

**An exploration of adolescents' experiences of  
parental AIDS-related  
illness and bereavement**

**By**

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## DECLARATION

I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Masters of Arts in Counselling Psychology in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Pietermaritzburg, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

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## **Thesis supervisor's approval of this thesis for submission**

As the candidate's supervisor I have approved this thesis/dissertation for submission.

Signed: .....

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## **Abstract**

South Africa is one of the countries most affected by HIV/AIDS, and the impact on children living in affected households and communities is significant. The loss of a parent or caregiver due to an AIDS-related illness has left many children orphaned. Understandings of bereavement- particularly amongst African adolescents- and adults' responses to orphans' psychological and emotional difficulties, remains under-developed. This paper explored adolescents' experiences of parental AIDS-related illness and bereavement. Ten adolescents participated in this study. Qualitative methods such as observation, individual interviews and a focus group were the means of data collection. Key findings of the study were that: adolescents were profoundly affected by the death of their parents with some showing signs of great anxiety in relation to their future; were in need of emotional and material support; and were affected by the intense stigma associated with HIV/AIDS which resulted in secrecy and shame. This study suggests that if we listen to the voices of children, we will learn about their emotional, psychological, developmental, and behavioural needs, which in turn will inform interventions working with vulnerable and orphaned children.

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# **Chapter 1**

## **Introduction**

This study aims to understand the experiences of adolescents' who have lost their parent/s due to an AIDS- related illness. Adolescents' feelings about death may not be the same as those of adults or younger children, and could be misunderstood. The purpose of this study is to explore adolescents' perceptions and experiences about death, how they have perceived themselves to have reacted (emotionally and otherwise) to the loss of a loved parent and possibly significant others as well, and the effects which an AIDS-related death has had on them. All of the participants in this study are considered to have experienced an AIDS-related parental death, although they may not have been able to acknowledge the cause of the death due to the harsh stigma associated with AIDS- related deaths.

This study hopes to advance an understanding of the grieving processes of adolescents by considering adolescent accounts of their own feelings related to multiple death and loss, through an AIDS-related death. This is an under-developed research area. It is important to examine adolescents' responses to death and loss, and how they make meaning of and cope with life's stressful events, so as to create suitable interventions that can adequately address their social and emotional difficulties following parental loss. Bauman and Germann (2005) argue that despite the urgency of children's needs, society and government have failed to adequately acknowledge children's anxieties, fear, mistrust, anger and guilt, and the impact of the stigma that saturates their lives. As a result of this failure, children often carry this burden alone, in silence and in isolation, without a parent or caregiver to guide them. In essence, Bauman and Germann (2005) demonstrate that if we listen to the voices of children, we will learn about their emotional, psychological, developmental, and behavioural needs.

### **1.1 Background and outline of research problem**

In essence, this study intends to understand adolescents' experiences of their parent's death, bereavement and HIV/AIDS. Vulnerable children are in desperate need of

psychosocial support in order to assist them in dealing with the complex and distressing situations which they face. The context of the research plays an important role in the way in which the study was conducted as the adolescents who were selected came from families who had low socio economic status due to unemployment, poverty and other life adversities. In light of this, the research was context specific and was designed in a manner that considered the various difficulties faced by the adolescents.

## **1.2 Aim and rationale for the study**

The increasing numbers of orphans in South Africa has indicated that children are vulnerable through the loss of parental figures. The illness and death of a parent is a crisis for each child left behind (Foster, Levine, & Williamson, 2005). Such a loss can have several effects on a child such as trauma, emotional and psychological distress. As a result of parental death, children may experience anxiety, depression and neglect, all of which can significantly affect a child's well-being (UNICEF, 2006). Loss for children often includes a progression of experiences from the onset of a parent's or caregiver's illness, through the physical and emotional impact of HIV/AIDS on their loved ones, to their death (Wood, Chase, & Aggleton, 2006). The aftermath of the death also has a severe impact as children worry as to who will take care of them and meet their needs. When a parent dies, a child is potentially denied love and nurturance as well as the protection of their biological parents; these are all fundamental aspects for the child's development (WHO/UNICEF, 1994).

Wood *et al.*, (2006) state that understanding of bereavement and grief among African children remains under-developed. The same can be said for adults' responses to orphans' psychological and social difficulties. These factors highlight a limitation of previous research within this field, and as a result, serve as a strong rationale for this study. Thus, this study aims to pay particular attention to African children, adolescents in particular, who have been both orphaned and made vulnerable by the affects of the HIV/AIDS pandemic and other life adversities. As suggested by Dane (2002), children of terminally-ill HIV/AIDS parents should be considered to be at risk developmentally, and in need of support services. It is essential to provide orphans and caregivers with mental health services, including bereavement and grief counselling, and psychosocial support (Zhao, Li, Fang, Zhao, Yang, & Stanton, 2007). Furthermore, public health workers, school teachers

and community leaders should be trained such that they can provide basic psychosocial support and referral services to orphans in need (Zhao *et al.*, 2007).

The pertinent question which serves as a rationale for this study is: how do adolescent orphans experience parental AIDS-related death and bereavement? This study aims to better understand adolescents' experiences, perceptions and understandings of death, bereavement and HIV/AIDS, how it affects them as individuals as well as how they understand death to affect those around them.

### **1.3 Overview of the study**

In chapter two the reader is introduced to the current literature surrounding the HIV/AIDS pandemic, its impact on communities and particularly on children, in relation to parental loss. Chapter three outlines methodology used as well as the aim of the study, the critical research questions, and the important ethical considerations. The process of sampling and data collection is also discussed. Chapter four describes the results of the research followed by the discussion of the results in chapter five. Chapter six reflects on the study while chapter seven provides a summary of the findings, ending with a conclusion.

## **Chapter 2**

### **Review of literature**

#### **2.1 Introduction**

This chapter presents an overview of the literature in the field of HIV/AIDS and its impact on children and their communities. This chapter pays particular attention to orphaned children, and the impact which parental loss has had on them.

#### **2.2 The impact of the HIV/AIDS epidemic**

HIV/AIDS has created tremendous change in the world in intense, and still-evolving, ways. The rapid evolution of the impact of HIV/AIDS tends to disguise the immediate general effects, but the cumulative effects registered over the last few decades is already producing, and will continue to produce significant changes across society (Economic Commission for Africa, n.d.). The vast majority of people with HIV live in the developing world. Sub-Saharan Africa has been described as the epicentre of the virus, with 23.2 million people estimated to have HIV or AIDS (Whiteside & Sunter, 2000). More than two thirds (68%) of all HIV-positive people live in this region where more than three quarters (76%) of all AIDS deaths in 2007 occurred (UNAIDS & WHO, 2007). HIV/AIDS continues to have a disastrous impact on the social and economic development of countries across the globe.

Morbidity and mortality due to HIV/AIDS and related illnesses is concentrated among adults between the ages of 25 to 50. Around half of the people who acquire HIV become infected before they turn 25 and typically die of the life-threatening disease called AIDS by the time they reach their 35<sup>th</sup> birthday, if not before (Piot, 2000). People in this age group are often described as at the prime of their reproductive and productive years: working and raising families. HIV/AIDS thrives among tragic human conditions such as poverty, abuse, violence, stigma and ignorance (Foster, Levine, & Williamson, 2005). Social and economic circumstances have been found to contribute to the vulnerability of the HIV infection and intensify its impact, while HIV/AIDS creates and magnifies the very conditions that enable it to thrive (Fredriksson & Kanabus, 2005).

HIV/AIDS is not a stand alone condition, but exists within a wider socioeconomic context that deepens the vulnerability of communities and nations (Economic Commission for Africa, n.d.). According to UNICEF (2003) “the worst is yet to come”, as HIV/AIDS continues to spread. HIV/AIDS is not only killing people, it is further dividing national societies. Severe economic changes in sub-Saharan Africa over the last decade have left some households more exposed to the impact of HIV/AIDS. Communities and households already suffering from conditions of poverty are most harmed by the loss of adult members to illness including HIV/AIDS.

In the same way that the HI virus depletes the human body of its natural defences, it also depletes families and communities of the assets and social structures needed for the successful prevention and provision of care and treatment for people living with HIV/AIDS (Richter, Manegold, & Pather, 2004). The economic costs of HIV/AIDS, the stigma surrounding the disease that leads to discrimination and withdrawal, and the inability to access social services combine to expand socioeconomic inequalities in society (Economic Commission for Africa, n.d.).

The impact of this virus extends beyond the people infected by it and encompasses those surrounding the infected people, having an effect on the extended family, community and society (Fredriksson & Kanabus, 2005). The presence of HIV/AIDS in a household quickly results in the depletion of household income earning capacity and of household savings and assets. Furthermore HIV/AIDS exacerbates and is exacerbated by prevailing economic conditions. Illness and death of adult members of a household reduces the ability of households to provide for themselves. Furthermore, dependency ratios increase, as fewer adults care for children and the elderly (Economic Commission for Africa, n.d.). The overall impact of this epidemic has major consequences on the lives of millions of individuals, including those directly and indirectly affected and infected.

### **2.3 HIV/AIDS in the South African context**

South Africa has been reported to have the largest number of HIV infections in the world (Simbayi, Kleintjies, Ngomane, Tabane, Mfecane, & Davids, 2006). No reason yet exists to

suggest that the HIV epidemic is significantly slowing down, and each day the continuing spread adds to the ramifications and duration of its devastating impact (Poku, 2005). With a national HIV prevalence of 12% in the general population and an estimated 1700 people being infected with HIV everyday in the country, South Africa has an estimated 5.3 million people living with HIV/AIDS (UNAIDS, UNICEF & USAID, 2004).

The epidemic varies considerably between provinces from 15% in the Western Cape, to 39% in KwaZulu-Natal (UNAIDS and WHO, 2007). In October 2005, newly released national HIV and syphilis antenatal seroprevalence survey figures showed that an estimated 3.3 million women, 2.8 million men, and over 100 000 children in South Africa were infected by HIV (Caelters, 2005). Furthermore, across South Africa, approximately one in five or six children lives with an HIV infected mother (Richter *et al.*, 2004), and almost two-thirds of children who have lost their mothers have lost them to AIDS.

Poku (2005) argues that communities across the country are experiencing day-to-day decline in their standards of living; reduced capacities for personal and social achievements and an increasingly uncertain future; with a diminished capacity to maintain what has been secured over past decades in terms of social and economic development. Not only does the epidemic spell an early, painful and stigmatised death for millions of individuals, it also threatens to derail the countries prospects of development (Poku, 2005). Population growth will slow as HIV/AIDS mortality increases. Furthermore, household structures will change, with more female, child and elderly-headed households (Economic Commission for Africa, n.d.). Some households may even dissolve altogether, either because of economic destitution or the death of parents and dispersal of children.

The economic impact and consequences of HIV/AIDS on communities has proven to be severe, and has been evident in the changes in income and longer term prospects for economic security. A study in KwaZulu Natal found that households that had experienced a death in the previous 12 months, had a mean monthly income equal to only 64% of households that had not experienced a death (Economic Commission for Africa, n.d.). Furthermore, this study showed that the burden of care giving deepened the poverty of a household, as more money had to be allocated to healthcare for their ill family members (Economic Commission for Africa, n.d.). This deepened poverty often meant that family members left work and children dropped out of school.

It has been strongly argued that the effects of poverty have exacerbated the spread of HIV/AIDS (Foster *et al.*, 2005; Schoepf, 2004). South Africa's former President Thabo Mbeki has argued that poverty is the main cause of AIDS (Murphy, 2003). This statement caused much controversy, and has been both opposed as well as defended. Van Niekerk (2005) argues that Thabo Mbeki's statement fails to highlight the distinction between the cause of the epidemic, and the social context within which the epidemic prospers. Furthermore, Van Niekerk (2005) argues that in order for a viral disease to become an epidemic, a niche or social context is required, and in the case of South Africa - and Africa as a whole - poverty is the main characteristic of this niche or social context.

Many people in South Africa deal with extreme economic hardship from day to day, and HIV/AIDS rapidly induces and deepens conditions of poverty, primarily affecting the poorest and most disadvantaged groups in our country. As a result of these social and economic problems an increased vulnerability to the devastating consequences of the epidemic is created (Demmer, 2007).

In the light of poverty, research has shown that bereavement is likely to be more complex as individuals are trying to deal with the loss of a loved one, while also having to deal with their economic hardship, poor housing conditions, malnutrition, and limited support services (Richter *et al.*, 2004). The impact of death on the household is further illustrated in Demmer's (2007) study in which participants expressed the distress caused when an adult and breadwinners in the family dies. Typically, a family member became critically ill and then loses his/her job, resulting in other family members having to find extra money as a means of survival. This was usually not possible, leading the household into further debt and complete disarray (Demmer, 2007). Overall, the AIDS epidemic has, and continues to cause deterioration in child survival rates, reduced life expectancy, over-burdened health systems and fragmenting socio-cultural coping networks (Poku, 2005).

#### **2.4 The Impact of HIV/AIDS on Children**

AIDS is destroying entire generations of young adults while simultaneously leaving behind a large legion of children without parents (Foster *et al.*, 2005). Between 1990 and 2010, the Joint United Nations Programme on HIV/AIDS estimates that the total number of children

younger than 18 who have lost one or both parents to AIDS will increase from 550 000 (1.9% of all orphans) to 18.4 million (36.8%) (Nyamukapa, Gregson, Lopman, Saito, Watts, Monacsh, & Jukes, 2008). Even when HIV prevalence stabilizes, or begins to decline, the number of orphans will continue to grow or at least remain high for years, reflecting the time lag between HIV infection and death (UNICEF, 2006).

Richter *et al.* (2004) argue that the impact of HIV/AIDS on children, families and communities is influenced mainly by the legal and policy environment, access to basic services, socio-economic status, the social and cultural environment, and the extent of knowledge about and acceptance of the HIV/AIDS as a problem which affects everyone (Richter *et al.*, 2004). Hunter and Williamson (2002) outlined the potential impacts of HIV/AIDS on children, families and communities. They identified that these potential impacts create a vicious cycle where one impact often creates and intensifies the next. The identified potential impacts on children include loss of family and identity, depression, reduced well-being, increased malnutrition and starvation, loss of health status, loss of educational opportunities, forced migration, homelessness, vagrancy and crime, and exposure to HIV infection (Hunter & Williamson 2002 as cited in Richter *et al.*, 2004). The impact on children also has ramifications for the families and households. Such impacts include grief, impoverishment, changes in family composition, changing family and child roles, stress and dissolution, inability to provide parental care for children, and decrease in the middle generation leaving the old and young (Richter *et al.*, 2004).

The impact of this epidemic extends further, from experiences of stigma, discrimination and human rights violation to psychological and emotional distress of humankind. Various programmes have needed to be developed as a means of addressing the impact of HIV/AIDS as, over the last decade, the number of orphans in South Africa has been estimated to reach 3.1 million by 2010 (Foster *et al.*, 2005).

#### **2.4.1 Defining orphanhood and vulnerability**

The definition of the word “orphan” derives from Greek and Latin roots meaning “a child bereaved by the death of one or both parents” (Foster & Williamson, 2000). UNICEF and UNAIDS (1999) define an orphan as a child under the age of 15 years of age: a single orphan has lost one parent, while a double orphan has lost both parents. An orphan due to



AIDS is defined as “a child who has at least one parent dead from AIDS” (USAID, 2004). Guidelines proposed by UNICEF and UNAIDS guard one against using the term “AIDS orphan” as it may contribute to “inappropriate categorization and stigmatization of children” (UNICEF & UNAIDS, 2004). Thus this term has been avoided in the context of this study.

Robson and Sylvester (2007) argue that the AIDS epidemic and the surrounding poverty are generating a context in which large numbers of children are becoming vulnerable. A vulnerable child, within the South African context, is defined as one who is: a) orphaned, neglected, destitute or abandoned; b) has a terminally ill parent or guardian; c) is born of a teenage or single mother; d) is living with a parent or adult who lacks income-generating opportunities; e) is ill-treated by step-parent or relatives; and/or f) is disabled (Richter *et al.*, 2004).

Similarly, the definition of vulnerability extends to address the loss of a parent through death, desertion, or chronic illness; hunger; lack of access to basic services; inadequate clothing or shelter; living with caregivers too ill or old to continue to provide adequate access to food, education, psychosocial or emotional support; factors specific to the child, including disability, direct experience of physical or sexual violence, or severe chronic illness (Robson & Sylvester, 2007). This definition of vulnerability extends further to include depriving children of educational, emotional, and social opportunities into their future (Wood *et al.*, 2006). The HIV/AIDS epidemic affects many children by changing the nature of the society in which they live.

As young and middle aged adults die of HIV/AIDS, hundreds and thousands of children are orphaned (Foster *et al.*, 2005). Though the absolute numbers are important, perhaps more important is the speed at which the number of orphans is increasing, indicating the mushrooming pressure on households, communities, government services, and civil society to address the needs of orphaned children (Economic Commission for Africa, n.d.).

#### **2.4.2 Defining adolescents**

The term “adolescence” describes the transition from childhood to adulthood that is marked by distinct biological, cognitive, and sociocultural changes. The World Health Organization

identifies adolescence as ages 10-19 years. Some societies and cultures mark the transition to adulthood not solely by physical changes or by the attainment of a certain age but by specific rituals through which young people must pass in order to be considered an adult by the standards of the community. The United Nations Convention on the Rights of the Child defines childhood as up to age 18 (UNICEF, 1989). This thesis uses the terms “adolescents” and “children” to refer to youth ages 11-16 years as this was the age group of special interest.

All adolescents face key developmental tasks, which may be particularly challenging for orphans. Adolescent orphans require different kinds of assistance to younger children. Although various programmes working with orphaned children have been implemented, there has not been enough focus on the particular needs of adolescents. Ruland, Finger, Williamson, Tahir, Savariaud, Schweitzer, and Shears (2005) argue that in some ways, adolescent needs are more complex than the needs of younger orphans because of physical and psychological development during puberty and the steps needed to move toward independence and adulthood. Ruland *et al.* (2005) identifies adolescent needs as including secondary education or livelihood training, sexual and reproductive health education and services, psychosocial and social support for the difficult transition to adulthood and adult mentors as role models.

A key developmental adjustment in adolescents is physical and sexual maturity (Sigelman & Rider, 2003). With this maturation comes the need to understand relationships, including intimacy and peer pressure. The move towards adulthood also involves challenging rules, testing cultural norms, finding a means of economic support and navigating risky behaviours (Sigelman & Rider, 2003). Ruland *et al.* (2005) identify connectedness to parents - including parental expectations regarding school completion - as one of the key protective factors associated with positive outcomes for adolescents. One positive outcome is avoidance of risky sexual behaviours, as sexual activity as well as substance abuse, begin during adolescence. Psychosocial and economic distress can heighten these risky behaviours (Ruland *et al.*, 2005). Without the protective factor of having supportive parents, adolescent orphans may become vulnerable to HIV infection themselves, as well as other sexually transmitted diseases and unintended pregnancy.

Orphaned adolescents are often susceptible to having more demands on them to head households after the death of their parents. As a result, adolescents are more likely to drop

out of school in order to earn an income and to support their younger siblings (Simbayi *et al.*, 2006). Such economic hardships can also deprive adolescents of recreation and participation in community activities (Ruland *et al.*, 2005), and as a result depression, hopelessness, and risky behaviour can be common reactions to these circumstances that need special attention and strong protective measures. As the number of orphans continues to increase, an estimated 55% of all orphans under the age of 18 are adolescents (Ruland *et al.*, 2005).

### **2.4.3 The psychosocial impact of HIV/AIDS on children**

Various studies show that orphaned children run the risk of increased psychosocial distress (WHO/UNICEF, 1994). Psychological risk factors also need to be taken into consideration when dealing with children orphaned by HIV/AIDS (Bauman & Germann, 2005). Cluver and Gardner (2007) define psychological risk factors as variables which increase the likelihood of psychological difficulties, and protective factors as variables which improve outcomes, despite environmental hazards.

In their study of risk and protective factors for psychological well being, parental (particularly maternal) bereavement was identified as a key risk for emotional and behavioural problems (Cluver & Gardener, 2007). Poverty was also perceived to be a stressful factor contributing to the lack of emotional and behavioural well-being of children. Cluver and Gardner (2007) identified homelessness, unemployment, and no medical care as the specific poverty-related risk factors. Housing also proved to be an area of concern, in that their research also took into consideration overcrowding, leaking and/or burnt down shacks.

Cluver, Gardner, and Operario (2007) in their study of 'Psychological distress amongst AIDS-orphaned children in urban South Africa' discovered that children orphaned by AIDS are particularly vulnerable in terms of emotional problems. This study revealed that depression and anxiety was common in orphaned children, and particularly more so with orphaned girls. Depression often led to orphaned children having suicidal ideation. Boys, on the other hand, tended to exhibit more delinquent behaviour. Post traumatic symptoms were also evident with both orphaned girls and boys. These outcomes highlight the complex nature of the effects of HIV/AIDS on children, families and societies at large, and

the way in which the impact of this epidemic replicates itself in numerous ways, economically, socially emotionally, and psychologically (Cluver *et al.*, 2007).

Children affected by HIV/AIDS experience profound psychosocial impact, moving beyond economic and macrosystemic boundaries. Killian (2004) argues that one method of understanding the psychosocial impact on children and their families as a result of HIV/AIDS is to follow their life paths. This involves exploring a number of stages which include:

- a) Children becoming aware of HIV/AIDS: they begin to realise that people around them are ill and are dying. This realisation has an emotional impact on children often causing them to become anxious and distressed.
- b) AIDS-related illness becomes personal: this is as children become aware of their loved ones showing signs of illness and suspect they may be HIV positive which links to fears of being stigmatised.
- c) Children become involved in caring for someone who is terminally ill: they often participate in taking care of their ill caregivers, and are exposed to the distressing nature of the HI virus as they see their caregiver/s deteriorating from the illness.
- d) Children experience loss: as the virus progresses, children experience the death of their parents and other members of their family.
- e) The post death period is often marked with extreme insecurity as children adjust to life without the parent/s and have to deal with numerous changes in their life circumstances.

As children experience these different stages, so their emotional and psychological well-being potentially becomes compromised. Grieving as a result of illness and death of a parent or loved one can be a very traumatic experience for a child, and lack of consistent nurture and support can increase psychological risk for a child (Richter *et al.*, 2004). Wood *et al.* (2006) further demonstrates Killian's (2004) argument that a child's loss often

includes a succession of experiences from the onset of a parent's illness, through the emotional and physical impact of HIV/AIDS on their loved ones, to their death and its aftermath. Furthermore, Wood *et al.* (2006) describe loss as highly complex and dependent on developmental stage, resilience, quality of care, and social support networks.

Hope and Hodge (2006) elaborate on this, stipulating that the relationship with the deceased, the circumstances of death as well as participation in rituals such as the funeral, are also contributing factors to the way in which a child deals with loss. Emotional and physical supports are factors which define and sustain childhood, and thus the illness and death of a parent can rob a child of such important support processes (Foster & Williamson, 2000). Children experience the stresses of parental illness. They may be withdrawn from school to reduce expenses as medical costs rise or to assist in the care of the sick parent. The emotional upheaval of seeing a dying parent may leave children feeling abandoned and increase their susceptibility to sexual abuse (Economic Commission for Africa, n.d.).

Bauman and Germann (2005) illustrate how the illness and course of the HI virus can be disruptive to children. Parents with AIDS exhibit noticeable physical changes, such as fatigue, disability, skin lesions and wasting; they may also show behavioural and cognitive changes, such as depression, memory loss or irritability. Thus, Bauman and Germann (2005) argue that the parent, whom the child relies on for stability and predictability, becomes unpredictable and undependable. This may result in a child feeling uncertain whether today may be a good or a bad day. Parents may also go through phases of hospitalization, and children may stay informally with family or neighbours, or even without adult supervision leading them to have elevated levels of distress.

Research indicates that ill parents are quite often themselves depressed. This display of depression and anxiety as well as low self-esteem may replicate itself in the children in the form of secondary stress whereby children experience disturbances in the parent's attention, care and support towards them (Ajdukovic & Ajdukovic, 1998). Generally, studies show that children and adolescents of depressed mothers have higher rates of psychological diagnosis and have poorer behavioural, emotional, and academic functioning than children whose mothers are not depressed (Bauman & Germann, 2005).

Overall, parental depression influences children's psychosocial functioning as depression affects parental behaviours and beliefs. Depressed parents may have less supportive relationships with their children. Parental depression may also affect the dynamics of the family environment in a way which may compromise children's emotional security, which in turn result in more parental outbursts and insecure parental attachment. When the illness is kept a secret, children are inhibited from developing relationships outside of the family as they may be told not to talk about the parent's illness with others (Bauman & Germann, 2005), or others may draw away from the child due to the stigma related symptoms associated with HIV and AIDS.

## **2.5 Elderly and child-headed households**

The silent legacy of HIV is a generation of motherless children and adolescents and a generation of grandparents and other older relatives who have become their surrogate parents (Joslin & Harrison, 1998). If not being raised by their grandparents, a number of orphaned children end up living alone with siblings and heading households (Simbayi *et al.*, 2006; Wood *et al.*, 2006). Child-headed households exist because no relatives are left to care for the children, or else the surviving relatives are already too burdened to adequately care for the children they have 'inherited' (Economic Commission for Africa, n.d.). Many children who become household heads have little option but to seek work in order to support themselves and their siblings. As a result, children may find their education being cut short.

Girls have been reported to be more likely to drop out of school than boys, as the burden of caregiving, and doing household chores, falls primarily on females (Economic Commission for Africa, n.d.). Due to the death of parents, older children in families are left with the responsibility of raising their younger siblings. UNICEF (2003) established that South Africa, along with other neighbouring countries, experienced an increasing number of orphans living in female-headed households (Simbayi *et al.*, 2006). Household chores such as cooking, cleaning, washing laundry, and carrying water are then shifted onto the children, as no adult is present (Foster & Williamson, 2000). Not only do children become parentified, but their schooling is also affected as responsibility lies with them, forcing them to stay home.

In their study of the impact of the HIV/AIDS epidemic on basic education for children at risk, Robson and Sylvester (2007) reported that children whose parents died often drop out of school due to economic stresses on households, change in family structure, new responsibilities to care for the sick, the elderly or siblings and loss of parental guidance. Thus school attendance begins to compete with many other duties (Richter *et al.*, 2004). Furthermore, stigmatisation may prompt children affected by HIV/AIDS to stay away from school rather than endure being isolated and excluded at school (Simbayi *et al.*, 2006). A child's schooling may also be interrupted by a shortage of money brought about by spending on a parent's ill health, or by periods of work in the home to help sick parents. By the time these children return to school, they are likely to be over age for their class, which in turn results in higher rates of dropping out (Simbayi *et al.*, 2006; Zhao *et al.*, 2007;).

The existence of child-headed households has also had an enormous impact on children's safety and protection. These children are at a greater risk of malnutrition, illness, abuse and sexual exploitation (Bauman & Germann, 2005; Simbayi *et al.*, 2006). Without the presence of an adult guardian, children often lose their sense of direction and are at risk of being harmed as no adult is present to protect the family unit. Children affected by AIDS are themselves highly vulnerable to HIV infection. As argued by Simbayi *et al.* (2006), their risk of infection arises from the potential for early onset of sexual activity, commercial sex, and sexual abuse; all of which may be precipitated by economic need, peer pressure, and a lack of supervision.

The lack of parenting has also forced children to become adults in their young age, making decisions and taking on senior roles which were previously conducted by their mothers and/or fathers (Robson & Sylvester, 2007). In Wood *et al.* (2006) study of 'Teenage orphan's experiences of parental AIDS-related illness and bereavement in Zimbabwe' a recurrent theme emergent from conversations was that young people's childhoods had disappeared. Most particularly, the teenagers felt 'grown up' or 'like adults' because of the emotional challenges they had been through having lost their parents (Wood *et al.*, 2006). Ultimately the result of these varying factors leads to psychosocial distress, which includes anxiety, loss of parental love and nurture, depression, grief, and sometimes dispersment of siblings among relatives to spread the economic burden of care (Bauman & Germann, 2005).

Although a large number of children - particularly the adolescents in the family - have taken the role of heading their households, the impact of HIV has also seen a large number of children being raised by their grandparents. Grandmothers are typical primary or sole caregivers to children whose primary parents are living with, or have died of AIDS (Joslin & Harrison, 1998). “Skipped generation parenting” has become a national trend over the past decades, with more and more elderly people taking on the responsibility of raising their grandchildren. In a world where death was once associated primarily with the elderly, roles have reversed, resulting in grandparents outliving and burying their sons and daughters (Whiteside & Sunter, 2000). In such instances, child rearing (for the grandparents) occurs in the context of grieving the loss of their own children.

Recent studies of grandparents serving as parents identify these older caregivers as a high risk population, more so if they are in poor communities or marginal economic circumstances (Brouard, 2006). In most cases, the elderly who now take on the responsibility of raising their grandchildren are retired, meaning that their minimum income does not suffice for the household and as a result of this, children may be forced to discontinue with school. These grandparents also have to contend with the fears of the remaining children, who have witnessed their parents’ death, becoming terminally ill. Those raising adolescents contend with the child’s grief and rage at the prospect of a shortened life and a disease that marks them as different from others (Joslin & Harrison, 1998).

## **2.6 The Issue of Stigma**

Since the beginning of the epidemic, people with HIV/AIDS have been stigmatized worldwide, interfering with effective societal response to AIDS and has imposed hardships on those infected and/or affected by HIV/AIDS (Dias, Matos & Goncalves, 2006). Campbell, Nair and Maimane (2006) describe that stigma found in people and communities, when people believe that a particular illness or something a person has done or feels, is shameful and brings disgrace on themselves, their family or their community. The stigmatized person is, therefore, seen to possess a spoiled or polluted identity that deviates from social norms and which deserves sanctioning (UNAIDS, 2002). Stigma is a deep issue, connected with intensely held attitudes and communal norms. Paterson (2005) argues that the one reason why stigma is so difficult to address is that it is woven, at the



very deepest level, into the fabric of society and into the subconscious patterns by which its members order their lives.

Morrisen (2006) argues that in order to understand HIV-related stigma and discrimination, one needs to break them down into their interrelated components. Three key components emerged as part of a cyclical continuum: stigma, discrimination and internal stigma. Stigma causes discrimination; discrimination leads to internal stigma; and internal stigma in turn, reinforces and legitimizes stigma (Morrisen, 2006). Stigma lies primarily in the realm of perceptions and attitudes, such as negative attribution to a group or individual.

Discrimination moves into acts and behaviours - a differential treatment based on those negative attitudes. Internal stigma is the result of the internalization and acceptance of the lived situations of stigma and discrimination that an individual or group endures over time (Morrisen, 2006). Internal stigma can have a profound effect on HIV prevention, treatment, and care. An example given by Brouard (2006) is of an HIV-positive mother in India who continues to breastfeed her child because failing to do so may cause family and community members to suspect her HIV status. Similarly a couple, both living with HIV and too ashamed to disclose their status, delay making future plans for the care and support of their children. In essence both examples illustrate how internal stigma - perpetuated by discrimination and external stigma - breaks down families and communities, as the fear of judgement and discrimination from others profoundly influences the way in which people living with HIV view themselves and cope with their HIV status (Brouard, 2006).

The history of public response to HIV infected and affected people in South Africa has been marked by fear and prejudice which is often based on incomplete understanding or mythical beliefs about HIV transmission and AIDS cures (Kruger, 2006). People living with HIV are stigmatized leading to relentless social consequences related to their rights, health care services, freedom, self identity and social interaction (Mawar, Sahay, Pandit & Mahajan, 2005). Much of what feeds stigma is fear. People tend to fear that of which is unknown and mysterious. This same fear is also caused by things which we do not understand. Campbell *et al.* (2005) explain that families are often frightened to acknowledge that anyone in their family has HIV/AIDS or has died from HIV/AIDS. However, the consequence of this denial means that families do not get the help they need. The shame associated with the HI virus also perpetuates the silence and denial. In Campbell *et al.* (2005) study 'Understanding and challenging HIV/AIDS stigma', a rural

woman in a community states that “saying that a person has AIDS is a shame to the community as a whole. It sounds better to say that someone has been bewitched” (Campbell *et al.*, 2005, p.22).

Children are equally impacted by the stigma associated with HIV/AIDS. Because of the stigma attached to AIDS, children fear that they will not be accepted by others if it is known that their parent has died of AIDS, and thus are not able to express their emotions and feelings caused by the loss of a parent (Nagler, Adnopo, & Forsyth, 1995). As a result of this, bereavement and successful grieving may be complicated by the effects of social stigma associated with HIV/AIDS and secrecy (Foster *et al.*, 2005).

Germann (2004) has identified the emotional stressors faced by children as a result of HIV/AIDS-related stigma, and has urged us to become more aware of children’s emotional stressors and not become preoccupied with the visible social and economic hardships consequent of HIV/AIDS. Children’s emotional distress is often displayed in terms of personal rejection in children’s daily environments, in which children fear that other children would not want to, or be allowed to play with them. Other research confirms this fear of social exclusion, illustrating that disclosure of HIV infection or an AIDS-related death in the family can mean the end of acceptance at school and in the neighbourhood of children (Kruger, 2006). Apart from being rejected by friends in play, HIV-affected children may be excluded from sharing meals in homes where they were previously welcome, even in the homes of relatives. As a result of this, they may feel deep hurt and unresolved stress (Kruger, 2006).

AIDS in many communities has also been perceived as a form of punishment for wrongdoing and has been associated with promiscuity. Individuals with HIV and AIDS are stigmatized because their illness is associated with behaviours that are not acceptable socially (Mawar *et al.* 2005). Due to this, children have been reported to suffer, facing stigma at school amongst their peers and are ashamed to share their anxiety, fears, and frustrations (Mallmann, 2002). Furthermore children also face distress and social isolation as a result of their parents becoming ill. This stigma not only occurs as children witness their parents becoming ill, but also after the death of their parents, as they may feel shame, guilt, and rejection (Foster *et al.*, 2005).

Children's education is potentially compromised as children may withdraw from school out of fear of being teased and called names. As a result of this, children may even withdraw from other children within the community. Campbell *et al.* (2005) study illustrates the impact which stigma has on children, whereby a young boy states that "*It's a shameful thing to have AIDS in this community. I think they would make a big gap between my desk and other learners' desk at school*" (Campbell *et al.*, 2005, p.19).

Due to the stigma attached to HIV/AIDS, affected families often cut ties with relatives and the community in fear of being ostracised. Children may make up stories about their family, and live in a fantasy world as a way of dealing with the circumstances at home (Mallmann, 2002). The burden of secrecy takes its toll on children as they have to control what they say, what they do, and what they are permitted to feel (Lewis, 1995).

## **2.7 Children's experience of loss, grief and bereavement**

Loss of a loved one is one of the most common stressful life events in adults and youth (Melhem, Moritz, Walker, Shear & Brent, 2007). When death of a beloved person takes place, individuals may experience a wide range of emotions commonly referred to as 'bereavement and grief' (Zhao *et al.*, 2007). Goldman (2001) describes grief as a normal, internalized reaction to the loss of a person, thing, or idea. It is our emotional response to loss as well as an intra-psyche process (Zhao *et al.*, 2007). Melhem *et al.* (2007) further describe complicated grief as "the constellation of symptoms that include longing and searching for the deceased, purposelessness and futility about the future, numbness and detachment from others, difficulty accepting death, lost of sense of security and control, and anger and bitterness over the death (Melhem *et al.*, 2007, p.493). Bereavement has been described as the state of having suffered a loss and can refer to the state of mourning (Sadock & Sadock, 2003). Grieving plays an important role in dealing with the death of a loved one, as we take the internal experience of grief and express it outside of ourselves (Goldman, 2001).

Children grieve following the death of a parent or loved one. Their feelings may be similar to that of grieving adults; however children express grief differently according to their understanding of death and their developmental level (Dowdney, 2005). Prior to the age of seven, children have not yet mastered the concept of irreversibility thus not understanding

that a person who has died cannot become alive again. As a result, children of this age may ask repeated questions about their parents. By the age of nine, children begin to have more of an understanding about death, the universality of it as well as its permanence, even though they may still wish for the deceased to return (Dowdney, 2005). By puberty, children have generally conceptualized death as irreversible and universal as well as inevitable (Sadock & Sadock, 2003).

Adolescents are said to have similar feelings and expressions of grief as that of younger children, depending on their cognitive grasp of the concept of death. Dowdney (2005) argues that adolescents may withdraw from family activities and/or seek support from peers, and death may lead adolescents to question the meaning of life. Some may challenge their own mortality with high-risk behaviours such as drinking and drug-taking. Bowlby (1973) describes child grief as a process beginning with initial disbelief in the parent's death, a yearning for them accompanied by a sense of their presence, and distress as the permanence of the loss is realized. Ferrell and Boyle (1992) argue that bereavement resolution eventually takes place whereby three stages are involved: detachment from the deceased; adjustment to an environment without the deceased; and the formation of new relationships.

Various theories have shown that there are a range of effects of loss on children which, when not resolved, can last well into the adult life. Studies show that emotional distress in adolescence and adulthood - including depression, alcoholism, anxiety and suicidal tendencies - is often linked with bereavement suffered in childhood (Jewett, 1982). The emotions and reactions a child experiences after the loss are just as severe including fears of personal survival, separation anxiety, an impaired ability to form emotional attachments, sadness, anger, guilt, shame and despair. Other factors include loss of self-esteem and drops in developmental energy along with pessimism and feelings of futility (Jewett, 1982). In the past, it may have been believed that not much could be done to help a mourning child, however in more recent years, more studies have been conducted exploring the nature of bereavement, and such studies have shown that much intervention can be done to help bereaved children (Wood *et al.*, 2006; Dane, 2002;). The classical work by John Bowlby (1969) on childhood mourning shed light on issues of attachment, separation and loss and such work gave rise to the effects of loss on children.

Research has shown that adults often fail to help children grieve the loss of a loved one due to several reasons. At times, children are denied help after a loss because those around them discount its effect on them (Wood *et al.*, 2006; Jewett, 1982), and sometimes caregiver's feeling equally devastated about the loss, are unable to attend to the child's need or acknowledge the child's feelings surrounding the loss. Jewett (1982) argues that quite often adults have no idea what a child needs after suffering a loss or how they can provide the help that is needed. When adults avoid talking to the child about the loss, the child can be left feeling confused, afraid and unable to resolve his/her emotions.

Turner (1998), having worked with grieving children, argues that children often express profound and often frightening fears and worries when provided with a listening and respectful accepting environment. These fears manifest themselves in dreams, day-dreams, or behaviour. " We cannot usually put right the loss, but we can gently help a young person to express something of the inner turmoil they are experiencing; and we can help to answer questions, clarify misunderstanding, and calm many irrational fears " (Turner, 1998, p13). In his work on separation and attachment, Bowlby (1969) argues that a child can resolve losses just as favourably as an adult given the following conditions: a) the child has enjoyed a reasonably secure relationship with his parents before the loss; b) he/she receives prompt and accurate information about what has happened, and is allowed to ask all sorts of questions and have them answered as honestly as possible; c) s/he participates in the family grieving, including funeral rituals; d) he/she has the comforting presence of a parent or adult whom he/she trusts and can rely on in a continuing relationship (Bowlby, 1969).

Wood *et al.* (2006) study on teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe revealed that many of the children who were misinformed about their parent's death developed feelings of hatred towards members of their family, and at times even towards friends. A particular child expressed that, "*when I discovered my Mum had AIDS I hated everyone, including my friends because maybe they knew and didn't tell me*" (Wood *et al.*, 2006, p1928). Such studies support Bowlby's theory and the need to give children accurate information regarding the loss of a caregiver and other loved ones as a means of helping children come to terms with the loss and to have a better understanding of what has occurred. Disclosure at developmentally appropriate times about the facts surrounding the death is important for the grieving process (Zhao *et al.*, 2007). Richter *et al.* (2004) argue that children often develop increased levels of anxiety as a result

of not knowing what the future holds, as well as from diminished love, attention and affection. Whatever the cause of loss or separation, the fundamental anxiety of a child is who will keep them safe. Jewett (1982) argues that this anxiety arises from the universal, primitive terror of abandonment and annihilation.

### **2.7.1 Complex bereavement**

HIV/AIDS bereavement has been said to be more complicated and difficult to accommodate than any other form of bereavement (Dane, 2002). Children living in families with HIV/AIDS tend to experience bereavement which is encompassed with stigma, shame, secrecy, guilt and fear of disclosure (Dane, 2002; Summers, 1998). This can result in those who 'remain behind' being unable to fully grieve the loss of their loved one. Furthermore, grief often precedes the actual death, whereby children experience anticipatory loss as they witness their parents physically deteriorating (Wood *et al.*, 2006). Not only do these children suffer from the idea of losing their parents, but also possibly have concerns about being infected themselves. Ferrell and Boyle (1992) argue that experiencing a large number of unmet needs during the bereavement, observing a loved one's protracted illness and death - particularly if the illness was associated with severe suffering - often causes one to have unresolved bereavement.

Bereavement due to AIDS-related loss is a severe stressor (Rogers, Hansen, Levy, Tate & Sikkem, 2005), and the complex nature of HIV/AIDS has also resulted in children not only losing a mother or a father, but in some instances both parents as well as other close family members such as siblings, aunts, uncles and grandparents. Multiple bereavements can have even more of an incrementally detrimental effect on a child's emotional and psychological well-being (Grollman, 1995). In Wood *et al.*'s (2006) study of orphan's experiences of bereavement, a child in the study expressed her complex emotional struggles as she experienced multiple bereavement: "*Let's say a replica happens of what happened with my mum (as it did to her aunt) - you want to follow her (die). Even if someone from the community dies, you think again of your Mum*" (Wood *et al.*, 2006). This child poignantly illustrates just how difficult it can be to deal with the death of a caregiver, and the complications of losing more than one person from one's life.

Because of the role of parents as nurturers and caretakers, their loss stirs up distressing

feelings of anxiety based on the ongoing attachment relationship and the dependency needs of the children regardless of their age (Webb, 2002). As illustrated by Hope and Hodge (2006) “Anyone old enough to love is old enough to grieve”. Thus it is important for us to explore and to better understand children’s grief processes as well as factors that affect adjustment to loss, as through this we can know how best to intervene.

### **2.7.2 Adjustment to parental loss**

Various studies have shed light on factors affecting children’s adjustment to the death of a parent, illustrating ways in which children can be better assisted in ways of adaptation. Research on adult grief has shown that adults tend to cope better after an anticipated death rather than a sudden death (Dowdney, 2005). However, it appears that this is not always the case with children. In a study where a sample of children who had experienced various types of deaths of loved ones, results indicated that the lengthiest anticipations of death were associated with the worst post-death adjustment (Hope & Hodge 2006).

Hope and Hodge (2006) propose that the anticipation of death or the stress of awaiting an impending death may be more difficult on a child emotionally and cognitively. The adjustment of the surviving caregiver can determine the way in which children adjust to the loss of their parents. Positive adjustment by the caregiver is strongly related to positive adjustment by the child. Research has shown that children who were living with a surviving parent who scored high on a measure of post traumatic stress disorder usually reported more symptoms of PTSD themselves (Hope & Hodge, 2006). This illustrates the importance of a bereaved child having an emotionally stable home environment.

Levels of openness in parental communication also play a critical role in helping children adjust to parental death (Foster *et al.*, 2005). A higher level of communication about the deceased and their cause of death often help children through the grieving process and can also help reduce depression and anxiety (Hope & Hodge, 2006). Such openness may also reduce the risk of children becoming overwhelmed, making their own assumptions regarding the death of their caregiver, which can often lead to self blame, confusion and unanswered questions (Jewett, 1982).

Wood *et al.* (2006) discovered that many orphaned children in Zimbabwe were not told the truth regarding the death of their parents and that in Ndebele tradition children were told

that their parents have ‘gone away’ rather than being told that they had died. Keeping quiet was a strategy that adults expected children and teenagers to use, as they interpreted withdrawal and quietness as a positive coping strategy, that the children were managing to achieve emotional maturity through perseverance (Wood *et al.*, 2006). In addition, adults themselves were often battling to cope with the loss and felt unsure of how to best support the children emotionally.

Children need to be provided with accurate information about the death and related events, as the secrecy of death and keeping children away from funerals as a means of protecting them ultimately exacerbates the children’s difficulties (Dowdney, 2005; Wood *et al.*, 2006). The complex emotional struggles of children are often compounded with multiple bereavements, where children struggle to deal with the loss of a parent while simultaneously losing other members of their family. This once again is further aggravated by the lack of openness and as a result children become confused, living in a world of death, with little comfort and reconciliation. Dowdney (2005) argues that explanations of death to children need to be age appropriate, clear, simple and truthful and may need repetition to aid understanding as children grow older and develop cognitively and emotionally. Further more, Dowdney (2005) argues for the importance of including children when the funeral takes place, as this recognizes the impact the death has had on the family as a whole, and gives a sense of inclusion in the family’s expression of grief.

### **2.7.3 Resilience and protective factors**

Despite the adversities children affected by HIV/AIDS face, particularly when faced with the death of caregivers and other family members, existing data suggests that resilience is a common response to loss. 50% to 66% of children growing up in circumstances of multiple risks seem to overcome the statistical odds to live lives marked with coping and resilience (Killian, 2004). Resilience refers to the capacity for successful adaptation despite challenging or threatening circumstances (Bauman & Germann, 2005). McWhirter (2004) further describes resilience to refer to those who demonstrate a good outcome in spite of high risk, sustained competence under stress, and recovery from trauma. Resilience and resiliency are not static traits, but are influenced both by internal and environmental factors.

Factors which contribute to resilience include individual characteristics, family



characteristics, external social support and environment and community strengths (Killian, 2004). McWhirter (2004) demonstrates this, explaining that “individual characteristics exhibited by children and adolescents form the trunk of the at-risk tree, which links the soil of environment and the roots of family and school to branches of behaviours” (McWhirter, 2004, p79). These characteristics can nourish positive and healthy development or risky behaviour.

Individual characteristics and attributes such as cognitive skills and intellectual ability are related to resilience (Killian, 2004). Children who have developed cognitive abilities and coping skills are better able, than their younger siblings, to understand the parent’s illness and what it means for the family future. Such children are able to use previous life experiences and decision making skills to adjust to the demands of HIV/AIDS (Bauman & Germann, 2005).

Family plays an important role in influencing a youth’s resiliency. Close attachments within the family can provide emotional support at times of stress (McWhirter, 2004; Sigelman & Rider, 2003). Parents who can function adequately under stress, and who are consistent and responsive to their children, will be better able to facilitate successful coping and adaptation in their children.

The social environment can provide children with opportunities for development and support despite adverse conditions (Simeonsson, 1994). External support systems can boost the young person’s competencies and provide a sense of meaning or a belief system in which to live (Sigelman & Rider, 2003). When a parent is ill, other adults in the child’s life such as teachers, neighbours, ministers, youth workers and mentors can play significant caring roles for the child. Research has also shown that children in Africa have a very different relationship to their extended families and communities than children in industrialized western cultures (Bauman & Germann, 2005). In light of this, the African belief that “a child is raised by the whole community” often comes into play in times of distress where a child has lost a parent. In such a case children regard extended family members as parental figures who traditionally assume responsibility for their relatives’ children. As a result of this, children in Africa may adjust to a foster parent who is a relative with ease than an American child would adjust to life with a foster parent who may or may not be a relative (Bauman & Germann, 2005).

Killian (2004) states that the extent and nature of the support a child receives, as well as the resources and structures available, may either build resilience or increase vulnerability. A child who receives great support from immediate family as well as from other spheres (school, community and greater society) is more likely to be resilient than a child who lacks such support. Supportive environments can also help to build and strengthen a child's personal qualities which in turn can help a child cope with adversity (Killian, 2004).

## **Chapter 3**

### **Methodology**

#### **3.1 Introduction**

This qualitative research explored adolescent orphans' experiences of parental AIDS-related illness and bereavement. The common focus within the field of qualitative methodology is the interest in human subjectivity (Babbie & Mouton, 1998). As a means of trying to understand the world in which we live in, qualitative approaches try to connect and broaden the power of language and expression (Strauss & Corbin, 1990). This was particularly important in this study as capturing the children's expressions of their experiences was the main goal of the research. Through these expressed experiences, a better understanding of orphaned adolescents will be obtained in order to inform interventions.

#### **3.2 The research question**

The study was explorative in nature, using open-ended research questions as a means of eliciting data. Babbie and Mouton (1998) argue that qualitative research generally attempts to explore or describe phenomena in depth rather than proving or disproving certain aspects of the phenomenon being studied. In light of this, qualitative research questions are usually phrased as a definition of the phenomena of interest to the researcher, and thus the aim of this research was to 'explore adolescent orphans' experiences of parental AIDS-related illness and bereavement'.

#### **3.3 Research design**

Qualitative methods, semi-structured interviews and a focus group were used in an attempt to understand the subjective realities of the adolescent participants in this study. The researcher worked in partnership with an NGO over a weekend camp in which various forms of psychosocial support were offered to orphaned and vulnerable children. Attending the camp was part of the research design, and it allowed the researcher to spend time with the children. The researcher participated in the camp, observed various activities and conducted individual semi-structured interviews and a focus group.

### **3.4 The research participants**

The study required a sample of adolescents who had experienced at least one parental death, and some who had experienced multiple losses. A multiple loss is defined as loss of more than one parent/primary caregiver or family member. All adolescent participants in this study had been orphaned, i.e. a child bereaved through the death of one or both parents (Foster & Williamson, 2000).

As a result of the criteria required for this particular study, purposive sampling was used. Kerlinger (1986) explains that purposive sampling is characterized by the use of judgment and a deliberate effort to obtain samples by including presumably typical areas or groups in the sample. Purposive sampling was particularly useful in this type of research, as this type of sampling used cases for theoretical reasons (Terre Blanche, Durrheim, & Kelly, 2006). The sample was thus chosen to satisfy the researcher's specific needs, i.e. orphaned adolescent children (Babbie & Mouton, 1998; Robson, 1993).

The sample was selected, in collaboration with the researcher, by an NGO which runs projects and workshops with vulnerable and orphaned children, addressing their psychosocial needs and well-being. Ten participants were selected for this project. This figure was chosen by the researcher, and was also the number which the NGO could accommodate for the psychosocial workshop which the participants would be involved in. Because of the organisation's experience in working with vulnerable children, they were able to identify those who had experienced bereavement through the loss or multiple losses of parent/s, caregiver, or loved ones.

From the large number of children with whom the organisation runs workshops, ten were selected for the research, five boys and five girls. The age group of the children ranged from 11-16 years. The sample was selected from a rural area in the Greater uMsunduzi area. With regards to "how many participants is enough", Kelly (2002) argues that the number of cases not only depends on the state of theoretical development in the field, but also depends on how much detail one is likely to gather in each case. Therefore a small number of participants were chosen for the study. Participants were engaged for two and a half days, at a psychosocial support camp, while the researcher gathered information within the various discussions and activities. It was anticipated that this would allow for more detailed and fruitful collection of data.

### **3.5 Context in which data was collected**

The research participants were part of a psychosocial workshop at an NGO, specifically designed for orphaned and vulnerable children. The two and a half days' psychosocial workshop included the use of various games and activities such as reading, writing, storytelling and group discussions, to facilitate the adolescent participants expressing and sharing life stories, emotions and cognitions associated with their life experiences. The researcher was a participant observer in the entire workshop. The structure of the psychosocial workshop dealt with the children's loss and ways in which they had been affected by the death of their parents. Thus, the workshop was in direct line with the research topic. The information was obtained during the course of the workshop and was included as data and analysed.

The context in which the research took place served as a positive factor, as it allowed for the researcher to spend two and a half days with the participants, getting to know them through interaction and taking part in the activities. This also helped to alleviate the power dynamics which may occur between researcher and participants, as the researcher became engaged at the children's level and was gradually fully accepted and trusted by them

### **3.6 Data Collection**

Data was collected through the use of individual semi-structured interviews, observation and a focus group. The semi-structured interview (see Appendix A) was used to allow the researcher freedom to explore within the predetermined inquiry area as well as to give each participant the space to elaborate on information. The initial individual interview was done for the purpose of establishing rapport, to gain basic biographical information and informed assent to participate in the study as well as to provide sensitive information which would help guide the structure of the focus groups (Van der Riet, Hough, & Killian, 2005). This sensitive information included finding out about the family structure and which parents had passed away. Knowing this information aided in the researcher having a better understanding of the children's experiences of loss, and contributed to the data. Ten participants were involved in the study, all of whom were orphans. They ranged between the ages of 11-16 years. All the participants, except for one, had siblings with whom they were living. As the children had lost their parents, five of them were living with their

grandmothers, two with their elder sisters, one with his aunt, one with her uncle, and one with his grandfather (See Table 1). This biographical information indicated that grandmothers were more likely to be the guardians to these orphaned children. This trend is supported by studies on the impact of HIV/AIDS on households (Foster & Williamson, 2005; Nyamukapa *et al.*, 2008), which have shown an increase of grandparents raising children.

All of the participants were living with an adult, and no child was unsupervised or heading a household. As the study aimed to explore the adolescents' experiences of bereavement, the interviews for the biographical information needed to find out which parent/s had passed away and the cause of death. Many of the children were not able to give the cause of death, but rather expressed that they had gotten sick and subsequently died. Two of the children expressed that their fathers had died from cardiac problems. Although the children did not say that their parent/s had died of an AIDS-related death, it can be presumed that most of the deaths were AIDS-related due to the demographics and the NGO involvement. Overall, none of the children were currently living with either of their biological parents and were being raised by members of their extended families, usually grandmothers.

**Table 1. Biographical information**

| P  | Gender | Age | Death in the family | Cause of death   | Currently staying with                               | Gaurdian/ caregiver  | Additional Information                                  |
|----|--------|-----|---------------------|--|--|----------------------|---|
| 1  | Male   | 14  | Father              | “was sick and died”  | Paternal grandmother                                 | Paternal Grandmother |   |
| 2  | Male   | 13  | Mother and father   | “was sick and died”  | Maternal grandmother, brother& sister                | Maternal grandmother |   |
| 3  | Female | 11  | Mother              | “was sick and died”  | Father & two older sisters                           | Sister               | Father currently has TB                                 |
| 4  | Male   | 11  | Mother and father   | “mom was sick and died”                                      | Maternal grandmother and younger sister              | Maternal grandmother |   |
| 5  | Male   | 14  | Father              | “was sick and died”  | Paternal grandfather, his younger sister and cousins | Paternal grandfather | Abandoned by his mother prior to starting school        |
| 6  | Female | 14  | Mother              | “was sick and died”  | Two elder sisters, and three elder brothers          | Elder sister         | Father is alive but does not support his family at all. |
| 7  | Male   | 14  | Mother and father   | Mother “was sick and died”; father died from cardiac problem | Maternal Aunt and older sister                       | Maternal Aunt        |   |
| 8  | Female | 16  | Mother and father   | Mother was stabbed to death, father “was sick and died”      | Maternal grandmother and elder sister                | Maternal grandmother |   |
| 9  | Female | 13  | Mother              | “was sick and died”  | Maternal grandmother and elder brother               | Maternal grandmother |   |
| 10 | Female | 16  | Mother and father   | Mother “was sick and died”, father had cardiac problem       | Paternal Uncle                                       | Paternal Uncle       |   |

\* Numbers correspond with the identifications notes provided in the results section.

The second data collection method was that of observation of the participants. Observational data are used for the purpose of description of settings, activities, people, and the meaning of what is observed from the perspective of the participants (Hoepfl, 1997). Observation can lead to deeper understandings than interviews alone as it provides insight into the context in which events occur, and may enable the researcher to observe things of which participants themselves are not aware (Patton, 1990). Therefore this method of data collection was selected as a means of enriching the overall data of this

study. Babbie and Mouton (1998) describe two observation strategies: simple observation and participant observation. In this study, the observational strategy chosen was participant observation, whereby the researcher simultaneously acted as a participant in the activities with the children, and as a researcher conducting the study. The researcher's participation allowed for the researcher and the children to get to know each other and so build rapport. At all times, the researcher's identity was known to the participants, and they were aware that the information collected would be used for research purposes. The participants were involved in informal discussions during the activities, and during these, the researcher made observations. While observing the participants, the researcher often deepened discussions to discover the children's opinions and perspectives. The methods of observing and having individual interviews and focus groups enabled the researcher to check the validity of the data.

The third data collection method was that of a focus group discussion. A focus group was used as a means of collecting data for various reasons. Focus groups are fundamentally a way of listening to people and learning from them. In addition, the larger process of communication that connects the worlds of the researcher and the participants (Morgan, 1997) was considered to be especially appropriate for this study as it drew on three of the fundamental strengths that are shared by all qualitative methods such as: (i) exploration and discovery; (ii) context and depth; (iii) interpretation.

As argued by Memon and Bull (1999), a focus group is not a group interview whereby a moderator asks the group questions and participants individually provide answers. It is a non-directive interview technique which encourages discussion between participants, thus interaction between the adolescents was used to elaborate on the concepts expressed by them.

A set of open-ended questions were developed to elicit an in-depth understanding of the issues from multiple perspectives (See Appendix B). The focus group allowed participants to agree or disagree with each other, and the researcher was able to see how the group felt about the issues at hand. "Careful and systematic analysis of the information provides valuable insights into participants' views about the area of research" (Memon & Bull, 1999).



Morgan (1993) further illustrates this point by arguing that focus groups have a strong advantage as the interaction in the group can provide an explicit basis for exploration of the topic. Within the group, one may also discover that each individual has several different opinions about the subject. The exchange among the participants also helps to clarify their opinions. By creating and sustaining an atmosphere that promotes meaningful interaction, focus groups convey a humane sensitivity, a willingness to listen without being defensive, and a respect for opposing views (Morgan, 1993).

Another key aspect of using a focus group is that it enabled the participants to see that they were not alone in their experiences of grief and bereavement, and this possibly helped them to be able to share their experiences more openly. Furthermore, through this group interaction, the children supported one another as they all shared similar experiences (Smith, 1995). Van der Riet *et al.* (2005) stated that the format of focus groups also potentially decreases the power dynamics between the researcher and the participants, because the adolescents also had the opportunity to talk among themselves instead of having to respond individually to the researcher.

As focus groups are a method of qualitative research, Krueger (1994) argues for two important factors in determining the size of a focus group. It must be small enough for everyone to have an opportunity to share their views and insights, and yet large enough to have some form of diversity among the subject's perceptions. The meaning of the interaction which takes place in the form of a focus group is determined by the context (Smith, 1995). The method and process of this data collection was adapted from Van der Riet *et al.* (2005) study "Mapping HIV/AIDS as a barrier to education". This type of method creates uniqueness of each adolescent's experiences as a source of data, as it allowed the children to engage with one another, and share their opinions and experiences. Audio recording equipment was used to capture the data. The data was then translated from isiZulu into English for the purpose of analysis, followed by transcribing the data and typing it out into transcripts with contextualized notes.

The focus group comprised ten participants. It was conducted by the researcher, with the assistance of a programme co-ordinator, and the social worker from the NGO. The focus group was viewed as a voluntary part of the camp programme in which participants could

decide to participate or not.

### **3.7 The procedure for using a focus group**

The process of using a focus group as a data collection technique began with a composition of questions which would explore the main research question. Having composed the questions, they were verified by the project supervisor. As the focus group involved adolescents, care was taken to ensure that the questions were at a developmentally appropriate level.

Prior to the research being conducted, the participants, along with the researcher, and the psychosocial workshop NGO staff took part in activities. These activities included ice-breakers, learning each others' names and biographical information, and playing games. The activities were used as a means of allowing the participants to become comfortable with one another as well as with the researcher and the NGO staff. An advantage to the group was that some of the participants already knew each other as some attended the same school, or lived in the same location and this helped create familiarity and rapport. Furthermore, the participants also knew the staff members from the NGO, and were thus comfortable around them.

Time was spent discussing and explaining the nature of the psychosocial workshop and what it would entail. The participants were formally introduced to the researcher whom they were meeting for the first time.

The nature and purpose of the research and the focus group was explained, Although the researcher had already obtained consent for conducting the focus group from legal guardians and from the NGO Director and Board, the participants were re-familiarized with the notion of consent and the researcher explained that participants could - at any point- withdraw from the focus group. Furthermore, it was explained to the participants that they were not forced to answer any questions which they were not comfortable with. They were informed of the use of the tape recorder, the type of questions they would be asked, and the confidentiality of the entire process. Before proceeding with the focus group, all the participants were asked if they were comfortable with the procedures and if they had any queries. They then individually signed informed assent forms (see Appendix C).

The focus group was structured in such a way that, the participants began by making memory cards out of magazine pictures, card paper, and pencil crayons. This drawing exercise, as a technique, was adapted from Van der Riet *et al* (2005) study. It was used to maximise the participation of the children, as well as create another medium of expression, so that the participants could express their understanding and experiences without relying solely on verbal communication. Each participant had the choice of writing a short story about a loved one who had passed away, what memories they had of that person, as well as what had changed since the death of their loved ones. As a group, the participants were given 40 minutes in which to make their individual memory cards, after which they would then be asked to share their stories with each other.

The chairs in the room were set in a circle around a table from which the participants worked such that each member of the group could see everyone else. The researcher, and the NGO staff members sat in and amongst the participants in order to create balance and a sense of equality. The entire session was conducted in isiZulu, which is the mother tongue of all the participants, so that they had a good understanding of what was being asked. The participants indicated when they wished to speak, so that there was no pressure created through a rotational method. The focus group questions (refer to Appendix B) were repeated if the participants needed assistance in remembering what was being asked.

The instruments used for the focus group were that of an audio tape recorder, which was placed in the middle of the group in order to pick up all the voices. The rationale for using this equipment is that it was most convenient in capturing the content of the focus group. Audio equipment is self-explanatory and involves no complications if used in the correct manner. Another reason for using this particular instrument is that it does not distract the participants in that, it was placed in the middle on the floor, and does not require one to constantly be attending to it as one would do with a video recorder. Thus, for the sake of ensuring that participants were as comfortable in this setting as possible, the researcher used this particular equipment.

### **3.8 Translating the focus group**

The data was collected in the form of textual data which was later analysed using thematic analysis. Before analysing the focus group transcripts, a translation from isiZulu to English was conducted. This was a lengthy process which was done by an experienced interpreter

and transcriber. The translation into English was necessary in order for the researcher to do a proper analysis as isiZulu is not her mother tongue, and her English was fluent. Adding to which, the research project was to be written up in English. On the occasion where an English word did not quite fit the definition of an isiZulu word, the translator used a word that was of very close resemblance. Thus, the original content and meaning was obtained to the best of the assistants' ability. A full back translation was not undertaken, but certain phrases were checked using back translation and discussion to ensure the accuracy of the translation.

### **3.9 Ethical considerations**

During the course of this research, ethical issues of working with human subject in general, and minors in particular, as well as the sensitive nature of the research under investigation were taken into consideration and examined. Ethics are typically associated with morality as both deal with matters of right and wrong (Babbie & Mouton, 1998), and play an important role within research. Participants had to be protected from all harm. It was imperative that all bases regarding ethical issues were covered, such as confidentiality, beneficence, and non-maleficence. Special care was taken in working with children who were vulnerable, and care was taken to try and off set the power dynamics between researcher and the participants (Van der Riet *et al*, 2006).

#### Informed consent

There is a long-standing moral and legal tradition that supports parents taking part in the decision-making for their minor children participating in research (Kodish, 2006). Equally important is to ensure that the child participants agree and are fully aware of their participation in research, the implications which the research has on them, and that their rights to withdraw are fully acceptable and understood. Informed consent thus needs to be addressed in research at all times, and was addressed in this research (Gregory, 2003). Informed consent for the psychosocial workshop was obtained by the NGO from the guardians of the children. Informed consent, stipulating the nature of the research, was also obtained from the guardians allowing the researcher to be a part of the workshop and to conduct research (See Appendix D). Lastly, informed consent was obtained from the UKZN Research Ethics (refer to Appendix E).

Today, the legitimate role of the child in decisions about research participation is recognized and is of paramount importance. The ethical concept of assent provides a framework to assist researchers and parents with efforts to incorporate the views of children who are recruited as research subjects. Assent is analogous to consent where the subject has a reduced capacity to understand the matter to which they are assenting (Kodish, 2006). Participants were under the age of 18, and their consent was obtained by the researcher. The purpose of the research was fully explained to the children in the consent form and was reiterated prior to data collection as a means of ensuring that all child participants were aware of their involvement in the research and the implications of their participation. Ethically, the children were allowed to withdraw from the research if they did not feel comfortable, and were informed of such before the focus group began. There were no aspects of the research about which the participants were not informed and they were free to ask questions throughout the process, if they had any queries. An introduction and lay out of the procedures was given before hand, thus the children were aware as to what was required of them and what the research entailed (see Appendix F).

### Confidentiality

Confidentiality is another fundamental ethical principle which was taken into consideration in this research (Gregory, 2003; Wassenaar 2006). The researcher and workshop facilitator maintained confidentiality of the participants' identity throughout. At the beginning of the focus groups, confidentiality was clearly explained to the children, explaining that the content of the session would remain private. The purpose of the research was not to focus on individuals but on the children as a group. Thus, no individual names were used (except during the focus group, when introducing ourselves) in the writing of the research, thus maintaining confidentiality as well as anonymity (Babbie & Mouton, 1998).

Confidentiality also needed to be maintained in the transcripts that were to be analysed, and this was done by omitting the children's names. The research data has been stored securely, also as a way of maintaining confidentiality. Research data will not be destroyed at the end of the research as it may be required for further use for future research.

Terre Blanche & Durrheim (2002) explain that research might not only pose a personal risk for participants, but also for a 'contextual risk'. Thus, it was important to inform

participants of what will be done with the results of the study and also give them an opportunity to consider ramifications, and this procedure was followed. Furthermore, it was agreed upon that once the project was fully compiled, the participants of the project would be informed of the results as well as the NGO involved.

### Beneficence and non-maleficence

The issue of non-maleficence and beneficence were also taken into serious consideration. Sadock & Sadock (1998) describe non-maleficence as the duty to do no harm, and beneficence as the duty to minimise the potential harms and maximise the potential benefits for the participants. Potential risks were noted to be involved in this research. Certain factors had the potential to increase the vulnerability of the children such as: the discussions in the focus group required the children to recall memories of parents who had passed away, evoking emotion and feelings, giving their views and input as to how they have been impacted by the death of their parent/s.

These discussions, at some point, lead to feelings of an emotional and painful history being evoked. This situation had to be taken into serious consideration, and it was important to ensure that the children were comfortable. A trust relationship had to be established in order to help the children feel safe and thus be able to take part in the focus group. The researcher (who is an intern psychologist) as well as a social worker from the NGO were available should children feel upset, or need comforting. As described by Capuzzi and Gross (2003), one needs to be sensitive to the needs and feelings of the children, and to have an “empathetic understanding rather than a sympathetic one”. Capuzzi & Gross (2003) place great emphasis on the understanding of the subject’s world from the subject’s point of view. Knowing the content of what the children had to say as well as the emotions behind their experiences, it was essential to consider the elements of empathetic understanding, which are required for these particular types of studies.

Although there was the possibility of an increase in the vulnerability of the children with regards to past experiences being evoked, they faced no other risks to their physical or health status. Participation in the focus group may have benefited the children as well as the greater society. Reasons for this are, the focus groups gave the children an opportunity to express their feelings, emotions and experiences of parental death and bereavement. The children’s contribution was crucial in this research as it shed more light into the

experiences of orphaned children, their perspectives on HIV/AIDS, and ways in which children experience bereavement. The children's contribution also helped for further research and intervention which are in aid of orphaned and vulnerable children.

### Justice

Wassenaar (2006) explores another ethical principle which needed to be considered within this research, that of justice. Wassenaar (2006) proposes that justice in research requires that the researcher treat research participants with fairness and equity during all stages of research. Justice was obtained in this research through: fair selection of the research participants, the participants have benefited from being part of the psychosocial workshop, the researcher in association with the NGO took responsibility and provided care and support for the children in the event that they become distressed during the focus group, and workshop as a whole.

### **3.10 Data analysis**

Thematic analysis was used to organise the interview material in relation to specific research questions and then by the emergent themes. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Rubin and Rubin (1995) describe how data collected for the research is organised under thematic headings in ways that attempt to do justice both to the elements of the research question and to the issues of the participants of the research. Thematic analysis required developing categories and themes, which in themselves required the researcher to familiarise oneself to the overall meaning of the text and information obtained (Rubin & Rubin, 1995). Analysis required taking apart the data in various ways and trying to put it back together again to form a coherent whole.

Thematic analysis enabled the researcher to use a wide variety of information in a systematic manner that increased the accuracy or sensitivity in understanding and interpreting observations about the participants and their situation (Boyatzis, 1998). This served as a rationale for using this particular technique. Furthermore, Boyatzis (1998) proposes that coding is a way of relating data to our ideas about the data. Thematic analysis required the researcher to have the ability to recognise patterns within the data, and to have an openness and flexibility to perceive the patterns, and this too was motivation for this

approach to the data analysis. Thematic analysis is also an approach which allowed one to deeply immerse oneself in the data, thus being able to closely relate to it as well as understand it better, and the researcher adhered to this approach (Braun & Clarke, 2006). This was a motivation as the type of information involved in the focus groups was personal, meaningful and needed to be analysed very closely as it involved children's emotions and experiences.

Thematic analysis involved a number of choices which are often not made explicit but which need explicitly to be considered. Braun and Clarke (2006) propose the following question: what counts as a theme? In addressing this question, Braun and Clarke (2006) illustrate that there may be a number of instances of the theme across the data set, but more instances do not necessarily mean the theme itself is more crucial. In light of this, researcher's judgment was necessary as well as looking at the different elements within the themes in relation to the overall research question.

Another aspect of thematic analysis was that of semantic themes. In a semantic approach, the themes were identified within explicit or surface meanings of the data. The analytic process involved a progression from description to interpretation where there was an attempt to theorize the significance of the patterns and their broader meanings and implications, in relation to previous literature (Braun & Clarke, 2006).

As thematic analysis is a coherent way of organising interview material in relation to specific research questions, the material was arranged under thematic headings in a way that attempted to do justice both to the elements of the research question and to the issues of the children interviewed (Rubin & Rubin, 1995). Several steps were taken in analysing the focus group material.

### ***Step 1- Familiarisation and immersion***

The first step, familiarisation and immersion (Terre Blanche, Durrheim & Kelly, 2006) involved the researcher familiarising herself with the material by reading over it several times in order to get an overall feeling of the content (Boyatzis, 1998; Braun & Clarke, 2006). The reading of the material required a fair amount of time as one had to thoroughly take in all the information and immerse oneself in the transcripts in order to have a thorough understanding of the material. Thus 'repeated reading' was necessary, reading the



data in an active way which included searching for meanings and patterns. Within this phase, it was useful to take notes and marking ideas for coding which I would then refer to in the subsequent phases of the analysis.

### ***Step 2- Inducing themes***

The second step required the researcher to induce themes. Terre Blanche *et al.* (2006) describe induction as inferring general rules from specific instances. It is thus a bottom-up approach, meaning that one looks at the material and tries to work out what the organising principles are that ‘naturally’ underlie the material. The process of inducing themes involved breaking down the material into meaningful sections and assigning labels to them (Braun & Clarke, 2006; Terre Blanche *et. al*, 2006). Once themes had been induced from the data, coding followed.

### ***Step 3-Coding sub-themes***

Coding entailed marking different sections of the data as being instances of, or relevant to, one or more of the themes (Terre Blanche *et. al*, 2006). Within each theme were a number of codes (which are referred to as sub-themes) which related to the theme. The coding involved taking phrases and sentences within the data and placing them under the relevant themes or more specifically to a code under a theme. An example of this is, with the theme ‘HIV/AIDS stigma’, the following sentence was abstracted “*If the person that was HIV+ was related to you, you sometimes hear people talking about that person and it hurts.*” as material that was coded as relevant to this particular theme.

The raw data was labelled in numbers, according to which theme the sentence or phrase was relevant to. For example, the sentence under the theme ‘HIV/AIDS stigma’ was labelled ‘2’, which indicated that it fell under this particular theme. In some instances, the content of a sentence fell under two themes, in which case it was numbered twice, according to the themes it best suited. Terre Blanche *et al.* (2006) propose that the main reason behind coding is to break down a body of data into labelled, meaningful pieces, with a view to later clustering the ‘bits’ of coded material together and in relation to other clusters.

### ***Step 4- Elaboration***

Having broken down the material, and placed it under the relevant themes, it was important to re-evaluate the data and explore the themes more closely, thus elaborating. The rationale for this was to capture any finer meaning, which may have been missed out in the previous steps. This required one to read over the transcripts again to extract more information under the themes (Braun & Clarke, 2006). This step in thematic analysis gave the researcher a chance to revise the coding system, in order to produce a thorough analysis (Terre Blanche *et al*, 2006). The advantage with this particular step is that one got to maneuver the material and make changes where necessary until the outcome of the themes and codes was of a satisfactory level.

### ***Step 5- Interpretation***

The final step of analysis involved interpretation and checking, which included putting together the interpretation and writing an account of the phenomenon studied (Boyatzis, 1998; Terre Blanche *et. al*, 2006;). The interpretation involved going through the material closely and drawing meaning from it. The interpretation was also a reflection of the researcher's understanding of the material. While going through the material, it was also important that the researcher fixed weak points, and looked out for over-interpretation. In this interpretation, the researcher also had to reflect on her role in collecting the data and how her personal involvement in the phenomena may have coloured the way in which data was collected and analysed (Terre Blanche *et al.*, 2006).

### **3.11 Summary**

This chapter has outlined the methodology used in the study, providing the aims and rationale for the selected methods. Ethical issues have also been outlined and have been taken into great consideration, particularly as this research dealt with minor participants.

## **Chapter 4**

### **Results**

#### **4.1 Introduction**

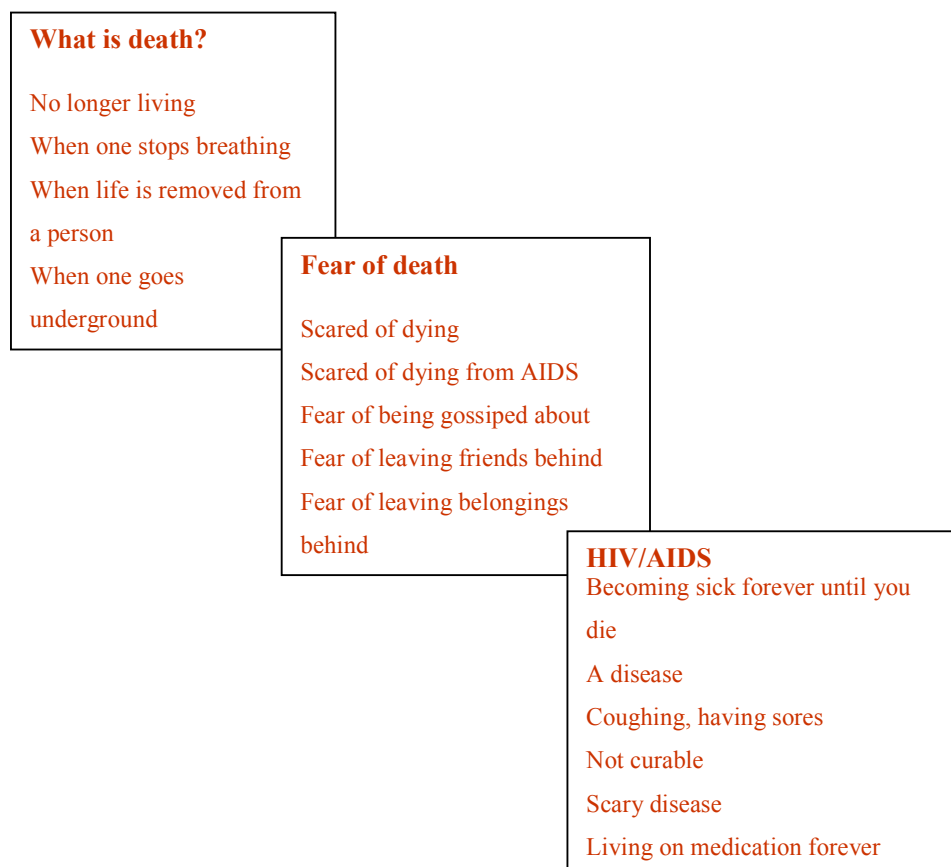
This study aimed to explore adolescent orphans' experiences of parental AIDS-related illness and bereavement. The aim of this chapter is to present the findings of the individual interviews, the focus groups, and the identified themes in the activity discussions, and to discuss these findings in relation to the concepts identified in the literature.

#### **4.2 Individual interviews**

The biographical information obtained from the five boy and five girl participants yielded some interesting information. The participants were aged between 11 and 16 with a mean age of 13.6. Orphaned children who participated in the study were living in a variety of family arrangements, the most common being a cohabitation with an adult relative - usually a grandmother - and several other children. Some of the participants were living in a household headed by an older sibling in their early twenties. See Table 1 in Chapter 3 for more details. In five cases the children had lost both parents, except for one child whose father was still alive but not living with him nor supporting him. Many of the children had experienced unstable home lives, moving between different relatives after the death of their parents. Most of the children moved to live with their grandmothers, while one moved to live with her uncle.

#### **4.3 Observation**

One of the camp activities involved story-telling, where a book about a young boy who had become ill and was subsequently dying was read to the children. The story explored the concept of death, the need to be loved and supported, and the young boy's fears of leaving friends and family behind, and dreams of an after life. Following the story telling, the children engaged in a facilitated discussion in which the following interdependent themes emerged:



**Figure 1: Diagrammatic representation of the themes emerging from facilitated discussion**

The facilitated group discussion allowed the children to engage with each other and to share their understanding on the issue of death, which subsequently led to the discussion of HIV/AIDS. Within the discussion, the children gave different explanations of what they understood death to be and when it usually occurred. Some of the children shared being scared of dying as one would leave friends and family behind. One child spoke particularly about being scared of leaving his belongings behind, such as his bicycle. Another child shared that death was scary especially as people of today were particularly dying due to HIV/AIDS. The issue of HIV/AIDS was broken down, with children expressing what they understood the disease to be. Descriptions included symptoms of HIV/AIDS such as getting sores around the mouth and body, coughing and getting tuberculosis. Some children also spoke of being on medication, which requires one to take pills on a daily basis, and for an extended period of time. What became apparent was that some of the children feared HIV/AIDS because it was not curable, and that death was inevitable. Others spoke of the

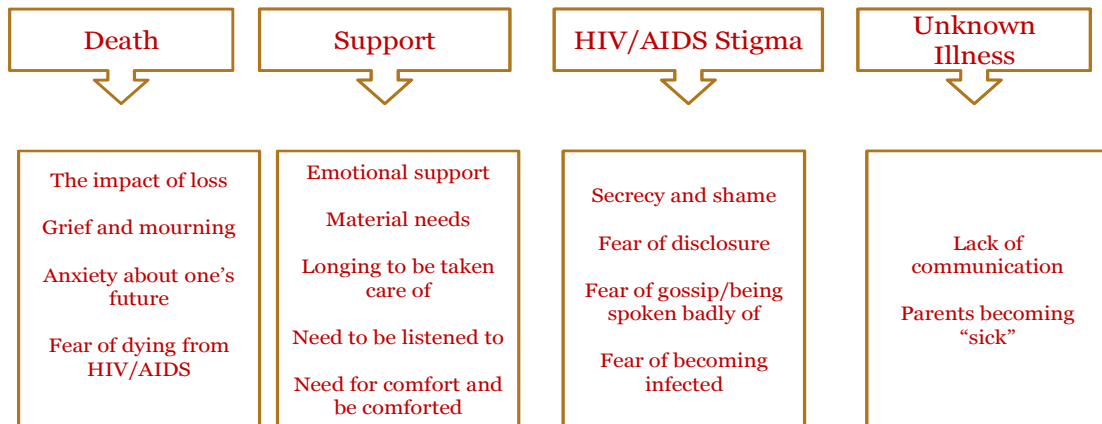
gossiping that occurred when people have HIV/AIDS, and how neighbours and people at school make fun of children whose parents or relatives might be ill. Furthermore, it was expressed that adults talk about each other, calling those who are ill with bad names.

This particular group discussion helped introduce topics, and elicited themes which would later emerge in the focus group. The emergent themes in the discussion surrounding the story-telling were discussed in more details and unpacked further in the focus group discussion. What became apparent in both these discussions was the prevalence of HIV/AIDS, the stigma associated with it, the fear it caused as one ultimately dies from the disease. It was also evident that the children feared death, and had personal encounters with death. All of them had experienced loss as a result of death in their family.

#### **4.4 Focus group discussion**

Thematic analysis was used as a data analysis approach in this study. Several themes and sub-themes were extracted from the focus group transcripts (See Figure 2 below). There was a clear inter-relationship between the various identified themes. As a result some of the themes have been discussed in relation to one another. However, for the sake of clarity, they shall first be discussed individually, and later discussed in relation to one another. Extracts from the focus group are used to illustrate the concepts discussed. The following notation is used in order to give an indication of the quote in relation to the interview.

## Main Themes



**Figure 2: Themes extracted from the focus group discussion**

- Participant 1, 2 etc denotes which participant in the group made the statement. As there were ten participants in the focus groups, they have been numbered participant 1, 2 3 etc. This is also to ensure that confidentiality of the participants is maintained.
- Researcher refers to myself as the researcher of the study
- Research Assistant refers to the NGO psychosocial workshop coordinator who helped facilitate the focus group
- ( ) comments in brackets will denote comments made by myself
- ... the use of dots in the beginning or middle of an extract indicates that part of the extract has been omitted in order to shorten it and to highlight only the relevant parts of the extract
- [ ] words in square brackets refer to words that I have added in order to help the reader understand the extract
- (p. ) will denote the page of the transcription in which the extract was found

### **4.4.1 Death**

Death was one of the most prominent themes. The reasons for this theme emerging fairly strongly may be as a result of 'death' and 'loss' being the central topic of the study. In relation to death, the children expressed the pain of losing a loved one. Judging from the discussion, it became evident that these children were profoundly affected by losing their parent/s. Some of the children indicated that they experienced psychological distress and anxiety due their loss.

*Participant 2 (p.10): .... I'm here to talk about my mother and how much her passing hurt me. ... When she passed away I don't want to lie I became disturbed mentally. I felt I couldn't go on and a lot of things didn't make sense to me anymore. Even now I still think about her and I want it to pass because she's no longer here... It still hurts a lot and I wish to put it behind me and concentrate on my studies.*

Although children who are grieving the loss of a parent may not necessarily be diagnosed with depression or anxiety, they often present with symptoms of depression such as sadness whereby the child feels despondent and hopeless; loss of pleasure or interest in activities; feeling of inner turmoil, being worried and irritable; as well as showing anxiety and at times even having suicidal thoughts (Sadock & Sadock, 1998). The psychological understanding of bereavement suggests that constructive grieving involves accepting the reality of the loss, experiencing its pain, adjusting to a changed environment and relocating the deceased within one's life (Wild, 2001). It had been 6 months since the child's mother had passed away, and in light of the above extract it seemed that this child had not yet come to terms with the death of her mother and had not adjusted to the changed environment.

This child spoke openly about a sensitive and personal experience, and helped to shed light on the intricate difficulties of experiencing loss. She spoke of feeling as though she couldn't go on and things no longer making sense to her, which indicates her overwhelming distress, a feeling shared by many orphaned children.

Other children shared their experiences:

*Participant 8 (p. 7): My name is K and I'm going to talk about my father. My father passed away in 2001 I don't remember in which month. He died in hospital. He loved me, whenever I asked him for something he would give it to me. My mother didn't live with me. He really wanted me to go to school and play soccer.*

*Participant 9 (p. 8): My name is Y. I'm going to talk about my mother. My mother passed away while I was living with her. We were about to go to bed, she was sick at the time, every time before bed she would ask us to bring her water. When we brought the water we found that she had died.*

*Participant 10 (p. 9): My name is BN and I live (unclear). I'm going to talk about my mother even though I don't know her. Growing up at home I was told my mother died a long time ago (crying – can't clearly make out what is being said). I don't even know what she looks like I only see her in photos. My father died in front of me.*

A sub-theme which emerged from the theme of death is that of 'anxiety about one's future'. Several participants appeared to have been anxious and uncertain as a result of their caregiver's dying, and this may have been due to supportive structures being compromised.

*Participant 1(p. 1): ... What hurt me was my mother's passing when I was 12 years old and in grade 5. It hurt because when I left to go and play she was not sick, when I came back, I was told she had passed away. When I got home I asked myself what is this that's happening to me. At first I didn't believe it but when they took her to the mortuary that's when I knew I would never see her again. I thought about her all the time for a week knowing I'd never see her again*

P1 expresses the loss and the grieving she experienced, the mourning for her mother is shown by her disbelief at the unexpected death, and thinking of her continuously as a means of trying to make sense of what had happened to her mother. It appears that this child was not prepared for her mother's death, and as a result was in shock and in disbelief. This child also seems to have experienced confusion, questioning how and why her mother died. She may have had a similar experience of grieving as participant 2 with regards to the confusion and anxiety that both their losses caused them (see above quotation on page 10, Appendix F).

Another participant shared her experience:

*Researcher: What has changed since your mother's passing?*

*Participant 2 (p.2): They were fighting over ownership of the house where I was staying and I had to go live with my uncle.*

*Researcher: You are clearly still hurting, how do you cope?*

*Participant 2 (p. 2): [sobbing] I lock myself in the house.*

*Researcher: Does that help you?*

*Participant 2 (p. 2): It helps. There is a book I usually read about a boy named Peterson, his mother died. There's a passage in the book that makes me strong.*



*Researcher: Would you like to share it with us? There might be someone who might also find comfort in it? Drink some water and take your time we're not in a hurry.*

*Participant 2 (p. 2): It says no matter how small you are you can still make your dreams come true and that even if you've lost a loved one you're not alone there are still a lot of people that you can talk to. I took that and tried it [sobbing] and I feel like a load has been lifted off my shoulders.*

*Researcher: Thank you Z. I know sometimes it's hard to talk about people that have passed away, know that we are here to support you.*

This child was emotional while sharing her story with us, and this indicated how she was still grieving the loss of her mother, and had not yet come to terms with her death. She needed to be comforted and listened to, and the researcher spent time with her separately after the focus group in order to ensure that she was comforted and contained. The impact of the loss was evident in her story telling. This child also shared with the group her coping mechanism, that of reading a book which she can relate to, and through this she highlighted a healing process which could perhaps be used with other children who have experienced a loss.

Another child shared his experience:

*Participant 7(p. 6): My mother passed away in May 2008. It hurt me very much because she died in front of me. She was living with us in the house. It hurt very much because I don't even know where my father is. I was at home the whole week until the funeral and I never saw my father. When my grandmother left, my mother was already sick. She then went into hospital and died.*

*Researcher: Your mother died in hospital?*

*Participant 7(p.6): Yes. It hurt me very much [inaudible – background noise].*

*Researcher: And your father?*

*Participant 7 (p.6): I don't know, I was told he had died.*

Judging from this child's story, he was very much affected by the death of his mother, even more so as she died in front of him and this could have been a very traumatic experience. He has also experienced another loss, as his father's whereabouts were unknown, only to be later told that he had died. In this regard, this child was grieving for both his parents, and this is indicated by his emphasis on the words "hurt me" and "very much" which reflect the great loss and sadness he experienced. He was quite clearly expressing how hurt he was both by the death of his mother and his father. This boy had great anxiety about the future, particularly as he seemed uncertain of whether his father had died.

Another participant spoke of losing his father and then his grandmother:

*Participant 6 (p.5): ...I was in my second year of school when he [his father] fell ill. We went to see him and he became better, he fell ill again and died. After his burial I asked my grandmother where my mother was and she told me only my father knows and he was now dead. I then lived with my grandparents. I knew my grandmother as my mother, she also died. I think it was last year, I now live with my grandfather...*

This child had experienced multiple losses as he lost his father, followed by his grandmother whom he thought of as his mother. Furthermore, this child had an additional loss as he has never known his biological mother. These multiple losses may have had a great impact on this child, who experiences great sadness. He may have had great fears about his future, as he lost two significant figures in his life, and one, whom he never knew.

Multiple bereavement can be more complex and overwhelming than individual bereavement as a child tries to cope with more than one loss at a time. Because of the role of parents as nurturers and caretakers, their loss stirs up distressing feelings of anxiety based on the ongoing attachment relationship and the dependency needs of the children regardless of their age. In light of this, participant 6 may have suffered a great deal from the multiple losses which he experienced.

Another child spoke of his experience:

*Researcher: How do you feel about your mother's death?*

*Participant 5 (p. 4): I'm fine but sometimes my aunt who I live with says I must call her mother. When ever I want to call her mother I'm reminded that my mother is no more. It would have been better if I had never known my mother and only known my aunt as my mother but it was my mother that I called mother and not her.*

*Researcher: Someone that you can talk to whenever you're feeling down?*

*Participant 5 (p. 5): No, there isn't because we don't even get along with our neighbours anymore. They are the only people I could talk to but now things have changed. My aunt is the one I should be talking to.*

This child gave the impression of having previously coped generally with the loss of his mother. However he is reminded of his loss, whenever his aunt requests he call her "mother". This may have been the aunt's way of showing the child love and support, but the child seems to struggle with this as it reminds him of his own loss. Apart from losing his mother, and now living with his aunt, this child has had other changes in his life, as the

neighbours with whom he was able to speak previously, seem to no longer be getting along with him and his family. The child did not express why or how the relationship with the neighbours changed, but one would imagine that this impacted on him as he had now lost a source of communication and an external support system.

Another child spoke of her loss:

*Participant 9 (p. 8): My name is Y. I'm going to talk about my mother. My mother passed away while I was living with her. We were about to go to bed, she was sick at the time, every time before bed she would ask us to bring her water. When we brought the water we found that she had died.*

She continued:

*Participant 9 (p. 8): It hurt me very much because my mother used to do everything for me now my father does nothing for me he lives with another woman. When I finish school I want to be a teacher.*

*Researcher: When was the last time you saw your father?*

*Participant 9 (p. 8): I haven't seen him in a long time.*

*Researcher: Does he know where you are?*

*Participant 9 (p. 8): He knows where we live but he does not visit us.*

*Researcher: How does that make you feel?*

*Participant 9 (p. 8): It hurts [sobbing].*

*Researcher: What hurts you the most?*

*Participant 9 (p. 8): That he does not support me in any way.*

*Researcher: Are you able to talk to your sister about things that hurt you?*

*Participant 9 (p.9): Yes I do talk to her.*

This child expressed having lost her mother and how much that loss affected her, as her mother was a supportive structure for her. Her loss seemed to be exacerbated by the absence of her father, who is still alive, and yet shows no support to her at all. As a result it appears that this girl was grieving the loss of both parents, and may have felt a sense of neglect or even rejection from her father. It was evident that she needed support and was still hurting from her loss.

Another child spoke of having lost both her mother and father. This child was another example of a multiple loss, having never known her mother and then having lost her father.

*Participant 10 (p. 9): My name is BN and I live (unclear). I'm going to talk about my mother even though I don't know her. Growing up at home I was told my mother died a long time ago [crying – can't clearly make out what is being said]. I don't even know what she looks like I only see her in photos. My father died in front of me.*

*Researcher: Your father?*

*Participant 10 (p. 9): Yes. He was sick, I didn't know what was wrong with him. He lived alone and I was living with my grandmother, when I went to check on him I found him dead. I went to call the mother of his other child and when she got there she confirmed that he was dead. The undertaker came to fetch him. At his funeral (unclear – speaking in-between sobs]. That's all I wanted to say.*

This child experienced a multiple loss, and may have been additionally traumatised by finding his father dead. He spoke of not ever knowing his mother and how she even looked, only having ever seen her in photos. This may have caused him to have a strong sense of longing for a maternal figure, imagining and phantasizing about what kind of person his mother might have been.

This theme gave a clear picture of the children's experiences of loss, grief and bereavement. There were signs of expressed anxiety, distress and sadness amongst the children. Thus it became evident that the children were very heavily impacted by the loss of their parent/s, and that death was indeed a very stressful life event for them.

#### **4.4.2 HIV/AIDS stigma**

The theme "HIV/AIDS stigma" was manifested on the level of the children having several fears in relation to HIV and AIDS. The themes which emerged under this category indicated that there was a fear of the HI virus and/ or family members being diagnosed with HIV/AIDS; fear of disclosure; fear of being spoken badly of, or gossiped about in relation to having HIV/AIDS; as well as the attendant secrecy and shame.

This theme particularly highlighted the presence of stigma in the community in which these children live. Furthermore, the discussion around HIV/AIDS indicated how some of the children held strong beliefs about HIV/AIDS which further emphasized the strong stigma within their society. The beliefs held by the children also shed light on the implications that such stigma can have on children's ability to disclose and seek appropriate help and

support. It seemed that the stigma prevented children from openly speaking out about personal issues either regarding them and/or their families.

When asked why he is afraid of death, a boy responded:

*Participant 6 (p.12): I'm scared of leaving a lot of things behind. People say bad things about you when you're dead.*

*Researcher (p.12): What do they say?*

*Participant 6 (p.12): They say you had AIDS, people just say silly things. Some of our parents say the same about other people. That's what I'm afraid of.*

The researcher then explored further:

*Researcher (p.12): Is it an embarrassment for someone to die because they were HIV+?*

*All (p. 12): No.*

*Participant 6 (p.12): But people treat it as if it is.*

*Researcher (p.12): What do people do to make it seem like an embarrassment?*

*Participant 7 (p.12): If the person that was HIV+ was related to you, you sometimes hear people talking about that person and it hurts.*

*Researcher (p.12): What do they usually say about that person?*

*Participant 7 (p.12): They sometimes say that they were not the only ones that were HIV+ and you start thinking that maybe you could also be the other one that has it.*

When asked if it was an embarrassment for someone to die because they were HIV positive, all the children said 'no'. However one child, contrary to having said no, made an additional remark which seemed to have encouraged another child to express his own views about the issue. Through this discussion, the issue of HIV/AIDS seen as an embarrassment resurfaced. Furthermore, the fear of being spoken badly of also came to the fore. This indicated that although the children felt that having HIV/AIDS should not be seen as an embarrassment, some felt strongly that it is *treated* as such.

Another aspect which was highlighted in this particular point of the discussion was the fear of infection, whereby some of the children indicated that they had fears of *themselves* being infected when a parent or other family member had died as a result of HIV/AIDS. It became evident in the discussion that these children had personally experienced forms of

stigma in their communities, and were thus speaking about personal encounters whether directly linked to them or their family members. Not only did they reflect on ways in which others spoke badly of them, but also how they became mistreated as a result of the stigma. This was particularly illustrated by two participants who reflected on how one could be mistreated by others:

*Researcher (p.12): So why are we afraid of HIV, because you end up dead?*

*Participant 6 (p.12): It's because you die before other people die.*

*Participant 8 (p.12): I'm afraid of HIV because you end up having to live on pills. People are disgusted by you and you're even scared to go outside.*

*Participant 7 (p.13): People get disgusted with you to the point that they don't even want to touch a spoon that you might have used. You start wondering if it's transmitted through utensils when people don't want to touch utensils that you've used.*

*Researcher: What causes that? When you see it in your community or in your school what do you think causes it?*

*Participant 6 (p. 13): It's the people that think they are better than everyone else.*

Participant 8 touched on the medical aspect of having HIV/AIDS, expressing his fear of relying on pills as a means of survival. He also expressed the fear of being in public where people may mistreat one due to one's illness. Both participant 8 and 7 expressed their fears in relation to people becoming disgusted in one for being HIV positive.

Another child touched on how different she felt from others when she lost her mother, and as a result avoided leaving home. This experience seemed to be common with children whose parents have had an AIDS-related illness, because due to the stigma of HIV/AIDS which surrounds the children and their families, the disease marks them different from others (Joslin & Harrison, 1998).

*Participant 3(p.2): Yes. My name is L and I live at (unclear). I'm in grade 7 at (unclear) and my mother passed away in 2003. I don't know what was wrong with her.*

*Researcher: Was she ill?*

*Participant 3: Yes.*

*Researcher: What happened?*

*Participant 3: After she passed away I felt I was different from other people, not at all like them. I tried to stay at home, it became better and I was then able to start talking to other people.*

*Research assistant: What happened to your mother? Tell us about that.*

*Participant 3: She was sick and she passed away.*

The issue of disclosure also arose in this theme where one participant felt strongly that it was a problem to disclose if one was ill:

*Participant 5 (p.14): I think it's a problem to tell someone. You can tell someone and that person might end up telling other people.*

*Researcher (p.14): Are you then afraid of telling someone about your problem even if you get sick?*

*Participant 5 (p.14): I would rather die, I'm scared.*

I felt this participant really placed emphasis on just how debilitating HIV/AIDS stigma can be. Expressing that he would rather die than to tell someone that he was HIV positive indicated that this particular child would rather suffer alone in silence. His statement may also be a sign of just how severe the stigma of HIV/AIDS is within his community, such that disclosure is far more of a risk than secrecy. Although this was the voice of one child, it reflected much of the fears which were present in the discussion.

Similarly, another participant expressed openly the shame which HIV caused on families, particularly those left behind:

*Researcher (p.16): If someone dies from HIV and another dies from something else, is there a difference between those people?*

*All (p.16): No.*

*Participant 1 (p.16): It's the same thing.*

*Participant 10 (p.16): But the person that dies of HIV leaves a bad name for the family.*

*Researcher (p.16): Why?*

*Participant 10 (p.16): Because they died of HIV.*

Initially all the children had the same response to the researcher's question, but one participant added to the response, indicating that he did not agree with his previous answer. The participant expressed that a person who dies of HIV leaves a bad name for the family. Through this, he indicated that death was not so much the issue, but rather *how* one died. His statement stipulated that death differed according to the cause, and particularly that

dying from HIV/AIDS was a 'bad' form of death. The participant's response, like much of the previous group discussions, emphasized the stigma surrounding HIV/AIDS, as well as the perceptions the group had about HIV/AIDS and the stigma which surrounds it

A participant within the group appeared uncertain about her mother's cause of death, but had been informed that her mother had been bewitched:

*Participant 5 (p. 4): ...My mother was a [sangoma] witchdoctor, when she fell ill she had to go live somewhere else to be treated and my aunt would go and check on her. One day just before she came back my mother fell seriously ill and she was brought back home to live with my aunt. There was another [sangoma]witchdoctor at home, I'm not sure and don't know the truth for sure but I hear that while we were gone, when we came back there was a bottle in the house and my mother just collapsed.*

*Researcher (p.5): You've described how your mother and your father died. Do you believe that someone did something bad to them?*

*Participant 5 (p.5): I'm not sure about my father but my mother we were told at home by other [sangomas] witchdoctors that someone was doing something. They pointed at someone that we live with at home who is also a [sangoma] witchdoctor saying it looks like it's her.*

Judging from this discussion, it seemed the child was uncertain of her mother's death. She did not state whether *she* felt something bad was done to her parents, but rather stated what she had been told. However, she mentioned not being sure and not knowing the truth for sure, which indicated that she may have doubted the explanation given to her about her mother's death. The explanation which the participant received about her mother's death may have been an alternative explanation as a means of avoiding being ostracized by the community in which they live. This again, raised awareness to the evidence of stigma which forces people to remain silent about AIDS-related illnesses. This particular child's situation also highlighted the powerlessness which children often feel where they cannot question or challenge adults' views even though they may not entirely agree with them. Although this child was not certain of her mother's cause of death, the power dynamics created between adult and child, resorted to her not querying the explanation given to her.

The theme of HIV/AIDS was one which was richly discussed. Various perceptions came to the fore, most of which are common stereotypical judgments made in relation to HIV/AIDS and those infected and affected by it. The discussion surrounding this theme raised awareness to the complexities of HIV/AIDS, the beliefs and perceptions which stem from it, as well as the impact which stigma has on the survival and support of people affected by HIV/AIDS.



The theme ‘HIV/AIDS stigma’ showed the intense fear of disclosure, the unwillingness to accept and support those with an AIDS-related illness, as well as the secrecy and shame which so strongly exists within the children’s communities. What was also very apparent was the fear that the children have about themselves being infected by HIV/AIDS. The fear of disclosure manifests itself through the gossiping centered around HIV/AIDS, and ways in which people are mistreated by others when one has an AIDS-related illness.

#### **4.4.3 The unspoken illness**

Although it was known that the children involved in the study had lost their parents, none of the children were able to give reasons for the cause of death of their parents. Within the focus group, each child was given the chance to talk about a loved one who had passed on. Each child spoke about either their mother or father, some even both. The most frequent response in relation to the cause of death was “she/he got sick and died”. Thus the cause of death was never specified, but rather referred to as a sickness.

*Participant 3(p.2): Yes. My name is L and I live at (unclear). I’m in grade 7 at (unclear) and my mother passed away in 2003. I don’t know what was wrong with her.*

*Researcher: Was she ill?*

*Participant 3: Yes.*

*Researcher: What happened?*

*Participant 3: After she passed away I felt I was different from other people, not at all like them. I tried to stay at home, it became better and I was then able to start talking to other people.*

*Research assistant: What happened to your mother? Tell us about that.*

*Participant 3: She was sick and she passed away.*

*Participant 9 (p. 8): My name is Y. I’m going to talk about my mother. My mother passed away while I was living with her. We were about to go to bed, she was sick at the time, every time before bed she would ask us to bring her water. When we brought the water we found that she had died.*

*Participant 10 (p. 9): My name is BN and I live (unclear). I’m going to talk about my mother even though I don’t know her. Growing up at home I was told my mother died a long time ago [crying – can’t clearly make out what is being said]. I don’t even know what she looks like I only see her in photos. My father died in front of me.*

*Researcher: Your father?*

*Participant 10: Yes. He was sick, I didn't know what was wrong with him. He lived alone and I was living with my grandmother, when I went to check on him I found him dead. I went to call the mother of his other child and when she got there she confirmed that he was dead.*

*Participant 4 (p.3): My name is S. My mother passed away. She loved me and I loved her. My mother was sick. I don't know what year she died.*

*Participant 5 (p.4) ...My mother was a [sangoma] witchdoctor, when she fell ill she had to go live somewhere else to be treated and my aunt would go and check on her...*

*Participant 6 (p. 5) ...I was in my second year of school when he fell ill. We went to see him and he became better, he fell ill again and died.*

*Participant 7 (p. 6): ...When my grandmother left my mother was already sick. She then went into hospital and died.*

*Participant 5 (p. 3-4): ...When I came back my father was already ill and my mother was not at home at that time. My father was in hospital. My mother was not the only woman he was dating he was also dating someone else. The other woman was the one looking after him when he was sick.*

All the extracts above show that the children spoke of their parents' death, relating to them as being sick or ill. This observation raised two questions: 1) Were the children not properly informed of their parents' cause of death? 2) Did the children intentionally choose not to discuss in detail the cause of their parents' death? Both questions were a possibility and may have been so for various reasons.

Previous studies on children's experiences of death and bereavement, have shown that children are often not well informed about the death of their parents (Wood *et al.*, 2006). Furthermore, children are often not included in the overall grieving process which may include rituals and the funeral. As a result of this, children have the risk of suffering more from the loss as a result of not fully understanding what has occurred. In light of this, the children in the focus group may have been misinformed about the death of their parents, causing them to not be able to give a clear reason for their death.

On the other hand, having discussed the issue of HIV/AIDS stigma, it was evident within the group that the group had very strong views about stigma, as many of the children spoke of the discrimination one endures when a family member has died from HIV/AIDS. It was also clear that stigma was very much present amongst the children as well as the communities they come from. As a result of this stigma, children who have lost their parents due to an AIDS-related illness have great difficulty disclosing their parents' cause of death due to the shame associated with the HI virus (Campbell *et al.*, 2005), and this may explain the children's reluctant responses when asked how their parents died.

#### 4.4.4 The need for support

The need for support was a running theme throughout the group discussion. As the children shared their stories in relation to their experiences of losing a loved one, it became clear that all of them needed support in some way or another. This need was expressed in terms of emotional support, being provided with material needs, having someone to talk to and feeling comforted, and being able to share one's grief. Some of the children were emotional while sharing their experiences, which showed that they still needed to be supported and comforted through their grieving process.

Some of the children also shared ways in which they coped with their parents' death:

*Researcher (p. 2): You are clearly still hurting, how do you cope?*

*Participant 2 (p.2): [sobbing] I lock myself in the house.*

*Researcher: Does that help you?*

*Participant 2: It helps. There is a book I usually read about a boy named Peterson, his mother (unclear). There's a passage in the book that makes me strong.*

*Researcher: Would you like to share it with us? There might be someone who might also find comfort in it? Drink some water and take your time we're not in a hurry.*

*Participant 2: It says no matter how small you are you can still make your dreams come true and that even if you've lost a loved one you're not alone there are still a lot of people that you can talk to. I took that and tried it [sobbing] and I feel like a load has been lifted off my shoulders.*

Participant 2 shared with the group her coping mechanism, that of reading a book. It appears that this was a positive coping mechanism for her as it comforted and consoled her, and helped alleviate some of her sadness and pain. Having lost their parents, some of the children expressed the changes they experienced as their parents were no longer there to provide for their material needs:

*Researcher (p. 6): How has your father's death changed your life?*

*Participant 6 (p. 6): Whenever I asked him for anything he would give it to me.*

Similarly, other children expressed:

*Participant 8 (p.7) ....He loved me (speaking of his father), whenever I asked him for something he would give it to me.*

*Researcher (p.7): Who now buys you the things that you need?*

*Participant 8 (p.7): My grandmother and my cousins.*

*Participant 9 (p.8): It hurt me very much because my mother used to do everything for me now my father does nothing for me, he lives with another woman...*

*Researcher (p.8): When was the last time you saw your father?*

*Participant 9(p.8): I haven't seen him in a long time.*

*Researcher (p.8): Does he know where you are?*

*Participant 9 (p.8): He knows where we live but he does not visit us.*

*Researcher (p.8): How does that make you feel?*

*Participant 9 (p.8): It hurts [sobbing].*

*Researcher (p.8): What hurts you the most?*

*Participant 9 (p.8): That he does not support me in any way.*

Participant 9 openly shared how the loss of her mother affected her as her mother used to provide for her. She was equally affected as her remaining parent (her father) did not support her nor ever came to visit her. This child was evidently still hurting from the loss of her mother, and the absence of her father, as she was crying during this particular section of the discussion. This in itself indicated the child's need for support, and having someone with whom she could share her grief.

Extended family members played a significant role in supporting these children. In most cases, the children were being raised by their grandmothers after having lost their parent/s.

*Researcher (p.9): When you need to talk to someone, who do you talk to?*

*Participant 10 (p.9): I only talk to my grandfather and my other sibling.*

*Researcher (p.6): So who do you talk to when you want to talk?*

*Participant 7 (p.6): My grandmother.*

Many of the children expressed being able to talk to their guardians when feeling sad and needing to talk to someone. This showed how the extended family members were taking on the parental roles for these children, as a means of supporting them. Therefore, the role which the grandmothers as well as other family members play, seems to have been a positive aspect in the children's adjustment to parental loss.

*Researcher: Who now buys you the things that you need?*

*Participant 8 (p.7): My grandmother and my cousins.*

*Researcher: Do you live with them?*

*Participant 8 (p. 7): [inaudible- background noise]*

*Researcher: Are you able to talk to them about things that make you feel sad?*

*Participant 8 (p. 7): Yes.*

This theme has shown the impact which parental death has had on the children involved. It has also proven how important it is that children have good and strong support basis surrounding them. Attending to children's emotional needs is one of the crucial requirements in order to build security in a child's development. Throughout the group discussion, different participant showed in various ways how much they needed to be supported and their needs taken care of through this difficult time, whether it be through talking to someone, being comforted, being nurtured and taken care of. Those whom were lacking this support suffered as a result, and this was evident in the way they expressed themselves.

#### **4.5 Summary**

This chapter has outlined the results drawn from the data collected in the study. A discussion of the results, in relation to the concepts identified in the literature, follows in chapter five.

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## **Chapter 5**

### **Discussion**

#### **5.1 Introduction**

This study aimed to explore adolescent orphans' experiences of parental AIDS-related illness and bereavement. The aim of this chapter is to discuss the findings of the study in relation to the concepts identified in the literature.

The themes extracted from the transcripts have shown insight into the lives of the children involved in the research, particularly the ways in which the death of their parents has impacted on them. The four themes individually highlighted some very important aspects of both the children's experiences of bereavement, and the influences of the context in which they live in.

#### **5.2 Death**

The psychosocial impact of children living with families affected by HIV/AIDS often leads to stress, which is characterized by anxiety, loss of self-esteem and confidence, stigma and depression. Such factors lead to the need for a child to be supported emotionally and psychologically. Some of the responses given by the children in the focus group discussion showed that the children were distressed due to the loss of their loved ones. This came as no surprise, as literature supports that children may suffer a great deal from losing a parent. As argued by Demmer (2007), the illness and death of a parent is a crisis for each child left behind, as economic, educational, and social aspects often change as a result of a lack of parental guidance.

Cluver, Gardner, and Operario (2007) in their study of 'Psychological distress amongst AIDS-orphaned children in urban South Africa' discovered that children orphaned by AIDS may be particularly vulnerable in terms of emotional problems. This study revealed that depression and anxiety were common in orphaned children, particularly so with orphaned girls and that depression often lead to orphaned children having suicidal ideation. Some children's way of expression indicated that they may have experienced psychological distress in the form of anxiety and depression. This became particularly evident as one of the children described becoming "disturbed mentally" after losing her mother, indicating the degree of distress she was under.

Many of the children spoke openly about sensitive and personal experiences, and helped to shed light on the intricate difficulties of experiencing loss. Furthermore, their openness in discussing their anguish was consistent with the literature surrounding orphaned children and the effect which parental loss has had on them (Wood *et al.*, 2006; Zhao *et al.*, 2007)

One of the sub-themes which emerged from the theme of death was that of ‘anxiety about one’s future’. Current literature shows that orphaned children are often anxious and uncertain when a caregiver dies, as their support structures often become compromised (Richter *et al.*, 2006). This anxiety appears to have been evident with several of the participants in the group. One participant spoke of losing her mother unexpectedly and how much this hurt her (see participant 1’s quotation on pg. 1). It seems this child was not prepared for her mother’s death, and as a result was in shock and in disbelief. As described by Kubler Ross (1969), the initial stage of coming to terms with death can be a period of shock and denial. Within this initial stage, one consciously and unconsciously refuses to accept the facts and reality of the death and so experiences a sense of disbelief. This participant seemed to have experienced this initial stage, finding it hard to come to terms with the death of her mother.

Through the group discussion one could see that the children were heavily impacted by the loss of their parent/s, and that death was indeed a very stressful life event. A wide range of emotions were expressed, some being in disbelief, shock, hurting emotionally, and experiencing intense anxiety. Bereavement due to HIV/AIDS-related loss has been argued to be a severe stressor (Rogers *et al.*, 2005) and the complex nature of HIV/AIDS has also resulted in children not only losing their mother or father, but in some instances both parents as well as other close family members. This multiple bereavement was evident in the data collected, as some children lost both mother and father or another loved one in the family. This can be more complex than individual bereavement as a child tries to cope with more than one loss (Dane, 2002), and can have even more of a detrimental effect on a child’s emotional and psychological well-being. Evidence of great loss was evident with participant 6 (quotation on pg.5) as he expressed the deep sadness he felt from his losses. Parents play the role of being nurturers and caretakers, and as a result, their loss stirs up distressing feelings of anxiety. This anxiety is based on the ongoing attachment relationship and the dependency needs of the children regardless of their age (Webb, 2002).

This theme also showed that many of the children were still having difficulty coming to terms with their loss and were in fact still grieving their parents. This theme gave evidence to the different ways in which children experience loss. It highlighted some emotional as well as psychological effects of death, and how these children reacted to and experienced their loss. Furthermore, the experiences of these children, are reflected in current literature (Jewett, 1982; Melhem *et al.*, 2007; Zhao *et al.*, 2007) indicating how a child's loss can include fears of personal survival, separation anxiety, sadness, anger, guilt, shame and despair. On the whole, the discussions around this particular theme showed that the children experienced deep sadness at the loss of their parents, and some had not yet recovered from their loss.

### **5.3 HIV/AIDS stigma**

The theme of HIV/AIDS stigma was one which was discussed a fair amount, highlighting the children's perspectives and the way in which stigma impacted on them. The sub-themes emerging from the discussions indicated that the children had a personal fear of the HI virus and members of their family being infected. Also present was the fear of disclosure; the fear of being gossiped about or spoken badly of, as well as secrecy and shame.

This theme brought about awareness of the stigma which was present in the community which the children came from. Several children expressed how people were spoken badly of if they had HIV/AIDS and as a result feared ever disclosing if they had to be infected with HIV/AIDS. They also expressed the embarrassment HIV/AIDS caused to families, and the discrimination one experienced from being affected and /or infected by HIV/AIDS. A particular point of discussion indicated that although the children felt that having HIV/AIDS should not be seen as an embarrassment, some felt strongly that it is *treated* as such.

This discussion reflected on many of the intensely held attitudes of our society surrounding HIV/AIDS. Areas of the discussion proved to be prevalent in current studies (Foster *et al.*, 2005) illustrating how children are impacted by the stigma associated with HIV/AIDS, as they often fear that they will not be accepted by others if it is known that their parents died of AIDS, and are thus not able to express emotions and feelings caused by the loss of a parent. The issue of disclosure was further emphasized by one participant who claimed he



would rather die than to disclose he was ill. Although this was the voice of one child, it reflected the voices of many children documented in previous research.

In Campbell *et al.* (2005) study, a young boy shared a similar experience to participant 5 of this study, where he stated “It’s shameful to have AIDS in this community, I think they would make a big gap between my desk and other learners’ desk at school”. The statement made by the participant in this study-as well as the one quoted in Campbell *et al.* (2005) reflect how deeply rooted HIV/AIDS stigma is, but also indicated that HIV/AIDS stigma is not only associated with adults, but that children also become shaped by these intensely held attitudes. As a result children become so moulded in these attitudes, that they cannot break the cycle and create a more open and accepting platform for their generation and those to follow, and thus the stigma manifests.

Furthermore, through this statement, one learned the severe consequences of discrimination due to stigma, and how perhaps many children suffer in silence and denial. The concern which arises from the silence and denial that is present, is that children- as well as adults- are thus not able to receive the correct psychosocial, psychological and medical support that they need. The consequence thereof would be of a generation being at further risk of HIV infection.

Another aspect which was highlighted in the discussion was the fear of infection, which too was prevalent in previous literature based on children affected by HIV/AIDS (Cluver & Gardner, 2007; Wood *et al.*, 2006), whereby children have fears of *themselves* being infected when a parent or other family member has died as a result of HIV/AIDS. This fear further complicates successful grieving, as, not only are children trying to come to terms with a loss of a parent, but are also concerned and anxious about their own well-being having no one with whom they can share their fears and anxieties (Joslin & Harrison, 1998).

The stigma of HIV/AIDS not only occurs as children witness their parents becoming ill, but also after the death of their parents, as they may feel shame, guilt and rejection (Foster *et al.*, 2005). It became evident in the discussion that these children had personally experienced forms of stigma in their communities, and were thus speaking about personal encounters whether directly linked to them or their family members. Not only did they

reflect on ways in which others spoke badly of them, but also how they became mistreated as a result of the stigma.

The medical impacts of HIV/AIDS were also outlined, where a participant expressed his fear of relying on pills as a means of survival. Furthermore he expressed the fear of being in public where people would mistreat one due to one's illness. Through this discussion the child highlighted the ostracism that one experiences from members of society as a result of the stigma associated with HIV/AIDS. Mallmann (2002) argues that families affected by HIV/AIDS often cut ties with relatives and the community in fear of being ostracized. The fear to "go outside" links back to the fear of the community gossiping about the one who is ill. As a result of this fear, one imagines the burden of secrecy which children bare as a means of protecting themselves and surviving the stigma of HIV/AIDS. The secrecy and shame which families go through may result in children making up stories about their family, and living in a fantasy world as a way of dealing with the circumstances at home (Mallmann, 2002).

As some of the children expressed being scared of death, it became clear that it was not so much death itself that they feared, but rather dying as a result of HIV/AIDS. Within the discussion, a participant expressed that a person who dies of HIV leaves a bad name for the family. Thus *how* a person died seemed to be much more of a concern. His statement stipulated that death differed according to the cause, and particularly that dying from HIV/AIDS was a 'bad' form of death. The participant's response, like much of the previous group discussions, emphasized the stigma surrounding HIV/AIDS, as well as the perceptions the group had about HIV/AIDS and the stigma which manifests. The participant's response is reflected in Campbell *et al.* (2006) and Dias *et al.*, (2006), where AIDS-related illness is looked down upon, and is rarely discussed as opposed to other causes of death.

The shame associated with HIV/AIDS perpetuates the silence and denial. A rural woman, In Campbell *et al.* (2005) study stated "saying that a person has AIDS is a shame to the community as a whole. It sounds better to say that someone has been bewitched" (Campbell *et al.*, 2005, p.22). As a result of the shame, adults may give children the wrong information in relation to the death of their parents, allowing them to believe their parents were bewitched. A similar scenario was apparent in the focus group where a child appeared

uncertain about her mother's cause of death, but had been informed that her mother had been bewitched.

Judging from the discussion, the child was uncertain of her mother's death. She did not state whether *she* felt something bad was done to her parents, but rather stated what she had been told. However, she mentioned not being sure and not knowing the truth for sure, which indicated that she may have doubted the explanation given to her about her mother's death. The explanation which the participant received about her mother's death may have been an alternative explanation as a means of avoiding being ostracized by the community in which they live. This again, raised awareness of the stigma which forces children and adults to remain silent about AIDS-related illnesses. This particular child's situation also highlighted the powerlessness which children often feel where they cannot question or challenge adults' views even though they may not entirely agree with them. Although this child was not certain of her mother's cause of death, the power dynamics created between adult and child, resorted to her not querying the explanation given to her.

Overall, the theme of HIV/AIDS stigma, was richly discussed within the group, bringing different perceptions to the fore. The group discussion generally correlated with the literature written on HIV/AIDS and the stigma which prevails from it. The discussion surrounding this theme raised awareness to the complexities of HIV/AIDS, the beliefs and perceptions which stem from it, as well the impact which stigma has on the survival and support of people affected by HIV/AIDS. The intense fear of disclosure, the unwillingness to accept and support those with AIDS-related illnesses, as well as the secrecy and shame which so strongly exists within the children's communities was evident.

The fear of disclosure was of particular concern, as it indicated that many of the children are possibly not receiving adequate psychosocial support in relation to being infected and/or affected by HIV/AIDS, as many would prefer not to disclose, and thus not seek appropriate help and support. This may also mean that the children do not have strong supportive structures within their communities where they can openly share, learn and talk about their fears and issues regarding HIV/AIDS. Over and above, the group discussion implied that the stigma which surrounds HIV/AIDS still strongly exists and has impacted negatively on the way in which these children deal with and understand HIV/AIDS, and continues to do so.

#### **5.4 The unknown/unspoken illness**

It was known that the children involved in the study had lost their parents, however none of them were able to give reasons for the cause of death of their parents, with the exception of two. Within the focus group, each child was given the chance to talk about a loved one who had passed on, each child spoke about either their mother or father, some even both. The most frequent response in relation to the cause of death was “she/he got sick and died”. Thus the cause of death was never specified, but rather referred to as sickness.

Previous studies on children’s experiences of death and bereavement, have shown that children are often not well informed about the death of their parents (Wood *et al.*, 2006). Further more, children are often not included in the overall grieving process which may include rituals and the funeral. As a result of this, children stand the risk of suffering more from the loss as a result of not fully understanding what has occurred. The consequences of such include children blaming themselves for the death of their parent, having anger towards other members of the family who may be more informed, having increased levels of anxiety as a result of not knowing what the future holds for them (Richter *et al.*, 2004).

Hope and Hodge (2006) argue that the relationship with the deceased, the circumstances of death as well as participation in rituals such as the funeral, are important contributing factors to the way in which a child deals with loss. Foster *et al.* (2005) argues that levels of openness in parental communication play a critical role in helping children adjust to parental death. A higher level of communication about the deceased and their cause of death often help children through the grieving process and can also help reduce depression and anxiety (Hope and Hodge, 2006).

Alternatively, having discussed the issue of HIV/AIDS stigma, it was evident within the group that stigma was present amongst the children as well as the communities they come from. As a result of this stigma, children who have lost their parents due to an AIDS-related illness have great difficulty disclosing their parents’ cause of death. This was clearly expressed within the group, as many of the children spoke of the discrimination one endures when a family member has died from HIV/AIDS. Campbell *et al.* (2005) explains that families are often frightened to acknowledge that anyone in their family has HIV/AIDS or has died from HIV/AIDS. However, the consequence of this denial means that families do not get the help they need. The shame associated with the HI virus also perpetuates the

silence and denial. It was also clearly expressed in the group discussion, that disclosure was a very difficult thing to do, and that more was at risk from disclosing than from keeping one's illness a secret. Therefore, the discussions surrounding HIV/AIDS highlighted the high level of stigma still present and would explain why many of the children did not elaborate on their parent's cause of death.

### **5.5 The need for support**

As the children shared their stories in relation to their experiences of losing a parent, it became clear that all of them needed support in some way or another. The need for support was expressed in terms of emotional support, being provided with material needs, having someone to talk to and feeling comforted, and being able to share one's grief. Some of the children were emotional while sharing their experiences, which showed that they still needed to be supported and comforted through their grieving process. A participant shared how the loss of her mother affected her, as her mother used to provide for her. She was equally affected as her remaining parent (her father) did not support her in any way. This child was evidently still hurting from the loss of her mother, and the absence of her father, as she was crying during the discussion. This in itself indicated the child's need for support, and having someone with whom she can share her grief with.

Extended family members have played a significant role in supporting these children. In most cases, the children were being raised by their grandmothers after having lost their parent/s, giving evidence to the increase in grandparents becoming surrogate parents (Joslin & Harrison, 1998). These guardians have become the children's support base and have assisted in the children dealing with their loss. Through the discussion, one learnt that many of the children talked to their guardians when feeling sad and needing to talk to someone. This showed how the extended family members were taking on the parental roles for these children, as a means of supporting them. Strong family characteristics such as supportive, caring and loving guardians have been shown to help children better cope with loss and such characteristics prove to be protective factors in the children's lives (Killian, 2004). Therefore, the role which the grandmothers as well as other family members partake, has been a positive aspect in the children's adjustment to parental loss. Recent studies of grandparents serving as parents however, have identified these older caregivers as a high risk population, more so if they are in poor communities or marginal economic circumstances (Brouard, 2006).

This theme has shown the impact which parental death has had on the children involved. It has also proven how important it is that children have good and strong support basis surrounding them. These children clearly indicated that they needed to be supported through their time of grief, whether it be through talking to someone, being comforted, being nurtured and taken care of. Earls and Carlson (2001) illustrate the need for children to be supported by arguing that children need a lot of security, love and emotional support. They also need guidance as they grow and mature emotionally, spiritually, physically and intellectually. The adjustment of the surviving parent or family members can often determine how children adjust to the loss of their parent. Positive adjustment of the remaining family members is strongly related to positive adjustment by the child. Hope and Hodge (2006) also argue for the importance of a child having an emotionally stable home environment.

The desire for support can be linked to the theme of death, whereby the children have lost a parent and have as a result lost the closeness, security and love they once received from that parent. These children would need assistance in adapting to the changes of not having a parent as well as adjusting to the new environment. Richter *et al.* (2006) argues that it is partly through emotional support that children are able to regain equilibrium after a loss. Jewett (1982) has illustrated how quite often adults are not fully aware what a child needs after suffering a loss, or how they can provide the help that is needed. When adults avoid talking to the child about the loss, it leaves the child confused, afraid and unable to resolve his/her emotions.

Despite the adversities children affected by HIV/AIDS often face- particularly when faced with the death of caregivers- literature suggests that resilience is a common response to loss. This resilience is one's ability to bounce back despite the difficulties faced. Factors influencing resilience are individual, family characteristics, social support and environment and community strengths. The support the children have received from their extended family members seems to have served as a protective factor in their ability to adapt to the loss of their parents. Although this is a protective and important factor, the issue of stigma surrounding the children remains of major concern. This stigma possibly highlights that although the children are supported by family members, the community does not fully serve as a strong basis in terms of how it has shown to react to those infected and affected

by HIV/AIDS. As a result HIV/AIDS stigma possibly continues to act as a barrier to the children's adjusting and coping with the death of their parents.

## **5.6 Summary**

This chapter has discussed the findings of the study in relation to the concepts identified in the literature, highlighting the children's experiences of bereavement, their perspectives on the loss of their loved ones, and the impact to which the loss has had on them.

Furthermore, this chapter has highlighted significant areas of concern for children affected by the HIV/AIDS pandemic, and helps to inform interventions which primarily focus on vulnerable children.

All four themes significantly highlighted some important feelings, expressions and opinions of the children in the study. The impact which parental loss has had on these children was evident as well as the external and internal changes experienced by the children following the death of their parents. The themes also pointed out the social realities of HIV/AIDS, and the impact which it has on communities, such as the stigma associated with the disease. Such realities need to be considered when informing interventions, as such realities can often hinder the healing process of a grieving child. One key finding in the discussions was the impact of HIV/AIDS stigma on the children. These findings indicated that disclosure of HIV status and AIDS-related illnesses was still very difficult and sensitive among communities. Furthermore, the fear of ostracism, discrimination and isolation was evident amongst the children, and raises awareness in relation to HIV/AIDS based interventions. If children fear being discriminated against and ostracised, the chances of them disclosing and seeking help and support are close to slim.

This heavy stigma also hinders the children's grieving process, as they may battle to come to terms with parental AIDS-related illness and cause of death, if and when surrounding people and communities are not able to accept this disease. As a result, children grieve in silence, in fear of speaking about their parent's cause of death and what this may mean to them. The consequence of such means that children may have been left with unanswered questions, which at times leads to self-blame as well as children having resentment towards surviving relatives.

The issue of stigma also links to the theme of support, in that children are not fully supported emotionally if, those surrounding them, gossip and speak badly of family members who have passed away, and stigmatizing surviving relatives. Thus in essence, another key finding, points to the community supportive structures being tainted with stigma and unfair treatment of those affected and infected by HIV/AIDS. Schools and communities play an important role in the raising of children, in educating them, and in instilling positive values and morals. When these very systems fail to adequately meet the needs of children, a major gap becomes evident in the development and growing up of children.

This gap is often illustrated in child delinquency, school drop-out, substance abuse but to name a few. Serious attention needs to be paid to such findings as they inform how future work with vulnerable children can be handled, and ways in which improvements can be made with current interventions.



## Chapter 6

### Reflections on the study

#### 6.1 Reflections on the study

The exploration of adolescents' experiences of parental Aids-related illness and bereavement is a study that aimed to capture and understand the adolescent experiences. This study hoped to advance an understanding of the grieving processes of adolescents by considering the accounts of the feelings of adolescents who have been affected by HIV/AIDS through parental death and at times, multiple losses. Thus the study examined adolescent's responses to death and loss and how they make meaning out of and cope with life's stressful events. The purpose was to inform suitable interventions that could address adolescents' social and emotional difficulties following parental loss. Bauman and Germann (2005) argue that despite the urgency of children's needs, society and government have failed to adequately acknowledge children's anxieties, fear, mistrust, anger and guilt, and the impact of AIDS-related stigma that saturates their lives. As a result of this failure, children suffer in silence, not having guidance from a caregiver or parent. Bauman and Germann (2005) say that if we listen to the voices of children, we will learn about their emotional, psychological, developmental, and behavioural needs.

Wood *et al.* (2006) argue that understandings of bereavement and grief among African children, particularly, remains under-developed. This highlighted a limitation of previous research within this field, and as a result served as a strong rationale for this study. Thus, this study aimed to pay attention to African children, adolescents in particular, who have been made both orphaned and made vulnerable by the affects of the HIV/AIDS pandemic and other life adversities such as poverty.

Through this study, various perspectives, some of which are already traversed in the existing literature, came to the fore. By listening to the voices of these children, this study hoped to expand on the literature and help inform interventions with vulnerable children. Furthermore, it was important to focus on adolescents who face key developmental tasks, which may be particularly challenging for orphans (Ruland *et al.*, 2005). In addition, Ruland *et al.* (2005) argue that young people who have lost one or both parents have

multifaceted needs, particularly in the era of AIDS, and that adolescents' needs may differ from those of younger children because of their physical and psychological development during puberty and the steps needed to move towards independence and adulthood.

Interventions need to cater for the broader needs of adolescents, such that they move into adulthood with a strong sense of security, lead healthy and goal-directed lives, have a longer life span, and be able to produce the next generation. Failing to do this will in future result in a generation hindered by the impact of the AIDS epidemic, where more children are orphaned and rendered homeless.

## **6.2. Limitations of the study**

As the topic of the study was sensitive in nature and involving children, the sample selection proved to be a challenge. The study required children who were orphaned, having lost one or both parents due to an AIDS-related illness. Taking into account the high levels of stigma associated with HIV/AIDS, many of the children did not disclose their parent's cause of death, although it could be presumed that most of the deaths were AIDS-related due to the demographics and the NGO involvement. Therefore, finding this specific sample initially proved to be a challenge. However, working through the NGO which specifically works with vulnerable children infected and affected by HIV/AIDS, purposive sampling was possible.

The size of the sample group may be a limitation, as this size does not allow for the results to be generalised to the greater population. However, due to the sensitive nature of the topic, it was important that the group remained small as a means of creating intimacy and a safe space for the participants. There was also a fear that confidentiality may be compromised if a larger sample had been used. Furthermore, the aim of this research was not to focus on quantity, but rather to capture in-depth experiences of adolescents.

The sensitive nature of the research meant that certain factors had the potential to increase vulnerability of the children such as: the discussions in the focus group required children to recall memories of parents who had passed away, evoking emotion and feelings, giving their views and input as to how they have been impacted by the death of their parents and so forth. In light of this, the researcher herself had to be sensitive and demonstrate an empathic understanding for the children. As the researcher was not solely a researcher, but

also an intern counselling psychologist, she incorporated some of her therapeutic skills into the process of the group discussions. In the context of working with these children, and considering their vulnerability, the researcher found it useful to incorporate some of her therapeutic skills in the process of data collection, as containment and comfort were necessary during the focus group discussions and more generally during the camp.

Reflexivity within this research needs to be reviewed as it played a significant role in the research process. Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process, and an acknowledgement of the impossibility of remaining 'outside of' one's subject matter, while conducting research (Willig, 2001). In light of this, reflexivity thus urges us to explore ways in which a researcher's involvement with a particular study influences, acts upon and informs such research (Gibson & Swartz, 2004). The researcher has an interest and passion for working with children. She has been involved in previous research and community projects that entailed working with children, particularly in relation to the psychosocial issues surrounding the HIV/AIDS epidemic and its direct impact on the younger generation. Her interest in the field of child development, and especially the impact caused by HIV/AIDS on children, has influenced and motivated this study. Therefore personal reflexivity has been a driving force informing this work.

Epistemological reflexivity has also been evident in the research study. Willig (2001) argues that epistemological reflexivity encourages us to reflect upon the assumptions about the world and about the knowledge that we have created in the course of the research, and the implications of such assumptions for the findings. As the researcher, I raise several questions in relation to this study: How has the research question defined and limited what can be found?; How has the design of the study and the method of analysis constructed the data and the findings?; How could the research question have been investigated differently?; To what extent would this have given rise to a different understanding of the phenomena under investigation?

Exploring adolescent orphans experiences of parental AIDS-related illness and bereavement, defined as well as limited what could be found in this research. The nature of this research question firstly required that the orphaned children had experienced a parental AIDS-related illness. Thus the sample was defined by certain demographics including the

cause of death of the parent/s. In addition, the research topic assumed that all children were informed and aware of the cause of their parents' death. Following this assumption was the notion that the children would be comfortable enough to openly disclose this information. However, no child disclosed their parent/s as having died due to an AIDS-related illness. Although some of this information was obtained from the NGO and the guardians of the children, it did not come directly from the children. This then raised the question of whether the children were aware of the cause of their parent's death, but chose not to disclose (for various reasons, such as the stigma associated with HIV/AIDS), or were these children simply uninformed? Thus, although the study was able to capture the experiences of the children in relation to parental death, it was limited in eliciting the children's feeling in relation to an AIDS-related death.

The research question could have been investigated differently, by first conducting individual interviews with the guardians of the orphaned children. This may have assisted in getting more in-depth information about the demographics of the family, the cause of death of the deceased, as well as what and how much children knew and understood about their parents' cause of death.

The aim of this study was to obtain an understanding of children's experiences of parental AIDS related death, in the hopes of learning about their emotional, psychological, developmental and behavioural needs. As a means of obtaining this information, qualitative methodological approaches were selected as most suitable. The semi-structured interviews and focus group discussion administered to the adolescent participants was chosen so as to involve the children in discussions in a group format, in the hopes that children would not feel isolated, but rather feel part of a group which shared similar experiences. Upon reflection, the focus group, while serving the basic research purpose, may have hindered the process of the children fully opening up about their experiences of parental loss. Perhaps a more in-depth, rapport building one-on-one with each child would have elicited more narrative.

Upon reflecting on the interpretation of the data, the researcher's own value system and subjectivity may have influenced the way in which she interpreted the data. Therefore being aware of one's personal frameworks was an important procedure.

### 6.3 Implications for further study

The HIV/AIDS epidemic has had an enormous impact on our nation and society at large. Research has indicated the detrimental effects the impact of HIV/AIDS has on children, rendering them vulnerable in many ways (Foster *et al.*, 2005). The vast increase of orphaned children as a result of HIV/AIDS, has forced government and members of civil society to actively become involved in research and interventions that will address the psychosocial needs of vulnerable children. This study has aimed to shed more light on the lives of orphaned adolescents, in the hopes to have a better understanding of their experiences.

The psychological and emotional impacts on children experiencing parental AIDS-related illness and loss, has received little research attention and thus remains under-developed (Wood *et al.*, 2006). Further studies are required that pay particular attention to African children (Whiteside & Sunter, 2000).

This study has identified several gaps which serve as implication for further studies. More in-depth and one-on-one interviews with the children could have helped elicit more information and a richer understanding of the children's experiences. Secondly, future research could involve the caregivers of the children, in order to have a better understanding of the context in which the children reside. Furthermore, the involvement of the caregivers could provide more information on the nature of the family structure, how the primary caregivers died, what and how the children understand about the death of their parents, and subsequently how they have been impacted by the death. Through this, more lucrative data could be obtained thus providing a fuller and richer picture of children's experiences of parental loss and bereavement.

On a more personal level, the researcher felt she could have learnt more by spending a longer period of time with the adolescents involved in the study. This could have allowed her and the children to become more familiar with one another, and in return may have given her the opportunity to hear and to learn more about the children's experiences. Thus future research could tap into more longitudinal studies, observing and working with the children for a longer period of time.

As the issue of stigma and secrecy was prevalent in the focus group with the children, future research could explore several interventions such as programmes which could target the secrecy, stigma and misinformation regarding HIV-related illness and death. Such programmes could include workshops with children affected by HIV/AIDS, whereby children unpack some of their own existing realities in relation to stigma and secrecy surrounding HIV/AIDS, and what they consider to be solutions to such issues. Through engaging the children in the problem-solving, perhaps we could begin to make a shift in the youth's attitudes and understanding of HIV/AIDS.

This research has shown that children are very much affected by the loss of their parents, and more research needs to be conducted as a means of learning directly from the children affected. Child research comes with various complexities, and especially so when considering the vulnerability of children affected by HIV/AIDS. Therefore child research needs to be conducted with caution, taking into account the circumstances of the children, so that informed interventions cater correctly for the needs of those children. It was evident in this study, that children have a strong voice, one which cannot be ignored or taken lightly. The impact of HIV/AIDS and the impact of parental loss was strongly expressed and was evident throughout this research. This calls for more and continuous work in the field of HIV/AIDS in relation to its impact on children.

## Chapter 7

### Conclusion

The aim of this study was to explore adolescents' perceptions and experiences about death, how they have reacted (emotionally and otherwise) to the loss of a loved one, and the effects which an AIDS-related death has had on them. All of the participants in this study have experienced an AIDS-related parental death.

Richter *et al.* (2004) argue that the impact of HIV/AIDS on children, families and communities is influenced mainly by the legal and policy environment, access to basic services, socio-economic status, the social and cultural environment, and the extent of knowledge about and acceptance of the HIV/AIDS as a problem which affects everyone. Hunter and Williamson (2002) outlined the potential impacts of HIV/AIDS on children, families and communities. They identified that these potential impacts create a vicious cycle where one impact often creates and intensifies the next. Studies show that emotional distress in adolescence and adulthood-including depression, alcoholism, anxiety and suicidal tendencies- is often linked with bereavement suffered in childhood (Jewett, 1982).

Overall, the findings showed that the children were impacted by the loss of their parents. The findings highlighted some important feelings, expressions and opinions of the children in the study. The impact which parental loss has had on these children was evident as well as the external and internal changes experienced by the children following the death of their parents. The study also demonstrated the social realities and stigma of HIV/AIDS, and the impact which it has on communities.

These findings indicated that disclosure of HIV status and AIDS-related illness was still very difficult among communities. Furthermore, the fear of ostracism, discrimination and isolation was evident amongst the children. The finding of this research also indicated the support which orphaned children need after parental loss, both from surviving relatives as well as the communities in which they reside. Although this support was lacking within parts of the community, findings revealed that grandmothers played a significant role in being surrogate mothers to many of the children.

The qualitative research design, with a small number of participants, as well as the use of purposive sampling, limits generalisability of the study findings. However it can be argued that the sample size was chosen specifically as a means of creating intimacy and a safe space for the children involved, taking into account the sensitive nature of the research topic. Overall the study obtained its goal of exploring children's experiences of parental loss, and it is hoped that it will inform future research in the field of HIV/AIDS and its impact on children, particularly adolescents as well interventions offering psychosocial support.



## Reference list

- Ajdukovic, M. & Ajdukovic, D. (1998). Impact of displacement on the psychological well being of refugee children. *International Review of Psychiatry*, 10, 186-195.
- Babbie, E. & Mouton, J. (1998). *The practice of social research*. Oxford: Oxford Press.
- Bauman, L.J. & Germann, S. (2005). Psychosocial impact of the HIV/AIDS epidemic on children and youth. In G. Foster, C. Levine & J. Williamson (Eds.), *A generatin at risk: The global impact of HIV/AIDS on orphans and vulnerable children (pp 93-133)*. Cambridge: Cambridge University Press.
- Bowlby, J. (1969, 1973). *Attachment and loss*. Volumes I-II. New York: Basic Books.
- Boyatzis, R.E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, California: Sage.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brouard, P. (2006). *A closer look: The internalization of stigma related to HIV*. Retrieved November, 2008 from [www.usaid.gov](http://www.usaid.gov)
- Caelters, D. (2005). *HIV cases double in the Western Cape over last three years*. HIV/AIDS News, 131. Retrieved October, 2008, from [www.learnscapes.co.za](http://www.learnscapes.co.za)
- Campbell, C., Nair, Y. & Maimane, S. (2006). AIDS stigma, sexual moralities and the policing of women and youth in South Africa. *Feminist Review*, 83, 132-138.
- Campbell, C., Foulis, S., Maimane, S. & Sibiyi, Z. (2005). I have an evil child in my house: Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95, 808-815.

- Campbell, C., Nair, Y., Maimane, S. & Sibiya, Z. (2005). *Understanding and challenging HIV/AIDS stigma*. Durban: Centre for HIV/AIDS networking (HIVAN). Retrieved August, from <http://www.hivan.org.za/booklets/stigma.pdf>
- Capuzzi, D & Gross, D.R. (2003). *Counselling and psychotherapy: Theories and interventions*. New Jersey: Upper Saddle River.
- Cluver, L. & Gardner, F. (2007). Risk and protective factors for psychological well-being of children orphaned by AIDS in Cape Town: A qualitative study of children and caregivers' perspectives. *AIDS Care*, 19, 318-325.
- Cluver, L., Gardner, F. & Operario, D. (2007). Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry*, 48, 755-763.
- Dane, B.O. (2002). Bereavement groups for children: Families with HIV/AIDS. In N.B. Webb (Eds.), *Helping bereaved children: A handbook for practitioners* (pp. 265-296). New York: The Guilford Press.
- Demmer, C. (2007). Grief is a luxury: Aids-related loss among the poor in South Africa. *Illness, Crisis & Loss*, 15, 39-51.
- Dias, S.F., Matos, M.G. & Gonçalves (2006). AIDS-related stigma and attitudes towards AIDS-infected people among adolescents. *AIDS Care*, 18, 208-214.
- Dowdney, L. (2005). Children bereaved by parent or sibling death. *Psychiatry*, 4, 118-122.
- Ferrell, J.A. & Boyle, J.S. (1992). Bereavement experiences: caring for a partner with AIDS. *Journal of Community Health Nursing*, 9, 127-135.
- Foster, G. & Williamson, J. (2000). A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS 2000*, 14, S275-S284.
- Foster, G., Levine, C. & Williamson, J. (2005). *A generation at risk: The global impact of HIV/AIDS on orphans and vulnerable children*. Cambridge: Cambridge University Press.

- Fredriksson, J. & Kanabus, A. (2005). *AIDS orphans-The facts*. Retrieved June 7, 2006 from <http://www.avert.org/aidsorphans.htm>
- Gibson, K. & Swartz, L. (2004). Community psychology: Emotional processes in political subjects. In D. Hook. (Eds.), *Critical Psychology*. Cape Town: University of Cape Town Press.
- Goldman, L. (2001). *Breaking the silence: A guide to helping children with complicated grief-suicide, homicide, AIDS, violence and abuse*. USA: Taylor & Francis.
- Gregory, I. (2003) *Ethics in research*. London: Continuum.
- Grollman, E.A. (1995). *Bereaved children and teens: A support guide for parents and professionals*. USA: beacon Press Books.
- Hoepfl, M.C. (1997). Choosing qualitative research: a primer for technology education researchers. *Journal of Technology Education*, 9, 47-63.
- Hope, R.M. & Hodge, D.M. (2006). Factors affecting children's adjustment to the death of a parent: The social work professionals viewpoint. *Child and Adolescent Social Work Journal*, 23, 107-126.
- Hunter, S. & Williamson, J. (2002). *Children on the brink: Strategies to support children isolated by HIV/AIDS*. Washington, DC: USAID.
- Jewett, C.L. (1982). *Helping children cope with separation and loss*. Massachusetts: The Harvard Common Press.
- Joslin, D. & Harrison, R. (1998). The "hidden patient": Older relatives raising children orphaned by AIDS. *JAMWA*, 53, 65-72.
- Kelly, K. (2002). From encounter to text: Data-gathering in interpretive research. In M. Terre Blanche, K. Durrheim & D. Painter (Eds.), *Research in practice: Applied methods for the social sciences*. Cape Town: University of Cape Town Press.

- Killian, B.J. (2004). A Generation at risk? In R. Pharoah (ed.), *HIV/AIDS, Vulnerable children and security in Southern Africa* (pp33-64). Monograph No 109, Institute of Security Studies, December 2004.
- Kodish, E. (2006). The ethics of research with children. *Online ethics centre for engineering*. Retrieved October, 2008 from <http://www.onlineethics.org/CMS/research/modindex/childres.aspx>
- Kerlinger, F.N. (1986). *Foundations of behavioural research* (3<sup>rd</sup> ed). New York: Holt Rinehart & Winston.
- Krueger, R.A. (1994). *Focus groups: A practical guide for applied research*. Thousand Oaks: Sage.
- Krueger, J. (2006). Children, community, and HIV/AIDS in South Africa. *Children, Youth and Environment, 12*, 199-222
- Kubler-Ross, E. (1969). *On death and dying*. London: Tavistoc Publications.
- Lewis, M. (1995). The special case of the uninfected child in the HIV-affected family. In S. Geballe, J. Gruendel & W. Andiman (Eds), *Forgotten children of the AIDS epidemic* (pp. 50-63). USA: Yale University Press.
- Memon, A & Bull, R. (1999). *Handbook of the psychology of interviewing*. England: John Wiley & Sons.
- Mallmann, S.A. (2002) *Building resilience in children affected by HIV/AIDS*. Namibia: Maskew-Miller Longman.
- Mawar, N., Sahay, S., Pandit, A. & Mahajan, U. (2005). The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma and discrimination and future needs. *Indian Journal of Medical Research, 122*, 471-484.

- McWhirter, J.J. (2004). *At risk youth: A comprehensive response for counsellors, teachers, psychologists, and human service professionals*. Canada: Thomson Learning.
- Melhem, N.M., Moritz, G., Walker, M., Shear, M. & Brent, D. (2007). Phenomenology and correlates of complicated grief in children and adolescence. *American Academy of Child and Adolescent Psychiatry*, 46, 493-499.
- Morgan, D.L. (1993). *Successful focus groups: Advancing the state of the art*. Newbury Park, CA: Sage.
- Morrison, K. (2006). *Breaking the cycle: Stigma, discrimination, internal stigma and HIV*. USAID. Retrieved November, 2008 from [www.usaid.gov](http://www.usaid.gov)
- Murphy, V. (2003). Mbeki stirs up AIDS controversy. BBC News Online. Retrieved June, 2008 from <http://news.bbc.co.uk/1/hi/world/africa/3143850.stm>
- Nagler, S.F., Adnopoz, J. & Forsyth, B.W.C. (1995). Psychological aspects of AIDS for children and adolescents. In S. Geballe, J. Gruendel & W. Andiman (Eds), *Forgotten children of the AIDS epidemic* (pp. 71-82). USA: Yale University Press.
- Nyamukapa, C.A., Gregson, S., Lopaman, B., Saito, S., Watts, H.J., Monasch, R. & Jukes, M.C.H. (2008). HIV-associated orphanhood and children's psychological distress: Theoretical framework tested with data from Zimbabwe. *American Journal of Public Health*, 98, 133-141.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods*. (2<sup>nd</sup> ed.). California: Sage publications.
- Paterson, G. (2005). *AIDS-related stigma: Thinking outside the box*. Retrieved August, 2008 from <http://www.norgeskristnerad.no/doc/stigma-small.pdf>
- Piot, P. (2000). Global AIDS epidemic: Time to turn the tide. *Science*, 288, 2176-2178.
- Poku, N.K. (2005). *AIDS in Africa: How the poor are dying*. Cambridge: Polity Press.

- Richter, L., Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town: HSRC Publishers.
- Richter, L., Manegold, J. & Pather, R. (2004). *Family and community interventions for children affected by AIDS*. Cape Town: HSRC Publishers.
- Robson, C. (1993). *Real world research: A resource for social scientist and practitioner researchers*. United Kingdom: Blackwell Publishers.
- Robson, S. & Sylvester, K.B. (2007). Orphaned and vulnerable children in Zambia: The impact of the HIV/AIDS epidemic on basic education for children at risk. *Educational Research*, 49, 259-272.
- Rogers, M.E., Hansen, N.B., Levy, B.R., Tate, D.C. & Sikkem, A. (2005). Optimism and coping with loss in bereaved HIV-infected men and woman. *Journal of Social and Clinical Psychology*, 24, 341-360.
- Rubin, H.J. & Rubin, I.S. (1995). *Qualitative interviewing: the art of hearing data*. Thousand Oaks: Sage.
- Ruland, C.D., Finger, W., Williamson, N., Tahir, S., Savariaud, S., Schweitzer, A. & Shears, K.H. (2005). *Adolescents: Orphaned and vulnerable in the time of HIV/AIDS*. Youth Issues Paper 6.
- Sadock, V.A. & Sadock, B.J. (1998). *Kaplan & Sadock's Synopsis of psychiatry* (8<sup>th</sup> Ed.). Philadelphia: Lippincott Williams & Wilkins.
- Schoepf, B.G. (2004) Aids, history and struggles over meaning. In E. Kalipeni, S. Craddock, J.R. Opong & J. Ghosh (Eds), *HIV and AIDS in Africa: Beyond epidemiology* (pp. 15-27). Oxford: Blackwell Publishers.
- Sigelman, C.K. & Rider, E.A. (2003). *Life-span human development*. USA: Wadsworth/Thomson

Learning.

- Simbayi, L.C., Kleintjes, S., Ngomane, T., Tabane, C.E.M., Mfecane, S. & Davids, A. (2006) *Psychosocial issues affecting orphaned and vulnerable children in two South African communities*. Cape Town: HSRC Press.
- Simeonsson, R.J. (1994). *Risk, resilience and prevention: Promoting the well-being of all children*. Baltimore: Paul H. Brooks.
- Smith, M.W. (1995). Ethics in focus groups; A few concerns. *Qualitative Health Research*, 5, 478-486.
- Strauss, A.L. & Corbin, J. (1990). *Basics of qualitative research*. California: Sage.
- Summers, J. (1998). Bereavement. *The Body: The Complete HIV/AIDS Resource*. Retrieved July, 2008 from <http://www.thebody.com/content/art14005.html>
- Terre Blanche, M & Durrheim, K. (2002). *Numbers, hypotheses and conclusions: A course in statistics for the social sciences*. Cape Town: Juta.
- Terre Blanche, M & Durrheim, K. & Kelly, K. (2006). First steps in qualitative data analysis. In M. Terre Blanche, K. Durrheim & D. Painter (Eds.), *Research in practice: Applied methods for the social sciences (pp 320 – 344)*. Cape Town: University of Cape Town Press.
- Turner, M. (1998). *Talking with children and young people about death and dying*. London: Jessica Kingsley Publishers.
- UNAIDS (2004). *Zimbabwe, 2004 update: epidemiological factsheets on HIV/AIDS and sexually transmitted infections*. Retrieved July, 2008 from [http://www.who.int/GlobalAtlas/PDFFactory/HIV/EFS\\_PDFs/EFS2004\\_ZW.pdf](http://www.who.int/GlobalAtlas/PDFFactory/HIV/EFS_PDFs/EFS2004_ZW.pdf)
- UNAIDS, UNICEF, & USAID (2004). *Children on the brink*. New York: UNICEF
- UNAIDS & WHO (2007). *AIDS epidemic update*. Retrieved June, 2008 from <http://www.unaids.org>

UNICEF (2003). *Children in distress: A best practice to children affected by HIV/AIDS*. Retrieved May 12, 2006 from <http://synkronweb.aidsalliance.org/graphics/OVC/documents/0000043e00.pdf>

UNICEF (2006). *Africa's orphaned and vulnerable generations: Children affected by AIDS*. Retrieved May, 2008 from <http://www.uniteforchildren.org/>

UNICEF & UNAIDS (1999). *Children orphaned by AIDS: Frontline responses from eastern and southern Africa*. New York: UNICEF.

United Nations Economic Commission for Africa. *The impact of HIV/AIDS on families and communities in Africa*. Retrieved November, 2008 from [http://www.uneca.org/CHGA/doc/impact\\_family.pdf](http://www.uneca.org/CHGA/doc/impact_family.pdf)

United Nations Convention on the Rights of a child (1989). General assembly of the United Nations: UNICEF.

Van der Riet, M., Hough, A. & Kilian, B. (2005). Mapping HIV/Aids as a barrier to education: A reflection on the methodological and ethical challenges to child participation. *Journal of Education, 35*, 75-98.

Van Niekerk. A. A. (2005). Moral and social complexities of AIDS in Africa. In A.A. van Niekerk & L.M. Kopleman (Eds.), *Ethics & AIDS in Africa: The challenge to our thinking* (pp. 53-69). Claremont: Davidphilip.

Wassenaar, D. (2006). Ethical issues in social science research. In M. Terre Blanche, K. Durrheim & D. Painter (Eds.), *Research in practice: Applied methods for the social science* (pp 60 – 79). Cape Town: University of Cape Town Press.

Webb, N.B. (2002). *Helping bereaved children: A handbook for practitioners*. New York: The Guildford Press.

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



Publishers Ltd.

WHO/UNICEF (1994). *Action for children affected by AIDS: programme profiles and lessons learned*. New York: WHO, Geneva & UNICEF.

Wild, L. (2001). The psychosocial adjustment of children orphaned by AIDS: A review. *Southern African Journal of Child and Adolescent Mental Health*, 13, 3-21.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.

Wood, K., Chase, E., & Aggleton, P. (2006). 'Telling the truth is the best thing': Teenage orphans' experience of parental AIDS-related illness and bereavement in Zimbabwe. *Social Science & Medicine*, 63, 1923-1933.

Zhao, G., Li, X., Fang, X., Zhao, J., Yang, H. & Stanton, B. (2007). Care arrangements, grief and psychological problems among children orphaned by AIDS in China. *AIDS Care*, 19, 1075-1082.

## **APPENDIX: A**

### **Biographical Interview Schedule**

I would like you to know that the purpose of this research is to explore adolescent orphans' experiences of parental death, bereavement and issues surrounding the nature of HIV/AIDS and its impact on adolescents. In the focus groups, we shall have discussions surrounding this topic, where you and the other learners can share your experiences and feelings. You should not, at any point feel obligated to say anything which you do not feel comfortable to. However, your contribution to the discussions will be very helpful towards the research. Today, I will be asking you several questions, also centered around parental death as part of the research process. If you are feeling uncomfortable about any of the questions, please do tell me and we shall stop. If there is anything you would like to ask me concerning the nature of the research process, please do so. As it was mentioned before, in the assent letter, all information will remain confidential, this includes what you and I talk about here today. If at any point you wish to withdraw as a participant of this research, you may do so.

#### **Personal details**

Name:

Surname:

Date of Birth:

Age:

Gender:

Place of Residence:

Contact details:

Next of kin (name):

Next of kin contact details:

#### **Academic details**

Name of School:

Grade:

Educator's name:

#### **Other questions**

##### **About yourself**

1. What are your hobbies?
2. What are your likes and dislikes?
3. What do you enjoy the most or least about school?
4. How many friends do you have?
5. What activities do you engage in when you are with your friends?

### **About your family**

1. How many members do you have in your family?
2. Who are the family members that you live with at the moment?

### **Research Project**

The topic that will be discussed in this research project is adolescents' experiences of AIDS related parental illness and bereavement. You will be asked to participate in focus group discussions on the topic and any information that you reveal will be kept confidential. The focus group discussions will be recorded on audio-tapes and these audio-tapes will be stored in a locked cabinet to ensure confidentiality. The duration of each focus group will be one to one and a half hour.

### **Questions:**

1. Would you like to know what the purpose of this research is?
2. Do you have an understanding of what 'stigma' refers to?
3. Do you understand what it means to participate in a focus group discussion and keep information confidential?
4. Do you feel comfortable about discussing the topic and your views being recorded on audio-tapes as you speak?
5. Do you have questions about the entire research process?

Having heard about the research purpose and process, would you like to participate in the study?

Please tick the one that is relevant to you?

Yes

No

Signature:.....

Date:.....

Researcher's signature:.....

Date:.....

Supervisor's signature:.....

Date:.....

## **APPENDIX: A**

### **Iminingwane ngawe**

#### **Mayelana Nawe**

Igama:

Isibongo:

Usuku lokuzalwa:

Ubulili

Indawo ohlala kuyo:

Inamba yocingo:

Umzali/Umnakekeli:

#### **Mayelana nemfundo**

Igama lesikole sakho:

Ikilasi ofunda kulo:

Igama likathisha:

#### **Eminye imibuzo**

##### **Mayelana nawe**

1. Yiziphi izinto othanda ukuzenza?
2. Yiziphi izinto ozithandayo nongazithandi?
3. Yini oyithanda kakhulu okanye kancane ngesikole?
4. Unabangani abangaki?
5. Yiziphi izinto ozenza uma unabangani bakho?

##### **Ngomndeni wakho**

1. Bangaki abantu abasemndenini wakho?
2. Obani abantu bomndeni ohlala nabo manje?

#### **Iminingwane ngocwaningo**

Ucwaningo luzobe lungezinqinamba intsha edlula kuzo mayelana nokugula nokushonelwa ngenxa yengculaza. Uzocelwa ukuba ubambe iqhaza ezingxoxweni ezine mayelana nokugula nokushonelwa abazali ngenxa yengculaza. Yonke into oyishoyo izogcinwa iyimfihlo. Izingxoxo zizogcinwa emakhasethini omsakazo. Lamakhasethi

azogcinwa ekhabetheni eliyimfihlo. Ingxoxo iyodwa izothatha ihora kuya kuma hora amabili.

**Imibuzo**

1. Uyathanda ukwazi ukuthi yini indaba ngenze lolucwaningo?
2. Uyazi ukuthi ‘ukushonelwa’ lusho ukuthini?
3. Uyazi ukuthi kusho ukuthini ukuba sengxoxweni yocwaningo nabanye abafundi?
4. Uzizwa ukhululekile ngokukhuluma ngokushonelwa mayelana nengculazi, nengxoxo ifakwa kumakhasethi omsakazo?
5. Unayo imibuzo ngocwaningo lonke?

Usuzwile ngenqubeko nangenhloso yocwaningo. Ungathanda ukuthatha iqhaza kuyona?

**Gcwalisa lapho kufanele wena**

Yebo

Cha

Sayina lapha.....

Usuku.....

Umcwaningi usayina lapha.....

Usuku.....

Umpathi usayina lapha.....

Usuku.....

## **APPENDIX: B**

### **Focus Group Questions**

#### **Exploring adolescents understanding of death and issues surrounding HIV/AIDS**

- How do you, as an adolescent, understand death?
- What are your feelings and your understanding of HIV/AIDS?
- What is your personal experience and perceptions of HIV/AIDS?
- What is your understanding of the nature of AIDS-related death?
- Do you think the experience of death is different when it is caused by HIV/AIDS?
- If so, how?
- How has your concept of death influenced the way in which you have experienced death in your family or community?
- What does it mean to you to have lost a parent/caregiver due to HIV/AIDS?
- What are the feelings associated with these deaths in the immediate, short term, and the long term adjustment periods?

#### **Exploring the external difficulties caused by parental death**

- What internal and emotional difficulties have you faced due to the death of your parent?
- What external difficulties have you faced due to the death of your parent?
- In what ways has death affected those around you?
- What have been the changes within the family structures after the death of your parent?
- Who has taken on the parental role since the death of your parent/s?
- Have you experienced any form of discrimination from family, community members, or school peers about the AIDS-related death in your family? If so, in what way?
- If you have experienced any form of discrimination, what kinds of feelings has the discrimination brought upon?
- What have you found particularly difficult since the loss of your parent/s?

#### **Exploring the social difficulties**

- What social difficulties have you faced since your parent passed away?
- Do you have someone with whom you have shared your grief?
- In what ways has that support system helped you?
- What kind of support do you think you want and need?
- What kind of help and support have you found helpful/not helpful?
- In what ways has the immediate family supported you in time of grief?

- In what ways have members of the community supported you in time of grief?
- How have your peers reacted to the death of your parent/s?



## APPENDIX: C



Child and Family Centre  
School of Psychology  
Private Bag X01  
Scottsville  
Pietermaritzburg  
3209  
Phone: +27 33 2065166  
Fax: +27 33 2605809

Dear Learner

I am a Counselling Masters Psychology student at the University of KwaZulu-Natal and am conducting research on adolescents' experiences of AIDS-related parental illness and bereavement. I will be conducting the study because findings have the potential to help already existing psychosocial interventions for vulnerable children, in that new information, perspectives and ideas could be obtained from the adolescents.

The research will be conducted whereby learners will be selected to participate in the study from your class list because we cannot include all learners in the study. Your name has been chosen and I would like to tell you about the research process, so that you can decide whether or not you want to participate.

I would like you to take part in an individual interview to begin with, when biographical information can be obtained, and this will provide me with the opportunity to get to know you. Following this, you will be asked to participate in a focus group discussions with other learners about your experiences of the issues that I am interested in researching. The group will last approximately one and a half to two hours.

It is very important for you to know that what you say in the interviews and the focus group will be kept confidential. This means that if you tell me something, no one else will know what it is that YOU told. If there are things which other learners in the group talk about, which you find upsetting, there will be an intern psychologist from the university who will be able to assist you. We will not tell your parents or teachers about the things you talk about within the groups.

It is also important that when you hear things in these groups, you must not go and tell other people who were not part of the group. This means that you are keeping the group discussion confidential and this helps all the learners in the group to feel free to openly discuss their true feelings within the group.

I would also like to record exactly what you say in the focus group. So I will be using tape

recorders and these will be kept very safe and will not be played to anyone outside of the research team.

Even if you agree to be in the process, you may also withdraw at any time if you do not want to be part of it anymore. If you have understood all of these things and want to be part of this research project, please read and sign the next sheet which is the consent form.

Yours sincerely

Unati Mbetse  
Supervisor: Bev Killian (PhD)

**Child Assent form**

I (Please write in your full name)..... in

Grade:.....

Please tick the one that is applicable to you

- Agree
- Disagree

To participate in the research process on adolescents' experiences of AIDS-related parental illness and bereavement.

Signature (of child): .....

Signature (of researcher): .....

Signatures (of supervisor): .....

Date:.....

## APPENDIX: D

**Child and Family Centre**  
School of Psychology  
P/Bag X01 Scottsville  
PIETERMARITZBURG, 3209  
South Africa  
Phone: +27 33 2605166  
Fax: +27 33 2605809



Dear Parent/Guardian

I am a master's counselling psychology student at the University of KwaZulu Natal and am conducting research on adolescents' experiences of AIDS-related parental illness and bereavement. I believe there may be various factors which have an impact on children's understanding of death, as well as their experience of a multiple loss and bereavement. Through this research study, I would like to try to understand adolescent's understanding of such issues, as a means of extending the current literature based on adolescents' conceptions of bereavement. Furthermore, this study has the potential to help already existing psychosocial interventions for vulnerable children, in that new information, perspectives and ideas could be obtained from the adolescents.

I would like the adolescents to participate in group discussions about their experiences of parental death, bereavement and issues surrounding the nature of HIV/AIDS and its impact on adolescents.

All information will be kept confidential. Your child will have the right to withdraw from the study at any time if s/he so wishes. Should any articles be published from this research, anonymity of the child will be maintained by not using any identifying information. In the event that your child finds the discussions distressing in any manner, I, as an intern psychologist will be available to comfort and debrief the child.

I am asking for your permission for him/her to take part. With this in mind, I ask that you give me, as the researcher, permission for your child to participate by signing and returning the attached form to the school as soon as possible. I will also be asking your child individually if they would be willing to take part in this research, but your permission is required as the first step.

Yours sincerely

Unati Mbetse

## PERSMISSION LETTER

I (parent/caregiver) \_\_\_\_\_ give permission for my child (child's name) \_\_\_\_\_ to participate in the research study on adolescents' experiences of AIDS-related parental illness and bereavement.

Child's age: \_\_\_\_\_

Child's gender \_\_\_\_\_

Home address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Contact number/ cellular phone: \_\_\_\_\_

Has there been a death in the family? \_\_\_\_\_

If so, whom? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What was the date and cause of death? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX: D

### Incwadi yemvumo yomzali nefomu



Child and Family Centre  
School of Psychology  
P/Bag X01 Scottsville  
PIETERMARITZBURG, 3209  
South Africa  
Phone: +27 33 2605166  
Fax: +27 33 2605809

Mzali/Mnakekeli womntwana

Ngingumfundi we Psychology wase Nyuvesi yakwaZulu-Natal. Ngenza ucwaningo ngemizwa ngezingqinamba intsha edlula kuzo mayelana nokugula nokushonelwa abazali ngenxa yengculaza. Ngizokwenza loluncwaningo ngoba uvo engiluthola kubantu abasha lungasiza ukuthi ngikhulise ucwaningo olumayelana nalezi zinto okuzoxoxwa ngazo ngoba abantu abasha bazoba novo olusha.

Ngiyacela ukuba abantwana babambe iqhaza kwimibuzo engabo, ukuze ngikwazi ukuthi ngibazi, ngazi nangezimpilo zabo. Emva kwalokho ngizocela umntwana wakho nabanye abafundi ukuba babambe iqhaza ezingxoxweni ezingovo lwabo mayelana nokucwasa okuqondene nengculazi kanye nokucwasa okuqondene nokushonelwa abazali.

Kusemqoka ukuthi wazi ukuthi yonke into eshiwo umntwana wakho izogcinwa iyimfihlo. Umtwana wakho futhi uzovumeleka ukuthi ayeke ukubamba iqhaza ocwaningweni uma engasathandi. Uma kwenzeka lolucwaningo luphuma emaphepheni, amagama abafundi, azogcinwa eyimfihlo. Uma umntwana wakho ephatheka kabi ngezinto ezishiwo ezingxoxweni, uzobakhona umuntu oqeqeshelwa ukuba udokotela wengqodo.

Bendicela ukuthi unginike imvumo ukuba umntwana abambe iqhaza ocwaningweni. Futhi, bengicela ukuthi usayine uphinde ubuyise ifomu elisekhasini elilandelayo elishoyo ukuthi uzobamba iqhaza umntwana wakho noma qha. Ngizocela nomntwana wakho ukuthi anginike imvumo ukuba abambe iqhaza kulolucwaningo, kodwa okokuqala besicela imvumo yakho.

Ozithobayo  
Unati Mbetse  
Bev Killian (Umphathi)

## **Incwadi yemvumo yomzali**

Mina (Mzali/Mnakekeli womtwana).....ngiyavuma ukuba  
umtwana wami abambe iqhaza kulolucwaningo ngokucwasa okuqondene nengculazi  
nokucwasa okuqondene nobuphofu.

Iminyaka yomntwana:.....

Ubulili.....

Ikheli lasekhaya.....

Inombolo yocingo.....

Umzali/umnakekeli usayina lapha.....

Usuku.....

Abacwaningi basayina lapha.....

Usuku.....

Umpathi usayina lapha.....

Usuku.....

**Appendix E**  
**Ethical clearance form**



RESEARCH OFFICE (GOVAN MBEKI CENTRE)  
WESTVILLE CAMPUS  
TELEPHONE NO.: 031 – 2603587  
EMAIL : [ximbap@ukzn.ac.za](mailto:ximbap@ukzn.ac.za)

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25 MAY 2007

MS. UB MBETE (206516823)  
PSYCHOLOGY


Dear Ms. Mbete

**ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0257/07M**

I wish to confirm that ethical clearance has been granted for the following project:

“An exploration of adolescent orphans’ experience of parental AIDS-related and bereavement”

Yours faithfully

  
.....  
MS. PHUMELELE XIMBA  
RESEARCH OFFICE

cc. Post-Graduate Office (Beulah Jacobsen)  
cc. Supervisor (Dr. B Killian)



**APPENDIX: F**  
**Procedures of the research**

Hello to all of you,

Thank you all for agreeing to participate in this research. Before we formally begin I would like to go over the procedures once again, in order to make sure that we all understand and are clear of what is expected of us. The purpose of this research is to explore adolescent orphans' experiences of parental death, bereavement and issues surrounding the nature of HIV/AIDS and its impact on adolescents. In the focus groups, we shall have discussions surrounding this topic, where you can share your experiences and feelings. You should not, at any point feel obligated to say anything which you do not feel comfortable to. However, your contribution to the discussions will be very helpful towards the research. Today, I will be asking you several questions, also centered around parental death as part of the research process. If you are feeling uncomfortable about any of the questions, please do tell me and we shall stop. If there is anything you would like to ask me concerning the nature of the research process, please do so. As it was mentioned before, in the assent letter, all information will remain confidential, this includes what you and I talk about here today. If at any point you wish to withdraw as a participant of this research, you may do so.

The discussions will be recorded with an audio recorder in order to capture all the information. The audio equipment looks like this (show them the equipment), and will be placed in the middle of the group so as to capture everyone's voices. You do not have to worry yourself about this equipment, as it does not make any noise, or require anyone to operate it during the discussion. The recorded information today, will then be used to write a study. This study hopes to inform interventions which are in aid of vulnerable and orphaned children. It is also to help those of us who work with vulnerable children, to better understand children and their perspectives, feelings and experiences.

I would like for us to listen to one another when we speak, as each of us is important and what we have to say is equally important. Is there anyone who would like to ask me any questions before we begin? If, before during and after the sessions anyone has any queries about the discussions, please do not hesitate to ask me.