noMalume bakho obundinike bona?
- 2.7. Do you live with any one of them? (Probe)  
Ingaba uhlala nomnye wabo?
- 2.8. What is it like growing up under the care of relatives? (Probe)  
Uva njani/kunjani ukukhulela phantsi kwenkathalelo yezizalwana zakho?
- 2.9. How many children did your parents have, and what are their ages and gender?  
Bangaphi abanye abantwana bakokwenu ngaphandle kwak kubazali bakho?  
Zingaphi iintombi, emangaphi amakhwenkwe, mingaphi iminyaka yabo?
- 2.10. Describe your relationship with each of relationship siblings? (probe)  
Ungakhe undichazele banzi ngobuhlobo phakathi kwakho nabantakwenu?

### 3. PARENT CHILD RELATIONS AND PARENTS DEATH:

#### Ubuhlobo bomzali nomntwana kwakunye nokusweleka kwabazali:

- 3.1. Can you please share your relationship with your mother? (Probe)  
Ungakhe undibalisele ngonxulumelwano/ngobuhlobo phakathi kwakho noMama wakho.
- 3.2. How did you find out about your mother/ father's HIV/AIDS status? (Probe)  
Ufumanise/uve njani ukuba uMama/ uTata wakho ugula yintsholongwane yeNgculaza/kaGawulayo?
- 3.3. How did you cope with your mother/ father's HIV/AIDS status? (Probe)  
Uye wamelana njani nalemeko yokuba umzali wakho ugula yiNtsholongwane yeNgculaza/kaGawulayo?
- 3.4. How did your mother/ father's illness impact on his/her parenting role? (Probe)  
Indima yobuzali iye yaphazamiseka njani ngexesha ebegula yintsholongwane yeNgculaza/kaGawulayo uMzali wakho?
- 3.5. How often did your mother/ father express their love to you as the child?  
Ebelibonakalisa kangaphi, njani uthando lwakhe uMama/uTata wakho kuwe njengoMntwana wakhe?
- 3.6. How did you cope seeing your parent in pain? (Probe)  
Uye wamelana njani nemeko yokubona umzali wakho esezintlungwini?
- 3.7. How did you react when you were told that your mother/ father had died? (Probe)  
Uye wenzani usakuxelwa ukuba uMama /uTata wakho uswelekile?
- 3.8. What was the reason for you to react that way? (Probe)  
Ibiyintoni na isizathu sokuba wenze ngolohlobo/ngalondlela?

- 3.9. Was there any particular person who helped you emotionally to deal with the death of your mother/father? (Probe)  
Ingaba kubekho Mntu na oye wakululeka ngokwasengqondweni kwintlungu obukuyo yokushiya ngumzali?
- 3.10. Who is the person who looked after your mother/ father during his/ her illness?  
Ngubani na uMntu obejongana nomzali wakho ngexesha lokugula kwakhe yintsholongwane kaGawulayo?
- 3.11. With whom were you staying at the time of your mother/father's death and in what province?  
Ngelixesha uMama/uTata wakho aswelekayo ubuhlala nabani na? kweliphi iPhondo?

#### **4. EDUCATIONAL EXPERIENCE**

##### **Amava ngokweMfundo/eSikolweni**



- 4.1. How was your education affected by your parent(s) illness? (Probe)  
Ingaba imfundo yakho yaphazamiseka njani kukugula komzali wakho?
- 4.2. Did you ever have to stay out of school because you had to care for your ill parent(s)? (Probe)  
Wakhe wahlala awaya esikolweni kuba kwakufuneka wonge umzali wakho?
- 4.3. Have you ever not been able to pay school fees because of the illness/death of your mother/father? (Probe)  
Ubukhe wakwimeko apho ungakwaziyo ukuhlawula iimali zesikolo ngenxa yokugula nokusweleka koMzali wakho?

- 4.4. Did you receive food from the school feeding scheme? (Probe)  
Ubukufumana ukutya kwinkxaso yokudla efunyanwa ngabantwana esikolweni/abangathathi ntweni?
- 4.5. In your opinion, how do teachers and other children treat children who have lost parents through AIDS at your school? (Probe)  
Kokwakho ukucinga/nokubona ingaba abantwana abazinkedama ngenxa kaGawulayo baphatheka njani esikolweni sakho?
- 4.6. Do teachers listen to the problems of children who have lost their parents through AIDS? (Probe)  
Ingaba abafundisi ntsapho/ootishala bayazimamela iingxaki abathi bahlangabezane nazo abantwana abaswelekelwe ngabazali ngenxa kaGawulayo?
- 4.7. What kind of support do teachers give to children who have lost parents through HIV/AIDS?  
Loluphi uhlobo lwenkxaso/loncedo oluthi lunikwe ngabafundisi ntsapho kubantwana abazinkedama ngenxa kaGawulayo?

## **5. HEALTH EXPERIENCE**

### **Amava ngokweZempilo**

- 5.1. How often did your mother/father have to attend the local clinics and hospitals? (Probe)  
Umzali wakho wayeqhele ukuya kangaphi kumaZiko oonyango nasesiBhedlele (Clinics and Hospitals)?
- 5.2. How can you describe the treatment your parent(s) received at the local clinics including the medication administration? (Probe)  
Ungakhe undichazele banzi ngempatheko umzali wakho ebethi ayifumana esiBhedlele naseKliniki kwakunye nendlela ebenikezwa ngayo amayeza akhe?

- 5.3. How are children who have lost their parents through AIDS treated at the local clinics? (Probe)  
Abantwana abaswlekelwe ngabazali ngenxa kaGawulayo ingaba baphatheka njani kwikliniki yasekuhlaleni?
- 5.3. What do you think are the reasons for children your age to normal go to the local clinics? (Probe )  
Ucinga ukuba yintoni izizathu ezibangela abantwana abakobu budala bakho baye ezikliniki ezisekuhlaleni.?
- 5.4. Can you share some of your experiences when you attend the local clinics to ask about HIV/AIDS or perhaps contraceptives? (Probe)  
Ungakhe wabelane nam ngamava akho xa ubukhe waya ekliniki esekuhlaleni nokubuza ngentsholongwane yesandulela sengculazi kunye noGawulayo okanye ngamayeza okuthithela?

## **6. RELIGIOUS EXPERIENCE:**

### **Amava ngokwaseNkozweni/Ecaweni**

- 6.1. Are there any projects or programs at your church run for children who have lost their parents through HIV/AIDS? (Probe)  
Ingaba enkonzweni/ecaweni yakho zikhona akhona amahlelo ezenzelwe abantwana abathe bashiywa ngabazali ngenxa kaGawulayo?
- 6.2. How does the congregation treat children who have lost parents through HIV/AIDS? (Probe)  
Ibandla/inkozo yakho libaphatha njani abantwana abathe bashiywa ngabazali nganxa kaGawulayo?

## 7. ECONOMIC PRESSURE

### Ubunzima ngokwesezimalini.

- 7.1. Who supported you financially before your mother/father became ill? (Probe)  
Phambi kokuba uMama okanye uTata wakho agule ngubani obekuxhasa ngokwasemalini?
- 7.2.1 Who supported you during his/her illness? (Probe)  
Ngubani oye wakuxhasa ngethuba lokugula loMzali wakho?
- 7.3 . How did the illness and death of your mother/father affect your family's financial situation? (Probe)  
Ingaba ukugula nokusweleka komzali wakho kwayichaphazela njani imeko yezemali efemelini/ ekhaya?
- 7.3.1 After the death of your parent(s) who provided for your basic needs like food, clothes and shelter? (Probe)  
Emva kokusweleka komzali wakho, ngubani owathi wajongana neemfuno zakho ezinjengokuba ufumane ukutya,impahl kwanendawo yokuhlala?
- 7.3.2 What was this person(s) doing that makes you feel that they are /were responsible for your basic needs? (Probe)  
Wayesenza ntoni loMntu eyathi yabangela uzive eluthathele kuye uxanduva lokuba ufumane ukutya, impahla kwakunye nendawo yokuhlala?

#### 4. SOURCE OF SUPPORT:

##### Iziko/umthombo wenxhaso

- 4.1. Who are the people that helped you deal with the illness of your parents? What did they do to support you? (Probe)  
Ngobani abantu abathi bakunceda ukukomeleza ukuba umelane nokugula komzali wakho, Benzani ukuxhasa wena?
- 4.2. How did the people that you lived with (at home) treat you when they heard that your mother/ father have AIDS? (Probe)  
Baye bakuphatha njani abantu ohlala nabo ekhaya bakuva ukuba uMzali wakho unentsholongwane kaGawulayo?
- 4.3. I would like you to tell me who your friends are? How long have you been friends? Why have you chosen the above mentioned as your friends? (Probe)  
Ungakhe undixelele ukuba ngobani abahlobo bakho? Lixesha elingakanani bengabahlobo bakho? Kwakutheni ukuze ukhethe bona njengabahlobo bakho?
- 4.4. Can you describe any changes in your relationships with your friends during their illness and after their death? (Probe)  
Ungakhe undichazele banzi ngentshintsho ezathi zenzeka bakathi kwakho nabahlobo bakho malunga nobuhlobo benu ngexesha lokugula nokusweleka koMzali wakho?
- 4.5. Besides your friends and family who else helped you deal with the death of your mother/father; was there a nurse, a social worker, psychologist, or a teacher who helped you? (Probe)  
Ngaphandle kweFemeli nezihlobo zakho ngubani omnye owathi wakunceda ukuba womelele umelane nokusweleka koMzali wakho kwaba balandelayo ingaba yaba nguMongikazi, nguNontlalontle, uMntu ojongana nabantu ngokwasengqondweni okanye umfundisi ntsapho?

- 4.6. Can you please share with me what this person has done for you to help you deal with the death of your parent(s)? (Probe)

Ungakhe undichazele ukuba wenza ntoni lomntu kuwe ukuncedana nawe ukuba womelele umelane nokusweleka koMzali wakho?

- 4.7. Do you know of any organisations in your community that supports children who have lost parents through HIV/AIDS? (Probe)

Ingaba unolwazi lwemizi enikezela iinkonzo ekuhlaleni ethi ixhase abantwana abaswelekelwe ngabazali ngenxa kaGawulayo?

