

**An exploration of the experience of a Memory Box Programme
by children affected by
HIV and AIDS.**

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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 (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/have not approved this thesis/dissertation for submission.

Signed:

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Abstract

The purpose of this research was to highlight the benefits of a Memory Box Programme on the social and emotional developmental functioning of orphaned children. The study focused on the memory box approach used by Sinomlando Centre with orphaned children. The Sinomlando Memory Box Programme has been in existence since 2000. The overall objective of this Memory Box Programme is to enhance resilience in vulnerable children and orphans affected by HIV and AIDS through the methodology of memory boxes

In contributing to the discourse on memory work, an interpretive method of data collection and analysis in the form of a focus group discussion and thematic analysis was utilized in this study. Three focus groups were conducted with 26 orphaned children between the ages of 12 years to 15 years. Sampling of the children was based on a purposive sample, targeting children orphaned by AIDS who attended a 5-day camp conducted through a local NGO.

The results of the study indicate that children who attended the Sinomlando Memory Box Programme had benefited from their involvement in the programme in diverse ways. They felt that being involved in a Memory Box Programme equipped them with better coping mechanisms and skills. These included the appropriate expression of feelings, the ability to talk about their parent's death, and overcoming their sense of alienation so they could better cope with their difficult circumstances.

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Chapter 1: Introduction

No amount of words or literature can fully describe the torment children grieving for dying or dead parents go through. The AIDS epidemic puts children at risk physically, economically, socially and emotionally (UNICEF, 2006). Children find themselves stigmatized or ostracised if their parent's death is associated with AIDS. It does not stop with stigmatisation; most plunge into poverty and insecurity caused or exacerbated by their parent's death (Stein, 2003). Some children, whether directly or indirectly affected, struggle to obtain essential services like health care and education.

Millions of children have been orphaned or made vulnerable by HIV and AIDS. Globally, the most affected region is sub-Saharan Africa, where an estimated 12 million children have been affected (UNICEF, 2006). Results from a population survey done in South Africa in 2002 revealed that 3% of 2 - 14 year olds had lost a mother, and 8,4% had lost a father (Shisana & Simbayi, 2002). This orphan population will increase in the next decade as HIV-positive parents become ill and die from AIDS (UNAIDS, UNICEF & USAID, 2004).

According to Rusakaniko, Chingono, Mahati, Mupambireyi and Chandiwana (2006), 11 countries in sub-Saharan Africa, including all 9 countries in southern Africa, will have 20-37% of children under the age of 15 years orphaned by 2010. The projections are worse for Botswana (37%), Swaziland (32%), Namibia (32%), Zimbabwe (34%) and Central African Republic (31%). UNICEF (2006) estimated that, at the end of 2005, at least 48.3 million children in sub-Saharan Africa were orphans. The number of orphans in sub-Saharan Africa is set to increase to over 50 million by year 2010 (see Figure 1). This calls for greater attention to the orphan situation in this part of the world. Such trends need to be taken into consideration when organisations do their intervention programming and planning.

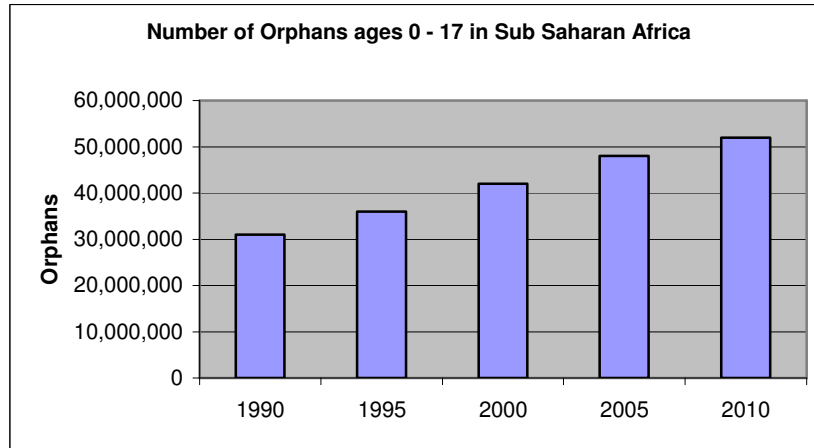


Figure 1: UNICEF (2006) estimates for number of orphans aged up to 17 years

The numbers of children infected with the HIV and AIDS virus has continued to increase. At the same time, the number of children born to HIV infected mothers increases, as the baby may contract the virus during pregnancy and birth. Others are infected through child sexual abuse or exploitation, with some even becoming infected through human-to-human blood contact. This ever-escalating rate of HIV infections may impact children in a number of ways. While studies of the long-term psychosocial effects of paediatric HIV and AIDS are scarce, studies of the affects of terminal and chronic illnesses in children indicate that they tend to impact many areas of a child’s life, including school, family, and social life. From an emotional perspective, Fischer (1999) notes that adjustment problems associated with terminal and chronic illnesses in children include increased risk for depressive symptoms, behavioural problems, academic difficulties, and feelings of isolation and withdrawal.

A large number of children have been, and continue to be, made vulnerable due to the impact of the AIDS pandemic, although they are not all orphans (Rusakaniko *et al.*, 2006). This includes children living with sick parents, children who are in precarious care as a result of being dependent on old, frail or disabled care-givers, and children in households that assume additional dependents by taking on orphaned children (Killian, 2004a).

The risks associated with being a child and/or youth multiply exponentially in communities with high rates of HIV and AIDS. A child in these circumstances faces a two to three times higher risk of dying before age of 1 due to mother-to-child transmission of HIV, and the risk of dying before age 5 has increased even more (Hunter, 2000). Because of HIV and AIDS, a child in a heavily infected country is much more likely to contract tuberculosis or another infectious disease, and is several times more likely to suffer the trauma of nursing a dying parent or guardian (Hunter, 2000).

HIV and AIDS has emerged as the greatest immediate threat to children and women in sub Saharan Africa (Annan, 2001). Women, children and the elderly are most vulnerable. In 2000, 12-13 African women are infected for every 10 African men (Umerah-Udezulu, 2001). According to UNICEF (2006), women tend to become infected far younger than men for both biological and cultural reasons: girls aged between 15-24 years are 3 times more likely to be infected with HIV than boys in the same age range. Moreover, the vulnerability of girls is exacerbated by denial and neglect of their rights, and gender-based forms of discrimination and violence (Smart, 2003).

Children infected or affected by HIV and AIDS face a number of stressors in their daily lives. These include loss of caregivers and loved ones, school dropout, being burdened with responsibilities which are beyond the maturity level, increased poverty, stigma, discrimination and social isolation, and loss of family assets (Killian, 2004b). Each of these negatively impacts the child's social and emotional development. Faced with insurmountable challenges, orphans and other children affected by HIV and AIDS are frequently marginalized and may quickly become the most vulnerable members of society. The following are some of the risks or challenges faced by orphans and other vulnerable children:

- During 2002, in rural Zimbabwe, households with orphans earned on average 31 per cent less than households not affected by HIV and AIDS.

- In the United Republic of Tanzania, the school attendance rate for children living with at least one parent is 71 per cent; for children who have lost both parents, it is only 52 per cent.
- In that same country, over half the children working full time in mining are orphans.
- In Addis Ababa, Ethiopia, more than 75% of child domestic workers are orphans.
- In parts of Zambia, 65 per cent of children engaged in commercial sex and 56 per cent of children living on the streets are orphans (Gulaid, 2004).

Although they are faced with these challenges, some orphans find solace in their extended families. African societies are proud of their rich and tight kinship system which has to this end been the first line of response to the epidemic. The deep-rooted kinship systems that exist in Africa are an age-old social safety net for such children. The kinship structure has long proved resilient even to some major social changes. Such kinship systems are becoming stressed as a result of a dramatic increase in the number of maternal and double orphans (Foster, 2004). Without AIDS, the total number of double orphans in sub-Saharan Africa would have declined between 1990 and 2010 (UNICEF, 2006). This number of double orphans in the region will increase to more than 10 million by 2010 due to AIDS (see Figure 2).

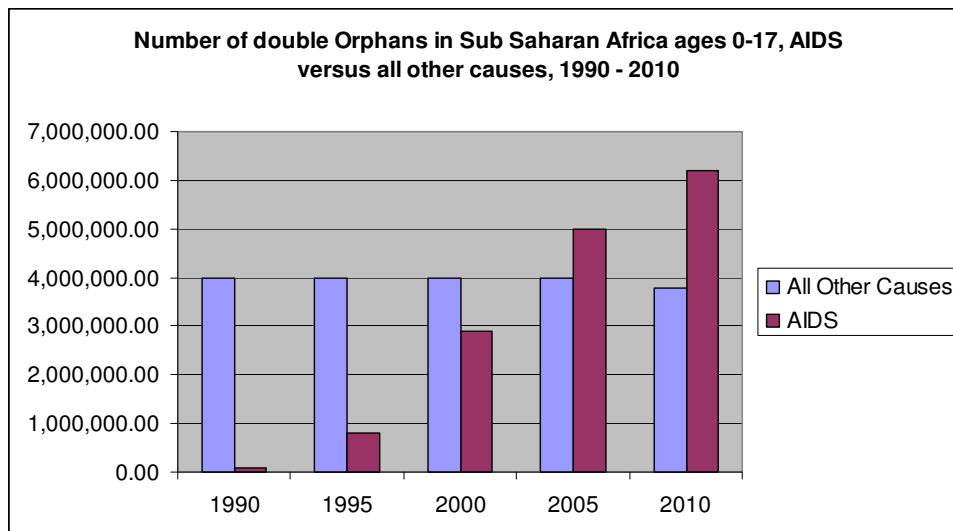


Figure 2: The estimated number of orphans in sub-Saharan Africa over the two last decades, (UNICEF, 2006)

With increased pressure on the kinship system due to the increase in the number of double orphans, thousands of community-based programmes have been implemented. These programmes are aimed at protecting the rights and ensuring the well-being of orphans. However, many of these responses are reactive in nature and regard children as ‘helpless victims’, providing only immediate and limited support, such as handouts of food and clothing (Gulaid, 2004). According to Williamson (2000), some of these programmes lack theoretical grounding which, in turn, limits their benefits.

Although the number of orphans is staggering, the social and emotional effects are only just beginning to be a focal area of research and evaluation. There has been limited attention given by empirical social science researchers to children’s experiences of parental illness, and death in general (Lewis, Hammond, & Woods, 1993), let alone with regard to HIV and AIDS more specifically. Altschuler (1997) points out that the belief that childhood should be a safe haven perhaps makes adults and social researchers unwilling to recognize the pain and confusion in children.

One set of programmes, which are fairly well rooted within a theoretical framework, is the memory focused programme. These programmes, within the context of a secure and containing relationship, enable children to recall memories about their parents and then develop a place in which to keep these memories so that the child can refer to their memory box whenever they feel the need arise. Memory work has close relations with narrative therapy. Narrative therapy is an approach to counselling and community work that centres people as the experts in their own lives and views problems as separate from people.

The proposed research intends to address this anomaly (attention given to social science researcher on children's experiences of parental illness, and death in general), with specific emphasis on the benefit of Memory Box Programme on the social and emotional development of children affected by HIV and AIDS. In its own regard, memory box (a memory work approach) has not received much attention from researchers.

1.1 Statement of the problem

The resources for effective development work in the context of a rapidly developing epidemic (HIV and AIDS) are very limited. However, in the face of an epidemic there is enormous pressure on learning what works best, how, and why. In light of this, those implementing memory work are eager to know the benefits of memory work on the social and emotional developmental functioning of children affected by HIV and AIDS.

Some research studies on memory work have been done. A pilot study to evaluate the impact of a specific memory box methodology on AIDS affected households was carried out jointly by Sinosizo Home-based Care Organization and the Sinomlando project (Denis, 2005). In another study, Vasquez (2004) highlighted the advantages of combining biomedical treatment with memory work. Nevertheless, these studies have not addressed the critical question of whether or not memory work has positive outcomes in the social and emotional development of children affected by HIV and AIDS. This need has prompted this study.

At a basic level, this study generated learning around the benefits of specific intervention. Such learning and evidence is generally recognized to be an essential component of any programme of development in health and social care. However, it is particularly important for a support programme to generate learning around the benefits of interventions for a number of reasons:

- Historically and globally, with few exceptions, what counts as an appropriate and effective intervention in response to HIV and AIDS has been the subject of controversy and a lack of consensus (African Development Forum, 2000). Those interventions that have been considered by staff at grass roots to be effective interventions, have frequently been the subject of much controversy, with a resultant lack of consensus over their monitoring and evaluation procedures.
- In countries where NGOs and CBOs have only recently developed, there is often a lack of documentation of the specific benefits and advantages of their approaches, as well as the factors that facilitate or inhibit their effectiveness.
- It has been difficult to identify valid and reliable indicators of psychosocial functioning, especially in terms of using these instruments as indicators of increased resilience in children.
- In addition, there is a dearth of reliable and valid psychometric instruments for use in the developing world, making almost all forms of positivist research rather unpredictable and hazardous in their application in the current context.

Despite the huge emphasis on children affected by HIV and AIDS, many authors have noted that the social and emotional development of orphans and other vulnerable children is seldom highlighted as a priority for research (Bray, 2003; Stein, 2003).

1.2 The purpose of the study

The purpose of the study is to:

- ❖ To explore children's benefit of memory work. Focusing on children in the age group twelve to fifteen years who are orphaned by AIDS.
- ❖ To contribute to the discourse around the social and emotional development of children orphaned by AIDS.

1.3 Research question

- ❖ What benefit does Memory Box Programme run by Sinomlando Centre have on the social and emotional developmental functioning of orphaned children?

The chapters which follow will look at:

- ❖ Psychosocial outcomes that occur for children affected by HIV and AIDS
- ❖ The description of memory work and resilience, and how memory work fosters resilience in children
- ❖ An overview of the Sinomlando Memory Box Programme
- ❖ The process of data collection through focus groups and the thematic analysis of the data
- ❖ Presentation of study results and discussion

Chapter 2: Psychosocial impact of HIV and AIDS on orphans and vulnerable children

2.1 Introduction

Many psychosocial issues associated with HIV and AIDS transcend economic, political and other macro-systemic boundaries. Children made vulnerable by the epidemic become embroiled in a downward spiral of distress and difficulties that affect multiple aspects of their lives (Killian, 2004a). However, orphanhood is not necessarily the critical point of escalating need. Long before being orphaned, many children suffer the long-term decline in health of their parents or guardians, reduced family income, and the psychological and material consequences of both (Jackson, 2002). HIV and AIDS is expected to cause a number of psychosocial impacts to the affected children. Initially, the illness of the infected parent is likely to deprive the child of adequate emotional support, nurturance and care; then, as the disease progresses, the parent's lowered economic productivity and increased medical expenses inevitably cause a drop in the resources that are available to meet the child's needs (Nampanya-Serpell, 2001).

A number of psychosocial outcomes that occur for children affected by HIV and AIDS have been researched. These include parenting with a terminal illness (Nagler, Adnopo & Forsyth, 1995), psychosocial impact of death (Fox 2000), and multiple losses and stigma (Cluver, 2003; Daniel, 2003 as cited in Stein, 2003). To understand the mechanisms through which the child is affected, it is important to start with an understanding of the child's environmental influences.

2.2 The social ecology of childhood

In investigating the psychosocial impact of HIV and AIDS on children, one has to appreciate the importance in determining the type of childhood experienced (Killian, 2004b). To study a child's development we must look not only at the child and his or her immediate environment, but also at the interaction of the larger environment (Paquette & Ryan, 2001).

Bronfenbrenner formulated a theoretical position addressing the lifetime development of the individual and accommodating the nexus of systems theory and child development (Boemmel & Briscoe, 2001). His theory is referred to as an ecological systems theory. The theory defines layers of the environment, each having an effect on how children develop. This theory has recently been renamed "*bioecological* model" to emphasize that a child's own biology is a primary variable fueling his or her development (Berk, 2006, p. 26).

Ecological theory sees the child as an interdependent member of a complex family system, which comprises a number of interactive and interrelated subsystems, characterised by stability, transformation, fluidity and boundaries (Boemmel & Briscoe, 2001). Within this complex system, the child plays different roles: an individual, a member of various family subgroups, a member of the family as a whole, and participant/member of the family's ecological environment (Minuchin, 1985). Elements within any systemic level can be imposed externally, or arise from within the organism, since children select, modify, and create many of their own settings and experiences (Berk, 2000).

Bronfenbrenner's model of ecological development proposes that the study of human development necessitates considering mutual accommodation of the actively developing individual and the dynamic characteristics of the immediate setting (microsystem) in which the individual develops. The microsystem encompasses the relationships and interactions a child has within his or her immediate surroundings (Berk, 2000). Structures in the microsystem include family, the child's class, and most immediate peer relationships; i.e. all those who have a daily ongoing and pervasive influence on the child.

Bronfenbrenner uses the term bi-directional to describe the influential interactions between the child and his or her immediate surroundings, understanding that the influences go in both directions (Boemmel & Briscoe, 2001). Adults affect children's behaviour, but children's biologically and socially influenced characteristics (their physical attributes, personalities, and capacities), also affect the behaviour and responses of adults (Berk, 2000). "For example, a friendly, attentive child is likely to evoke positive and patient reactions from parents, whereas a distractible youngster is more likely elicit responses of restriction and punishment" (Berk, 2006, p. 27). At the microsystemic level, bi-directional influences are strongest and have the greatest impact on the child. However, interactions at outer levels can still impact the inner structures (Paquette & Ryan, 2001). Bronfenbrenner says that there are two environmental conditions that are necessary for human development. The first is that one or more adults must love the child unconditionally; the second is that the adults must encourage the child and spend time doing joint activities with the child, in and out of the home environment (Boemmel & Briscoe, 2001).

The mesosystem consists of the inter-relationships between two or more of the children's immediate settings and surroundings (microsystems), that influence development by their joint contributions (Berk, 2000), but with which the developing person is not in direct contact. Examples include the connection between the child's teacher and his parents, between his church and his neighbourhood, and so forth (Paquette & Ryan, 2001).

An exosystem is made up of social settings that do not contain the children but nevertheless affect their experiences in immediate settings (Berk, 2006, p. 29). Indirectly, an exosystem can have a huge affect on the child. For example, if a parent works for a company that does not have a flexible work schedule, the parent may not be able to spend as much quality time with the child as needed (Boemmel & Briscoe, 2001).

A macrosystem refers to a larger, cultural context - the attitudes and ideologies of the culture in which the more proximal settings are embedded. This may include both dominant cultures and subcultures. The effects of larger principles and values, defined by

the macrosystem, have a cascading influence throughout the interactions of all other layers. For example, if it is the belief of the culture that parents should be solely responsible for raising their children, that culture is less likely to provide resources to help parents. This, in turn, affects the structures in which the parents function. The parents' ability or inability to carry out that responsibility toward their child within the context of the child's microsystem is likewise affected (Paquette & Ryan, 2001). "What place or priority children and those responsible for their care have in such macrosystems is of special importance in determining how a child and his or her caretakers are treated and interact with each other in different types of settings" (Bronfenbrenner 1977, p. 515 as cited in Boemmel & Briscoe, 2001).

Children live in an environment which is forever changing. The chronosystem encompasses the dimension of time as it relates to a child's environments. The timing of the environmental changes affects the emotional and social development of the child such as the timing of a parent's death, or the physiological changes that occur with the aging of a child (Paquette & Ryan, 2001).

Changes or conflict in any one layer will ripple throughout other layers. It is therefore important to look at a child's development not only at an individual level but to consider the role played by all other factors around them. An environment that is responsive to children's issues is important for their normal development. In times of HIV and AIDS, maintaining a 'perfect' environment for children might be a challenge due to multiple effects of HIV and AIDS on the child and its support system.

2.3. The emotional impact of HIV and AIDS

One of the most important effects of AIDS on children is emotional (Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda, 2001) Research is depicting a reality of worry, sadness, fear, and hopelessness among children and adolescents during their parents' AIDS-related illness and death and, subsequently, in orphanhood (Birdthistle, 2004).

In Uganda, researchers conducted in-depth interviews with the children, guardians, and teachers, facilitated focus groups with teachers, and observed the home situation. Nearly 40% of the orphans reported that they felt sad and hopeless when their parents fell sick (Sengendo & Nambi, 1997). When parents were very sick, 50 % were afraid the parent would die. These findings highlight the need to support children long before the passing on of their parent(s). The majority felt anger about their parents' death, especially those staying with relatives; children were least likely to be angry if they stayed with a surviving parent or on their own. Children living with widowed fathers were significantly more depressed than those living with widowed mothers. And, among children living with widowed fathers, 10 to 14 year olds were found to be significantly more depressed than the older children between 15-19 years (Sengendo & Nambi, 1997). The findings suggest that whoever takes over the care-giving role after the death of a parent or parents has a significant effect to the children's emotional wellbeing.

Stigma and discrimination continue to accompany the HIV and AIDS epidemic (UNAIDS, 2002). Children are not immune to stigmatization. In cases of stigma, children begin to be rejected early, as their parents fall ill with AIDS. Some children may be teased because their parents have AIDS, while others may lose their friends because it is assumed that proximity can spread the virus (Salaam, 2005). Teachers may turn children away for lack of school supplies, with no consideration of their family circumstances (Gilborn *et al.*, 2001). Some guardians may reject and neglect orphans as they view them as a burden (Gilborn *et al.*, 2001).

One study in Kenya found that 77% of the children orphaned by AIDS said that they had no one outside of their families to "tell their troubles to" (Salaam, 2004, p. 11). The feeling of isolation can be heightened if the orphaned children are separated from their siblings, as often occurs when family members split up the child rearing duties (Salaam, 2004).

Because of the silence surrounding HIV and AIDS, children tend to worry alone about their future. In Uganda, for instance, most children wanted their parents to talk to them about

being HIV-positive, and about what will happen when the parents die, but parents feared and avoided doing so (Gilborn *et al.*, 2001).

Much remains to be understood, including the specific emotional effects by age, type of orphanhood, and living arrangements (Birdthistle, 2004). As a relatively new area of inquiry, research on the psychosocial wellbeing of children orphaned and affected by AIDS is currently limited to small studies, often without comparison groups to be able to attribute findings to the effects of orphanhood, as opposed to being orphaned through HIV and AIDS (Birdthistle, 2004). A number studies assess children who are connected with a humanitarian project or programme, without adequate explanation of how these client households were selected (Birdthistle, 2004).

2.4 Illness and young carers

Over 95% of people living with HIV and AIDS (PLWHA) live in lower-income households in developing countries; and, nearly two-thirds of PLWHA globally live in sub-Saharan Africa (UNAIDS, 2004). It is likely that as the number of those infected with HIV increases, the gap is widening between the demand and availability of, health care services. In the past few years, hospitals have become overcrowded (Mohammad and Gikonyo, 2005). The influx of patients in hospitals may influence the quality of care provided. The increasing number of patients hospitalised for an extended period of time has stretched the resources of the health care system.

As more households are affected by HIV and AIDS, there is a growing need for assistance with care and support at home. Increasingly, households are faced with coping with the needs of sick members, including assistance with daily living, treatment, physical care and psychosocial support and care (Mohammad and Gikonyo, 2005). Given the limited availability of formal, inpatient programmes, households rely upon informal caregivers, including children.

Family structure is an important factor that pushes some children into unpaid care work. With the main mode of HIV transmission being sexual, if one partner is HIV positive, both are likely to be (Cullen, 2006). When one parent dies from an AIDS related illness, there may be no other adult family member to care for the remaining parent when they become ill. The burden of care is therefore falling more and more on the children in the family.

Many children affected by HIV and AIDS, particularly older children, become the principal caregivers of a dying parent, and see them through a long and painful illness. The issue of the ‘availability’ of other family members is critical here. Becker (2000, p. 5) defines young carers as “*children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.*”

The young carers provide the following services:

- *General and nursing care work*, which included organising and administering medication, injections, and lifting and moving parents (Dearden & Becker, 2004).
- *Emotional support and supervision*, particularly to parents with severe and enduring mental health problems (Aldridge & Becker, 2003).
- *Intimate care work* including toileting and bathing (Aldridge & Becker, 2003).
- *Child-care responsibilities* in addition to their caring roles for other family members (Dearden & Becker, 2004).
- *Other household responsibilities*, including translating (where English is not the first language), dealing with professionals, the family’s money management etc (Aldridge & Becker, 2003).
- Purchasing provisions for the family and collecting grants and pensions on behalf of their sick relatives – this goes against the cultural norms in which the financial status of the family is not regarded as part of the business of children (Aldridge & Becker, 2003).
- Household responsibilities of cleaning, cooking, collecting wood, taking care of livestock, and so forth

The Zimbabwe Human Development Report 2003, quotes UNAIDS (2000), as stating that young children between 8 and 11 years have become the main carers, since older children tend to leave home. Bourel (2001), quoted in the same report, says that children as young as 3 years old are involved in caring, running small errands like fetching water and bringing food. Many children can be socialised into unpaid caring roles from an early age (Aldridge & Becker, 1993; Robson & Ansell, 2000).

Research suggests that girls are more likely to take on all forms of unpaid care work and more of it, than boys; although boys may share responsibilities other than physical care (Becker, 2000). Often it is culturally and traditionally more acceptable for girls to take on this responsibility. Boys sometimes feel ashamed, and become confused, about their caregiving role and gender identity (Martin, 2006)

Other factors that pull children into unpaid care work include the fact that children are co-resident (they most often live in the same household as the person with care needs, particularly if it is a parent) *and* they have strong bonds of attachment (and love) for the person who needs their help. Children are immediately available to be able to provide care that is responsive to the changing needs of the person who has a need for care (Aldridge & Becker, 2003).

The existing research evidence suggests that the reasons why a particular child becomes a carer within any family will be complex and will vary from household to household and from situation to situation. Factors such as the nature of the illness/condition, love, attachment and co-residency, socialisation, a lack of choice and alternatives, low income, family structure, gender, all push or pull some children into unpaid caring roles and help to explain why a child might become, or remain, a carer in any household (Becker, Aldridge, & Dearden, 1998). Robson and Ansell (2000), from their interviews with young carers in Zimbabwe, confirm that these same factors explain equally as well why some children become young carers in Zimbabwe, as much as they do in the United Kingdom.

The general illness of parents adversely affects children in other ways besides the time they spend taking care of them. Most of the orphans interviewed by Human Rights Watch (2001), even those who could not identify the illness, described the terrible and exasperating ordeal of watching their ill parents become frailer, endure severe pain, and suffer stigmatization and rejection at the hands of health workers.

Between 1996 and 1997, in three urban areas of Lusaka, Poulter (1997) paid repeated visits to 66 households receiving home-based care. Parents said their children felt worried and sad when the parents were not well; they stopped playing, and stayed near to them. Others said their children tried very hard to help in the home. From the Child Behaviour Checklist questionnaire, children in affected homes were significantly more likely to worry about many things, be fearful of new things or situations, do things alone, and appear unhappy, tearful, miserable and distressed. No differences existed on items relating to behavioural disturbances, such as telling lies and stealing. Therefore, affected children seem to be depressive rather than exhibit antisocial behaviour. This is supported by Killian's (2004) study in which there was a significantly higher probability of children internalizing their distress, and only about 20% of orphaned and vulnerable children externalised their distress by exhibiting anti-social and aggressive behaviour patterns.

Dearden and Becker (2000) found that caring developed children's knowledge, understanding, sense of responsibility and maturity as well as a range of life, social, and care-related skills. Caring also helped to bring many children closer to their parents, in terms of a loving, caring, relationship. However, while Dearden and Becker (2000) noted that these positives were real outcomes for some children in their sample, they also observed that all the children experienced some negative consequences as well, and that these were often severe. These included stress, depression, and restricted social, educational and career opportunities.

Failure to support these children will have negative impacts on society as these children fail to function optimally. Some authors recognize that many children will have nursed their parent(s) through the disease, borne responsibilities well beyond their years, and coped with grief (Robson, 2001).

Home Based Care (HBC) organisations can become involved in the care of affected children in two important ways: by promoting an enabling environment for psychosocial care and support for vulnerable children, and by helping to create an expanded response by families, communities, governments, faith-based organisations and other organisations promoting psychosocial care and support for children. To that end, HBC services can become part of a larger response to orphan care. In particular, this larger response can help affected children by:

- Promoting programmes that support orphans and vulnerable children psychologically, economically and socially.
- Acknowledging children's changing roles: children quickly have to act like adults.
- Ensuring access to children's rights.
- Creating an enabling environment by building on children's own resources and peer support.
- Involving youth in finding solutions.
- Talking about death and dying.
- Providing access to education, health, and social services.
- Setting clear, firm targets to improve the lives and prospects of orphaned and vulnerable children.
- Making a long-term commitment to community and human development (WHO, 2002).

Research, as yet, has been unable to adequately isolate 'caring' from other key factors (variables) that can impact on children's health, well-being and development, in particular factors such as low income, family poverty and other forms of disadvantage. Some have suggested that focusing on family or children's resilience may offer some explanation here

(Newman, 2002). While the strength of existing research in this area has been making visible what had hitherto been invisible, and in charting and describing the broad landscape of young carers' experiences, the research evidence base is still under-developed in terms of critical analysis of outcomes (Becker, 2000).

2.5 Impact of parental death: Grief and bereavement

Despite the increased availability of highly active antiretroviral therapy (HAART), death is still a common outcome of HIV and AIDS. Each year, millions of children lose one or both parents to AIDS (Close & Rigamonti, 2005). A death in the family results in crisis, and one opinion on this crisis resulting from death is that "every aspect of the daily routine is upset" (Lippincott, Williams, & Wilkins, 2000, p. 1197). Death of a family member can create a profound family crisis by severely disrupting family stability (Kiser, Ostojka & Pruitt, 1998).

Bereavement can be defined as the state a person is in when they are deprived of something important to them. It is particularly applied to the loss of a relative through death. Grief can be defined as a deep mental pain or torment. It is particularly applied to those who have experienced bereavement (International HIV/AIDS Alliance, 2005).

The AIDS epidemic has created a sizable population of bereaved individuals. With each AIDS-related death, an extensive network of family, friends, colleagues, neighbours, and health care providers is left behind to grapple with the loss. "*A culture of mourning has emerged in which multiple and chronic loss has become the environmental norm for individuals in high-risk groups*" (Summers, 1998, para. 2).

Beyond the sheer volume of loss, AIDS-related bereavement differs from other forms of mourning in several distinct and important ways. The stigma associated with AIDS persists and, in turn, impacts the survivor. AIDS-related loss has been shrouded with shame, guilt, and fears surrounding transmission, sexuality, and society's inability to concede the sense of loss experienced by survivors (Summers, 1998).

When a parent or caregiver approaches the end stages of AIDS, it is extremely important that a plan of care be created for the children. This is referred to as permanency planning (Close & Rigamonti, 2005). A number of alternative parenting arrangements can be made during this period, i.e. adoption, guardianship, or single parenting made prior to the death of the seropositive parent(s). In this process, the seropositive family members help prepare for the well-being of the surviving children and adults (McEntire, 2003). Although difficult, such efforts to ensure the reasonable placement of surviving children often initiate a process of adaptation critical to the grief resolution process for both the bereaved children and any surviving parent.

Children whose parents do not complete permanency planning are at increased risk of developing emotional and behavioural problems (Rotherum-Borus, Lester, Wang & Shen, 2004). When this step is not taken, children are left in a state of uncertainty about who will care for them. This can compound the loss felt by the child after a parent's death. The child may be separated from siblings and may experience frequent shifts from place to place in search of a proper home (Oneill, Selwyn & Schietinger, 2003).

How do children react to the death of a loved one? Bereaved children may become anxious over the safety of other loved ones or themselves (Baker & Sedney, 1996; Worden, 1996). Parents and teachers may observe outbursts of anger and acting-out behaviour among children who have lost a loved one (McEntire, 2003). The need for assurance that they will be safe, loved, trusted and cared for becomes very important to them. Children may express guilt when they recall how they misbehaved before the parent died or when they remember missed opportunities to express affection (Worden, 1996).

Children's psychosocial needs are often overlooked, and the children are not given full recognition or support after their loss. This is usually due to the belief that children are too young to understand what is happening or are better off not dwelling on their loss (Close & Rigamonti, 2005). Consequently, children are often not properly supported in their time of mourning.

Understanding the death requires the provision of information to these children on how or why the death occurred. Some experts believe that vague abstractions may leave a child believing that deceased parents could return if they wanted to do so (Corr & Corr, 1996). For example, some children are told that their deceased parent has gone on a long trip. The child's expectation is that the deceased parent will come back. Encouraging the child to ask questions and providing simple and concrete responses can help foster an open atmosphere that promotes the mourning process (Summers, 1998).

For children of all ages, support is a key factor in the grieving process. This support can come from their families, friends, and communities. Rituals are a central part of death and grieving for communities around the world (Close & Rigamonti, 2005). Sometimes participating in rituals can help children with the transition and acceptance of a loved one's death. It seems that there is nothing to lose, but much to gain, by children attending the funeral, with the 'golden rule' to give children the choice and neither force them to attend, nor forbid them from attending (Holland, 2005). It also seems important to prepare children for the experiences of attending the funeral.

For children who have lost parents or family members, grief can be overwhelming and hard to understand. Grief and bereavement experiences are unique to each individual. Grief can cause a series of different types of responses, including physical, emotional, behavioural, cognitive, spiritual, and social (Close & Rigamonti, 2005). Social responses are particularly important because of the high rate of stigmatization associated with HIV and AIDS (Oneill, Selwyn & Schietinger, 2003). It is also imperative that grieving children be able to acknowledge their loss and be provided with an opportunity to release their grief. Without such an opportunity, they may experience psychological ramifications well into adult and may indeed never recover from their loss (Close & Rigamonti, 2005).

It is common for children to experience a regression in their behaviour during their period of mourning (Oneill et al., 2003). They may begin to display behaviours they have not exhibited in a long time, such as sucking on their thumbs or becoming increasingly clingy – both actions that help increase their sense of security in a time of confusion. Some children

will also try to gain attention through acting-out behaviours. Attention helps children remember they have not been forgotten, so children will act out to get this attention, even if the attention is negative in nature.

Table 1: Children’s developmental stages of grief (Adapted from: Oneill, Selwyn & Schietinger, 2003)

<i>Children’s developmental stages of grief</i>			
Age	Thoughts	Feelings	Actions
3-5 years	<ul style="list-style-type: none"> •Loved one will return •Loved one is just away 	<ul style="list-style-type: none"> •Fearful of separation •Anxious •confused 	<ul style="list-style-type: none"> •Cry •Temper tantrum •Nightmares •Regression/clingy behaviour
6-8 years	<ul style="list-style-type: none"> •Wonder if loved one can return •Deceased can still function •Magical thinking 	<ul style="list-style-type: none"> •Confused or anxious •Fearful of separation •Fearful they might die too 	<ul style="list-style-type: none"> •Temper tantrum •Nightmares •Regressive/ clingy behaviour •Difficulty concentrating
9-12 years	<ul style="list-style-type: none"> •Understand finality and irreversibility of death •Magical thinking 	<ul style="list-style-type: none"> •Sad •Anxious •Lonely •Confused •withdrawn 	<ul style="list-style-type: none"> •Aggressive/impulsive behaviour •Engage in risky behaviour •Decline in school performance •Difficulty concentrating
13-18 years	<ul style="list-style-type: none"> •Understand finality and irreversibility of death •Magical thinking •Begin to look beyond death 	<ul style="list-style-type: none"> •Sad •Anxious •Lonely •Confused •Withdrawn •Guilty 	<ul style="list-style-type: none"> •Aggressive/impulsive behaviour •Engage in risky behaviour •Decline in school performance •Difficulty concentrating •Exhibit powerful emotional bursts

Dowdney (2000) states that grief and disturbance fluctuate with the passage of time. Children also differ in the way they grieve, such that children reported as not depressed at one point can be so at another point. Even more troublesome is the possibility that some bereaved adolescents may seem to be doing fine, but are actually affected by the loss

(Offer, Ostrov, Howard & Atkinson, 1988). These adolescents want to make the world think they are functioning well when they are actually hiding many pains inside.

Although patterns of bereavement can be discerned in particular groups, individual grief responses remain as diversified as the lives of the deceased themselves. The healing can be derived from acknowledging the special qualities of the shared relationship with the deceased, participating in private as well as communal rituals, and recognizing the value and worth of the role one's parents/caregivers played in one's life (Summers, 1998).

2.6 Education

Education plays a vital role in the well-being of children. It offers them a chance for their future as well as developmental stimuli. The impact of HIV and AIDS on the educational system has resulted in a decreasing number of teachers due to mortality, a growing number of children who are not able to attend or stay in school, and rising numbers of pupils whose ability to take advantage of schooling is undermined by other factors including poor nutrition and psychological stress (Family Health International, 2001).

The death of a parent to HIV and AIDS may leave children without any effective support for their education. Attendance in school often declines as children find themselves without their primary source of support, encouragement, and financial assistance. For many, the death of a parent means being chased from school because of inability to pay school fees or other mandatory expenses, even in countries with policies of free primary education.

Orphans are sometimes kept away from schools by caregivers in order to suppress their future economic potential (Human Rights Watch, 2005). Staying in school offers orphaned children the best chance of escaping extreme poverty and its associated risks. In cases where orphans moved in with caregivers who had their own biological children, orphans are less likely to be in school than the biological children (Human Rights Watch, 2005). One of the main reasons is overstretched financial resources.

As highlighted earlier, children face a lot of emotional challenges due to their loss. At school, orphans may face incidents of embarrassment and fear at being stigmatised as AIDS orphans. On top of the emotional difficulty of losing a parent, children orphaned by AIDS are sometimes teased by classmates for being orphans or in some cases teachers and classmates assume that they also have AIDS (Sengendo & Nambi, 1997). However, other orphaned children have reported that their teachers have been their primary support base at school.

Orphaned children can also experience discrimination and exploitation within their new households. School gives many students a welcome distraction from the pain. Some children report that their loss feels the greatest when they return home (Sengendo & Nambi, 1997). Sometimes orphans are not in school due to the heavy domestic responsibilities most of them have to do before going to school. During certain agricultural seasons they are also expected to provide labour in the morning before going to school and in the evening after school (Ayieko, 1997).

The preoccupation with the illness or death of their parents, the isolation due to the loss of friends, and the undertaking of additional work that comes with caring for ill parents or supporting oneself after one's parents have died often make it difficult for orphaned children to concentrate in school (Ayieko, 1997). It is common for teachers to report that they find orphaned children daydreaming, coming to school infrequently, arriving at school unprepared and late, or being nonresponsive in the classroom (Human Rights Watch, 2005).

A frequent response of schools to the needs of orphans has been to provide free meals to encourage orphans to attend school. But principals readily acknowledged that these measures are not enough, and that AIDS-affected children continue to drop out in large numbers (Human Rights Watch, 2005). This indicates the need for a support system focused on more than just the physical needs of these children.

In many cases, children dropped out of school temporarily only to return later; in others, the death of a parent concluded a period of instability caused by the parent's sickness, particularly when extended family members offered to support the child's education.

Evidence that education itself protects against HIV is strong. Data for the late 1980s and early 1990s, when the HIV and AIDS pandemic was just emerging, mostly showed a negative correlation between level of education and rates of infection (Kelly, 2000). A study in Zambia, for example, found a marked decline in HIV prevalence rates in 15- to 19-year-old boys and girls with a medium to higher level education, but an increase among those with lower educational levels (Kelly, 2000).

Table 2: Education and HIV and AIDS (*Adapted from World Bank, 2002*)

Education can protect women from HIV and AIDS

An analysis of demographic and household surveys from 32 countries since the early 1990s found that nearly half of all illiterate women lacked the basic knowledge to protect themselves against HIV and AIDS. Studies have shown that:

- Women with a post primary education were three times more likely than uneducated women to know that HIV can be transmitted from mother to child.
- In Zimbabwe, secondary education had a protective effect against HIV infection for women that extended at least into early adulthood (Gregson, Waddell & Chandiwana, 2001).
- In Zambia young women with a secondary education were less likely to be HIV-positive than those who had not received a secondary education. During the 1990s the HIV infection rate fell by almost half among educated women, with little decline for women without any formal schooling (Vandemoortele & Delamonica, 2000).
- In 17 countries in Africa and 4 in Latin America better-educated girls tended to delay having sex, and were more likely to require their partners to use condoms (UNAIDS, 2000).
- In Uganda, while infection rates among young women of all educational backgrounds fell, the decline was greatest for women with a secondary education (UNAIDS, 2000).

Education is among the most powerful tools for reducing the social and economic vulnerability that exposes women to a higher risk of HIV and AIDS. Girls' education can go far in slowing and reversing the spread of HIV by contributing to poverty reduction, gender equality, female empowerment, and awareness of human rights. It also has crucial implications for female economic independence, delayed marriage, family planning, and work outside the home.

2.7 Community and family safety nets

The extended family has sometimes been described as the first ring of security for the separated child if his or her own family is unable to provide care and protection. In many societies, the boundary between the nuclear family and the extended family is a highly permeable and open one, and children are often seen as belonging to the wider family, with almost automatic responsibility accepted by relatives in the event of the parents dying or becoming separated (Tolfree, 2003).

Frequent deaths due to AIDS are weakening the extended family support system. Orphans are the major victims of the incohesiveness settling on the community (Ayieko, 1997). Some communities are feeling unable to cope with and absorb the large numbers of children who are orphaned (Stephenson & Miles, 2001).

In the past, the sense of duty and responsibility of extended families towards other members was almost without limits. Even though a family did not have sufficient resources to care for existing members, orphans were taken in (Foster, 2004). Children are no longer the collective responsibility of communities due to the over stretched household resources and the discouraging number of deaths in communities from HIV and AIDS (Ayieko, 1997). As the impacts of AIDS manifest, there are increasing numbers of institutions such as children's homes and orphanages (Foster, 2004).

Generally, however, institutional homes are seen as the last option for orphans. While they may provide some of the 'nurture', typical institutions do not provide the holistic care that children are entitled to for all round development (Phiri & Webb, 2002). Children need

more than good physical care. They need the affection, attention, security and social connections that families and communities can provide (Foster, 2004). Children also experience poor socialization and loss of cultural roots when removed from their home communities (International Coalition on AIDS and Development, 2006).

Research cited in Phiri and Webb (2002) has shown that children in institutions have lower levels of educational attainment; have problems adjusting to independence after leaving the orphanage, lack basic living skills; have more difficulties with relationships, lack parental skills and some of them often have a misplaced sense of entitlement without a parallel sense of responsibility (Powell 1999; Williamson, 2001).

One factor that makes orphanages an attraction is the perception among some members of impoverished communities that they will provide the food, education, health and other services that the caregivers are unable to provide to the children. For example a study in Zimbabwe showed that 75 per cent of the children in institutions had contactable relatives (Powell, 1999).

Although not in the overall best interests of the child, there are some advantages to orphanages. In Uganda, Zimbabwe, Zambia, Tanzania and South Africa, orphanages have better accommodation and sanitation than family homes in the villages (Germann, 2005). Diet and nutrition are often more balanced, and thus health records of children are generally good (Germann, 2005). Education for children in orphanages is in most cases good compared with the education children would receive in their home communities (Tollfree, 1989). Correctly managed institutions can provide emergency temporary care particularly to protect orphans at risk of abuse (Phiri & Webb, 2002).

If children cannot be supported by their extended families, they would likely receive better support through foster placements, local adoption, or smaller-scale residential care in home-like settings. Of course, situations vary, and some children fare better in a children's home or an orphanage than they would in alternative arrangements (International Coalition on AIDS and Development, 2006).

Similar to the institutionalisation of children, foster care has its own risks. Children in foster care are at high risk for emotional, behavioural, developmental, and physical health problems (Halfon & Klee, 1991). Studies indicate that children and young people in foster care tend to perform more poorly academically than children not in care, lag behind in their education by at least one year (Jones & Moses, 1984), and have lower educational attainment than the general population (Festinger, 1983).

With the ever increasing number of adults dying as a result of AIDS, changes are taking place in caregiving arrangements for affected children. The increase in the number of double orphans has led to the establishment of households headed by children, mostly in their teens, but with some headed by children as young as ten to 12 years old (Foster, 2004). This form of arrangement has its own strengths and weaknesses as illustrated by the table below.

Table 3: Strengths and weaknesses of child headed households (Adapted: UNICEF Regional Conference Satellite in November 2002 in Windhoek)

Strengths	Weaknesses
Siblings stay together, which reduces loss experiences.	Development of older children is hampered by the new parent role they have to take.
Children do not have to move away from their home and neighbourhood. They remain with their friends.	Heads of such households often drop out of school due to having to provide an income and care for the household. This leaves them with inadequate time and resources for school.
Households can be supported by their community and neighbourhood. In comparison to orphanages they maintain their social connections and community relations.	Such households lack protection.
Children receive cultural guidance and mentoring by elders from the community.	Children in such households often lack parental guidance and there is lack of intergenerational skills transfer.
Property (e.g. land or house) is protected and remains an asset for the children.	Life can be a daily struggle in such households.

The growing recognition of social and emotional needs of children affected by HIV and AIDS and the importance of a responsive environment has seen the emergence of the Memory work, which seeks to respond to the social and emotional needs of those affected by HIV and AIDS. The different techniques of Memory work aim to encourage children to tell and share their stories in a way that allows them to make sense of their experiences, thus fostering resilience, communication and empowerment.

Chapter 3: Memory work and resilience

3.1 What is memory work?

Memory work might be defined as the deliberate setting up of a safe space in which to contain the telling of a life story (Morgan, 2004). This space might be a room, the shade under a tree, a map, or a memory box, basket or book. The perspective of memory work is interdisciplinary. It attempts an integration of the methodologies of oral history, lifestory work, narrative therapy and child counselling (Denis, 2005).

The scope of memory work is not restricted to the past. Its purpose is often to deal with difficulties in the present and its main orientation often generates a focus and hope on future planning and the evolving life story. Denis (2003) argues that in creating this safe space, adults and children discuss trauma in the family and recollections of domestic happiness. Indeed, these disparate personal accounts are known to aid healing (Denis, 2005)

Memory work approaches are designed to help the millions of families affected by HIV and AIDS in Africa to cope with the disease, death and grief, and to plan for the children's future adjustment and well-being. With huge numbers of people infected and affected by HIV and AIDS, individual counselling is too expensive and impractical to deliver. Group-based user-friendly models of counselling and psychosocial support are needed. Memory work is one such approach.

After parents and adult relatives die, many orphans go and live with foster parents, in institutions or on their own. Cut off from family, children's memories - their personal history – could fade quickly. Orphans risk growing up without a clear sense of identity and roots, without the traditions and beliefs of their heritage.

Memory work has different approaches under it. The approaches include, tracing books, memory books and memory boxes. Memory boxes help children to build an identity and

strengthen emotional capacity, to understand the past, and to be less afraid of the future. As the family collects photos and souvenirs, draws a family tree and writes about their life, they grow closer. The process creates an opportunity for parents to disclose their HIV-positive status and to talk frankly about the child's future (IRIN, 2005).

The parents of someone who has died of AIDS related illness tend to speak only of the person's illness or death. By inviting them to speak also about the childhood, youth and the active life of the deceased, the memory facilitators help them to see the family's story in a more positive and holistic way. They help them to 'Re-author', as expressed by a narrative therapist, the family history, present and future.

Memory box work rests on the hypothesis that it is good for children to know their family history, however painful this might be, but only if that history is recounted in a warm, non-judgmental way (Denis, 2005). If the child knows his/her parent's history, s/he is better able to overcome the suffering caused by illness or death. S/He accesses this knowledge through memory – his/her own and that of those close to him/her (Denis, 2004).

3.2 Narrative therapy

Memory work has close relations with narrative therapy. Narrative therapy is an approach to counselling and community work that centres people as the experts in their own lives and views problems as separate from people. For narrative therapists, the person is not the problem; the problem is the problem on its own. Narrative therapy is of the assumption that human life is highly influenced by stories we make about ourselves and that poor associations surround the structure of these stories (Barry, 1997). In some cases, these poor associations cause people to reach a negative conclusion about their lives. Narrative therapy involves unearthing the most important moments which shape a person's life, the turning-points, the key relationships, and those good memories which are considered insignificant (Morgan, 2000). Narrative therapy assumes that people have many abilities, attitudes, and principles that will assist them despite prevailing set-backs.

Within narrative therapy, the word 'narrative' is mostly used to place emphasis upon the stories of people's lives and particular changes which can happen through re-authoring of these stories (Morgan, 2000). Narrative therapy seeks to make sense of people's life stories, and ways of re-authoring these stories in collaboration between the therapist / community worker and the people whose lives are being discussed. Thus, as with Memory work, history is a fundamental aspect of Narrative therapy. It is also interested in the broader context that is affecting people's lives and the ethics of therapy.

When it is understood that people's relationships with stressful situations are shaped by history and culture, it is possible to explore how gender, race, culture, sexuality, class and other relations of power have influenced the construction of the situation (Russell & Carey, 2004). Like Memory work, Narrative therapy allows people to notice the effects of the beliefs and ideas on the person's identity. This gives people power over the effects of labels and the challenges which are usually experienced by people as negatively affecting their lives (Morgan, 2000).

Our life is shaped by many influences, relationships and events. Events happen in our lives that cannot be changed. People experience trauma and losses that cannot be undone (Russell & Carey, 2004). Stories in a Narrative therapy context are made up of events, linked by a theme which occurs over time and according to a plot. The stories we have about our lives are created through linking certain events together in a particular sequence across a time period, and finding a way of explaining or making sense of them. This meaning forms the plot of the story. We give meanings to our experiences constantly as we live our lives. A narrative is like a thread that weaves the events together, forming a story (Morgan, 2000).

The way we have developed the stories is determined by how we have linked certain events together in a sequence and by the meaning we have attributed to them (Morgan, 2000). As the story takes shape, it invites the teller to further select only certain information while ignoring other events so that the same story is continually told. Narrative therapy assumes that each story is ideological, and that representation of reality is ideological (White, 1987).

Whereas the life stories are co-authored daily within a society, and within the context of work, school, church and family structures, there are other elements of life which are omitted and viewed as insignificant. It is these omitted elements which can be re-told and make people's life story different.

Like with Memory work, Narrative therapy is more about looking at the whole story, and not about looking at the positives and ignoring the negatives. The first step is to acknowledge and respect the present situation, experiences and problems people have had. A good starting point will be to look at why and how people have held on to their dreams despite all the hardships they have faced.

In Narrative therapy, there are conversations which try to reincorporate the person's relationship with a lost loved one. These conversations contribute to making available the touch and voice of the lost loved ones. These conversations allow people to break from desperation, despair, and from the sense of emptiness that had become the central experience of their lives, and reclaimed a familiar and comforting sense of identity (White, 1997).

According to Pennebaker and Seagal (1999) one's involvement in narrative therapy helps to 'repackage' the memories of a difficult situation. Being able to compose a story about a stressful experience presumably reduces the size and complexity of the original experience into a smaller unit that "lets memory work less hard" and "provides a constancy of lessons to be learned that does not need to be constantly re-examined" (Schank & Abelson, 1995, p. 42).

Narrative therapy and memory work acknowledge the importance of significant others in our life. Our identities are forged through our relationships with other people. How others see us, how we experience ourselves with others, how we participate with others, all influence who we are. Archbishop Desmond Tutu has described this succinctly as ubuntu; people become people through other people (Morrison, 2002). Significant figures in a person's life are often the holders of memories of events in which the person consulting the

therapist displayed certain skills, traits and abilities. The significant person's knowledge of these events can be linked with other events in the alternative story that is being generated. Linking together events in the alternative story in this way contributes to rich descriptions (Morgan, 2000).

In summary, Narrative therapy and Memory work are interested in reviewing of personal historical events, and the finding of a plot that can take one forward into the future with renewed energy or a new perspective. In a conscious way, one then begins to tentatively perform this alternative and hopeful story about oneself. Narrative therapy and Memory work then become the gathering and notching up, and then the laying down, of new positive memories which help people to overcome their stressful situations (Morgan, 2004). When people are able to overcome a stressful situation, their skills, abilities, interests, competencies and commitments become more visible. The more visible these skills become, the more available they are to people to access (Morgan, 2000).

3.3 The Sinomlando Memory Box Programme

With the reality that AIDS is taking away parents and adults with rich family heritage, orphans risk growing up without a clear sense of their identity and roots. Memory boxes help children to construct an identity and reinforce emotional capacity, to understand the past, and to be less afraid of the future. As the family develops their memory boxes together, they grow closer (Morgan, 2004). These become treasures that give an orphan an identity and a sense of belonging that they can otherwise easily lose.

Sinomlando is a Zulu word which means 'we have a history'. The Sinomlando centre was established in 1994 at the school of religion and theology, Univeristy of Natal. Its mission was to capture memories of indigenous South Africans who had experienced apartheid. The Sinomlando Memory Box Programme has been in existence since 2000. The overall objective of this Memory Box Programme is to enhance resilience in vulnerable children and orphans affected by HIV and AIDS through the methodology of memory boxes (Denis, 2005). The memories of the families are kept in a memory box which may contain the story

of the family in general or may be focused on deceased parents as well as various objects pertaining to their history (Denis, 2005).

“The phrase memory box must be understood as a symbol: it is a means that encourages children whose parents are deceased (or will soon die) to conserve their memory of them in a way that will allow these children to grow up despite all” (Denis, 2005, p. 5). Memory box might also refer to a container that holds important family documents, photos, and letters from a deceased family member or any other significant item.

3.4 Memory box methodology

Sinomlando conducts three types of interventions which help them meet their objective of the Memory Box Programme. The interventions are family interviews, children's camps and school partnerships.

3.4.1 Building the foundation

The family interview is essential in the process of memory box. During the family interview, Sinomlando facilitators encourage the sick parent or caregiver to narrate the family history. Prior to this interview, the facilitators try to develop a bond with the family through preliminary gatherings.

These preliminary gatherings help the facilitators explain the memory box concept. It is important for the family to understand this concept before committing themselves. The preliminary visits also serve other purposes, including:

- (i) Building the family members' confidence in that the memory box process is confidential.
- (ii) Making sure that all important family members are not excluded from the memory work process.

- (iii) Finding ways in which children can confidently participate in the process.
- (iv) Making an appointment for the interview.
- (v) Negotiating the use of a tape-recorder (Denis, 2005).

3.4.2 Family interview

The interview is the core of the memory box process. Only after the family has consented will the interview be conducted. The whole family is encouraged to be part of this interview. Older children are encouraged to take part in the conversation. The whole interview process is normally audio recorded. The use of an audio recorder will aid the facilitators during transcription.

During the interview, parents or caregivers are given the space to share about the family history. In instances where the parents or caregivers are shy, the facilitator helps them along by asking questions that will help them open up. For family members who know what they want to say, the facilitator's role is to support the person who speaks by nodding when necessary and asking questions of clarification to help the conversation along (Denis, 2005).

3.4.3 Transcription of interview

The interview is then transcribed, but not verbatim. As the facilitators transcribe, they make sure that the language is made simple for the children to understand. What is important is to have a text which will help the children and the other members of the family to remember (Denis, 2005).

The transcribed notes are packaged into a booklet. The family members are given the opportunity to correct any mistakes or to make additions in the booklet.

3.4.4 The box

Family members need to create a container to store their transcribed booklet and any other items that they deem to be important for the children to have. The container is usually a shoe box or wooden box. The outside of this box is decorated in whichever way the family wants it to look like. It is important for children to be involved in the creation of this box as this might foster ownership.

3.4.5 The memory box contents

Once the creation of the box and the transcription of the interview are complete, the next stage is to fill the box with items such as:

- A booklet containing the family history
- Photographs
- Family trees
- Audio cassettes capturing singing and messages
- The audio tape of the interview
- Letters from the parents, caregivers or children
- Children's drawings

3.4.6 The closure process

When the memory box is complete, family members, the facilitators and community volunteers meet to celebrate their achievement. During this meeting family members receive their memory boxes from the facilitators and get to share their thoughts on the whole memory work process. Facilitators encourage family members to continuously update the memory box.

3.4.7 Follow up

As a follow up to the family interviews, the memory facilitators organise children's workshops with the assistance of their partner organisations. Children between the ages of 6-12 years (in some cases the age range can go up to 15 years) are selected to attend this workshop. These workshops normally take place after school, during the weekends or during the holidays (Denis, 2005). The primary purpose of the workshops is to provide orphans with life skills, thus building their level of resilience. During the sessions the children are guided and assisted in creating their memory boxes.

A similar intervention takes place in schools, usually in the context of the Life Orientation course, one of the subjects that are part of the mainstream curriculum in South African schools. Many teachers want to provide emotional support to the learners but they lack the necessary skills (Denis, 2005). The Memory Box Programme provides them with training and supervision to provide this emotional support.

3.5 Studies on memory work

Memory work is a relatively new psychosocial support approach hence there has been little empirical work on the benefits of memory work per se. This section will review empirical work around memory work.

In 2001, the Sinomlando Project and Sinosizo Home-based Care launched a pilot study to assess the effects of the memory box in twenty Zulu-speaking families in the Durban area. The findings of the study indicated that children with clearer memories of their parents were better able to cope with the hardships of AIDS- induced parental death. One outcome of the Sinomlando/Sinosizo pilot study was that the participant children knew what had happened to their parents (Denis, 2003); whereas it seemed that many other orphaned children did not actually know positively or directly about the death of a parent. Lewis (2001) argues that children with limited or partial knowledge of parental death experience additional distress when full explanations for parental illness or death are not provided.

In a study comparing levels of anxiety in children who are told of their parents' terminal illness and those who are not, the results were significant. Children who were informed of their parent's terminal illness showed significantly less anxiety than children who were not told (Rosenheim & Reicher, 1985). In another study on disclosure to children, conducted by Marcus (1999) in KwaZulu Natal, it was found that children are frequently excluded from discussion about both the imminent and recent death of a parent, on the grounds that death is an inappropriate topic for adults to discuss with children. The inclusion of children in the process of coming to terms with an HIV diagnosis is critically important (Stein, 2003). Without clear communication with adults regarding their situation, children are left feeling isolated and alone. Thus, the Memory Box Programme creates space for such discussions to take place in a non threatening way.

In a study on memory work carried out in South Africa, Vasquez (2004) noted that through personal narratives the individual creates both self awareness and awareness of others, recognizing and identifying vulnerabilities and strengths in each other. The point of narratives is to enable human beings to achieve an identity (Skultans, 2000). Vasquez (2004) also notes that after gaining self awareness, the participants in her study spoke more positively about the disease (HIV and AIDS). They started to see HIV and AIDS as any other disease that can be managed.

In Vasquez's (2004) study, it was apparent that language played a major role in memory work as it served to build self confidence. Through the language that we use, we construct meaning about our world and our belief systems. It is in language that societies create their views of reality. Our language tells us how to see the world and what to see in it. Putter-Murdoch (2004) describes language as the creator of the nature we know.

As illustrated by the studies one might conclude that the objective of this Memory work is to enhance resilience in vulnerable children and orphans, their families and communities affected by HIV and AIDS.

3.6 Understanding resilience

According to Stein (2003), studies have indicated that children affected by HIV and AIDS show heightened levels of internalising problems such as depression and anxiety. Some social scientists have further argued that HIV and AIDS negatively impact children in a number of ways, for example, increased insecurity, lack of social attachment to significant others and major impairments to their cognitive, social, behavioural and moral functioning (Killian, 2004b).

Resilience studies have indicated that children have different tolerances for stress. The ways in which they respond are also varied, meaning that not all children will be adversely affected by HIV and AIDS in similar ways. Understanding this helps us to objectively look at the impact of HIV and AIDS on children. The question that the study of resilience tries to address is: How is it that not all children growing up in some very difficult circumstances develop significant emotional or social problems in leading their lives in childhood or adulthood (Apfel & Simon, 1996)?

The study of resilience on how children cope in spite of serious challenges to their development emerged when researchers were confronted with examples of successful development of children at-risk (Masten, Best & Garmezy, 1990). The term resilience is commonly understood as the display of positive adaptation in the face of adversity (Masten & Coatsworth, 1998). In research on children, resilience generally refers to good outcomes in spite of serious threats to development (Masten, 2000).

Resilience is not a static characteristic or attribute of an individual (Werner & Smith, 2001). It is a dynamic process that must be understood within the context of experiencing stress (Masten & Coatsworth, 1998) and the emotional, cognitive and social adjustment of children in the context of their ecology (Garmezy, 1994; Rutter, 1985). Ecological theory thus helps to explain the concept of risk and resilience. Ecological theory looks at the individual in his/her environment. The theory argues that children's development is strongly influenced by an interdependent system which includes the family, school, peers, neighbourhood and community contexts in which they live (Fraser, 1997).

In linking ecological theory to resilience, a resilience nurturing context is one that promotes high expectations, provides caring, support, and opportunities for participation (Bernard, 1991; Werner & Smith, 1992). Memory work seeks to create such a nurturing context, in which children can exhibit resilient qualities such as social competence, autonomy, and a sense of purpose and future (Bernard, 1991 as cited in Rausch, Lovett & Walker, 2003).

3.7 Models explaining resilience

A number of factors do contribute to the reduction of risks faced by individuals in difficult circumstance. Mechanisms which contribute to this reduction have been studied by different social scientists. Although researchers have sometimes suggested different models, many have given the same mechanisms different names (O'Leary, 1998). Garmezy, Masten and Tellegen (1984) have identified three models used to describe the impact of stress on the quality of adaptation: the compensatory model, the challenge model, and the protective factor model (O'Leary, 1998).

3.7.1 Compensatory model

Compensatory factors are considered to counteract exposure to risk (O'Leary, 1998). According to this model, a compensatory factor helps an individual to neutralise a stressful situation. Memory work can be considered as vehicle for promoting compensatory factors. Memory work promotes high self esteem, healthy relationships and reliance on spirituality, all of which have a beneficial consequence regardless of risk level. The compensatory model is based on the assumption that the ability to have a balanced life in the face of risk suggests a higher than normal level of resources. The compensatory factor does not interrelate with a risk factor but has a direct and independent influence on the outcome (O'Leary, 1998). These factors either decrease risk initially or ameliorate risk throughout development. A major goal of Memory work is to improve the level of one's self esteem

3.7.2 Challenge model

In the challenge model, the risk factor has the potential to enhance successful adaptation, provided that it is neither excessive nor moderate (O’Leary, 1998). Excessive amounts of the risk factor may leave the individual helpless. Reasonable levels of the risk factor present the individual with a challenge that they stand a chance to overcome. Overcoming a risk factor strengthens competence and prepares the individual for the next risk factor (Zimmerman & Arunkumar, 1994). This model explains the finding that children who have been exposed to adversity and have learned to cope well are likely to feel more competent in coping with future difficulties.

In the present context, this might indicate that some children exposed to moderate amounts of stress resulting from high levels of poverty, HIV and AIDS, or both in their community would develop coping skills that would enable them to deal with other threats such as abuse and neglect (Rausch, Lovett & Walker, 2003).

3.7.3 Protective factor model

A protective factor model proposes that there are processes that interact with risk factors in reducing the probability of a negative outcome. Protective factors work by moderating the effect of exposure to risk and by modifying the response to risk factors (O’Leary, 1998). For example, in many studies of the impact of traumatic experiences on children, it has been found that the presence of at least one stable and supportive caregiver can protect or buffer the child, thereby reducing the risk that the child develops serious problems later in life (Cairns, 1996). An example of this in the present context would be a youth worker who intervenes to provide ongoing support for a child orphaned by HIV and AIDS, thus reducing the affects of isolation and marginalization on the child (Rausch et al., 2003).

Cumulative effects also take place with protective factors (Dryden, Johnson, Howard, & McGuire, 1998). There seem to be positive chain reactions, or clustering effects, with protective factors, such that exposure to Memory work might enhance self esteem, then

improve social and academic functioning. Simply put, the more protective factors that are available to a child, the more likely they are to experience resilience in the face of adversity (Baylis, 2003).

Resilience may change over time when circumstances change, so it is not necessarily a fixed attribute for an individual (Rutter, 1987). Protective factors may not be enough to provide resiliency if the levels of risk are too great. Studies also suggest, however, that children have varying degrees of resilience at different points in their lives (Rausch et al., 2003). Children who seem resilient in one set of circumstances may suffer when other difficulties arise, or vice versa. This suggests that it is the interaction and accumulation of individual and environmental risk factors that contribute to both risk and resilience (Killian, 2004b).

Protective factors have been described in relation to three primary systems in the child's world - family, school and community (Howard & Johnson, 2000). Caring and support in the family, school and community not only establish the basis for trusting relationships throughout life (Erikson, 1963) but also have a powerful impact on children's development (Howard & Johnson, 2000).

3.7.3.1 Personal factors

Children normally have multiple risk factors and multiple resources interacting /influencing their lives (Masten & Coatsworth, 1998). In initial studies of resilience, researchers were looking for a single risk factor, only to realise that children's lives are often loaded with many risks and recurring stressors (Masten & Coatsworth, 1998).

Children who have lost their parent/s due to AIDS related illness not only carry the burden of the loss of the love of a parent but are faced with numerous other challenges. In most cases the emotional scars remain, accompanied by poverty, stigma and fighting with relatives over property rights. Such events will linger in their memories. Or as Bowlby (1951, p. 114 as cited in Gilligan, 2001).puts it "Children are not slates from which the past can be rubbed by a duster or sponge, but human beings who carry their previous

experiences with them and whose behaviour in the present is profoundly affected by what has gone before”.

While unexpected life events can either protect or threaten children’s well-being, a noteworthy group of protective factors looks at the personal characteristics and skills of individuals. The combination of positive dispositional characteristics, personal coping strategies and beliefs about personal efficacy and agency contribute to individual resilience (Howard & Johnson, 2000).

Memory work fosters resilience by helping children develop a sense of autonomy. Autonomy is being able to know who you are (identity) and to have an ability to act independently and to exert some control over one's environment, including a sense of task mastery, an internal locus of control, and self-efficacy (Bernard, 1995). Resilience is also manifested in having a sense of purpose and a belief in a bright future, including goal direction, educational aspirations, achievement motivation, persistence, hopefulness, optimism, and spiritual connectedness (Benard, 1995).

More recent studies of children in war zones have stressed that children can survive traumatic situations if they feel emotionally secure and cared for (Poulter, 1997). Having a sick parent can lead to a child feeling similar uncertainties and fears as those felt by children in war zones. However, unlike in a war-time situation, families with chronic illness may feel isolated from others in the community, either as a direct result of the nature of the illness or by the consequences, such as poverty.

3.7.3.2 Family factors

The most important protective resource for development is a strong relationship with a competent, caring, pro-social adult (Masten, 1997). Reliable parenting skills that support attachment and emotional bonding promote resilience (Howard & Johnson, 2000). Siblings and members of the extended family can play a supportive role as they can also provide emotional and material support. These relational requisites can be provided in many types of families, not just in conventional nuclear families (Howard & Johnson, 2000).

Richter (2004) suggested that despite a large number of children affected by HIV and AIDS being taken into the stable and caring homes of family and neighbours, many are likely to develop mental health problems because they will not be exposed to several formative influences. These include the:

- Early bonding experiences critical for good, caring human relationships;
- Modelling, boundary setting and development of value systems necessary for moral development; and
- Support, caring and discipline needed for emotional stability.

According to Bell (2001), being bonded, attached, and connected permits the growth of the capacity to recall and invoke images of good and sustaining figures. Memory work facilitates supportive family relationships which can lead to bonding and attachment. Memory work facilitators encourage supportive family ties through good communication, appreciating each other, bringing forth positive aspects of each family member, giving positive statements and appreciating family profile. By appreciating the family profile (i.e., beliefs, values, emotional warmth, support, organization, and communication) plans can be developed within the family to strengthen it, thus enhancing resilience (Bell, 2001). Insufficient parental warmth and affection coupled with lack of cohesion and high levels of conflict and hostility are linked to a lack of support within families (Bell, 2001).

Families with high cohesion count on each other to provide meaningful and tangible support, encouragement, and even rebuke, when appropriate. In other words, there is an assumed, unspoken level of trust and commitment to one another that seems to defy logic (Edwards, 2002). Stinnett and DeFrain (1985) note that certain psychological and social characteristics are present in strong families that promote resilience. These characteristics include commitment, appreciation, communication, time together, faith and values, and coping skills (Hall, 2000).

i. Commitment:

In families with high commitment, each family member puts the family's well being as the most important priority. Members of resilient families support each other through good and tough times. They solve their problems as a family. They pull their resources together as a family to make things work for them.

ii. Appreciation:

Strong families frequently let each other know that each person in the family is appreciated. They do not spend time blaming each other but seek to understand the opinions of other family members. Through Memory work families can learn to value each other's contribution to the family.

iii. Communication:

Resilient families effectively communicate whether the issue at hand is trivial or very important. The message effectively flows from the sender to the receiver, thus conflict and misunderstandings are avoided. Memory work creates space for families to communicate in a non threatening way.

iv. Time together:

Taking part in Memory work activities allows family members to spend quality time together. Quality and quantity time go hand in hand in developing strong relationships (Weigel, 2006). Resilient families find a balance between togetherness and individual time. They see themselves as part and parcel of their community and find it easy to offer support to their community or to receive such support from others within the community.

v. Spiritual wellness:

Resilient families have a sense of a greater good or power in life, and that belief gives them strength and purpose (Weigel, 2006)

3.7.3.3 School factors

Werner and Smith's (1989) study, covering more than 40 years, found that, among the most frequently encountered positive role models in the lives of resilient children, outside of the family circle, was a favourite teacher (Benard, 1995). In most cases the teacher was not just an academic source for the youngsters but also a confidant and positive model for personal identification (Benard, 1995).

Besides having teachers who are role models, schools should be a safe place for children. Schools should also help children develop a sense of autonomy and sense of belonging. Schools can be used as a source of developing valuable life skills such as social problem-solving as well as social competence (Howard & Johnson, 2000). Of paramount importance, schools can ensure that children develop the fundamental academic competencies needed for further learning and the development of positive self esteem (Howard & Johnson, 2000).

3.7.3.4 Community factors

The hypothesis of studies on social support is that social support buffers the adverse effects of stress (Cohen & Wills, 1985). Baron and Byrne (2000) define social support as the physical and psychological comfort provided by other people. As a coping strategy, social support protects against physical and psychological risks (Baron & Byrne, 2000). Still

when helpful social ties are just a potential resource of support, their perceived accessibility encourages successful coping with stressful events (Lazarus & Folkman, 1984). Interacting with others rather than remaining isolated helps people avoid the effects of stress. People who are reluctant to express their emotions and who are afraid of intimacy are unlikely to seek or to receive much social support (Baron & Byrne, 2000). Social isolation and the lack of social ties from which support may be drawn have long been associated with reduced psychological well being.

Communities can provide opportunities for child empowerment through allowing them to participate in social, sporting and cultural activities. These activities promote feelings of belonging and connectedness that are central to the development of resilience (Howard & Johnson, 2000).

Table 4: Some factors that promote children's resilience (*Adapted from Apfel & Simon, 1996*).

Some factors that promote children's resilience under conditions of adversity

Resourcefulness-This includes the gift of being able to extract even very small amounts of human warmth, and loving-kindness in the most dire of circumstances, including at times from these children's enemies or persecutors. There is skill at attracting and using adult support, which in turn leads to an early sense of the children's own power and competence. Resilient children do not merely get adults to care about them and take care of them, but they somehow promote reciprocity in their exchanges with adults, so that the adults also feel they are deriving something from the relationship.

The Ability to Conceptualize-This ability also entails the child's comprehending her or his experience not only as a personal travail but as a phenomenon affecting others as well. Such understanding diminishes feelings of isolation, failure, and defectiveness and may also contribute to the development of empathy

Flexibility in Emotional Experience-This refers to the ability to be in touch with a variety of emotions -- not denying or suppressing major affects as they arise. At the same time, there is some ability to defer or defend against some overwhelming anxiety or depression when emergency resources are needed.

Access to Autobiographical Memory-This refers to the ability to remember and invoke images of good and sustaining figures, usually parental figures. These images might at times be critical and demanding as well as warm, loving, and encouraging. It appears that the critical voice of the parent is important for maintaining certain ideals and standards, as well as for keeping in touch with some sense of the security that comes with belief in a "normal" moral order. The ability to remember, imagine, and be in touch with sustaining family stories and community legends is also important.

Need and Ability to Help Others-The unspoken assumption is that altruism also serves one's selfish benefit. A "learned helpfulness," in contrast to a "learned helplessness" is a powerful aid to survival. This skill often draws upon identification with parents who themselves have instantiated the effectiveness of altruistic acts. Altruism as expressed by the child toward others may be modelled on the altruism of adults.

3.8 Memory work and resilience

Projects designed to promote improved development in children at risk may well present the paramount test of theories about resilience, if they are theoretically designed and cautiously evaluated (Masten & Coatsworth, 1998). The role of memory work in improving children's emotional and social development has often been discussed in literature on helping children deal with grief and loss. Providing a warm, safe place for children's narratives allows the caregiver and the child to remember (Denis, 2005). The act of remembering liberates them from a heavy weight; remembering will therefore enhance their resilience (Denis, 2005).

Memory boxes are developed using two types of interviews: those occurring in the presence of the ill parent or those that take place after his/her death. While the parent is still alive, the memory facilitators' work consists of helping the child to acquire memories. They create a context in which the sick parent can speak to the child, and the child can listen. In this way, the child is better able to preserve the memory of the parent's voice, face and words when the parent has died. He is also better able to provide a measure of control over the emotions evoked in remembering the dead parent. The act of remembering is presumed to promote resilience in children (Denis, 2005).

Memory box goes further than promoting remembering, it also facilitates inter-generational dialogue within the family. Grandparents, uncles and aunts get to share with the children the richness of their family values and culture and the good way of life. Memory box work is similar to traditional story telling. Our children's cultural strength or resilience can also be fostered by the oral tradition of storytelling (Heavy-Runner & Morris, 1997). The stories shared during the development of the memory box can be shared now and again, and as the story is retold, new things are learnt by the child. They are protective factors that express culturally specific levels of caring, support, and opportunities for participation (Weigel, 2006).

Memory boxes are also seen as providing children with the world view through historical and cultural lens. Through these lenses children understand where they came from, where there are today, and where there are going (Heavy-Runner & Morris, 1997). Our cultural identity is our source of strength (Heavy-Runner & Morris, 1997). Mapping out a life story assists the writer to alter his/her existence within a background and by inserting it into his/her current situation (Denis, 2005). It is important that social scientists and social service providers realise the legitimate and positive role history and culture plays in supporting children in tapping into their resilience.

Having looked at the literature it becomes evident that the provision of programmes which reduce the psychosocial impact of HIV and AIDS on communities and in particular on orphans and other children are important for the social and emotional development of children. Through the application of Memory Box Programme it is possible to provide children with an avenue through which to understand their past or present and express some of their reactions to the many dramatic changes in their lives thus fostering resilience. This is what the current study is going to examine more closely.

Chapter 4: Methodology

4.1 Introduction

The assumption underlying this research was that orphaned children who participate in the Sinomlando Memory Box Programme develop a healthier social and emotional functioning. In contributing to the discourse on the role of memory work, an interpretive method of data collection and analysis in the form of a focus group discussion and thematic analysis was utilized. This chapter outlines the process of the data collection and analysis.

4.2 Research question

Currently social and emotional support programmes for OVC in developing countries are fairly new and vary in design and focus. Many authors have noted that the social and emotional development of orphans and other vulnerable children is seldom highlighted as a priority for intervention research (Bray, 2003; Stein, 2003). The purpose of this research was to help unpack the benefits of Memory Box Programme facilitated by Sinomlando Centre. Thus the research question: What benefit does Memory Box Programme run by Sinomlando Centre have on the social and emotional developmental functioning of orphaned children?

4.3 Research design

4.3.1 Interpretative perspective

Dilthey (1988) argues that cultural differences coupled with social world changes make it impossible to discover laws as in the natural sciences. Instead he believed emphasis should be placed on understanding the individual (Woods & Trexler, 2001). He suggested “the social sciences must be descriptive as opposed to explanatory and must concentrate on interpretive understanding” (Dilthey, 1988, p. 152). As such, the interpretive perspective attempts to understand phenomena through the participants’ own experiences and the

meanings they assign to them (Myers, 1997). Carr and Kemmis (1989) emphasized that to identify the actor's motives and intentions correctly is to grasp the subjective meaning the action has for the actor.

In using the interpretive approach, the perceived meaning and effects of memory work are not objective phenomena with known properties or dimensions (Rowlands, 2005).

Therefore in this research, the experience of Memory Box Programme was subjective and best understood in terms of participants' subjective meanings rather than the researcher's objective definitions. Mouton (2003) argues that interpretive research searches for an insider perspective and not an outsider perspective, where the researcher attempts to understand people in terms of their own definition of the world.

Interpretive researchers appreciate phenomena through accessing the meanings that participants assign to them. In contrast to positivist studies, interpretive researchers reject the possibility of an objective or factual account of events and situations, seeking instead a relativistic, albeit shared (between the researcher and the interviewee) understanding of phenomena (Rowlands, 2005).

4.3.2 Research participants

In order to identify suitable participants for the research, the researcher had to answer a couple of questions, e.g. what is the purpose of the Sinomlando Centre? What is the purpose of their Memory Box Programme? What is the purpose of the focus group? What specific kind of information is needed from the group? How will the information be used (Rennekamp & Nall, 1993)?

Participants were selected from the Sinomlando Centre which has a number of research and community development projects. The Sinimlando Centre was established in 1994 and conducted its first pilot study on memory boxes in 2001. The pilot study led to the development of various guides and manuals targeted at those working with orphaned children. In 2004, twenty six organisations partnered with the Memory Box Programme.

With such developments Sinomlando Centre is becoming one of the well respected Memory Box Programmes in South Africa.

The Sinomlando Centre endeavours to help underprivileged communities take ownership of their history. One way of doing this is through the Memory Box Programme. The Memory Box Programme helps families affected by HIV and AIDS to record their stories as a way of enhancing resilience in their orphaned or soon to be orphaned children (Denis, 2005). Memory box is one of the techniques used in memory work (Morgan, 2004).

The basic assumption of Sinomlando Memory Box Programme is that it is essential for one to know his/her history, no matter how painful this might be. The recounting of the history should be done in an affectionate way. It is assumed that if children know the history of their parents, they are better able to overcome the suffering caused by their illness or death (Denis, 2005). This knowledge is gathered through the memory of those close to the child and the child himself/herself.

This study looked at the benefits of Memory Box Programme on the emotional and social development of orphans, which then limited the selection and type of participants. Selection of participants, thus, was based purely on the purpose of the research, looking for those who had participated in memory box workshops facilitated by the Sinomlando Centre. Purposive sampling was used for this research, with researchers selecting participants based on the project and on the potential contributions of participants (Miles & Huberman, 1984). In line with the interpretative research approach, emphasis was placed on an information rich sample that would provide the researcher with rich data.

The size of focus groups varies according to what sort of information is needed and how involved the participants are in it (Lewis, 1995). However, most focus groups consist of between 6-12 people (Raczka, 2005). The number of participants within a study is often influenced by the type and nature of the study (Morgan, 1998). Merton (1990, p. 137) suggests that:

"the size of the group should manifestly be governed by two considerations...it should not be so large as to be unwieldy or to preclude adequate participation by most members nor should it be so small that it fails to provide substantially greater coverage than that of an interview with one individual".

Since there are no strict rules on the number of participants per focus group, this researcher had 26 participants for the study. The participants were split into 3 groups, allowing for easy management of the discussion.

For this kind of research, homogeneity in focus group participants was of necessity. Participants were selected bearing in mind that the research was specifically targeting orphaned children who were exposed to the Memory Box Programme. Participants were from the same community and race (black). The groups had a fair mixture of boys and girls aged between 12 years and 15 years. Most researchers prefer a homogeneous group with the common threads being the issues for discussion (Vaughn, Schumm & Sinagub, 1996). In this approach it is believed that having too many different voices could detract from the overall purpose (Barnett, 2006). It is best to select people that are relatively homogenous because this tends to reduce inhibitions and facilitate interaction (Linda, 2005). Composing a group with highly different characteristics may decrease the quality of the data. Individuals will tend to censor their ideas in the presence of people who differ greatly from them.

4.4 Focus Group Discussion

4.4.1 Rationale for selection of focus group methodology

Over the past decade, focus groups have emerged as a popular technique for gathering data of an interpretative nature (Gibbs, 1997). Focus group research involves organized discussion with a selected group of individuals to gain information about their views and experiences of a topic (Lewis, 1995).

The term focus group was coined by Merton in 1956 to apply to a situation in which the interviewer asks group members very specific questions about a topic (Denzin & Lincoln, 1994). Robson (2002) defines a focus group as a group interview on a *specific* topic, which is where the ‘focus’ comes from. For the purposes of this research, focus group is defined as a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research (Gibbs, 1997). Given the adopted definition, the researcher selected and grouped orphaned children who attended a memory box camp run by Sinomlando Centre. The main purpose of focus group discussion was to draw upon respondents’ experiences and reactions to Memory Box Programme and how they have benefited socially and emotionally from it.

Morgan (1997) attributes three reasons to why social scientists often use focus groups. Firstly, as the principal method of data collection in which the results can stand alone; secondly, as a supplementary source to embellish another data source such as a survey and thirdly, in multimethod studies. In this research, focus group was used as the primary data collection method.

Focus groups are suitable for projects requiring exploration and discovery, thus they are suitable to look at issues of memory work. They are normally used for topics that are poorly understood, because the discussion between people will provide data. Focus groups provide detailed insights into peoples’ beliefs and experiences (McDonagh-Philp, Denton, & Bruseberg, 2001).

Focus group methods combine both context and depth. They encourage the investigation into, and comparison of, differences between preferences at a detailed level (McDonagh-Philp et al., 2001). On the other hand, they provide reasons for individual opinions and experiences (Morgan, 1998). Focus group discussion assisted the researcher to look at Memory Box Programme from multiple perspectives, and to interpret the significance of the way people talk about it (Linda, 2005).

The hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group (Morgan, 1988). While it is true that certain attitudes and opinions that people have may be independent of a group setting or its social significance, it is also true that the same attitudes and opinions are more likely to be revealed via the social setting and group environment that a focus group provides (Grudens-Schuck, Allen, & Larson, 2004). Focus groups elicit information that paints a portrait of combined local perspectives. Therefore focus groups capitalize on the interaction between and among participants to stimulate and refine thoughts and perspectives (Raczka, 2005). The method relies upon the interaction between the individuals during the discussion, also referred to as the synergy of the group (Kitzinger, 1994). In a focus group, the object of the analysis is the interactions among the group members, how the group collectively creates meanings and negotiates definitions of whatever is discussed (Linda, 2005). It is believed that this synergistic approach generates more insightful information and encourages participants to give more candid answers (Nassar-McMillan & Borders, 2002).

One obvious advantage of focus groups is that greater amounts of information can be gathered in shorter and more efficient time spans (Krueger, 1994). Focus groups do lead to important insights about topics and allow the facilitator to probe a group's thinking on matters both scripted and that arise spontaneously through conversation. The group synergy fosters more creativity and therefore provides for a greater range of thoughts, ideas, and experiences (Vaughn et al., 1996). Fourth, focus groups allow participants to feed off one another's ideas and spark thoughts that may not have been captured in isolation (Holsman, 2002). Fifth, peer validation inherent in such groups also can serve as a catalyst for the expression of these. Finally, researchers are able to observe the interaction between group members, which sometimes provides additional valuable insights regarding a topic or phenomenon (Nassar-McMillan & Borders, 2002).

4.4.2 Developing questions for focus groups

In preparing for the focus group discussion, the development of questions is of paramount importance. The questions should enable the researcher to effectively solicit for information, thus the questions should encourage participants to respond. A focus group discussion should have 10 questions at most (Kreuger, 1988). Stewart and Shamdasani (1990) propose that most interview guides consist of fewer than a dozen questions. The researcher developed questions which were linked to the research question and also related to the purpose of the study.

The questions were put into classes that allowed for a smooth flow of the group discussion. According to Rennekamp and Nall (1993), there are five general types of questions used in focus group discussions. These five types of questions were used in this study. The five types of questions normally follow each other in the manner shown below:

Table 5: Five types of questions used in FGD (*Adapted from Rennekamp & Nall, 1993*),

1 **Opening questions** are used to get people talking and feeling comfortable. They should be easy to answer, but should not emphasize differences among group members.

Example: *Please tell us your name and how long you have been participating in the Sinomlando Centre Memory Box Programme.*

2. **Introductory questions** are used to get the group to start thinking about the topic at hand. They help focus the conversation.

Example: *How was it that you first learned about the Memory Box Programme?*

3. **Transition questions** provide a link between the introductory questions and the key questions. They typically ask participants to go into more depth than introductory questions.

Example: *Think back to when you first became involved with the Memory Box Programme. What were your first impressions?*

4. **Key questions** focus on the major areas of concern. The majority of the time is devoted to discussions of these questions.

Example: *In what way is your life different because of your participation in the Memory Box Programme?*

5. **Ending questions** bring the session to closure.

Example: *Is there anything we should have talked about, but didn't?*

4.4.3 Logistics

Conducting groups involved some planning and making logistical decisions, such as where the groups should be held, at what time, and for how long (Krueger, 1994). The meeting time was conveniently chosen to accommodate all the participants, bearing in mind that it was during school days. Each focus group discussion (FGD) was scheduled to take 1 hour

30 minutes, with 15 minutes break. Participants were told in advance how long the FGD was to take. This helped to increase commitment and willingness to participate (Barnett, 2006). The venues for the FGD were selected to suit the participants.

Keeping in line with ethical guidelines, the moderator, through Sinomlando programme officer, discussed the purpose of the study and obtained informed assent from participants and informed consent from their primary caregivers before the FGD. The consent was for their participation in the research as well as for audio-taping. Participants were encouraged to freely share their own thoughts and ideas.

The person running a focus group is usually referred to as facilitator. The facilitator's attributes were very crucial as FGD comprised of children who had been affected by HIV and AIDS. Facilitator attributes may contribute to successful interviews. According to Kreuger (1988), facilitators must be mentally alert and free from distraction, anxieties and pressures. Lewis (1995) argues that a good facilitator is anticipatory; alert to establish rapport; naive; analytic; paradoxically; nonreactive; nondirective and therapeutic; and patiently probing. For this study, the researcher, with the supervisor's assistance, managed to identify sensitive and competent facilitators. These three facilitators were Psychology students at the University of KwaZulu Natal. Their selection was based on their ability to facilitate FGD with children and fluency in IsiZulu. All FGD participants were Zulu speakers which meant that the researcher could not facilitate the FGDs since his first language is Shona and cannot communicate in IsiZulu. The researcher arranged a meeting with the facilitators where facilitators went through the study subject matter (memory box), study objectives, and question, FGD questionnaire and the FGD process. For one of the facilitators, memory box was a new concept hence the researcher had to meticulously take them through the concept.

4.4.4 The focus group discussion

The FGD were carried out between December 2006 and July 2007 at the participant's community halls. The recommended pattern for introducing the group discussion includes the welcome, overview of the topic, explaining the use of audio recorder, ground rules and the first question (Lewis, 1995). It is important to note that IsiZulu was used for the FGDs as it was the most preferred language for the research participants.

As participants arrived they were welcomed by the moderator. The moderator explained clearly that the purpose of the discussion was to find out how Memory Box Programme has contributed to their emotional and social wellbeing. Participants were told that the facilitator was not looking for any right or wrong answers but that s/he wanted to learn what each participant's views were. It was made clear to all participants that their views were valued. The facilitator assured them that their candid responses would have no negative consequences on their involvement with Sinomlando Centre. The Sinomlando Centre project coordinator expressed her desire to utilize the information they learned in improving their programme.

Although participants were already aware (as they had signed the assent form) of the audio recording, the facilitator explained that the notes and audiotapes would be kept completely confidential (Barnett, 2006). Experience reveals that, compared to a video recorder, an audio recorder is much less intrusive and less likely to stifle discussion (Barnett, 2006). In an effort to build rapport, members were asked to introduce themselves. Stewart and Shamdasani (1990) suggest that it is a good idea to have group members introduce themselves and tell a little about themselves. To effectively break the ice, the facilitator led participants through an activity that allowed them to relax.

Thereafter, the facilitator discussed ground rules with the participants. Participants agreed to respect each others' opinions and not to divulge any confidential information to people outside the group.

The introductory question (How was it that you first learned about the programme?) was used to get the group to start thinking about the topic at hand. This was followed by transition questions. As participants become more comfortable, the facilitator then moved to more specific (key) questions.

From there on, the facilitator's main role was primarily to help them stay on track as necessary and also to help the group members in articulating their perspectives on memory boxes. Probes were used to clarify questions when the group members seemed not to be responding. The facilitators also used questions which helped participants give deeper or richer explanations for their answers.

The facilitators created a permissive and nurturing environment that encouraged different perceptions and points of view (Marczak & Sewell, 1998). At times, the facilitators deemed it necessary or beneficial to probe into deeper issues. In probing specific topics, the facilitators were careful not to encourage individual participants to discuss any topic against their will.

When no new ideas were being offered, the facilitators wrapped up the session by summarizing the discussion to make sure that they captured what the participants said. The facilitators provided a closing statement, thanking the participants for their time and assuring them that their responses will be kept completely confidential. Each FGD was completed in less than 1 hour 30 minutes with 15 minutes break. This allowed for participants to refresh and be able to concentrate throughout the FGD. The opportunity for follow up was offered through consulting with the Sinomlando Centre project coordinator.

4.5 Ethical considerations

The basis of research ethics is to protect research participants from any unfair practices. The upholding of research ethics should be of paramount importance for social researchers in all aspects of their planning, designing, implementing and reporting research with human participants (Wassenaar, 2006). When researching a vulnerable and marginalized

population, one needs to be consciously and consistently aware of power dynamics in the research (O’Kane, 2000). Research participants may see the researcher as having authority over them.

Every effort was made to uphold the highest ethical standards while conducting this study. The researcher was aware of the stigma and human rights issues around HIV and AIDS. It was clear to the researcher that, research participants may experience psychological and social harm, even when precautions are taken (Family Health International, 2005).

There are generally four philosophical principles guiding ethical research namely: autonomy, nonmaleficence, justice and beneficence. Based on these philosophical principles, Emanuel et al. (2004 as cited in Wassenaar, 2006) have developed an ethical research framework based on eight practical principles:

1. **Collaborative partnership:** The research should be sensitive to the values, cultural traditions, and practices of the community. The research upheld this principle, for example, going to primary caregivers to seek their consent.
2. **Social value:** The problems being studied should lead to knowledge/interventions that will be of value to the participants and/or society.
3. **Scientific validity:** The design, methodology, and the data analysis applied in the study should be rigorous, justifiable, feasible, and lead to valid answers to the research question. The researcher used scientifically accepted methods and data analysis.
4. **Fair selection of study population:** research participants should be selected in line with what the research seeks to achieve. All participants took part in the Memory Box Programme and were in a position to articulate their experience of the programme.
5. **Favourable risk/benefit ratio:** the researcher should seriously weigh the potential risks of the research against its benefits. A research with risks that out-weigh the benefits should not be carried out.
6. **Independent ethical review:** The research proposal was to be approved by an ethical review committee prior data collection.

7. **Informed consent:** prior to taking part in the research, participants should be fully informed about the research. The primary caregivers and the FG participants were fully informed on the study before they were asked to sign the consent and assent forms respectively.
8. **Ongoing respect for participants and study communities:** participants should be treated with respect during a study, that their individual information remains confidential (Wassenaar, 2006). The actual names of the FG participants were not used. Participants were also briefed on the importance of confidentiality and they all agreed to uphold this principle.

The upholding of these eight practical principles was critical in helping reduce harm to research participants in this research.

Acknowledging vulnerability

The research acknowledged that the research participants are from a vulnerable, marginalised group, i.e., children affected by HIV and AIDS. The UN Convention on the Rights of the Child states that:

State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (Kehily, 2004, p. 157).

Earlier research tended to be *on* children, regarding children as subjects of the research. Increasingly, research is now conducted *with* children, who are being involved as active participants (Hill, 1997).

Incentives

No incentives were offered during this research. The researcher was cognisant of the fact that the research was carried out on a vulnerable group and that incentives might have lured them to agree to take part in the research in a manner that may have affected their autonomy. It was hoped that by participating, the participants would benefit therapeutically

through expressing their feelings and having the opportunity to develop their narratives and thereby enhance emotional and social wellbeing.

Confidentiality

Confidentiality issues were explained to the children in a way that they could understand. Only the researcher, facilitators, and supervisor had access to the data gathered during the research. A coding system was used as the research will endeavour to protect the participants' identities.

Informed consent

The principles for conducting research contained in the Declaration of Helsinki (2000) apply to all human subjects, adults and children. Research with minors is ethically and legally complex and should, as a rule, be done only with the consent of legal guardians and the assent of the minors (Wassenaar, 2006).

The informed consent form included:

1. Explanation of the purpose for which the data was collected, the expected duration of the participant's involvement, and a description of the procedures to be followed.
2. Description of any reasonably foreseeable risks or discomforts.
3. Description of any reasonably foreseeable benefits to the participant or others.
4. Description of the measures to be taken to ensure the confidentiality and anonymity of the participant's records.
5. Information about who could be contacted for questions about their rights as a participant.
6. Explanation that participation is entirely voluntary and that refusal to participate would not result in a penalty or loss of benefits and that the participants could freely refuse to answer any questions, Furthermore, it was permissible to withdraw from the study at any time, with no adverse consequences.

Copies of the consent and assent forms are to be found in Appendices A and B.

The researcher offered the participants a clear explanation of the aims of the study and the tasks required of them, and answered any questions or concerns that they might have had regarding the research. Participants were referred to the project coordinator of Sinomlando Centre in the event that they required more information.

Limits to confidentiality

Focus group discussions present complications concerning confidentiality, as the researcher cannot guarantee that all group members will treat the information of other persons with the respect it deserves (Wassenaar, 2006). To counter this problem, group members were asked to verbally consent that they would keep the issues discussed as confidential.

Withdrawal from the study

Participation in the research had to be freely volunteered, with the understanding that the research participant could withdraw at anytime without penalties. Participants were informed of their right to withdraw from the process at any stage.

Research findings

Reporting of the research findings is an important step and a way for research findings to reach both the participants and the community at large (Sarantaos, 1998). The results generated from the research will be made known to the participants. A meeting will be arranged to share the results with all of the participants.

Risks and referral

What is the possible impact of the research on the child, during and after the research? The researcher anticipated the possibility of uncovering emotional distress, poverty, or other

crises during the interview process. For this reason, the researcher worked in close collaboration with NGO's and set up a referral system for children prior to the start of the research. This referral system was put in place with consultation with the community gatekeepers (Horizons, 2005).

4.6 Data analysis

Data analysis involves examining, categorizing, and recombining the data collected during the focus group to address the initial purpose of the study (Rennekamp & Nall, 1993). Analysing focus groups is basically the same as analysing any other qualitative data. At the very least, the researcher draws together and compares discussions of similar themes and examines how these relate to the variables within the sample population (Kitzinger, 1995).

4.6.1 Thematic analysis as a methodology

Thematic analysis is a frequently used qualitative analytic tool within and beyond psychology (Boyatzis, 1998). Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes the data set in rich detail. However, it frequently goes further than this, and interprets various aspects of the research topic (Boyatzis, 1998).

Unlike many qualitative analytic tools, thematic analysis is not tied to any pre-existing theoretical framework. This gives it the leeway to be used within different theoretical frameworks. Any theoretical framework carries with it a number of assumptions about the nature of the data, what they represent in terms of the ideal and, the reality. A good thematic analysis will make this transparent (Braun & Clarke, 2006).

In thematic analysis, the identification of themes is commonly determined by a number of factors. Firstly, themes within data can be identified in one of two primary ways: in an inductive way or in a theoretical or deductive way. The inductive approach allows research

findings to emerge from the frequent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies (Thomas, 2002). On the other hand, theoretical thematic analysis takes individual factors and weighs them against the current knowledge about such things to come to a conclusion. Since memory work is still a relatively new intervention, inductive approach was utilized as it allows the researcher to consider every item in the data set.

Secondly, themes are grouped into two levels. At the semantic level, themes are identified within the surface meanings of the data. At this level, the researcher is purely looking for what the participants said. The latent level goes beyond this, seeking to investigate the underlying ideas, assumptions and conceptualisation and ideologies that are theorised as shaping or informing the semantic content of data (Braun & Clarke, 2006). The latent level was adopted to shape the discussion of results for this study.

Thirdly, Braun and Clarke (2006) argue that thematic analysis can be conducted within both realist/essentialist and constructionist paradigms. With a realist/essentialist approach, one can theorise motivations, experience, and meaning in a straightforward way, because a simple, largely unidirectional relationship is assumed between meaning and experience and language (Widdicombe & Wooffitt, 1995). In contrast, from a constructionist perspective, meaning and experience are socially produced, rather than inhering within individuals (Burr, 1995). In this study, the realist/essentialist paradigm was utilized since the researcher was seeking to understand experiences of those who are exposed Memory Box Programme. Interpretive understanding is only possible by way of uncovering or deconstructing the meanings of a phenomenon. Thus, a distinction between explaining how something operates (explanation) and why it operates in the manner that it does (interpretation) may be a more effective way to distinguish the effects of memory boxes (Thorne, 2000).

Step 1: Familiarising with the data

It was important for the researcher to submerge himself in the data to the extent that he was familiar with the intensity and breadth of the content. Submerging involves back and forth reading of the data and actively searching for meanings and patterns within the data.

Audiotape content was transcribed to allow for analysis of the data (Lloyd, Williams & Sullivan, 2004). The researcher's task was to prepare a statement regarding the collected data. The first step was to transcribe the entire FGD. This provided a complete record of the discussion and facilitated analysis of the data (Lewis, 1995).

It is important that the transcript retains the information one needs from the verbal account, and in a way which is true to its original nature (Thorne, 2000). Some researchers even argue it should be seen as "a key phase of data analysis within interpretative qualitative methodology" (Bird, 2005, p. 227), and recognized as an interpretative act, where meanings are created, rather than simply a mechanical act of putting spoken sounds on paper (Lapadat & Lindsay, 1999).

Step 2: Generating initial codes

The first major analytic phase of the research consists of coding the data. In short, coding is the process of defining what the data are all about (Braun & Clarke, 2006). The aim of this analysis was to look for trends and patterns that reappeared within the focus group (Lewis, 1995).

The subsequent coding process concerned the researcher actively going through the transcribed data, looking for regular thematic categories into which the data could be organised, and allocating code words to each category (Lloyd, Williams & Sullivan, 2004). Codes identify a feature of the data (semantic content or latent) that appears interesting to the analyst, and refer to "the most basic segment, or element, of the raw data or information

that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63).

Every line, paragraph, or other section of text was coded for relevant themes. Also, codes that were rarely used were dismissed and some categories broadened to accommodate the lost code. Important to note is that this type of analysis (coding) is not linear, but circular. Constant comparison means that the researcher was continually going back to the transcript (Glaser & Strauss, 1967).

Step 3: Searching for themes

A theme highlights essentials about the data in relation to the research question. This also exposes some level of patterned response or meaning within the data set. The importance of a theme in this research was not necessarily dependent on quantifiable measures but rather on whether it captured something important in relation to the overall research question (Braun & Clarke, 2006). This phase focused at the broader level of themes, involving sorting the different codes into potential themes. This involved classifying similar codes into a theme and deriving meaning from the themes.

Step 4: Reviewing themes

After the themes were identified they needed to be refined. The process of refinement had two levels. Level one consisted of reviewing at the level of the coded data extracts. The researcher read all the collated extracts for each theme, and considered whether they appeared to form a coherent pattern (Braun & Clarke, 2006). Level two involved a similar process, but in relation to the entire data set. At this level, the researcher considered the validity of individual themes in relation to the data set.

Step 5: Defining and refining themes

At this point the researcher then defined and further refined the themes. Defining and refining means identifying the value of what each theme is about (as well as the themes overall), and determining what aspect of the data each theme captures (Braun & Clarke, 2006). With the themes identified, the researcher then began the process of writing the themes and describing how they were interrelated. Rewriting continued until the researcher felt the themes (parts) and the relationship between the themes (whole) captured as accurately as possible the way these children experienced the Memory Box Programme.

4.6.2 Reliability and validity

Qualitative research, broadly defined, means “any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification” (Strauss & Corbin, 1990, p. 17). Thus, a number of leading qualitative researchers argue that reliability and validity are terms which are derived from the quantitative paradigm and are not so important to the qualitative inquiry (Morse, Barrett, Mayan, Olson, & Spiers, 2002). It has been suggested when it comes to qualitative inquiry, researchers should adopt new criteria for determining reliability and validity, thereby ensuring rigor in the process (Morse *et al.*, 2002)

Guba and Lincoln (1985) opted to replace reliability and validity with the parallel concept of trustworthiness, which contains four facets: credibility, transferability, dependability, and confirmability (Morse *et al.*, 2002). The most important aspect in relation to trustworthiness is for researchers to convince the world that the findings are worth taking note of (Lincoln & Guba, 1985). Table 6 shows comparison of criteria for judging the quality of quantitative versus qualitative research.

Credibility determines the truth value of a qualitative study. According to Sandelowski,

A qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it from those descriptions or interpretations as their own (Sandelowski, 1986, p. 27).

Table 6: Quantitative and qualitative terms (*Adapted from Hoepfl, 1997*).

Quantitative terms	Qualitative terms
internal validity	credibility
external validity	transferability
reliability	dependability
objectivity	confirmability

The researcher chose member checking as a technique to enhance credibility of this study. Member checking refers to the process by which data, conclusions, and interpretations are presented to members of the groups from which the data were collected.

The preliminary results of this research were presented to participants who were part of the original focus group. The purpose of the session was to correct factual errors, as well as to hear reactions to the overall conclusions of the study. Not only did the discussion strengthen the interpretation of the findings, but it also created ownership of the findings among the participants.

Since qualitative research relies on purposive rather than random sampling, there is no expectation that findings from this research can be statistically representative of a larger population. Transferability was achieved by producing detailed and rich descriptions of contexts. The researcher collected detailed descriptions of data in context and reported them with sufficient detail and precision to allow judgments about transferability to be made by the reader. These understandings are anticipated to be transferable to new contexts in other studies to provide a framework with which to reflect on the arrangements of meaning and action that occur in new contexts (Van der Riet & Durrheim, 2006).

In quantitative research, consistency or reliability of results is a key aspect of trustworthiness. If another researcher conducted the same study using the same or similar methods on the same or similar population, would the same results be obtained? Reliability in qualitative research is based on the premise that researchers and study participants are intimately related, and their interaction inevitably shapes the research process.

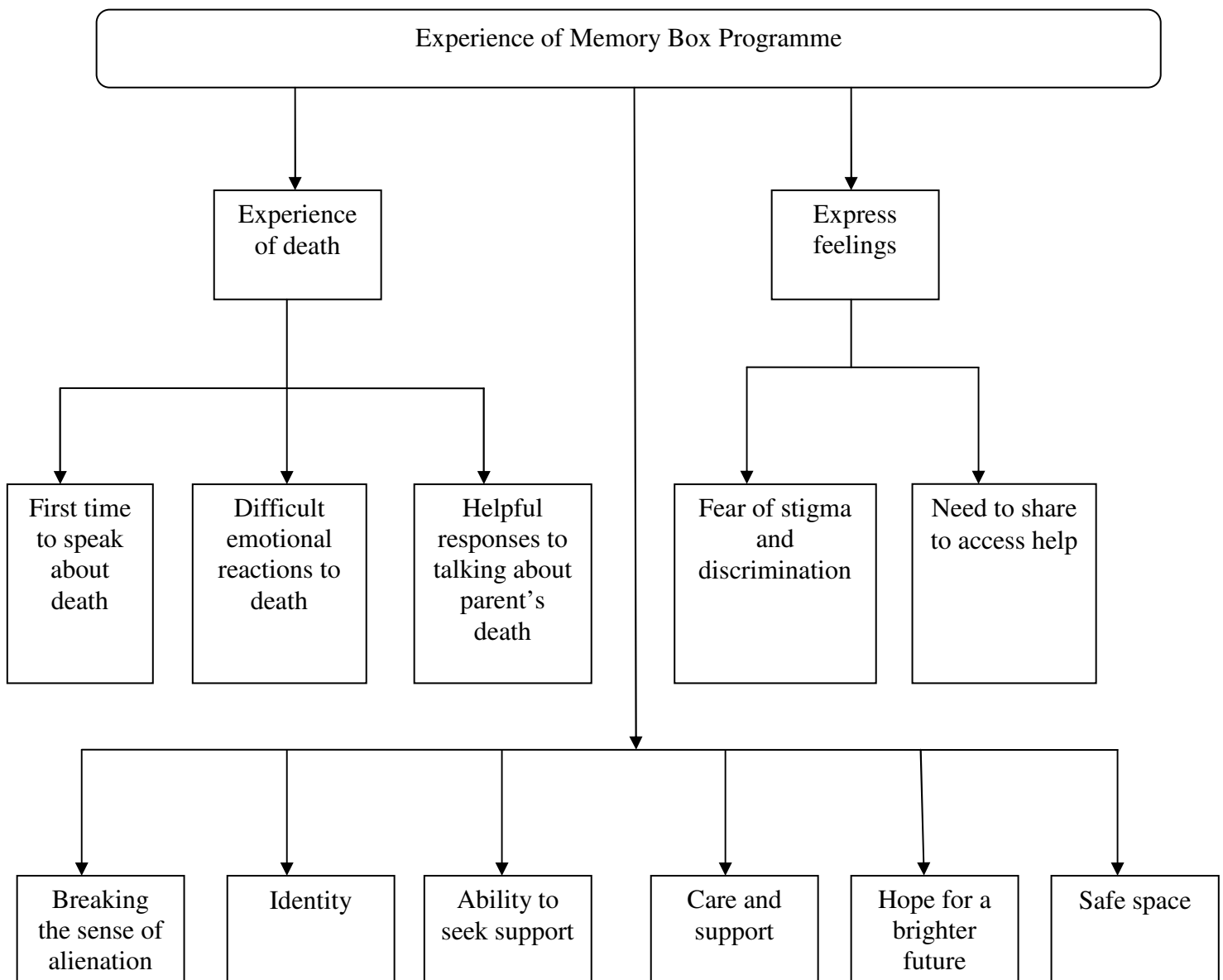
An inquiry must also provide its audience with evidence that if it were replicated with the same or similar respondents (subjects) in the same (or a similar) context, its finding would be repeated. Qualitative research is assessed by its dependability. Dependability was achieved through rich and detailed descriptions that showed how certain actions and opinions are rooted in, and develop out of, contextual interaction. Dependability was also achieved by providing the reader with a frank statement of the methods used to collect and analyse data (Van der Riet & Durrheim, 2006).

Qualitative researchers argue that subjectivity is unavoidable, and that the interaction between participants and researchers actually enriches qualitative research. The neutrality of the data rather than that of the researcher are sought, using the criteria of confirmability. Confirmability is the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher. In this research, audit trails helped establish confirmability. The auditor determined if the conclusions, interpretations, and recommendations could be traced to their sources and if they were supported by the inquiry.

Chapter 5: Results

The aim of the research was to consider children's experiences of Memory Box Programme in relation to their social and emotional adjustment following their parent's death. Qualitative investigation of the Memory Box Programme took place through focus group discussions with three groups of memory box participants. This chapter is wholly dedicated to the presentation of results. The process of data analysis is described in the previous chapter. The diagram below illustrates the themes obtained from the data analysis.

Diagram 1 Themes illustrating experiences of involvement in Memory Box Programme



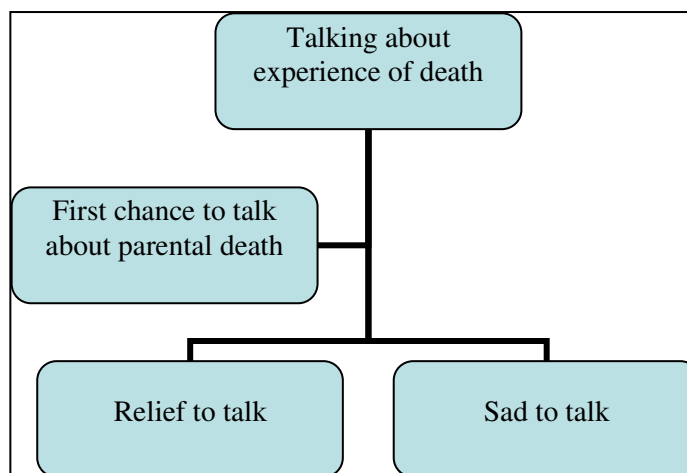
Extracts from the focus groups will be used to illustrate the concepts discussed. The following notations will be used in this chapter as a way of presenting the results.

- **FG 1/2/3:** will be used to denote which focus group (whether 1, 2 or 3) the individual quotation is extracted from.
- **F:** will be used to denote facilitator of the focus group
- ...The use of an ellipse within a quotation indicates that part of the extract has been omitted in order to shorten it and to highlight only the most relevant parts of the extract.
- **P:** will be used to denote participant

5.1 Experience of death

The common denominator in the focus groups was that all the participants had lost one or both parents. Losing a loved one triggers emotional reactions, which if not attended to can negatively affect one's wellbeing. It does not necessarily mean that these emotional reactions are bad but prolonged mourning can cause psychosocial problems. The experience of death thus becomes an important theme to discuss. This theme is divided into three interrelated sub themes (see Diagram 2).

Diagram 2: Different experiences associated with talking about death



5.1.1 First time to speak about death

The above section suggests that it is helpful for children to talk about their parents' death. Surprisingly some children are not afforded the opportunity to talk about their loss. Most children indicated that the Memory Box Programme offered them the first real opportunity to talk about their parents' death. For most participants the Memory Box workshop which took place at Labri camp in Pietermaritzburg offered them the opportunity to share about their parents' death. Their response shows that the Memory Box Programme creates the space and time for children to talk about their parents' death.

P: I started at Labri, my mom died when I was young (FG3).

P: I started at Labri, my father abandoned me and my mom died (FG3).

P: I started after Labri; I talk with my friend, whom I trust (FG3).

P: I started after Labri to talk about my parents (FG3).

P: I first started at the camp (FG2).

P: At the camp (FG2).

P: At the camp (FG2).

P: I say it has changed; because at the camp it was the first time I spoke about my situation. I spoke to other people (FG2).

A sizable number of participants in focus group 3 indicated that they had prior opportunities to share about their loss before their involvement in the Memory Box Programme. In some families and communities, children are given the opportunity to talk about their loss.

P: I started before we went to Labri, at home they told me about the death of my mother (FG3).

P: I started before I went to Labri, I told my friends that my father committed suicide and my mother was sick (FG3).

P: Before Labri, I don't know my father and my mom was sick before she died (FG3).

5.1.2 Difficult emotional responses to death

Participants in the focus groups indicated that when their parent died, they felt sad, worried and angry. How long these emotional reactions last depends on a number of factors ranging from the individuals' internal locus of control to the support they receive while mourning. Some participants indicated that they have continued to experience feelings of sadness, anger and worry long after their parents have died:

F: Now tell me which feeling do you still experience even it has been sometime after your parents death?

P: I feel sad sometimes when I think of my mother (FG3).

P: I feel sad (FG3).

P: Worried (FG3).

P: Angry (FG3).

P: Sad (FG2).

The loss of a loved one is difficult to get over. One needs to go through a process of grieving and mourning. Participants gave a number of reasons why they still felt sad, worried and angry. Chief amongst them is unmet parental roles. Participants indicated that they miss their parents more when they see their friends having fun and being provided for by their parents:

F: R2: Why was it sad?

P: It is painful for me. In December, other children go to Durban, so you think to yourself that if your parents were still alive, you would also go (FG2).

P: It's painful because other children go to school, and you find that you do not go. Their parents pay for them. So you think to yourself that if your parents were still alive, you would also be going (FG2).

P: It hurts because other children talk about their parents, and you think to yourself that if your mother was still alive, we would also talk about her (FG2).

5.1.3 Helpful responses to talking about parents' death

The Memory Box Programme affords children the opportunity to talk about their parents' death. For some focus group participants, talking about their parents' death was therapeutic as it relieved them of the pain that was hurting them. It also allowed them to be bold and to go out and face the world. Most children in the focus groups thus indicated that talking about their parents was helpful:

P: For me it was helpful to talk about the death of my parents. It made me to be comfortable and not to be scared to talk to other people (FG 3).

P: It is okay to talk about parents. If you hide it, you end up feeling pain. Losing your parents is painful to your heart. It burns (FG2).

P: It was helpful to talk about my parents, Before when people asked me how my parents died, I used to cry. But not anymore, now I can talk about them without crying and I feel comfortable (FG 3).

P: It is okay to talk about your parents because I couldn't keep something painful inside my heart (FG2).

Losing a parent can bring much pain and heartache. While some people may find it easy to talk about their loss, others find it extremely difficult. Some find it very difficult as

discussing the issue might trigger painful memories. Some focus group participants found it challenging to talk about their loss:

P: I didn't like talking about my parents because it made me think about them and wish that they were still alive (FG1).

P: I was afraid to talk about those things, to talk to other children about the fact that my parents had died (FG2).

5.2 Breaking the sense of alienation

Some people find themselves confined to their own world after losing a loved one believing that the experience of parental death and the associated grief is unique to them. Participants of the focus groups spoke about their own experience of being different to other children. Prior to their involvement in the Memory Box Programme, most children believed they were the only ones who had lost parents. Meeting others who have experienced a similar situation brought comfort and realization that they were not the only ones facing these difficult circumstances.

P: It helped; I used to feel that I have bad luck because my parents passed away, but after knowing that there are many children who have lost their parents, everything changed (FG3).

P: I feel comfortable to talk about my parents with my friends; it makes me feel as part of them (FG3)

P: I did find it helpful, because I thought that I was the only child who had lost their parents. But, I saw that there are other children as well, and I was able to talk in front of them. I saw that they also do not have parents. So, for me it was helpful (FG2).

Some of the focus group participants got to realize that their situation was much better as compared to what other children were going through.

P: Just to talk about your parents. You find that for others it is worse for them, maybe it is even worse still for others. Maybe it is better for you (FG2).

Interestingly one participant in focus group 2 had a different experience as they were overwhelmed by the fact that more children than s/he anticipated had lost their parents.

F: Finding other children in the same situation as yours? Did it help you?

P: It did not help me (FG2).

F: It did not help you?

P: No (FG2).

P: It was painful. I thought I was the only one without parents, but I ended up seeing others who also do not have parents (FG2).

5.3 Express feelings

Expressing emotions is not easy, especially when one does not know how to express them in the first place. Children can bottle up their feelings, not because they do not know how to express them, but they might not feel that they have someone with whom to share their feelings. Children go through sadness, anger, and other feelings as any normal human being would.

Expressing one's emotions is therapeutic, as it is a way of releasing emotional pressure that may foster psychosocial problems if not controlled. The Memory Box Programme offers the opportunity for children to learn how to express their emotions and also offers them people (adult camp facilitators and peers) with whom they can share their emotional issues.

P: It helped me because I found people that I could talk to when I am feeling sad about my parents (FG2).

Focus group participants highlighted that it was helpful for them to learn how to express their feelings. This helped them once they had returned home after the camp, as they felt able to effectively communicate how they were feeling. Before the Memory Box Programme, some focus group participants used to cry without being able to talk about their feelings.

P: It was a good idea because they helped me, as before, I did not know how to talk about my feelings. I just cried (FG3).

P: I saw it as a good idea, because now I can talk about how I feel (FG3).

P: I found all that I was looking for. I found that I can now talk to people about things that made me sad (FG2).

P: If you do not express something that hurts you, if you do not talk about it, you end up feeling even more heartache (FG2).

Those who found it difficult to talk were taught another technique to help them express their feelings. Children were taught how to use their writing skills as a mechanism through which they could express their inner feelings:

P: I can write down what made me happy and sad now (FG3).

Before one can express their feelings, they firstly need to develop a trusting relationship with the recipient of the information. Participants expressed the need to share their problems, but only to someone who can assure them that the information they share, will be kept confidential.

P: I felt good to be at the camp. I learnt that when there is something that has upset you, you need to tell someone you trust or your guardian (FG3)

P: I talk to someone I can trust (FG2).

P: I talk to someone I can trust, someone I can see will not go around spreading my business (FG2).

5.3.1 Fear of stigma and discrimination

Orphans often find themselves isolated due to stigmatization. Due to stigma and discrimination, several children spoke of their concern about being cautious about who to speak to. They try to identify someone who is not reckless with the information they receive. The children fear becoming the brunt of jokes and gossip.

P: For me it depends on how much I trust my friend, because sometimes you can tell someone, and then he goes out, and tells other people, and at the end you become a joke (FG3).

Two participants in one of the focus groups indicated that they trusted no one and so would not share personal information.

P: I don't tell anyone because I am afraid that they will tell others (FG3)

P: I don't tell anyone because I don't trust people (FG3)

5.3.2 Need to share to access help

Expressing one's emotions might be a signal for help. Besides trust, the focus group participants indicated that they share what they are emotionally going through so that they can receive help from the recipient of the information.

P: I feel comfortable to talk to them, because if I don't, they will not help me when I need something. But if I do, they could (FG3).

P: I think it is a good idea to talk with your friends, because when you tell them they might be able to help you with other things (FG3).

P: I feel comfortable to talk with my friends, because they have parents which I don't have, they could help me with many things (FG3).

P: I also talk because there are people who help me (FG2).

P: I talk to someone who can help me (FG2).

5.4 Ability to seek support

The ability to seek support is an important attribute which orphans need to have. Without the ability to seek support, orphans might suffer adverse situations on their own that could consequently cripple their lives. Because of fear, shame and rejection, some would find it difficult to seek support. The Memory Box Programme equips children with skills to enable them to seek support. The project also provides information on where to get specific support. A number of the focus group participants indicated that they have the ability to seek support.

F: Okay. So when you need support, how do you find it?

P: I ask from an adult. I talk to them when I have a problem.

P: When I need support, I ask someone for their time, for them to just sit with me, and hear me out if I have a problem.

5.5 Care and support

Care and support can help reduce difficulties faced by orphans. Orphans need the support and care of their family, friends and the community in general. Before attending the Memory Box Programme, some focus group participants thought that only their parents had the ability to care for them, and now that they were gone, no one had the capacity to love and care for them. The Memory Box Programme exposed them to love, care and support, bringing new hope to them.

P: I learnt that others can treat and take care of you the way your parents took care of you (FG1).

P: I learnt that there are other people, except your parents, that are capable of taking care of one (FG1).

P: It helped me because I used to think that when my parents die, no one will ever love me again (FG2).

P: I also gained a lot, because even though we do not have parents, there are people who will help us (FG2).

Providing care and support to orphans can simply mean finding time to listen to what they want to say.

P: I also gained a lot, but the most important thing that I gained was people that I could talk to about what made me sad about my parents (FG2).

P: Mine has changed, because I found people that I could talk to about things that I did not want to talk about (FG2).

5.6 Identity

Knowing who you are in terms of family history can help shape your future. The Memory Box Programme facilitates the gathering of important family information. Children in the focus groups believed that it is important and helpful to know who your parents are, and how they lived their lives.

P: It helped me by knowing how my parents grew up and who raised them up and how (FG3).

P: It is helpful, children need to know how their parents died because sometimes people ask and it is easy to answer them if you know (FG3).

P: It is helpful so that you know where you come from (FG3).

Focus group participants not only thought of themselves but also saw this information as vital for their own children.

P: It is important. Because you will grow up and your children will want to know their grandmother (FG2).

P: It is important for your children to know the people who bore you (FG3).

P: I say it is important because when I have children, I want them to know their grandmother and grandfather (FG3).

The participants in focus group three found the information to be helpful as it gave them insight into their parent's life. For some, having this information will help them avoid the pitfalls that their parents encountered.

P: It helped me by knowing their background and mine so that I don't become the person I am not (FG3).

P: It is helpful to how your mom behaved so that you can follow her footsteps if it was good behaviour (FG3).

P: It is helpful, because I know that my father abandoned me and mom died (FG3).

P: Helpful whereby I learnt the mistakes that they made in their lives, that helped me because I won't do the same mistakes again (FG3).

5.7 Hope for a brighter future

Most orphans find life generally tough. With no constant financial supply, and bills to pay after the death of their parents, some orphans soon find themselves out of school.

Education is the key to success in most cases, thus missing out on education can effectively mean that one faces a dark future. Some orphans lose hope after the death of their parents, not finding any reason for continuing their life. The Memory Box programme endeavours to give orphans hope for a brighter future, allowing them to envision a life where they will also contribute positively to the world

P: I learnt that one can have a brighter future and can also carry on living even if one's parents have died (FG1).

P: I learnt that in life, people fall, but they also get up and dust themselves off, and carry on with life (FG1).

Most interestingly, children in focus group two saw themselves becoming professionals that are people- and caring-centred.

P: And we have people in life that we admire and want to be like. Who is your role model and why? (FG2)

P: I want to be a social worker. So I can help people like me (FG2).

P: I want to be a doctor. So I can help the sick (FG2).

P: I want to be a teacher. I want to provide people with knowledge, because in these times, one cannot find a job if they are not educated (FG2).

5. 8 Safe space

Memory work provides a safe space in which to contain the telling of a life story. This space might be a room, the shade under a tree, a map, or a memory box, basket or book.

Children in the focus groups found having their own memory boxes very useful and liked it very much.

P: What I like about the memory box is that it reminds me of the letters that we wrote at the Labri camp, we were told that we need to keep our parents' things so that we remember them.....(FG3)

P: For me a memory box help a lot because when I am angry or if someone has shouted at me I write down what happened and put it in my memory box, it helps me a lot (FG3).

P: I like a memory box because I put things that make me happy or sad even when you are old you can open your memory box and read about the things you did while you were young (FG3).

P: It helped me by keeping my documents which are not supposed to be read by other people (FG3).

The children now have a safe space where they can keep their own confidential information and items that remind them of sad and happy moments. It is also a place to keep their important documents.

5.9 Discussion

The aim of the research was to consider children's experiences of the Memory Box Programme in relation to their social and emotional adjustment following their parent's death. The discussion is based on eight themes extracted from the transcripts which have shown great insight into the children's experiences and how they benefited from the Memory Box Programme.

The death of a parent is one of the most painful losses a child can experience. For the majority of children, parents are the most significant people in their lives. When a parent dies, life as the child knows it is changed. The love they were experiencing is suddenly taken away from them. A child who is not exposed to love will feel neglected and unappreciated. They might find themselves unable to cope with life's challenges, leading to feelings of helplessness and hopelessness. Without love, children will find it difficult to form secure attachments. The loss of a parent and consequently love, represents a deep psychological challenge that might affect a child's social and emotional trajectory (Osterweis, Solomon, & Green, 1984). Children in the study indicated that the death of their parent(s) brought with it pain, sadness, anger and worry. According to Phiri and Webb, (2000), these feelings are normally evident in many children who have lost their parent.

Some children in the study reported that they were not told about the death of their parent(s) death. Adults often find it difficult, or feel it inappropriate, to tell children what is happening or to involve them in decision-making in the belief that they are protecting them. The lack of discussion with children about death and bereavement can threaten children's emotional well-being (Fox, Oyosi & Parker, 2002). Adults need to identify qualitative differences in children's levels of understanding at different ages (Hawthorne, Jessop, Pryor & Richards, 2003). This understanding depends on their developmental level, cultural norms, personality characteristics, religious or spiritual beliefs, input from the media, and previous experiences with death.

The reason why adults fail to communicate with children about death stems from two possibilities. First, there is the adult's own emotional concern which may prevent him or her from confronting death-related issues. This may stem from actual experience or from fear of emotional losses. The second root is a general uncertainty about what to say or where to begin. It is hard to know what issues will be of immediate concern and which will be unimportant.

Some children indicated that the Memory Box Programme presented them with the first real opportunity to talk about their parents. The availability of facilitators who are willing to listen provides the right environment for children to share their feelings. Some children work through their emotions by talking about them with an adult who is an effective listener. Adults should have the ability to listen without interrupting the child and reacting negatively to what they say.

The Memory Box Programme afforded children the opportunity to talk about their parents' death. For some focus group participants, talking about their parents' death was therapeutic as it relieved them of the pain that was hurting them. Most children in the focus groups thus indicated that talking about their parents was helpful.

Children in the study indicated that when their parent died, they felt sad, worried and angry. How long these emotional reactions last depends on a number of factors ranging from the individuals' internal locus of control to the support they receive while mourning. Being part of the Memory Box Programme allowed children to discuss their emotions and concerns.

Emotional needs need to be responded to in a supportive environment which help children to cope. Communicating with children and gaining their trust is an important source of support for children, (Richter, Manegold & Pather, 2004). Focus group participants highlighted that it was helpful for them to have an empathetic listener, one who let them

know that their reactions are normal and expected. They also indicated that it was important to learn how to express their feelings.

Memory work helps children to make sense of what is happening in their lives. Taking part in the Memory Box Programme also encouraged children to develop effective means of coping as they discovered that their peers share similar situations. People need contact with others with similar concerns, commitments and goals in order to support and affirm one another (Paine, 1999). The Memory Box Programme helped children to see that their situation is not unique, that they are not alone in their feelings and experiences. Prior to their involvement in the Memory Box Programme most children believed they were the only ones who had lost parents. Meeting others who have experienced a similar situation brought comfort and realization that they were not the only ones facing these difficult circumstances. This allowed them the opportunity to share experiences, ideas and resources.

Children who have lost one or both parents need a lot of support. Due to stigma and discrimination, several orphaned children find it difficult to seek support. Without the ability to seek support, orphans might suffer adverse situations on their own that could consequently cripple their lives. They have to deal with grief as well as survival.

Children usually know what kind of help they require and are also capable of selecting their confidant accordingly (Butler, Scanlan, Robinson, Douglas, & Murch, 2003). The Memory Box Programme equipped the children with skills to enable them to seek support and information on where to find the required support. According to Hawthorne *et al.*, (2003) children seek and gain support from people outside the immediate family, and grandparents are commonly involved. Some children also build informal systems of support in their communities. These could include a friend, a teacher and minister of religion. Receiving support helps children regain some sense of security as it is deeply undermined by the loss of a parent (Stein, 2003).

Fox (2002) identifies fear, insecurity and hopelessness as emotional traumas experienced by children facing the death of their parents. The Memory Box Programme endeavoured to give children hope for a brighter future, allowing them to envision a life where they will also contribute positively to the world. Most interestingly, children in focus group two saw themselves becoming professionals that are people and caring-centred. Mallmann (2002) states that having hope for the future and an ability to envisage a personal future are protective processes.

Knowing who you are in terms of family history can help shape your future. The Memory Box Programme facilitates the gathering of important family information. Our identity is more like a story of ourselves, where we come from, where we fit into social life, and to whom we are related. The identity is part of our idea of our self. Children in the focus groups believed that it is important and helpful to know who your parents are, and how they lived their lives. If children are to develop a positive view of themselves, they need to build their own story of biographical memory through contact with family and friends.

Children need an opportunity to discuss their experiences in a safe, accepting environment (Lazarus, Jimerson & Brock, 2002). Children in the study indicated that the Memory Box Programme provided activities that enabled them to discuss their experiences in a safe way. Through storytelling, drama and play, children who participated in the Memory Box Programme could express their feelings and behaviour, such as anger. It is important that programmes which seek to strengthen children's resilience provide a safe environment for the children to enable them to share their feelings.

Mallman (2000, as cited in Stein, 2003), suggests that a child's inner resources can be developed in a wide variety of ways. These include:

- increasing a child's ability to express emotions in words and actions
- increasing a child's autobiographical memory in order to facilitate their recall of positive relationships etc
- increasing a child's sense of belonging within the community so that they are able to look for and find emotional support

- increasing a child's ability to envision a future

All the above ways mentioned by Mallman were highlighted as themes in this study, thus the Memory Box Programme provides children with mechanisms which helps them to be resilient.

Chapter 6: Reflection and summary of study

The aim of this chapter is to provide an overview of the study by presenting a reflection and summary of the study.

Children affected by HIV and AIDS face a number of stressors in their daily lives. These include loss of caregivers and loved ones, school dropout, being burdened with adult like responsibilities, increased poverty, stigma, discrimination and social isolation, and loss of family assets (Killian, 2004b; Wild, 2001). Each of these negatively impacts the child's social and emotional development.

Until recently the majority of programmes for orphans and other vulnerable children in Africa have focused on fulfilling children's basic needs for tangible things like food, school fees, supplies, and clothing. Few programmes specifically addressed the social and emotional needs of AIDS affected children. There is now growing recognition of the importance of social and emotional aspects of children's development and growing interest in addressing these issues programmatically.

This growing recognition of children's psychosocial needs has seen the emergence of memory work programmes that seek to respond to the social and emotional needs of those affected and infected with HIV and AIDS.

The resources for providing such social and emotional support are far from adequate. Therefore, a primary strategic objective for Sinomlando Centre has been to scale-up the provision of psychosocial support (PSS) for communities and in particular for orphans and other children rendered vulnerable in the wake of the HIV and AIDS pandemic. This social and emotional support is brought together through the Memory Box Programme, which allows children to make sense of their family history, their own experiences, and future, thus fostering resilience, communication and empowerment.

Four key points emerged from the literature reviewed.

Psychosocial issues: associated with HIV and AIDS transcend economic, political and other macro-systemic boundaries, as children made vulnerable by the epidemic become embroiled in a downward spiral of distress and difficulties that affect multiple aspects of their lives (Killian, 2004b).

Memory box: rests on the hypothesis that it is good for the child to know his family history, however painful this might be, but only if that history is recounted in a warm, non-judgmental way (Denis, 2005). If the child knows his parent's history, he is better able to overcome the suffering caused by their illness or death. He accesses this knowledge through memory - his own and that of those close to him. (Denis, 2004)

Facilitating resilience through access to autobiographical memory: AIDS is taking away parents and adults with rich family heritage. Orphans risk growing up without a clear sense of identity and roots, without the traditions and beliefs of their heritage. The ability to remember, imagine, and be in touch with sustaining family stories and community legends is important in facilitating resilience.

Using ecological theory, one sees the child as an interdependent member of a complex family system, which is constructed of interactive and interrelated subsystems, characterised by stability, transformation, fluidity and boundaries (Boemmel & Briscoe 2001). Within this complex system, the child plays different roles as; an individual, a member of various family subgroups, a member of the family as a whole and participant/member of the family's ecological environment (Minuchin, 1985).

What previous research has been done?

The Sinomlando/Sinosizo pilot study investigated children's knowledge about what had happened to their parents (Denis, 2003). The study highlighted that many orphaned children did not actually know positively or directly about the death of a parent. Lewis (2001) argues that children with limited or partial knowledge of parental death experience additional distress when full explanations for parental illness or death are not provided. The Memory Box Programme allows children the opportunity to gather information about their parents' death.

Marcus (1999) found that children are frequently excluded from discussion about both the imminent and recent death of a parent, on the grounds that death is an inappropriate topic for adults to discuss with children. The present study has shown that although it is emotionally difficult for children to talk about the death of a parent, children in the study found it helpful to talk about such issues.

The assumption underlying this present research was that orphaned children who participated in the Sinomlando Memory Box Programme benefited socially and emotionally from the programme.

Reflecting on the study; selection of participants was limited only to those who had participated in Memory Box Programme facilitated by the Sinomlando Centre. This effectively meant that not only did the researcher have a limited choice in terms of the research participants but that the choice for a sampling method was also limited hence the researcher settled for purposive sampling. All FGD participants were Zulu speakers which meant that the researcher could not facilitate the FGDs since his first language is Shona and cannot communicate in IsiZulu thus the researcher had to look for Zulu speaking facilitators. This meant that the researcher had very minimal influence in the way the conversations went on during focus groups. Thus the researcher had to make sure that the facilitators understood what the research was on and what the outcomes of the FGDs were.

The transcripts point to the difficulty which facilitators faced in trying to get the participants to share. This is quite understandable since death is a difficult topic to talk about with someone you have just met. In some instances participants gave answers without depth. This prompted the facilitators to ask follow up questions, e.g. an extract from FG3

F: now tell me which feeling do you still experience even it has been sometime after your parents death?

P: I feel sad sometimes when I think of my mother

P: I feel sad

P: sad

P: worried

P: sad

P: angry

P: sad

P: sad

P: angry

P: sad

F: when you feel all these feelings what do you do? Do you tell others how you feel or you keep them inside yourself?

If we hold all other variables constant, the results from the study assume that:

- Children who participated in the Memory Box Programme conducted by Simolando are able to express their feelings.
- Children who participated in the Memory Box Programme conducted by Simolando are able to seek and access social support.
- Children who participated in the Memory Box Programme conducted by Simolando have a positive attitude towards their own future.
- Children who participated in the Memory Box Programme conducted by Simolando have sense of identity.

The results of this study point to the benefits derived from participating in the Memory Box Programme. In light of this, it can be assumed that the Memory Box Programme run by Sinomlando Centre has a positive contribution to the social and emotional developmental functioning of orphaned children.

The limited number of participants in the sample, as well as the nature of the sampling method cannot be used to generalise the results of the study to larger populations.

Furthermore, potential risks to study validity may include:

- Extraneous factors could have confounded the interpretation of attributable outcome. These may include the presence of other intervention activities that the respondents benefited from and “endogenous changes” or some kind of change outside the project’s control (political events, economic shifts and personnel changes) or maturational trends.
- Inability to use probability sampling.
- The information gathered and analysed through this research approach may see interpretations distorted by subjectivity as to an understanding the key issues.
- It may have been useful to develop a tool to collect quantitative data. This data could have been used to supplement data obtained from the FGDs.

Future studies should look at evaluating the effectiveness of memory work with children affected by HIV and AIDS. The direct impact of memory work interventions on the social and emotional development of children needs to be evaluated.

Sample hypotheses: There will be a significant difference in the healthy social and emotional developmental functioning of children affected by HIV and AIDS who participate in memory work compared to those who are similarly affected but who have not participated in memory work focused interventions.

To ascertain if there is a significant difference between emotional and social developmental functioning for children affected by HIV and AIDS enrolled in memory

work and those who are not part of this form of intervention programming. The following selection criteria could apply:

- The HIV and AIDS affected children will be selected on the basis of having one or both parents having passed on due to AIDS-related causes.
- The age range of respondents will be between the ages of 15 years to 18 years.
- A parent should have died within 6-12 months of the study.
- The participants in the experimental group will be exposed to a memory work intervention while those in the control group should not participate in a memory work intervention programme.

It can be assumed that if the social and emotional resilience of children gravely affected by HIV and AIDS is bolstered these children might be able to live positively with the prevalence and potentially harmful effects of HIV and AIDS. The Memory Box Programme allows children to understand their family profile, thus paving way for the development of autonomy and sense of a brighter future. At a basic level, this study generated learning about the benefits of Memory Box Programme. Such learning and evidence of benefit is generally recognized to be an essential component of any programme of development in health and social care. However, it is particularly important for a support programme to generate learning about the impact of interventions

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Appendix A: Informed consent form

Informed consent to be signed by the primary caregiver:

I, (Name of primary caregiver).....

Being the legal guardian or adult primarily responsible for the care and well being of
(name of the child).....

Whose date of birth is (write in child's birth date).....hereby give my
consent for (write in name child)

Who is usually called).....

to participate in the focus group discussion on the benefits of the Memory Box Programme
run by the Simolando Centre.

The focus group discussion will take place at (write in date and time)

.....on (write in venue).....

.....

I understand that the group facilitator will not be held liable for any legal claims or loss
howsoever caused.

I also understand that all information disclosed by my child will be held in strictest
confidence, with no information being disclosed that will reveal either my child's or my
identity in any publications that may result from this research.

I have read and understood the information provided above.

I understand that I may withdraw my consent at any time and discontinue my child's
participation without penalty.

Signed

Date.....

Witness.....

Date.....

Audio taping

I have received an adequate description of the purpose and procedures for audio-taping session during the course of the proposed research study. I give my consent (to allow _____ [*indicate child's name*]) to be audio-taped during participation in the study, and for those audio-tapes to be listened to by persons involved in the study. I understand that all information will be kept confidential and will be reported in an anonymous fashion, and that the audio-tapes will be erased after an appropriate period of time after the completion of the study. I further understand that I may withdraw my consent at any time.

Print Name_____

Signature of parent/legal guardian_____Date_____

Print Name_____

Signature of participant_____Date_____

Explanation of study before signing the consent form

Your child is invited to participate in a master's research study conducted through the School of Psychology, University of KwaZulu Natal. I hope to discover more about the benefits of Memory Box Programme and to learn about the emotional and social developmental functioning of children. This study will contribute towards my obtaining a Masters Degree in Psychology.

Your child was selected as a possible participant in this study because of his/her exposure to memory work. If you decide to let him/her participate, he/she will participate in a focus group discussion. He/she will be asked to describe his/her experiences after attending the Memory Box Programme. The focus group discussion will take approximately 2 hours to complete. The discussion will be audio recorded for further reference during the study.

The only risks involved with this study involve the possibility that sensitive questions regarding his/her life may be asked. Although he/she will not benefit directly from this study, results from the study will improve the understanding of social and emotional development of children who have been exposed to Memory Box Programme as well as ways in which children's resilience could be developed after they have been exposed to difficult life circumstances.

Any information that is obtained in connection with this study and that can be identified with him/her will remain confidential and will be disclosed only with your permission. Only the researcher and supervisor will have access to data gathered during the research. After the analysis and final results are compiled, the data shall be kept in a lockable cabinet by the researcher. A number coding system shall be used as the researcher will endeavour to protect your child's identity. The audio tape shall be erased one year after the study.

Your child's participation is voluntary. Your decision whether or not to participate will not affect your relationship with University of KwaZulu Natal or any organization you are involved with. If you decide to participate, you are free to withdraw your consent and discontinue participation at any time without penalty.

If you have any questions, please feel free to contact: Brighton Gwezera on telephone number +263 91 413745 or write to AC800 Ascot Bulawayo, Zimbabwe. You can also contact Dr. Beverley Killian on +27 33 260 5371 or at the School of Psychology, University of KwaZulu Natal, Golf Road, Scottsville, 3209, Pietermaritzburg.

Brighton Gwezera

Bev Killian (PhD)

Appendix B: Assent form

Assent form to be signed by group participants

I (write in child's name).....

Understand that the group that I'm asking to be a part of will talk about my experiences after attending the Memory Box Programme. I know that at times it will be very hard to talk about these things and that I will not be forced to talk about things against my will.

I promise not to talk to anyone outside the group about the things that the other children in the group talk about themselves. I can speak about the things that happen to me.

I understand that the focus group will last about two hours and that it is scheduled to take place on just one occasion at

I understand that the things that I share during the group sessions will not be shared with people outside of the group although they will be used for research purposes. My identity will be kept confidential at all times.

Signed:

Date:

Witness:

Date:

Facilitator:

Date:

Appendix C: Focus group introduction

Hello and welcome. My name is (facilitator's name), I'm a student at the University of KwaZulu Natal.

Today we will be discussing the workshop you attended at Labri camp in September and your involvement in Memory Box Programme. The purpose of the workshop was to equip you with knowledge on how to develop memory boxes. During that workshop you learnt a lot about yourself and the family you come from.

Brighton Gwezera, the researcher, asked me to have this discussion with you. He needs to find out how the workshop has benefited you and those around you. I encourage you to give as much information as possible. I'm not looking for any right or wrong answers but I want to learn from views and experiences. All your views are valued. I assure you that your candid responses would not have any negative consequences on your involvement with Sinomlando Centre.

I will run the group discussion and if you agree, I will audio tape the discussion. Your names will not be used during this process. I will give name tags with codes, e.g. MB1, MB2 etc. MB stands for memory box. The tape will be locked up at the University and no one will have access to it except Brighton and Bev Killian (his supervisor).

Our discussion will take about 1 hour 30 minutes. We will have a break of 15 minutes we shall have refreshments during this time. You have the right to withdraw from this discussion at anytime.

Are there any questions that you want me to answer? If not, let us start off by having an 'ice breaker'

Icebreaker There is a fire on the Mountain

Set the ground rules first. Facilitator to spend about 5-8 minutes on these, but get a participant to write these up on a board, make the atmosphere casual, trusting and participative. Main aim is to establish rapport, create trust and encourage deeper sharing.

Appendix D: Focus Group Questions

1. Sinomlando Memory Box Programme

- 1.1. Please tell us your name and how long you have been participating in the Sinomlando Centre Memory Box Programme.
- 1.2. Let us begin by each of you telling us what you thought about the idea of a memory box? Do you think it is a good or bad thing for kids to remember about their parents who have passed away? Please explain your answers and maybe tell us about yourself, or your friends, or brothers and sisters that have made you think certain things about memory work.
- 1.3. When you first heard that at the Sinomlando Centre and at the camp, you were going to be spending a lot of time talking about your own personal memories and about your family loss, how did you feel? Did you think it was a good idea or a bad idea? It would be helpful if you explain your answers to us.
- 1.4. It is sometimes hard to talk about the death of loved ones. When you have shared about the death of your loved ones at the camp or elsewhere, has it been helpful for you?
- 1.5. And for other children?
- 1.6. Do you now feel comfortable sharing with your friends about your family death/s?
- 1.7. When was the first time you shared about your own loss outside of your own family?
- 1.8. What have been the benefits of knowing your own family history?

- 1.9. In what way is your life different because of your participation in the Memory Box Programme?
- 1.10. Do you think that it is useful for kids who have lost their parents to know about their family's history? In what way and can you explain how?
- 1.11. Would any of you like to add anything else about memory work before we have a short break and then carry on with other questions.

BREAK – 15 minutes break to have juice and biscuits

Now we are going to talk about other topics that are similar but hopefully not quite as difficult as our first topic.

2. Expressing feelings

- 2.1. Let us begin by asking you how do most kids feel when their parents' or loved ones pass away? Let us just write out a long list of the different feelings that people may experience when someone dies.
- 2.2. Let us now go around the group and see which feelings each of you still experience now even though it is sometime since you lost a loved one in your family.
- 2.3. Do you find that you can express these feelings, or do you tend to keep your feelings inside of you? Or only express your feelings in certain situations? Would you mind also explaining how you express your feelings? Or, if you do not express your feelings, what prevents you from expressing them?
- 2.4. Did you learn anything on feelings when you were at the memory work camp? What did you learn?
- 2.5. How have you applied this in your life?

3. Knowledge of cause of parental death

- 3.1. When bad things happen to us some people want to protect us by not telling us the truth. Has anyone told you what caused your parent's death?
- 3.2. Who told you and how did they tell you?
- 3.3. If not, how did you find out?
- 3.4. Has the Sinomlando Centre Memory Box Programme helped you understand more about the cause of your parent(s) death? How?

4. Ability to seek support

- 4.1. As we go through life we sometimes get to a point where we need help from others. Do you sometimes find yourself in need of support from other people?
- 4.2. What kind of support?
- 4.3. How do you get the support you need?
- 4.4. Have you ever asked for someone to support you?
- 4.5. If not, why?
- 4.6. What did you learn on seeking support from Sinomlando Centre Memory Box Programme?
- 4.7. Has this helped you in anyway? How?

5. Giving support to other children

- 5.1. We also sometimes meet people who need our support. Do some children ask you for help?

5.2. If they do, how do you help them?

6. Hope for the future

6.1. We all have people that we admire and want to be like them. Who is your role model and why?

6.2. What do you want to be in the future and why?

6.3. After the Sinomlando box camp do you ever think of your future? What did you think of? Please tell us more?

7. Conclusion

7.1. I have been asking a lot of questions. Now it's your chance to ask me on what we have been talking about. Do you have any questions?

7.2. Finally do you think that it has been a good thing for you to have participated in the Sinomlando Memory Box Programme and in what way? Please explain and tell us how and in what ways.

7.3. Do you think it has helped you to cope better with the loss of your parent or loved ones? Please explain and tell us how and in what ways.