

CHAPTER 1

If AIDS takes a parent, it usually takes a childhood too...for the children who have lost their parents to AIDS, grief is only the beginning of their troubles¹

INTRODUCTION

In 2004, South Africa celebrated ten years of post-apartheid democracy. This important milestone was overshadowed by the HIV and AIDS pandemic that has devastated this country. South Africa has become synonymous with HIV and AIDS. The situation is particularly adverse for children and youth. First, with parents and adults sick or dying, young children carry the burden of caring for siblings and family members living with HIV and AIDS. Second, a significant number of children are themselves infected with the virus (Moletsane, 2003). Yet children's experience with the HIV and AIDS pandemic is mainly voiced through adults who act and speak on their behalf (Oakley, 1994).

Without question, AIDS is one of the most urgent problems in the world today. The extent of children not necessarily infected, but also affected by HIV having lost one or both parents to AIDS, is evident in the number of children orphaned on account of AIDS, which is documented in the statistics in the next chapter.

Needless to say, this has resulted in a parallel epidemic of grief for those who have lost loved ones to AIDS. In South Africa, AIDS has reached crisis proportion.

Most of those affected by HIV and AIDS in South Africa struggle with multiple stressors on a daily basis including extreme poverty, social stigma, violence, poor health care and inadequate social support (Demmer, 2005).

¹ Newsweek, 2000:42

Literature on HIV and AIDS had generally focused at the macro-level within the quantitative research approach. Little attention has been given to micro-level of analysis of the life experiences of children orphaned on account of AIDS. It was envisaged that a micro-level research, using the qualitative method, could elicit different information and offer valuable insights. South Africa includes a disproportionately large number of orphans and vulnerable children. This demands unprecedented efforts from the government, civil society and the business sector to strengthen and support communities so that they are able to meet the physical, emotional and psycho-social needs of our children (School of Education and Development, 2006).

Loss and bereavement combined with poverty are major risk factors for poor psychosocial adjustment amongst children. The consequences of experiences of loss and sorrow might include a host of problems such as chronic depression, low self esteem, and low levels of life skills, learning disabilities and anti-social behaviour amongst children. The study set out to explore how children orphaned on account of HIV/AIDS experienced loss and bereavement. The study was designed to assess the social, economic and educational consequences of AIDS on children; explore how children cope with AIDS-related loss and grief; understand the caregiver's views on children that are orphaned on account of AIDS; determine the caregiver's motivation in taking on the role of caring for children orphaned on account of AIDS; and examine the resources and support systems available to caregivers in fulfilling their roles in relation to children.

1.2. The Research Problem

We know very little about the experiences of children orphaned on account of AIDS in South Africa as asserted by Demmer (2005). There are valuable lessons we can learn from research on AIDS-related bereavement from other countries. However, at the same time we need to understand the unique stressors and needs of children and caregivers who have lost their loved ones to AIDS. Interventions need to be developed that are tailored to the South African context to address the needs of those who have lost loved ones to AIDS in the past, as well as those who will lose loved ones in the future (Demmer, 2005).

1.3. Research Questions

The aim of this study was to gain insight into and make discoveries about the life experiences of a sample of children orphaned on account of AIDS, in the Kwa Nzimakwe area, which falls within the UGU District Municipality of KwaZulu Natal, South Africa. In depth interviews were conducted with eleven children and their caregivers.

KwaZulu-Natal is one of the nine provinces in South Africa and it has the largest population of about 9.5 million people. According to 2001 census, the total population of South Africa is 44.8 million (Statistics South Africa, 2003). Nearly 85% of the population in KwaZulu Natal is Black African. The home language of just over 80% of the population in KwaZulu Natal is isiZulu (Statistics South Africa, 2003).

The research site was within the UGU District Municipality which is situated along the coastline in the southern portion of KwaZulu- Natal. The area is bordered on the north by the eThekweni Municipality, western side by the uMgungundlovu and Sisonke Municipalities, southern side by the Eastern Cape Province and eastern boundary being the Indian Ocean. The current population of UGU is estimated to be 704 028, sixteen percent urban and eighty four percent rural. The population comprises 450 000 adults and 300 000 children. Of this population, 90 000 adults are estimated to be HIV positive (UGU District Municipality Annual Report, 2004). The population infected with HIV/AIDS in UGU, increased from five percent in 1996 to over thirteen percent in 2004.

According to more recent statistics released by UNAIDS, around twenty one percent of people in the UGU district are HIV positive. The 2008 antenatal clinic sero-prevalence rate was forty percent, meaning approximately 150 000 people are living with the virus. These statistics were reported at an AIDS conference in Pietermaritzburg, organized by the Office of the Premier, Dr Zweli Mkhize (South Coast Herald, October 23, 2009)

The study set out to explore the following specific research questions:

- *What are the experiences of children orphaned on account of HIV and AIDS?*
- *What consequences does the HIV and AIDS pandemic have on children?*
- *How do children cope with AIDS-related loss and grief?*
- *What are the caregiver's roles, experiences and perceptions regarding children orphaned on the account of HIV and AIDS?*
- *What resources and support systems are available to caregivers in fulfilling their roles in relation to children?*

1.4 Rationale for the Study

The researcher's interest in investigating the life experiences of children, orphaned on account of HIV and AIDS, arises from her vocation. She is employed as a social worker by Child Welfare SA, Margate, where there is a high prevalence of children orphaned on account of HIV and AIDS. Child Welfare SA, Margate is a non-governmental organization, based in KwaZulu Natal, responsible for protecting and promoting the well being of children in the magisterial district of Margate. The work environment of social workers is riddled with new and complex social problems, often draining the available resources. Social workers are confronted with huge numbers of orphaned children in need of urgent statutory intervention, mostly because of the economic burden brought by their "orphan" status (Biya, cited in Louw, 2005). Due to heavy workloads, poor service conditions and high staff turnover, very little attention is given to the socio-emotional care of children orphaned on account of HIV and AIDS.

Despite the high AIDS- related mortality rate in South Africa, very little attention has been given to the impact AIDS has on children and the concrete responses and experiences of children, especially children orphaned on account of AIDS (School of Education and Development, 2006). The literature search pertaining to this study revealed limited information on the life experiences of children orphaned on account of AIDS. The

research literature on HIV and AIDS generally focuses on HIV and AIDS prevention, treatment and the community's responsibility for the pandemic. Having identified the gaps in literature, the study focused on exploring the life experiences of children orphaned on account of HIV and AIDS as well as the roles and experiences of their caregivers. The study gives "voice" to children and their experiences. The study would make significant contribution to the existing literature by examining how children respond to and cope with AIDS- related loss. The study combined the practitioner-researcher role and concentrated on children already on the caseload of the researcher. This research can contribute to the knowledge base of practitioners and guide their intervention according to the challenges and needs of the children.

1.5 Theoretical Framework

Bronfenbrenner's (1979) social ecology model provided the theoretical framework for this study. Drawing on the environmental model of ecology, a social ecology of childhood draws on many and varied factors, some are temporary and others more enduring. The social ecology model focuses on the person, the environment and the interaction between the two. Child development can be influenced in many ways and from many sources. They are as follows:-

- Person factors: includes the individual biological, temperamental, intellectual and personality characteristics of the child and significant others in the child's life, such as parents, caregivers and educators.
- Process factors: includes the forms of interaction that take place between individuals (supportive, destructive, informative, inclusive and power-based)
- Contextual: includes families, communities, cultures and ideologies
- Time variables: takes into account changes that occur over time (Dawes and Donald, 1999).

There are five systems that impact on the child during the course of his/her life. The relationships between them are referred to as microsystems, ecosystems, exosystems, macrosystems and chronosystems. These change over the course of a child's life (Bronfenbrenner, 1986). The microsystem involves behaviours and interactions of the bereaved individual with his or her environment (e.g., home). The ecosystem involves interrelationships between the bereaved individual and other settings such as the extended families, neighbours friends, community and the church. The exosystem includes those settings that influence bereavement but do not play a direct role. Examples are the health and welfare system. The macrosystem involves traditional and cultural beliefs about death, mourning and how to grieve. It also includes political and economic policies of the government regarding HIV and AIDS and the care and support of people infected with HIV and AIDS. Finally the chronosystem includes political, cultural and social changes as well as medical advances over time that may influence the bereavement experience (Demmer, 2005).

In terms of this study, the ecological model was apt because a child affected by HIV and AIDS does not exist in isolation but in association with a number of other sub-systems within the environment. A parent infected with HIV and AIDS impacts on the child because the support systems that the child needs may be absent or totally inadequate.

This would be discussed in detail in Chapter 3

1.6 Research methodology

I preferred to report in the first person, throughout this dissertation. This is generally supported with qualitative research. The qualitative research design was used in this study in obtaining an in-depth understanding of the phenomenon under study. Qualitative research, according to Uys (2003: 118), refers to a “collection of data that reflects the quality or nature of a particular phenomenon, in the form of description”. Feelings, thoughts and experiences were taken into account as I obtained an in-depth understanding of the children's and their caregivers' experiences. Babbie and Mouton (2001) claim that

qualitative studies provide deeper understanding and new insights that might escape quantitative studies.

The purpose of this study was to explore the life experiences of children orphaned on account of HIV and AIDS. Thus, a collective case study design was used. In-depth collective case studies that explored children's lives and experiences were therefore appropriate. The defining characteristic of a case study is its emphasis on an individual unit. A holistic case study on each child was conducted. In the study, the primary instrument used for data collection was semi-structured interviews. I utilized more than one method to collect data, namely, multiple interviews with each child and his/her caregiver (key informant); observation techniques and analysis of existing case files in order to triangulate the data (Marlow, 1998).

The preparation for data collection involved decisions about the sites of data collection, the sample size as well as sampling procedures. In this study, a purposive sampling strategy was used. Purposive sampling is concerned with providing a sample of information-rich participants (Marlow, 1998). There were two sample groups, which were drawn from the Child Welfare South Africa, Margate's clientele population. A sample of eleven children was recruited from the caseload, two children being siblings. The child participants were between the ages of thirteen and seventeen years and they lost one or both parents to HIV and AIDS. There was a combination of male and female participants. The caregivers of all eleven children were also interviewed. I decided about this sample and site as this was most accessible to me. A limitation to this study was the small sample group of eleven children and their caregivers as participants. Hence the study cannot be generalized. However, this is not an obstacle in qualitative research that seeks in depth context specific information rather than general trends.

In-depth data collection methods were utilized, which involved multiple sources of information that were rich in content. I conducted in-depth interviews with each child. I had two interviews with nine child participants and extended interviews with the other two child participants. The frequency of the interviews was in consultation with the

participants. Developments in qualitative research have highlighted the need to collect data on several different occasions over a time period (Seidman, 1991). Due to the subject matter and the potential emotional strain on children, the duration of each interview was between thirty minutes to an hour. Interviews were communicated in isiZulu and English. The caregivers of each child were involved in separate, individual interviews. The purpose of interviewing caregivers was to ascertain their views on children that are orphaned on account of AIDS and determine the caregiver's motivation in taking the role of caring for children orphaned on account of AIDS.

Although I am English- speaking, I have a basic proficiency in IsiZulu. However, due to the nature of the study that required in-depth information and description of feelings, I used my colleague, who is an IsiZulu-speaking social worker, to assist me with the translation and interpretation for some of the interviews. He was briefed on the entire process. All the interviews were audio-taped. This helped to capture the feelings, texture, tone, silences, hesitation and emotional responses of the participants. I also maintained a journal to record my thoughts, feelings and reactions and my on-site experiences. This supplemented and assisted in the analysis of the data. The children and caregivers are from my caseload and are known to me. Both were prepared for the process. Consent in writing was received from each participant (See Appendix I). The consent form included permission to audiotape or videotape the interviews as well as transcribing them for analysis. Participants participated voluntarily and they were given the right to decline. I also conducted visits to the homes of each participant and observed them in their natural environment. I looked for larger trends or patterns of behaviour that were pertinent to my study. Each participant already had a case file at our offices and this was utilized as an additional data source.

In this study, semi-structured in-depth interviews with children lent itself to content analysis. De Vos (2002) recommends that the content of interviews be analyzed while they are still fresh and preliminary coding which is characteristic of content analysis may be useful. De Vos (2002) states that employing qualitative analysis in interviews will attempt to capture the richness of the themes emerging from the participants' responses.

From the transcripts, categories of information were identified, as well as prominent themes. Sub-themes were also recorded and grouped together. Interpretation meant making sense of the data. The final phase presented packaging of what was found in text.

1.7 An Overview of the Chapters

At its broadest and most general level, this is a study of children's experiences in an HIV and AIDS context. A brief description of each chapter follows:

Chapter 1: Introduction

In this chapter, I provided a broad overview of the study. The rationale, purpose, research questions, theoretical framework and methodology for the study was briefly discussed. It also located the context for the study in a country where the HIV and AIDS pandemic is high. This part of the chapter set the stage for exploring how children's life experiences were impacted upon by HIV and AIDS.

Chapter 2: Literature Review:

In this chapter, I presented a critical review of what has been done in the field of study and identify gaps in the literature as it relates to the experiences of children orphaned on account of HIV and AIDS. The review identified areas of controversy in the literature. I also highlighted the consequences of being orphaned on account of HIV and AIDS; resilience and vulnerability of children. One of the critical areas that needed further research was in-depth experiences of orphans and their communities through the eyes of the orphan and caregivers. Also significant was the manner in which dominant traditional family structures had been disrupted to constitute various configurations of individuals brought together by the severity of circumstances. The review also discussed kinship care and pointed to the discourse on children's rights and how these were in jeopardy.

Chapter 3: Theoretical Framework

In this chapter I presented the main theoretical anchor of the study. The concepts derived from the Bronfenbrenner's (1979) model of ecological development and perspectives in understanding grief and bereavement were used to illuminate the data and provided insight into the various factors and relationships that have affected children orphaned on the account of HIV and AIDS.

Chapter 4: Methodology

This chapter presented a description of the methodology used in the research. Explanations were given about the research tools as well as the effectiveness of the tools. It detailed the sampling strategy utilized in the study, the methods of data collection, analysis of data and issues of validity and reliability. Ethical considerations and the challenges presented by the study were also presented.

Chapter 5: Data Analysis

This Chapter focused on the presentation and analysis of the data obtained from the investigation. It comprised of a biographical profile of the participants and the demographic details of the participants.

Chapter 6: Presentation of Findings and Discussion

The intention of this chapter was to map various factors that affected the lives of the children and how they cumulatively impacted on the children's social, psychological and physical well being.

Chapter 7: Presentation of Findings and Discussion

This chapter highlighted the factors that contributed to the resilience of the child participants.

Chapter 8: Presentation of Findings and Discussion

In this chapter, I discussed how the participants coped with AIDS-related loss and grief, the resources/support available to them; the views of the caregivers of the child participants and what motivated them to take on the caregiving role.

Chapter 9: Reflections, Conclusions and Recommendations

I concluded the thesis by pooling together the key findings that have emanated from the study, the different themes that have emerged in the analysis of the data and provided recommendations at various levels for possible interventions and implementation.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

As stated by Rogers and Bouey (1993:388), ‘the literature review is a key tool for providing information on what is new, important, believable, and useful’. Leedy (1993: 87) emphasized how critical it is for researchers to review the related literature because, ‘when you know what others have done, you are better prepared to attack the problem you have chosen with deeper insight and more complete knowledge’. This chapter outlines a review of related literature to the study.

HIV and AIDS is no longer just a disease. It is now a pandemic, an entirely different, though clearly linked phenomenon. HIV and AIDS poses a unique challenge as it kills adults in the prime of their workforce, fractures and impoverishes families, orphans millions and shreds the fabric of communities (Department of Social Development, 2003).

South Africa will have an estimated 1, 95 million children orphaned on account of HIV and AIDS by 2010. Thirteen point two million children have been orphaned since the beginning of the epidemic worldwide (Reuter, 2005).

South Africa is the country with the largest number of HIV infections in the world. HIV prevalence data collected from the latest round of antenatal clinic surveillance suggest that HIV infection levels might be leveling off, with prevalence among pregnant women at 30% in 2005 and 29% in 2006 (Department of Health ,South Africa, 2007). In addition, the decrease in HIV prevalence amongst young pregnant women (15–24 years) suggests a possible decline in the annual number of new infections. The pandemic varies

considerably between provinces, from fifteen percent in the Western Cape to thirty nine percent in the province of KwaZulu-Natal (Department of Health South Africa, 2007).

KwaZulu-Natal (KZN), South Africa's largest province (population 9.4 million), is the province most affected by the HIV/AIDS pandemic. Many children as well as their families and caregivers that are infected or affected by HIV/AIDS live in economically disadvantaged communities in KwaZulu Natal (Whiteside & Sunter, 2000).

In this literature review, I provided a critical review of what has been done in the field of study and identified significant gaps in the literature as it relates to the experiences of children orphaned on account of HIV and AIDS. The literature review enabled me to identify areas of controversy and to formulate questions that needed further research. The review has been structured as follows: Firstly, I explored the impact factors of HIV/AIDS on children and families; secondly, I explored the concepts of resiliency and vulnerability as binary concepts in the context of HIV and AIDS; thirdly, I engaged with the literature on children's rights and how these are in jeopardy; and lastly, I concluded the review by exploring how the structure of family is disrupted through the role of caregivers or kinship carers. Demmer (2004) writes that there is little empirical research on the experiences of children orphaned in Sub-Saharan Africa. The researcher concurs with this opinion, as social workers experience a need for more information in practice.

2.2 The consequences of being orphaned on account of HIV/AIDS

Children affected by HIV and AIDS face many challenges, especially since many orphaned and vulnerable children live in contexts of multiple adversities. Very often these include poverty, violence, displacement, abuse and neglect. The extent of the HIV and AIDS pandemic has a devastating impact on children and the multiple challenges facing orphaned or vulnerable children are compounded by the number of such children that require care. In this section I explored various factors that exacerbate the plight of children orphaned on account of AIDS.

Social Factors

AIDS is generating orphans so quickly that family structures can no longer cope. Traditional safety nets are disintegrating as young adults die of AIDS-related illnesses. Families and communities can barely fend for themselves, let alone care for the orphans. Extended family networks of relatives and grandparents are an age-old safety net for such children. But the capacity and resources have been stretched to breaking point and those providing the necessary care are in many cases already impoverished, often elderly and have often themselves depended financially and physically on the very son or daughter who has died. Many children are left on their own in child-headed households (United Nations Children's Fund, 2003).

While stigma and discrimination on the basis of HIV status has been linked to HIV/AIDS since the early stages of the pandemic, there has been little research on the extent and exact nature of stigma and discrimination against children infected with or affected by HIV and AIDS in South Africa. Nor has a broad understanding of how this stigma affects children, their families and caregivers' lives and access to such rights as health care been reached. In a study on South African children, Strode and Grant (2001) argue that children who are either known to be living with HIV or are thought to have the virus, or who begin to exhibit symptoms of HIV, are stigmatised and isolated by their communities. Children living with and affected by HIV and AIDS are very vulnerable and extra support is needed to ensure good early childhood care and development.

The vulnerability of children orphaned by AIDS starts well before the death of a parent. The emotional suffering of children usually begins with their parent's distress and progressive illness. This is compounded as the disease causes drastic changes in family structure resulting in heavy economic toll, requiring children to become caretakers and breadwinners and fuelling conflict as a result of stigma, blame and rejection (United Nations Children's Fund, 2003). Eventually the children suffer the death of their parent

and the emotional trauma that results. Then they have to adjust to a new situation, with little or no support.

Children orphaned on account of AIDS are often at a greater risk of illness, abuse and sexual exploitation. They may not receive the health care that they need and sometimes this is because it is assumed that that they are infected with HIV and their illness is incurable. They often run a greater risk of being malnourished and stunted. Children grieving for their deceased parents are stigmatized by the community through their association with HIV and AIDS. The distress and social isolation experienced by these children is strongly exacerbated by the shame, fear and rejection that surround people affected by HIV and AIDS. Children may be denied access to schooling and health care. They are also denied their inheritance and property (United Nations Children's Fund, 2003).

Children may not only become victims but also perpetrators of crime. Growing levels of poverty, the emotional trauma associated with AIDS-related parental death, reduced levels of parental guidance and control and loss of positive role models may encourage delinquency and criminal behaviour (Schonteich, 1999). In a study conducted in South Africa, Moletsane (2003) found that there are growing numbers of street children and other abandoned and destitute children in homes and other care centres who are vulnerable to abuse (physical, emotional and sexual) from extended family members and other members of their communities. The abuse and neglect of children in AIDS-affected households is an indicator of the reduced ability of adults to cope (Ewing, 2002). Children will be abused because they lack shelter and protection or because selling sex is their only means of survival. Abused children are more likely to take greater sexual risks or find themselves in abusive relationships in adulthood. The trauma of rape can destroy a person's self-esteem. Orphaned girls are particularly vulnerable to sexual abuse because they assume adult responsibilities, such as caring for dying parents or raising siblings, without the maturity to understand quite what has happened to them (Ewing, 2002). McKerrow (cited in Smart, Pleaner & Dennil, 2001) agrees that the abuse of young girls and children within families is on the increase highlighting three myths or theories

apparently linking child sexual abuse and HIV and AIDS. The prevention theory is based on the assumption that all sexually active people are likely to be HIV infected and, in order to be 'safe', one must choose a partner who is not yet sexually active. The cleansing theory suggests that having sex with a child will cleanse the infected individual of the virus. Finally, the retribution theory is linked to the deliberate spreading of infection to all sectors of society (Smart, Pleaner & Dennil, 2001).

Growing up without parents, and being badly supervised by relatives and welfare organizations, this growing pool of children orphaned on account of HIV and AIDS would be at greater than average risk to engage in criminal activity (Schonteich, 1999).

Schonteich (1999) further points out that the absence of a father figure early in the lives of young males tends to increase later delinquency. Such an absence will directly affect a boy's ability to develop self-control. An insecure attachment will lead to lower levels of empathy and self-control, and to an increase in violent behaviour. Institutional care may be needed on a temporary basis to offer children a temporary home until a more permanent solution can be found. But as a long term solution, this intervention should always be seen as being the last resort for vulnerable children. Should the extended family not be available for any reason then the community could provide a better alternative than an institution (McKay, 2002; McKerrow, 1999). (This would be discussed in detail later in this chapter)

Psycho-social Impact

Demmer (2004) is of the opinion that affected family members are at risk of prolonged grief and psychiatric problems as they mourn an AIDS death. However, there is very limited research conducted in sub-Saharan Africa on psychosocial issues in general and related to HIV and AIDS in particular. Children are exposed to a multitude of stressors when their household is exposed to HIV and AIDS. Fear, worry, observing and caring for ill parents in pain, stigmatization, hospital visitation, shattered hope and eventual loss are all experiences shared by these children. The effects that parental illness and death have

on a child's mental health and ability to cope are complex, and depend on the child's developmental stage, resilience and culture (Germann, 2004).

Griesel-Roux (2004) support this line of thought in terms of the psychological impact of HIV and AIDS. The author states that the impact of psychological needs of persons infected and affected by HIV and AIDS are often overshadowed by physical and social needs in a setting with limited resources, and is thus often ignored. Affected and orphaned children are often traumatized and suffer a variety of psychological reactions to parental illness and death. In addition, they endure exhaustion and stress from work and worry, as well as insecurity and stigmatization. Loss of home, dropping out of school, increased workload and social isolation may impact on current and future mental health (Forehand, Steele, Armistead, Simon and Clarke; 1999).

Children who grow up without love and care of adults are at a higher risk of developing psychological problems. A lack of positive emotional care is associated with a subsequent lack of empathy with others and such children develop anti-social behaviours (Wild, 2002). Long-term studies of children in difficult circumstances have shown that they cope in different ways with traumatic stress situations (Fox, Oyosi & Parker, 2002) One study of South African children identified emerging social problems with children in distress, namely:- petty criminal acts; rape; teenage pregnancy and promiscuity; and lack of discipline (Fox, Oyosi & Parker, 2002). While some children experience severe impairment in their overall development, others seem to emerge strengthened by difficult circumstances. It is said that the context in which the traumatic experience takes place seems to be more important than the experience itself. If favourable conditions can be created both before and after the parent dies, then chances are that a child will be able to successfully overcome the trauma of separation from a loved one.

Children's emotional well-being is threatened during the course of change in the household, both before and after the parent dies. In the Eastern Cape, orphans identified other less tangible needs that they were missing from their parents, including love, care when they are sick, play time, guidance, friendship and recreation (Fox, Oyosi & Parker,

2002). Generally, children who lose their mothers suffer immense grief over the loss of love and nurturing, whilst the loss of the fathers is more directly related to decline in their standard of living. In many instances, the issue of dying is not discussed with children, so they are left to draw their own conclusions as to what is happening until the time when the parent dies, causing them to lose their sense of security. Where one parent remains, the child may live in fear that he/she will die as well and uncertainty about the future, where they will go and who will take care of them, can weigh on these children's minds. Because they so often don't readily understand the situation, children cannot express their fears and grief effectively and they keep it to themselves. With this sense of inability to affect the situation, children tend to lose hope in the future.

Whiteside and Sunter (2000) point out those children who lose a parent suffer loss and grief. However, for those who lose a parent to AIDS, their loss is exacerbated by prejudice and social exclusion, and can lead to the loss of education and health care. Moreover, the psychological impact on a child who witnesses his or her parent dying of AIDS can be more intense than for children whose parents die from more sudden causes. There are typically months or years of stress, suffering or depression before a person dies. Malaney (2000) also makes the same point that the death of a parent can be expected to have deep psychological effects on children. There is increased time spent by children in mourning for loved ones.

For a child living with a parent who has AIDS, the disease is especially cruel as HIV is sexually transmitted. Consequently, once one parent is infected, he or she is likely to pass it on to the other parent. Children who lose one parent to AIDS are thus at considerable risk of losing their remaining parent as well. For children, therefore, AIDS will, over time, cause a major diminution in social capital in the form of lack of social skills, knowledge and unclear expectations. It will also lead to detectable and quantifiable declines in levels of formal education (Whiteside & Sunter , 2000).

Further, research suggests that two often-overlooked impacts of AIDS are the increasing number of children who do not wish to attend school because of the stigma they

experience coming from AIDS-affected households and the psychological trauma and shock they feel after the death of a family member (Hepburn, 2002).

In addition these children are at risk of exploitation. Hepburn (2002) agrees that the psychosocial effects of losing a parent to a debilitating illness are severe and can have long-term effects on a child's behavioural development. As they endure the loss of parental support and nurturing, many orphans experience anxiety, depression and despair. Further complicating these emotions, siblings are often divided among several households within an extended family to mitigate the economic burden of caring for the children. Relatives or neighbours who have agreed to care for the orphans may contribute to the despair by taking their property or inheritance and leaving them more vulnerable to exploitation.

The provision of psychosocial support is relatively new and is often overlooked in general early childhood development programming. This gap is therefore being highlighted in the context of how best to support HIV and AIDS affected young children. Psychosocial support is one way of increasing the capacities of young children and their caregivers to cope and to improve development. Psychosocial support can be defined as providing the possibility of individual disclosure of feelings and emotions and expressions of personality combined with influencing the social environment to reintegrate affected children into their usual setting and encourage broader understanding of their specific situation. Psychosocial support can build children's resilience within a wider supportive environment. Developing a supportive environment for young children is crucial especially in HIV and AIDS affected communities where children may need time and space to rebuild, restore and re-establish relationships (Hyder, cited in Fox et al, 2002).

Economic Impact

When HIV and AIDS strikes a household, the stress of illness, death and uncertainty about the future can be overwhelming. HIV and AIDS puts enormous economic stress on households as they care for sick family members, experience the loss of productive

adults, or take in orphans. HIV and AIDS is not only an increasing cause of death among adults, infants and young children, but it is also slowly impoverishing and dismembering families. At every stage of the HIV and AIDS pandemic, most of the social and economic consequences fall on families. In fact, the greatest economic impact of HIV and AIDS comes from the high costs of treatment and the need to assist surviving family members. Families and communities coping with AIDS-related illness and death shoulder a heavy burden, and the epidemic takes its greatest toll at the household and community level (Foster, Levine & Williamson, 2005).

Smart et al (2003) indicate that affected children are vulnerable to malnutrition, due both to scarcity of food and to the weak position they occupy within their guardian's homes in the household resource distribution process. Demmer (2004) quotes research that shows that AIDS affected families have less money to spend on food, clothing and education. To reduce their food costs, affected households may reduce the frequency and quality of their meals. Children are plunged into economic crises and insecurity by their parent's death and struggle without services or support systems in impoverished communities. Studies reveal that income in orphan households is lower than in non-orphaned households (Foster and Williamson, 2000). Studies on urban household show that when a family member has AIDS, the average income falls by as much as sixty percent. Expenditure on health care quadruples, savings are depleted and families often go into debt to care for sick individuals. Other studies suggested that food consumption might drop by as much as forty one percent in orphan households. Asset selling to pay for health care, loss of income by breadwinners and funeral costs may deplete all household savings (UNICEF, 1999).

Children are affected both emotionally and materially when a parent has HIV or AIDS-related symptoms and is ill for a protracted period of time. Out of necessity, children assume adult roles, such as caring for an ill or dying parent, providing care for siblings and generating income to support the family (Humuliza,1999). The addition of these responsibilities restricts their access to education and children in these circumstances may drop out of school after a period of time. In both the short and long term, loss of

education can lead to various negative externalities. Female children of sufficient age whose mothers die are especially vulnerable to dropping out of school, as they may be required to take on domestic chores previously carried out by the mother.

In the case of an ill breadwinner, family income dwindles, while at the same time, household expenses, especially those related to traditional or clinical treatment increases. Reduced income contributes to poor nutrition in the household and can create a cycle of poverty that the next generation cannot escape (Strode and Grant, 2001). With the loss of income from the patient, who is usually the breadwinner and the substantial increase in household expenditure for medical expenses, school-going children are forced to drop out of school and care for the sick. Death results in permanent loss of income. Loss of skills also occurs because fewer or no adults are present to be involved in livelihood activities. In child-headed households, children may suffer loss of their home and livelihood through the sale of livestock and land for survival as well as through asset stripping by relatives (Schonteich, 2003). In some instances in child-headed households, their farms are taken away; hence they have nowhere to grow food. Children survive by begging and through petty crimes (Fleshman, 2001).

The financial burden of HIV and AIDS adversely affects the living standards and the quality of life of all household members, leading to food insecurity, malnutrition, poor hygiene and loss of opportunity (Giese, 2002). Malaney (2000), Giese (2002) and Moletsane (2003) state that there are financial consequences from the loss of parents. They point out that as children are orphaned they often lose their primary source of financial support. Young children are often forced to find work to support themselves and their younger siblings, thereby causing them to drop out of school. Moletsane (2003) further adds that the demand for child labour tends to go hand in hand with absenteeism and tardiness, and may impact negatively on the child's ability to learn and/or stay in school. With family responsibilities on their shoulders, attending school or doing well in their studies becomes impracticable.

Children and their families are affected the most (Ebersohn and Eloff, 2002). Many children, who are orphaned as a result of AIDS, grow up as street children or in child-headed households, with very little income and, therefore, no possibility of attending school (Moletsane, 2003). Some are brought up by grandparents, mostly grandmothers, and survive on monthly state social pensions of R 1010-00 (rate as per April 2009).

Educational Impact

Orphans are less likely to have proper schooling. The death of a prime-age adult in a household will reduce a child's attendance at school (Barnett and Whiteside, 2002). This household may be less able to pay for schooling. An orphaned child may have to take on household or income-earning work. When a child goes to another household, after his or her parent's death, the obstacles become greater as the child is not their own. With the decline in the number of economically active people, children, most of who are orphans and/or live in child-headed households, are left to fend for themselves. Under these circumstances, unable to access resources for their basic needs, education becomes either a nuisance or a luxury. Whiteside and Sunter as cited in Moletsane (2003) argue that when money is available, most of it is spent on medical and nutritional care of the sick and dying. Thus the possibility of successfully educating children becomes remote, and that of keeping them in school almost impossible. The result is high failure rates and eventually high dropout rates from school.

As increasing amounts of money is spent on medical care, this means there are less resources for the children and often one or more of the children drops out of school either to care for the sick parent or because there is no money for attending school. More often than not it is the female child who is asked to drop out of school first. Children may have to work to generate income for food, or look after other siblings to free up the mother's time. With the loss of labour and money spent on treatment, the family can quickly slide from a relatively secure position into increasing poverty, vulnerability and ill health (Whiteside and Sunter, 2000).

The death of a caregiver may have a negative impact on school attendance, and many orphans have difficulty gaining access to schools. This may be because of various factors such as the cost of school fees, uniforms and books, transport difficulties, caring for younger siblings and other responsibilities at home. It has also been repeatedly shown that school attendance is one of the most important protective factors in relation to emotional and social wellbeing.

School fees are another critical factor that excludes children from education and schooling. Whilst the Constitution of the Republic of South Africa Act, 108 of 1996, states that education is free, the reality in South Africa is that education has become a commodity. In order to improve the quality of education, schools are imposing school fees that parents/guardians have to pay. Most schools are struggling financially and depend to a large extent on the payment of school fees.

Parents who are unable to pay school fees run the risk of their children being expelled from school, being held back in a grade, having report cards withheld, being threatened by teachers or being embarrassed or ridiculed (Badcock-Walters, 2002). They further argue that the inability to pay school fees may indeed prohibit the entry of the child to school. While there is clear national policy insisting that every child has the right to access, school principals are faced with issues of institutional viability and routinely turn away learners unable to pay fees. Even if a school was to permit entry, the fact is that the child would be hard pressed to pay for stationery and textbooks, as well as transport to school and food at school.

According to Williamson (2004), the additional expenses and loss of cash income from employment that comes with illness force families to re-direct their financial resources. Compulsory school uniforms, the cost of which has been found to be beyond reach for many of the families in rural and township schools, is another stumbling block to children's access to education (Williamson, 2004, Moletsane, 2003). For HIV-infected and affected children, the burden of paying for education is, therefore, considerable. To supplement household income, children often have to drop out of school in order to

engage in income-generating activities, or care for the sick and dying, as well as the surviving siblings (Moletsane, 2003). This problem is not peculiar to South Africa. In commenting on education in sub-Saharan Africa in general, Hepburn (2002), in a study conducted amongst teachers in Botswana observed that primary education is not universally free. Families, through locally imposed fees, must pay a substantial proportion of the costs of operating a school. In addition to school fees, families are often required to pay for teaching materials and supplies, uniforms, recreational activities and levies for school development, maintenance and construction. Smith (2003) argues that children become disaffected from schooling when they see that their teachers are a source of infection, that schools are not geared to counsel them in their grief and that nothing exists to help them through this most difficult period of their lives.

Malaney (2000) also concurs with Giese (2002), by stating that there are financial consequences from the loss of parents. She points out that as children in households affected by HIV/AIDS, the school attendance of children drops because their labour is required for subsistence activities. In the face of reduced income and increased educational expenditure, the money earmarked for school expenses is utilized for basic necessities, medication and health services. In addition, stigmatization may prompt affected children to stay away from school, rather than endure exclusion or ridicule by teachers and peers (Williamson, 2000).

Children that are orphaned, they lose their primary source of financial support. Young children are often forced to find work to support themselves and their younger siblings, thereby causing them to drop out of school. In many cases orphans are taken in by extended families who often cannot afford to keep all these children in school.

There are many influences in a child's life, such as family, community, peers, school and culture, all of which are potentially contradictory and confusing for the child. School is important to children in general but because of the difficulties children affected by HIV and AIDS experience at home and the rapid disappearance of support from family,

teachers and other students play an even greater role in supporting their self-esteem. Support from others in the community can also lessen the stress of the surviving parent. When illness invades the household, children's concerns and problems change, and as a result of this, their behaviour towards others can also change (Humuliza, 2000). Responsibilities at home may directly affect their school lives, contributing to being away from school for short or extended periods of time. Worrying about an ill parent can cause a child to be distracted in class or the child can become aggressive when playing with others.

Without a proper understanding of the student's home life, a teacher may identify the behaviour and actions with those of a 'problem child' in need of reprimanding instead of a child acting in response to his or her situation. The more teachers and members of communities are aware of the situation of these children and become involved in activities to support them, the greater the chances of meeting the child's needs. The same need for understanding applies to other students. In many classrooms, the separation between students with parents and orphaned children is obvious. Some orphans even feel physically different from other children with parents (Humuliza, 1999 & Fox, 2001).

Impact on Health

The most startling evidence is the effect that the HIV and AIDS pandemic is expected to have on the health of children where a parent/s or a caregiver is HIV positive and those children who are orphaned on account of HIV and AIDS. Giese (2002) concurs with Piwoz and Preble (2000) that poor health and increased rates of stunting among children living in HIV-infected families, is common. Children living in households with HIV-infected persons are more exposed to opportunistic infections, such as tuberculosis and pneumonia. With caregivers sporadically sick or absent, the child is less likely to get the medical attention s/he needs and more likely to have repeat infections. Food security in HIV-infected households is affected by reduced household income and increased expenditure on healthcare which leaves less money available to purchase appropriate food. Preparation of food is also affected by compromised caregiving. The child may also be unable or unwilling to eat due to a range of physical, emotional and psycho-social

factors which play a role in appetite suppression (Ebersohn and Eloff, 2002; Giese, 2002; Piwoz and Preble, 2000).

As children under eight face increased health and developmental challenges in the context of HIV and AIDS, the nature of early childhood care is changing. Parents, caregivers and service providers need to know and understand the impact of HIV and AIDS on very young children. They also need support to provide the necessary holistic care (UNESCO, 1993).

Attention to all children is important; fostering positive gender socialization sensitive to early childhood education is vital to reduce inequalities between girls and boys. This includes addressing patterns of learned behaviour among boys as well as girls. Girls are more likely to be adversely affected in early childhood due to discrimination and need to receive equal opportunities in terms of nutrition, intellectual stimulation and opportunity to play (World Bank, 2003). Girls are also more likely to experience sexual and violent abuse, something that has been documented for older girls in schools in Africa. In Southern Africa the prevalence of gender violence has led some to talk of a 'twin epidemic' of HIV and AIDS and violence against women. In this cultural context, the idea that sleeping with a virgin cures AIDS, places girls as young as six at risk (Campbell, 2003).

One of the challenges of working with children affected by HIV and AIDS in situations of extreme poverty is around meeting the physical needs of the child and family. Of course in addition to normal developmental needs, children who are HIV positive or living with AIDS require extra nutrition to boost their immune systems. Where only minimal food quantities and diversity is available, this poses a great challenge. The need for warmth to protect the body from temperature fluctuations and the need for comfort during illness is another difficult challenge. Hygiene needs are of course crucial considerations when supporting someone who is HIV positive or living with AIDS. These are all practical challenges faced by families and caregivers which cause extreme distress.

2.3 Resiliency and Vulnerability

Often emotionally vulnerable and financially desperate, orphans are more likely to be sexually abused and forced into exploitative situations such as prostitution, as a means of survival. They are also more likely to drop out of school and be drafted into child labour. The eldest child often find themselves taking the role of mother or father or both, doing the household chores, taking care of the other siblings and caring for an ill or surviving parent. Most children, who lose their parents, are often in the care extended families. More often, these families use the children to benefit from the foster care grants (Cheek, 2000).

In some cases where there is no family to care for the children, they end up living in the street. While the actual number of street children in South Africa itself has never been counted, estimates in sub-Saharan Africa are that there are around one million children living on the streets. The majority of these children appear to be boys, possibly because girls have more marketable skills at a younger age, notably, domestic skills. Rather than compete for domestic jobs, boys tend to try and earn money on the street (Subbarao, Mattimore & Plangemann, 2001). A 1996 study in Rwanda estimated that one-third of street children were orphans. Researchers also found that 60 000 to 85 000 households were headed by children, three-quarters of who were girls (Subbarao et al, 2001). In ninety five percent of these households the children had no access to health care or education, were frequently exploited and abused sexually and were often denied inheritance rights of land and houses.

The plight of orphans has entered the international spotlight and many organizations and communities have created programmes to address children's issues. In an effort to create projects to assist children, various research studies have attempted to identify their needs. In most studies, (Ali, 1998; Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda, 2001) children will identify material needs as their most pressing need, as demonstrated in a

study of South African children (Fox et al, 2002) who identified as their most urgent needs :- food, clothing, bedding, medical care, money, grants, shelter and school requirements such as lunch, books and uniforms. It is therefore understandable that where basic needs are not being met, programmes tend to focus specifically on providing money for material needs rather than on counselling or other forms of emotional support. While financial aid is critical for the immediate survival of the child, initiatives should not stop there (Fox et al, 2002).

Understanding the impact of death and dying on a child's emotional well-being is also critical. The organizations working directly in the sector on addressing the needs of children affected by HIV and AIDS all speak of the challenges relating to addressing a diversity of needs. Many of the children affected by HIV and AIDS are also living in conditions of extreme poverty, without access to adequate nutrition, clothing, shelter or access to education. Many children affected by HIV and AIDS have inadequate adult supervision and care, let alone psychosocial support for the specific difficulties associated with the illness. Additional social problems such as risk of abuse and stigmatization form part of the multiple challenges in working with children living in difficult circumstances. (National Department of Health, 2004)

According to research in the United States, most children who are affected by HIV and AIDS will have clinically significant levels of psychological disturbance at some time during the trauma; more than half will qualify for the diagnosis of a psychiatric disorder. Research has shown, however that resilience, the capacity for successful adaptation despite challenging or threatening circumstances and protective factors, such as an easy-going disposition and the presence of supportive adults, can reduce the intensity and longevity of these symptoms (Masten, Best & Garnezy, 1990).

One factor that affects how children respond to the risks associated with HIV and AIDS is developmental age and stage. Older children, for example, are at increased risk because they may need to assume an adult role prematurely. Cultural beliefs can also affect the level of comfort and support children receive during times of crisis. Cultures have

complex norms that govern assistance provided to ill members, and informal rules about familial responsibilities concerning the custody of orphaned children. Children may find their ordeal considerably ameliorated if they experience love and support from their extended family and the larger community. To the extent that children live in communities already plagued by discrimination, poverty, violence and demoralization, however, cultural resources may be lacking. In many developing countries, AIDS has already demanded extraordinary sacrifices from communities, particularly from grandparents, who often must care for multiple grandchildren from several of their dead children. Children may have an easier time coping with loss if they still have a healthy remaining parent who can help them grieve successfully (Foster, Levine & Williamson, 2005).

Children who are old enough to have developed cognitive abilities and coping skills are better able than their younger siblings to understand the parent's illness and what it means for the family's future, and they can use previous experience and social and decision-making skills to adjust to the demands of HIV and AIDS.

Children with strong intellectual ability and cognitive maturity are more likely to be classified as resilient (Werner & Smith, 1992). Parents and other caregivers are the most important and consistent protective factor for children under stress (Masten et al. 1990). Parents who can function adequately under stress and who are consistent and responsive will facilitate successful coping and adaptation in their children. The strength of the attachment of parent and child is the best predictor of whether a child will develop self-reliance and positive self-regard (Sroufe, 1997). Children who are insecure in their attachment are vulnerable; they have experienced unavailable or inconsistent support from caregivers and are more likely to develop psychopathology in the face of major stresses. Other family factors that may provide buffers against the harmful effects of parent death include protective parenting styles, family resourcefulness and adaptability.

Parents are the most important guides and partners in the construction of a child's personality. In particular, open communication between an ill parent and a child may

facilitate the child's long-term adjustment after parental death, especially when there is a discussion of the likelihood that a parent might die and the parent was able to tolerate the child's expression of strong emotion, such as grief or anger.

Although the pivotal role of parents and the social support in buffering trauma for children is well documented, there has been little attention to the impact of the loss of parental support. The illness and the death of a parent combine the most traumatic risk factors for children's adjustment with the loss of their most powerful and important resource for coping- their parent's love and support (Bretherton, 1993). Children benefit from having a social support network outside the immediate family. Children with at least one adult mentor are more likely to overcome adversity. When a parent is ill or incapacitated other adults in a child's life; such as neighbours, teachers, ministers or elder mentors who can play caring roles (Werner & Smith, 1992).

2.4 Children's Rights in Jeopardy

Children's rights are designed to offer a framework for policy and implementation allowing for the enhancement of human and social development of children within a protected environment, and improving the situation of all children. In the context of high prevalence of HIV and AIDS and vulnerabilities posed for children, it is expected that the rights of children as outlined internationally and nationally would serve as guidance for the development of HIV and AIDS strategies. The UNAIDS International Guidelines on HIV and AIDS and Human Rights state that:

“One essential thing learned in the HIV and AIDS epidemic is that universally recognized human rights standards should guide policy-makers in formulating the direction and content of HIV-related policy and should be an integral part of all aspects of the national and local response to HIV and AIDS”

(Strode and Grant, 2001:4).

For this review, an examination of some of the rights of children provides a guiding framework in understanding the role and implications of local responses to HIV and AIDS for children. Barnett and Whiteside (2002) mention that the rights of children may

be threatened by the orphan pandemic. The International Convention on the Rights of the Child in principle provides a protective framework for children. It accords them the following rights outlined in the Table 1, which are to be protected by signatory governments, like South Africa:

Table 1 : Convention on the Rights of Children

Convention Article	Rights of children
Article 2	To non-discrimination and to be protected from all forms of unfair discrimination.
Article 7	To be cared for by his or her parents
Article 6	To preserve identity, name and family relations
Article 18	To be brought up by parents or guardians whose basic concern is his or her best interests.
Article 19	To protection from physical or mental ill-treatment, neglect or exploitation.
Article 27	To conditions of living necessary for his or her development.
Article 28	To education
Article 32	To protection from economic exploitation and performing any work that interferes with his or her education or is harmful to his or her mental, spiritual or social development.
Article 34	To be protected from all forms of sexual exploitation and sexual abuse.

In normal circumstances many of these rights are violated. HIV and AIDS increases the number of children at risk. In extreme cases, orphans turn to the street, where their physical needs and financial desperation makes them vulnerable to crime and sexual exploitation (Barnett & Whiteside, 2002).

As noted by Strode and Grant (2001), responses in addressing the HIV/AIDS pandemic have to be rights based if it is to protect our children and youth. They provide an overview of rights pertaining to children, some of which are summarized below:

- In October 1997, South Africa ratified the United Nations Conventions on the Rights of the Child (CRC) 1989, which is premised on the survival, development, protection and participation rights of children.
- Article 2 of the CRC sets out the right to non-discrimination and provides children with the right to be protected from all forms of unfair discrimination. Full implementation of Article 2 facilitates the prohibition of discrimination of children based on real or perceived HIV status.
- Article 27 of the United Nations CRC declares that every child has the right to a standard of living adequate for his or her physical, mental, spiritual, moral and social development.
- In January 2000, South Africa ratified the African Charter on the Rights and Welfare of the Child. It is based on the rights of children as stated in the CRC, yet is more reflective of African cultural concerns and considers issues as the position of the girl child, the idea of collective rights and community responsibilities, and the participation of children in armed conflict (CINDI Report, 2006)

HIV and AIDS is impacting tragically on children's rights to be protected and to participate in their society, and on their ability to protect and manage themselves. One of the enduring traumas for affected children is that the discrimination associated with HIV and AIDS can put certain of their rights, such as their rights of access to care and learning in jeopardy of others, like their right to confidentiality (Fox et al, 2002).

2.5 The Role of Caregivers/ Kinship Carers

Whilst reviewing the literature, it becomes evident that authors do not use a single term to refer to kinship carers. Some definitions place emphasis on the relationship between the carer and the child such as “grandparents as caregivers to grandchildren” (Burton(1992); Jendrek, (1993); Roe and Minkler,(1998); cited in Petty, 2002), and Gibson’s (1999), cited in Petty, 2002) term, “grandmothers as ‘mothers’ again”. But the mostly widely used term in the literature appears to be kinship carers.

There do not appear to be a universal definition of kinship care, but rather descriptions of what kinship care is. Berrick (1997: 286) described kinship care as, ‘a developing phenomenon, falling somewhere between family preservation and foster care’ Grogan-Kaylor (2000:133) defined kinship care as “a particular form of family foster care in which children are placed with foster parents who are biologically related to them, most often, these kinship foster parents are grandparents of the child or an aunt or uncle”. When parents of a child can no longer care for him/her or dies, then a close relative takes over the responsibility for the child. Hegar and Scannapieco (1995: 201) quoted Billingsley who indicated that “people can become part of a family unit or form part of a family unit simply by deciding to live and act towards each other as family”. Scannapieco and Hegar (1996:567), describe kinship care as a “strategy for family preservation”.

Kinship carers are left to care for children whose parents are unable to fulfill their parental responsibilities because of illness, death, poverty, or other debilitating social factors. In many instances the children arrive into these placements as a result of tragic circumstances and are thus in need of remedial intervention. The rapid growth of this phenomenon has superseded the development of relevant services for kinship carers and their wards (Petty, 2002). Kinship care offers a significant challenge to social work in terms of the growing numbers of these placements, the complexities of the relationships amongst the kinship carers, the children in their care, and other family members, the economic consequences of caring for a child or children that are not planned, the

economic consequences for the welfare system and the social consequences to what often is a “three generation” scenario (Gibson, (1999), cited in Petty, 2002: 14).

The alarming incidence of AIDS has caused many children to experience psychological trauma. After the death of their parents, many children find themselves living with members of extended families. Joubert (cited in Petty, 2002) pointed out that in many instances, a grandparent, aunt or older sibling, becomes the most significant caregiver of a particular child. Because of the economic burden placed on kinship carers, some children become victims of neglect or abuse or suffer secondary trauma (Petty, 2002).

The extended family can be described as a network of connections among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations. The extended family continues to play an important role in supporting HIV and AIDS affected households. The role of the extended family includes caring for the children of other relatives to ease the burden on the family while a parent is sick. In rural contexts this is more feasible as urban dwelling families generally live far from other relatives. The security net provided by the extended family system has been weakened by HIV and AIDS and is often supplemented by alternative strategies. The expense of the introduction of a relative’s children in the household may threaten the financial stability and, as a matter of course, imposes additional financial burdens. Children in this situation may be neglected and, depending on their ages, may be required to make additional contributions to the household tasks, whilst at the same time receiving insufficient attention and care (Foster & Williamson, 2000).

Because many communities affected by poverty and conflict tend not to prioritize the needs of children, one may find oneself neglecting the suffering of children while attempting to implement more systemic programmes. For example, it becomes difficult to encourage community based support for orphans when community members are struggling to find sufficient resources for themselves and their own children. Similarly, it is difficult to expect community based organizations to offer psychosocial support to

children affected by HIV and AIDS or trauma when they themselves might be experiencing the same problems.

Hence the balance between stepping in to provide direct support to children in extreme distress and stepping back to facilitate preventive initiatives is a constant tension inherent in this work. Primary caregivers of children affected by AIDS, like relatives or extended family members, play a crucial role in respect of the children's psychosocial wellbeing, access to education and of course physical well being. Therefore, the provision of support to the people caring for children, such as the child support or foster care grants, would be beneficial to the carers. Many families caring for children affected by AIDS are burdened by limited resources, and thus helping the caregivers to be able to provide better resources to and psychosocial care of their children is an important aspect of Children in Distress (CINDI) Members' work (Fox et al, 2002).

When reviewing the literature, I was unable to locate much published findings that reflected the extent of the growth of these placements in South Africa. But because of my experience in a child welfare setting and my discussions with other welfare agencies, I am aware of the overwhelming amount of social worker's time being spent processing applications for foster care by kinship carers. Welfare agencies consulted identified these carers as typically a group of single women, who are struggling with limited incomes. Child Welfare South Africa has 170 affiliates in the country. A total of 138 398 children were placed in foster care in 2007. The highest statistics being KwaZulu- Natal with 130 358 children committed for the first time to a foster home. (Annual Statistical Report, 2007, which was presented at their General Assembly in November 2008).

Child Welfare SA, Margate currently have 1531 children in foster care, with an escalation of an average of 230 new applications per annum(Monthly Statistical Report, October 2009). This statutory load which was initially managed by two social workers in 2006, is now managed by five social workers.

The high statistics of kinship care placements are incongruent with the services and resources developed to help these families. Mental health professionals need to find ways to strengthen the coping strategies of these families, whilst at the same time assisting the children to deal with the losses and trauma (Petty, 2002).

Much of the burden of care for orphaned children is currently being borne by grandparents. Sadly, my experience suggests that these groups of carers are given little assistance to deal with the children left in their care, despite the evidence that many of these children had been exposed to various forms of child abuse and neglect, loss or trauma. Abused and neglected children are more socially immature, have more maladaptive social skills, are more aggressive, and are more easily distracted and more prone to temper tantrums and delinquency (Rittner and Sacks, 1995).

Kinship care placements enable children to live with people that they know and trust, support the transmission of a child's family identity, support the child's cultural and ethnic identity; help the child stay connected to siblings and help the child build and retain connections to the extended family (Scannapieco and Hegar, 1996). It can be surmised that many carers care for children who have been emotionally or socially damaged by their circumstances. Kinship carers are expected to care for these traumatised children independently, with little professional assistance.

Kinship placements offer more stability and permanency. It also offers more support to children. At a time of crisis, the child receives the support and care of not just the caregiver, but a group of caring individuals associated with the child and the kinship carer in some way. These existing, established relationships provide the child with a large, familiar network of support that can be relied on in various situations (Petty, 2002). Because the members of this network of support are familiar to the child, they lessen the trauma associated with separation. Another advantage pertains to the emotional security experienced by children in kinship placements (Dubowitz; Hegar and Scannapieco; Leslie, cited in Petty, 2002). The continuity of relationships between siblings and the support they receive from one another protect these children from feeling that the family has

disintegrated totally and allows them to have a greater sense that they will not be easily abandoned.

Whilst there are many positive reasons documented for kinship care placements, there are also drawbacks. Kinship placements do not receive adequate professional services for the screening and monitoring of the quality of care that the children receive. Many kinship carers lack the resources to refer children in their care to specialized treatment and sadly, they seem to be left on their own to just get on with the responsibility of caring for these children. Furthermore, they are not expected to undergo training before the children come into their care, which is of concern because as indicated, kinship carers are often older than non-kin foster parents.

Grandparents as kinship carers may experience further constraints as their age affects their level of physical activity. Low levels of energy and lack of knowledge about current child rearing practices are commonly experienced issues associated with the wide age difference between the older kinship carers and children in their care (Petty, 2002). The kinship carer's family has to be re-arranged when a child is suddenly placed in their care. There are many role shifts to be made and new responsibilities to honour. These changes place new demands on all concerned. The demands often create considerable strain.

Many kinship carers report being overwhelmed by the numerous logistical and physical demands placed on them. They struggle to keep up with school, social and physical demands of these children, at the same time struggling to meet the financial costs in caring for them (Burton, Grogan- Taylor, in Petty, 2002). Because of the severe financial constraints, carers are often unable to ensure that children in their care, who have easily identifiable health problems, receive the necessary treatment (Grogan- Taylor, 2000).

Handling so many stressors impacts on the personal lives of kinship carers. Jendrek (1993) found that grandmothers who are carers for their grandchildren complained of being physically tired. A high percentage, eighty-six percent, reported feeling depressed or anxious most of the time, sixty-one percent noted that they smoked more heavily and

thirty-five percent complained of medical problems like diabetes and arthritis (Petty, 2002).

There has been a strong move away from institutional care of orphaned and vulnerable children. CINDI (Children in Distress) supports this change and the Department of Social Development's policy of placing children with extended families in communities, instead of in institutional care which is considered a last resort. Created in 1996, CINDI is a network of autonomous, self-funded non-governmental organizations (NGOs) and provincial government agencies that seek to respond effectively to the growing numbers of children in Pietermaritzburg and surrounding areas. Organizations like the Child and Family Welfare agencies, across the country deal with a high number of children in extreme distress. These children may be HIV positive and abandoned by caregivers, orphaned, abused or neglected, forcing urgent removal and temporary care at a place of safety or children's shelter.

Four basic social safety-nets were developed as key strategies for caring for large numbers of children in distress, on which CINDI's principles and those of member organizations are based:

- First choice was the extended family of the orphan that may need to be empowered to accept children and raise them effectively;
- The next best safety-net was a neighbour or community-based structure, enabling children to be raised in familiar surroundings;
- The third level was economic empowerment for caregivers;
- The safety-net of last resort was residential care, which includes existing residential facilities, foster parenting and cluster foster care (Cindi, 2001)

There is much debate among social workers in the child welfare field around the benefits of family care versus institutional care (McKay, 2002). Williamson (2002) indicates that Children's Homes are much more expensive to maintain than assisting families to care for children. He further stated that countries with long-term experience with institutional

care for children have seen the problems that emerge as children grow into young adults and have difficulty re-integrating into society. Foster families are known to experience similar challenges. McKay (2002) indicated that experts are predicting that by the year 2010, there will be between two and three million orphans in the country and these experts are asking what will happen when grannies die. A large number of foster placements are family-related placements and this concern becomes very relevant. Given the steady decline in traditional family living due to HIV/AIDS, poverty and unemployment in South Africa, the dominant view that foster care is a superior option to care in a Children's Home, may therefore not be plausible.

Chama (in Williamson, 2002) calls for the revival of the old African tenets of extended families and strong community life. He adds that given the strenuous challenges brought about by the HIV and AIDS pandemic, the Black African extended family is perhaps much weaker now than hundred years ago but the resilience and the spirit of community life is still there for the current practitioners to tap into. This resilience, however, needs structural sources of support to be strengthened. It therefore appears necessary, in the absence of this support, to challenge the dominant view of family care as the best option for vulnerable children. Although the African extended family is resilient as the grannies forsake their well being and use their old age pensions to provide for the basic needs of multigenerational family units, the state views this as a family preservation strategy and it is a cheaper option than to maintain a child in a child and youth care facility. Sewpaul (2005) confirms this in her critique of the draft National Family Policy (2005) by writing that the Policy places responsibility for quality of living squarely on the family, and/or reflects a fear and anxiety about those undeserving poor who might abuse state resources and become dependent. Extended families are therefore rare, given these enormous strains.

The study by Perumal (2007) is a comparative study on the experiences of children living in foster care and those living in Children's Homes. Her sample comprised of thirteen children between the ages of seven and seventeen, foster parents of the participants and key informants at the Children's Homes, where the children were placed. In exploring

where children preferred to live, it was concluded that children preferred to live with families of origin irrespective of their families' circumstances of inability to keep them safe. However, between the alternative care options, a majority of children preferred to live in foster care as opposed to Children's Homes. Children's Homes may be financially equipped to care for children but lack a strong human resource component, which unfortunately compromises the care of children. It can therefore be concluded that the centrality of the family, which supports the dominant ideology that family care supersedes all other forms of care, cannot be negated. Every effort should be made to support the family to enhance their functioning, as children preferred to live in family settings as opposed to Children's Homes. In spite of Children's Homes receiving more financial support to care for the children, human resources within Children's Homes needs to be strengthened to ensure optimum care for children. This was in direct contrast to Perumal's assumption that Children's Homes may be better resourced to care for vulnerable children as opposed to foster families. The dominant view nationally and internationally, supported by various legislative tools, is that vulnerable children are best cared for in foster homes as opposed to Children's Homes (Morei, 2002 & McKay, 2002).

As the HIV and AIDS pandemic tightens its grip on communities already weakened by poverty, traditional family systems to care for parentless children have been forced to change. Examples of this kind of change are care by maternal rather than paternal kin where the latter is more traditional, more widespread care of children by grandparents, or the emergence of a new form of coping with care provided by child headed households (Ali, 1998).

In countries severely affected by HIV and AIDS, the development of residential care is sometimes justified on the grounds either that families or communities are so overwhelmed by children orphaned by AIDS that there is no other alternative than to consider institutional care. Donors sometimes favour residential care because it provides tangible and visible manifestation of their investment. Institutions also have high media

appeal, are perceived to be easier to monitor than family care, and can be favoured by social service professionals because they are organizationally convenient (McKay, 2002).

The research literature and my experience as a social worker, however, provide extensive data on the principal disadvantages and the negative impacts of residential care. Even where the physical conditions are good and the standard of education excellent, a number of problems are almost inevitably associated with residential forms of care. These include lack of stimulation and personal care and affection, institutional dependence, and the difficulties in adjusting to the outside world when leaving. Significantly, there is virtually no empirical evidence to contradict these findings. Institutional care is inappropriate because it contravenes children's rights and undermines their development. From a policy standpoint, it also produces poor results for small numbers at high cost per child. Cost is an important consideration because of the vast scope of the epidemic. Where institutional providers are government agencies, the diversion of a disproportionate percentage of state funding into the care of relatively small numbers of children distracts attention and much-needed resources away from the greater priority of supporting family- and community-based care. Unfortunately, disinvesting in institutional care always seems more difficult than investing in it. By contrast, community-owned initiatives that aim to promote local solutions based on family and community resources achieve good results for large numbers at low cost per child. Families increasingly are feeling the strain of shouldering a disproportionate burden of taking in more children when, strangled by pervasive poverty, they already live in extremely difficult circumstances. The impact of this inordinately heavy strain is manifesting itself in various ways. These families and communities need help (Perumal, 2007).

Even with an optimistic forecast of the spread and impact of HIV and AIDS, it seems likely that, in some contexts, the needs of children lacking protection and care will exceed the capacity of the extended family and the community to provide for them. If alternative forms of care need to be developed, placement within a family setting is almost always preferable to institutional care (Foster; Levine & Williamson, 2005).

Many families undertake foster care under already difficult living conditions. Several CINDI Members are involved in supporting these foster carers. At times it is necessary to recommend removal of children where foster care placements have clearly been accepted by adults purely interested in monetary gain. In these situations the foster care grant does not reach the intended child who is often severely neglected and even abused. Most very young children born to HIV positive parents spend their first few years with ill and tired caregivers. Under conditions of poverty, ill-health and stress, parents and other caregivers struggle to meet nutritional, health and psychosocial needs of young children at a critical formative stage. Very young children are often caregivers themselves, either to ill parents or other siblings. The lack of attention will have an impact on the quality of young children's current and future lives.

Another viable option of care is cluster foster care. Cluster foster care can be described as a model of care where volunteer women and couples are recruited and trained in the basics of child care. Up to six children are placed with each volunteer who receives foster care grants and material support. Community workers link these volunteers to other resources such as day care centres which relieve foster parents of child care duties in order to undertake income-generating activities McKerrow (1999).

Pietermaritzburg Child and Family Welfare Society have developed a cluster foster care scheme for children with HIV and AIDS. In terms of this scheme, potential cluster foster care (CFC) parents are recruited, screened and trained in home-based care, universal precautions and the management of children with HIV and AIDS. They are provided with a start-up pack of, *inter alia*, milk formula, clothing, toiletries and, in some instances, material support until the foster care grant is received. CFC parents are also visited monthly to offer support and to ensure that children are well cared for.

The concept of one foster mother caring for several children in a communal setting is used by at least two other CINDI partners, God's Golden Acre and Kenosis (CINDI Report, 2006). Nielson & Somnath (cited in Sewpaul, 2001) described the establishment and maintenance of community family care centres that provide children with a family life experience, in a context similar to that of their community; cater for the physical,

social, psychological and spiritual development of children and provide children with stability.

A major impact of HIV/AIDS is that caregivers of very young children, whether they are parents, grandparents or extended family members are pushed to financial and practical limits. Caregivers in communities affected by HIV/AIDS therefore need support. This can be done in multiple ways, namely: - through counselling and training in parenting skills, burial and lending credit associations, agricultural and shared childcare projects. It is the most productive generation of breadwinners that is dying from AIDS. The social, political and economic development of communities and nations will also be affected as millions of adults grow up without the key skills and emotional intelligence for survival, learning and socialization. There are even possible links between poor early childhood experiences and a higher risk of HIV infection in later life.

The literature suggests that the kinship carers love the children in their care, are committed to them and at times experience this “newly acquired” parenting role as gratifying. Whilst the role of “parent” is foisted on them at a time when they may feel less prepared for the enormous responsibilities associated with this, they often report acquiring a sense of purpose in their lives again. (Burton; Gibson & Jendrek in Petty, 2002: 26). A renewed sense of purpose and the sheer joy that children can bring into a household are amongst the benefits cited by grandparent caregivers. Caregivers are left to struggle with other difficult issues, such as how to protect children in their care from stigma associated with their parent’s shameful past (Grogan-Kaylor; Roe & Minkler, in Petty, 2002) and how to provide positive role models for the children to identify with. In some instances, the kinship carers may be criticized by other members in the family for the time and money she invests in the child, who is placed in the home as this limits the attention or resources that those members would have benefited from had the child not being there. Handling so many stressors impacts on the personal lives of the carers.

I support what Maluccio, Fein and Olmstead (1986) indicated that the bonds of attachment between a child and his/her family of origin remains strong even after being placed in alternate care. These strong bonds are indicative of a child's sense of belonging within his/her family of origin. I also concur with Moodley (2006) that family preservation needs to be given priority as the removal of children in some instances may be avoided. This empowerment strategy will capacitate families of origin and enhance/strengthen relationships between children and their caregivers. Furthermore, it is within the family that the child grows up, develops and forms a sense of identity and competence. It is therefore imperative for government to competently address poverty of all South African families. I also agree with Sewpaul (2005), that structural sources of support are necessary since the South African context testifies to a historical unequal distribution of resources for different racial groups, rendering many of them incapable of comprehensively caring for their children.

Kinship care raises many challenges for the carers and the professionals that serve them. A multitude of factors makes it difficult for kinship carers to positively contribute to the healthy development of children in their care. Whilst economic support is a most pressing need for many kinship carers, support and parenting skills are likely to empower, restore their self-confidence in their roles as carers, and enable them to address these challenges. Kinship carers require educational and supportive services (Petty, 2002). (This is discussed further in Chapter 9).

2.6 The System of Social Security

The Treatment Action Campaign (TAC) believes that the implementation of a Basic Income Grant (BIG) may be an effective HIV and AIDS preventative measure (BIG Financing Reference Group, 2004).

There also exists the stereotyping of teenage girls who are accused of becoming pregnant to obtain child support grant (CSG). Many in society, including people in government, churches and the media seem to take this unsubstantiated link for granted (Case, Hosegood & Lund, 2003).

The South African Constitution, adopted in 1996, mandates the right of access to health care, food, water and social security under Chapter 2, the Bill of Rights. Specifically, Section 27 (1) (c) states that everyone has the right of access to social security, including, if they are unable to support themselves and their dependents, “appropriate social assistance.” The immediate following subsection 27 (2) states that: “The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights” (South African Constitution, 1996).

The sentiment of Ex-Finance Minister Trevor Manuel’s comment that “people must learn to work instead of living on handouts” (Cape Argus, February 11, 2007) is highly indicative of a value that underlines a residual approach to social welfare. This comment by the Ex-Finance Minister again creates a false impression that there exists in South Africa a social assistance system that would enable people to choose between social grants and work. The sentiment also creates an equally false impression that jobs are available to anyone who wants them. It is difficult to ascertain what “learn to work” means in an economic environment where the supply of unskilled and semi-skilled labour so vastly outstrips demand.

A BIG would help ensure that: 1) unemployed persons could undertake intensive skills training or education to improve their chances of securing work without worrying about their family’s survival for the duration, 2) people could undertake higher risk job search involving expenditure, and 3) people’s overall health improves (through better nutrition and the ability to access health services) which would enhance their ability to undertake demanding full-time work and undertake intensive job search (BIG Financing Reference Group, 2004).(This is elaborated in Chapter 9).

2.7 Conclusion

HIV and AIDS affects the South African Society in virtually all spheres of life. The disease grew from being virtually unknown in the 1980s into a pandemic, unsurpassed by any other illness or natural disaster. South Africa appears to be particularly vulnerable to the spread of the disease because of a number of social factors, amongst others, poverty,

income inequality unsafe sexual practices, gender inequality, and social dislocation. In this literature review I presented a critical review of what has been done in the field of study and identified significant gaps in the literature as it relates to the experiences of children orphaned on account of HIV and AIDS. The review identified areas of controversy in the literature. One of the critical areas that needed further research was in-depth experiences of orphans and their communities through the eyes of the orphan and caregivers/ kinship carers. The system of social security for kinship carers was briefly discussed. The review also pointed to the discourse on children rights and how these are in jeopardy.

In the following chapter, I discuss the theoretical framework for the study.

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 Introduction

Bronfenbrenner's (1979) social ecology model provided the theoretical framework for this study. Urie Bronfenbrenner's bio-ecological perspective offered an insightful lens for understanding families' experiences with the HIV and AIDS pandemic. Bronfenbrenner's approach to understanding families was helpful because it was inclusive of all of the systems in which families are enmeshed and because it reflected the dynamic nature of actual family relations (Garbarino, 1992). This study however points out that the structure of families has been disrupted. Nevertheless, the concepts offered by Bronfenbrenner are useful in understanding the push-pull forces in the households where the orphans in the study were placed. The framework is also based on the idea of empowering families through understanding their strengths and needs. I have also reviewed the literature on grief and bereavement to understand grief and bereavement from various and contradictory perspectives. The ecological model of development by Bronfenbrenner and perspectives of grief and bereavement form the theoretical anchor for this study.

3.2 The Social Ecological Model

Drawing on the environmental model of ecology, a social ecology of childhood draws on many and varied factors, some are temporary and others more enduring. Child development can be influenced in many ways and from many sources. They are as follows:-

- Person factors: includes the individual biological, temperamental, intellectual and personality characteristics of the child and significant others in the child's life, such as parents, caregivers and educators.

- Process factors : includes the forms of interaction that take place between individuals(supportive, destructive, informative, inclusive and power-based)
- Contextual : includes families, communities, cultures and ideologies
- Time variables: takes into account changes that occur over time
(Dawes and Donald, 1999).

These variables change over time as a child matures and as the environment changes. The rate of change in the environment varies but the HIV and AIDS epidemic is causing rapid changes. For the purpose of this study, significant others in the child's life would be his/her caregiver. Contextual factors would include institutional support structures and other community support structures. The way in which a child's development is influenced by these dimensions depends on how various people, process and contextual dimensions interact with each other and with external influences. The way in which children and key role players understand and think about events and circumstances is critically important in determining their impact. A child who is being raised in the midst of the AIDS pandemic is going to experience a different childhood to the one raised in a middle suburbia, where in general, mainly older people die. Also a child raised in an impoverished community is different to the one raised in a highly materialistic family in which much value is placed on possessions. A value of this study is to document the unique ways in which these dimensions intersect to influence the life experiences of children (Bronfenbrenner, 1995).

Contextual factors are critically important in determining the type of childhood experienced. A child usually lives in a family. A family lives in a neighborhood within a community. Communities in turn form sub-cultural groups within particular socio-political systems. Political and cultural systems adopt particular ideologies about how to raise and value children. Each of these systems consists of a collection of activities and resources that exist within definable social and physical boundaries. Each has a purpose and regulates social exchanges. Each also has rules, roles and power relations which determines activities and the use of resources (Bronfenbrenner, 1995).

To elaborate the ecological systems model as conceptualized by Bronfenbrenner (1979) involves the following: (1) the individual level, termed the microsystem., which comprises the roles and characteristics of a developing individual; (2) the immediate social environment, termed the mesosystem, the social systems with which the developing person interacts, such as the family, the school system, the neighborhood, and the church; (3) the social environment which exerts an influence on the individual but without the individual's direct interaction, termed the exosystem; and (4) the macro level, the broader social environment, such as the socioeconomic level within which an individual is nested and the various cultural influences which might exert an influence.

A **Microsystem** consists of a pattern of activities, roles and interactions experienced by children in their immediate environment; for example the interactions that develop between a child and a parent, sibling or educator. Bronfenbrenner (1995) demonstrated that it is these face-to-face interactions between children and other people that are most influential in shaping stable aspects of development, since they are likely to develop into repetitive and predictable patterns.

When children are young, it is likely that their major microsystems will be found within their family. As they grow up, peers and school are likely to become significant. But what constitutes a family for children affected by the AIDS pandemic? The structure of the family has been re-constituted in the context of HIV and AIDS (Bronfenbrenner, 1986).

Such relationships may either promote or restrict development and adaptation. Bronfenbrenner emphasized that it is the way a child perceives these relationships that is crucial. Supportive microsystems can facilitate optimal development. Such microsystems are characterized by a network of enduring and caring relationships. Conversely high risk microsystems are characterized by a lack of mutually rewarding relationships and the presence of destructive interactions. For example, where a family's focus is primarily on caring for someone who is sick, the chances are high that the children will feel neglected or of secondary importance (Garbarino and Ganzel, 2000). The study raises the question

of the kinds of relationships that exist between children and caregivers, who may not be family.

A **Mesosystem** consists of the linkages that exist between two or more microsystems in which the child plays an active role. The mesosystem consists of sets of microsystems and the interrelationships between them. Examples of mesosystems include relationships between families and schools and between children and their community members. It is important for children to have several positive connections between their families and others. In the absence of significant generations, namely the parental generation, the study questions the potential for positive connections in this system. A beneficial mesosystem has a number of strong, positive connections that can offset the negative influence of other aspects of children's lives. For example, a child's mother may be very ill and dying, but the child's close relationship with his aunt together with a shared faith in God and commitment to their church-going community may provide an emotional haven (Garbarino & Ganzel, 2000).

The **Exosystem** includes those settings that influence children's development but in which they do not play an active role. An example of an exosystem is a weak health care system which, unable to provide adequate medicines, increases the hopelessness experienced by terminally ill patients and their families. Another example is the service conditions of caregivers at their place of employment that influence the development of the child, like medical aid and flexi-time. Exosystems are likely to become particularly important in the context of the HIV and AIDS pandemic. (Lachman, Poblete, Ebigbo, Nyandiya- Bundy & Bundy, 2002).

The **Macrosystem** is the cultural "blueprint" for any given society; the combination of ideological and institutional systems that characterize a particular culture or sub-culture. (Bronfenbrenner, 1997). The macrosystem dictates children's place in society. Each community has a specific cultural history that includes various traditional practices, rituals and beliefs pertaining to children. Within the context of HIV and AIDS, these

include religious and traditional customs about how children take on the responsibilities within the home, care for sick people and are to behave at funerals and during mourning periods. Beliefs about what happens once someone has died can be considered as part of the macrosystem. A country's economic and welfare policy and legislative framework also forms part of the macrosystem. South Africa, for example is a signatory to the Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child. These documents prescribe how children are legally defined, prioritized and treated within the South African context (UNICEF, 1989). This study has explored how children's rights are abused and do not conform to legislative frameworks. It explored how these abuses are compounded by the HIV and AIDS pandemic.

The fifth and final system, the **Chronosystem**, considers the cultural and historical changes that transform all of the person, process and contextual variables. The historical features may contain both relatively stable elements such as family structures and conceptions of childhood as well as disruptions created by economic depression, political changes etc. South Africa is experiencing very rapid rates of change due to political, cultural and technological transformation. The impact of this changing world in children has been exacerbated by the HIV and AIDS pandemic (Bronfenbrenner, 1997).

In terms of my study, the ecological model is apt because a child affected by HIV/AIDS does not exist in isolation but in association with a number of other sub-systems within the environment. A parent infected with AIDS impacts on the child because the necessary primary support systems that the child needs may be absent or totally inadequate. The model is however limited in that it identifies what factors and relationships are necessary for the optimal development of the child but does not question what causes the absence or presence of these factors, nor does it delve into the dynamics of power that allows certain factors to prevail.

The ecological model takes cognizance of the reciprocity and the mutually reinforcing influences of families and the larger socio-political, economic and cultural systems that surround them. Whilst the draft National Family Policy (2005) pays cursory attention to

the impact of environmental factors on family life, it stresses that “the family is a powerful agent for political, economic, cultural and social change”. Sewpaul (2005) however argues that families are also subject to the powerful influences of socio-political, cultural and economic factors.

3.3 Understanding Grief and Bereavement

Bereavement is an objective situation of having lost someone significant. Grief is the emotional response to one’s loss. Mourning denotes the actions and manner of expressing grief, which often reflects the mourning practices of one’s culture (Stroebe, Hansson, & Schut, 2001). Loss may be the single most aspect of existence to come to terms with. Bereavement, the reaction to loss through death has core emotional reactions, known collectively as grief. The way children react to death will be determined by their age and understanding of death, their prior relationship with the deceased and how they have been prepared. The main components of grief are shock, denial, guilt, aggression, anxiety and depression (Jensen, 1999).

The early years are considered to be a critical stage in any child’s development. The 0-8 year period has a tremendous effect on the future health, cognitive development, cultural competencies and productivity of the individual. An even more critical formative period is age 0-3 years. Young children who do lose either one or both parents to AIDS often experience their traumatic illnesses prior to their death. For young children dependent upon mothers this event can be even more significant. Bereaved and stigmatized, they are absorbed into extended families in which many primary caregivers are grandmothers whose situation is also often overlooked (Help Age International Policy Report, 2004).

Reducing the financial and emotional resources available to children, causing trauma and alienation and effectively limiting the realistic aspiration of the youngsters affected, it is feared that the epidemic may create a generation of disenfranchised and potentially

dysfunctional young children who lack the socialization necessary for constructive social engagement (Barnett and Whiteside, 2002).

Many orphans will grow up as street children or will form child-headed households. Others would be brought up by grandparents with limited capacities to take on parental responsibilities. All will have been traumatized by the illness and the death of her parents. Trauma will be exacerbated by stigma and secrecy that hampers the bereavement process and exposes children to discrimination. They are more susceptible to becoming HIV infected through abuse, prostitution or emotional instability leading to high-risk relationships (Steinberg, Kinghorn, Soderlund, Schierhout & Conway, 2000).

Besides poverty, a major determinant of poor psycho-social adjustment for children impacted by HIV/AIDS is likely to be loss, separation and bereavement (Richter, 2004: 23-24). Children have to experience the trauma of watching their parents die, then they have to worry about who is going to care for them, once their loved ones have demised. Just as human beings form attachments, so they lose them. When a parent dies, many teenagers are told to ‘be strong’ and ‘carry on ‘for the surviving parent. These teenagers may not know whether they would survive, let alone support the rest of their family. Teenagers are no longer children, yet neither are they adults. Leaving the security of childhood, the adolescent begins the process of separation from their parents. The death of a parent can therefore be a devastating experience, during this already difficult period. During their period of bereavement they are also faced with psychological, physiological and academic pressures. They need consistent and compassionate support. If children are not assisted with the necessary counseling and support, during the bereavement process, they might develop suicidal tendencies (Wolfelt, 2007).

It is said that the best way of assisting children, is to prolong the parent’s life, which can be done at the family level through healthy eating and a positive attitude. Access to anti-retroviral and adopting a healthy lifestyle with proper nutrition could prolong the lives of many infected with HIV (Department of Health, cited in South African Child Gauge, 2009).

While positive living makes the family's present situation easier, the issue of death is not something that can be avoided altogether. Children can see that things are changing at home and while they may not completely understand the implications, it can make them feel anxious, guilty, depressed and misunderstood. They may not want to upset the situation further or may feel overwhelmed and internalize their emotions. Because children are not generally encouraged to talk about themselves and how they feel, when they are given the opportunity they often have trouble verbalizing their emotions. Grief that is not expressed can manifest itself in various ways, including nightmares and anxiety. Allowing the child to anticipate the death while the parent is still alive facilitates the process of grieving (Demmer, 2005).

When physical bonds are broken by death, the slow process of grieving begins. During this period, the bereaved person is faced with turmoil of emotions, life can seem meaningless and there can be a constant feeling of anxiety. Although processes of grief differ for everyone, Ross's (1969) five phases namely; denial, anger, bargaining, depression and acceptance offer a useful starting point. But when the death is caused by AIDS, the difficulties experienced can be compounded. Denial of the presence of the virus and the eminence of death is common in families that are affected by HIV/AIDS. Fear and stigma also contribute to denial, which can result in the reluctance to disclose the illness to children or other family members. However, in some aspects, initial denial can be healthy in that it allows patients to remain focused on life and the tasks of living (Demmer, 2005)

It is widely noted that the age of children determines how they understand death. Before the age of three or four, children are ignorant of the reality of death. Instead, they equate it with abandonment and assume that the dead person will eventually reappear. Between the ages of three and seven years, children personalize events and lack the ability to discriminate reality from fantasy. This is called 'magical thinking' and children may feel guilty because they believe that their own thoughts, wishes and actions are responsible for the death. Around the age of six, children have more concrete thinking and begin to

understand that death is final. They think in absolutes, 'good/bad' or 'always/never' and can recognize the permanence of death but feel vulnerable about sharing their grief and uncertainties. Adults who are unaware of these dynamics may find it odd if a five-year-old continues to play directly after being told of the death or a ten-year-old does not cry. This is not to say these children are not affected by the death, they just deal with it at different levels. In the case of older children, when their emotions are repressed, grief can manifest itself in various ways such as insomnia, headaches and nervousness. Some children may even experience regressive behaviour such as unwillingness to be separated from parents or the desire to be 'babied' (Jewett, 1994 & Furman, 1974).

However, when parents or caregivers meet the child's needs of love and support, these regressive behaviours recede. While adults spread their love among several meaningful relationships, such as a spouse, work, children and friends, children bond closely with their parents and therefore have a difficult time dealing with a parent's absence. The effects of bereavement on individuals vary, but whether or not they appear to be affected, the death of a parent always impacts significantly on the child. Psychological impacts can emerge at any time, even years after a traumatic event, and can greatly reduce a child's ability to integrate into family and social activities. The loss of consistent nurturing from a parent can lead to developmental problems and the loss of guidance makes it more difficult for the child to reach maturity and to be integrated into society (Fox, 2001).

Bowlby & Parkes (1970) agrees that the ability of children to resolve their losses can be facilitated by involving them during the period of dying and upon bereavement. He gives several factors that enable the child to cope, namely:-

- when the child has a secure relationship with the person who is leaving or dies;
- when the child receives prompt and accurate information on the situation from adults;
- when the child is allowed to participate in grieving both publicly and privately and;
- when the child has easy access to a trusted parent or other adult who can be relied on for comfort and a continued relationship.

All of these might be denied to the child in the context of HIV and AIDS, especially in South Africa. Generally, there is stigma attached to HIV and AIDS. Hence, parents or caregivers do not willing disclose the HIV status of the parent to children

While each stage of the process of mourning as identified by Ross (1969) is important to reach, the time frames can be cut short because of the plethora of people dying in communities. Once death is imminent, discussing it with the child prevents anxiety and distress that builds once the child perceives that something is wrong. Discussion can allow children to prepare for what lies ahead and give them confidence to manage the grief. Allowing the child to say goodbye and exchange wishes and thoughts is healing for the child and leaves less unfinished business to complicate grief. Creating a supportive environment can allow the child to positively begin the grieving process before the actual death.

Little attention has been paid by researchers and theorists to understanding grief and bereavement from an African perspective. It is widely acknowledged that there is a huge gap in our understanding of the perspectives of different cultures as it relates to death-related phenomena, in particular grief and bereavement and this has been identified as an important area for future research (Demmer, 2005).

3.3.1 Children's Bereavement reaction compared to adults

Children's bereavement reactions tend to differ from those of adults. Their grief can vary widely by developmental status, but some general reactions are well characterized.

These include shock, denial of the loss, feelings of guilt (the child feels responsible for the death), anger (which may be targeted at the dead parent or others), somatic expressions of grief (stomach and other pains, headaches, weakness or breathlessness), depression, fear that they or others will also die, curiosity about the death and what happens after death, and limitation, in which the child adopts behaviours or mannerisms of the dead relative.

In contrast to grieving adults, children often fluctuate between intensely feeling the grief of their loss and denying that it occurred. They may cry uncontrollably, and then play happily. This alternating pattern may confuse and concern adults, but it is quite normal and reflects the immature ability of children to tolerate the pain of their grief for more than short periods. Children are also more likely to try to maintain internal relationships with the dead parents- talking to them, seeing them re-appear- as an attempt to bring them back to life .Little research has been done to document the consequences of losing both parents, particularly when deaths occur sequentially. One possibility is “bereavement overload,” a concept coined to apply to the elderly who experience many losses; multiple deaths may later leave children vulnerable to life-long disruption (Kastenbaum cited in Demmer, 2005).

It is critical for the child to have adult support in the process. Children need the encouragement of an adult to talk about the death of loved ones. Otherwise they are likely to avoid the grieving process and even deny the death. For children whose parents have died of HIV, it is important to avoid surrounding the cause of death with secrecy, which gives the child the impression that something shameful has happened. In contrast though if the reason for the death is public, children may be teased or rejected by other children. Such stigma has shown to cause psychological problems and poor school achievement. Adults need to encourage children to talk about their feelings of guilt, loss, anger, and sadness; such talk has shown in many studies to enhance the adjustment of children to parental death (Foster; Levine & Williamson, 2005).

The stigma and secrecy that surrounds AIDS in families can be expected to have a negative impact on children’s ability to mourn openly. Well children may worry that they have acquired AIDS from their parent and need to be reassured (Siegel and Gorey, 1994, cited in Demmer, 2005).

3.3.2 Stage Models of Grief

When physical bonds are broken by death, the slow process of grieving begins. During this period, the bereaved person is faced with turmoil of emotions, life can seem meaningless and there can be a constant feeling of anxiety.

Bowlby & Parkes (1970) indicated that the grief process was divided into 4 successive phases: numbness, yearning and searching; disorganization and despair and re-organization. In the phase of numbness, the bereaved is stunned and there may be varying degrees of denial that loss occurred. In the phase of yearning and searching, there is a strong urge to locate and be re-united with the deceased. Finally in the phase of re-organization, the bereaved loosens their attachment with the deceased and begins to establish new ties with others. Bowlby & Parkes (1970) recognized that there were variations in responses to loss and that not all the bereaved went through these phases in the same way or at the same speed (Bowlby & Parkes, 1970).

A similar model proposed by Engel (cited in Demmer, 2005), who described the normal sequence of grief as follows:

- ❖ Shock and Disbelief: the bereaved is stunned and tries to numb the pain by blocking out the loss and painful feelings.
- ❖ Developing Awareness: acknowledgement of the loss begins and anger, guilt, crying or self destructive behaviour presents.
- ❖ Restitution: mourning rituals such as funerals provide social support to the bereaved and stimulate the expression of emotions.
- ❖ Resolving the loss: the bereaved attempts to deal with the void left by the deceased, there may be preoccupation with the deceased that includes the loss experience as well as the relationship with the deceased.
- ❖ Idealization: most negative and hostile feelings towards the deceased are repressed, yearning and sadness diminishes, there is acknowledgement that the deceased would want the bereaved to continue living.

- ❖ The Outcome: after a year or so, successful healing occurs and the bereaved is able to comfortably remember the positive and disappointing aspects of the lost relationship.

Engel (cited in Demmer, 2005) viewed grief itself as a disease because it produced various psychological and physiological symptoms, it caused a lot of mental anguish and it impaired daily functioning. Although processes of grief differ for everyone, perhaps the most widely recognized stage model of grief was developed by Kubler Ross (1969), who outlined five phases an individual goes through when coping with death. These phases are denial, anger, bargaining, depression and acceptance of the loss. The first phase consists of shock and denial, which is considered a normal initial reaction. As the shock wears out, the individual may become angry over the lack of control over the loss and may be followed by bargaining for the return of the deceased with the promises of change in behaviour and lifestyle. When these bargaining thoughts yield nothing, hopelessness sets in and the individual may experience a period of depression, sadness, even despair. The final phase involves the individual fully accepting the loss and being capable of thinking about the deceased without the same emotional upheaval as well as having positive thoughts about the future.

But when the death is caused by AIDS, the difficulties experienced can be compounded. Denial of the presence of the virus and the imminence of death is common in families that are affected by HIV and AIDS. Fear and stigma also contribute to denial, which can result in the reluctance to disclose the illness to children or other family members (Boyd-Franklin et al, 1995; Bupa, 2001, cited in Demmer, 2005).

The implication of stage models of grief is that the bereaved individual must wait because “time heals all wounds”. A number of theorists have challenged the underlying assumption that grief is a passive process and have advocated a perspective of grief as an active process of accomplishing certain tasks that will help individuals adjust to their loss.

Parkes and Weiss (cited in Demmer, 2005) proposed that the bereaved need to accomplish the following three tasks in order to recover from grief, namely:-

1. Intellectual recognition and explanation of the loss: The bereaved must recognize and be able to explain how the loss occurred to avoid further anxiety.
2. Emotional acceptance of the loss: Through the constant review of memories, thoughts and feelings, the bereaved reaches a point where the reminders of the loss are not too painful.
3. Assumption of a new identity: Gradually the bereaved adjusts to an altered life situation and develops a new identity.

Worden (cited in Demmer, 2005) built on the perspective that there are things that the bereaved could do to facilitate their adjustment to their loss. He outlined four tasks of grieving that need to accomplish before grief is complete. These tasks are to accept the reality of the loss, experience the pain of grief, adjust to an environment in which the deceased is missing and withdraw emotional energy and re-invest it in another relationship. Niemeyer (cited in Demmer, 2005) re-formulated these tasks as “challenges”. These challenges are acknowledging the reality of the loss, opening oneself up to the pain; revising one’s assumption about the world, reconstructing one’s relationship to the deceased and rebuilding one’s identity.

3.3.3 Grief as a Dual Process

Rubin (cited in Demmer, 2005) noted two approaches that underlie most of the literature related to loss. One approach focuses on the difficulty of working through loss, particularly as it relates to separation from the deceased and weakening in ties to the deceased. The other approach focuses on the biological, behavioral, cognitive and emotional effects/ outcomes of bereavement. Stroebe and Schut (1994) criticized the model for not focusing on the coping process itself. As a result, they proposed a dual process model of coping with bereavement. In their view, the bereaved oscillates between two types of coping: loss-oriented coping and restoration- oriented coping. This means

that there are times when the bereaved will be focused on the thoughts of the loss (for example: - yearning for the deceased, crying, examining old photos), which is loss - oriented coping. It is also appropriate at times to put aside one's grief, adjust to changes and make plans for the future (for example: -finances, selling one's home, or develop a new identity from one's spouse), which is restoration- oriented coping.

Worden (cited in Demmer, 2005) identified a range of normal grief behaviours which he placed in 4 categories, namely:-

- 1) Feelings: sadness, anger, guilt, anxiety, loneliness, fatigue, shock, numbness etc.
- 2) Physical Sensations: hollowness in stomach, tightness in chest, weakness, lack of energy, shortness of breath, extreme sensitivity to noise.
- 3) Cognitions: disbelief, confusion, pre-occupation with the deceased, hallucination.
- 4) Behaviours: sleep disturbances, appetite disturbances, social withdrawal, dreams of the deceased, restlessness, crying, treasuring objects that belonged to the deceased, visiting places that remind them of the deceased.

Doka (1989) proposed the concept of “disenfranchised grief”, which he defined as “the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported.” Certain types of death may also be disenfranchising, such as those deaths due to AIDS or suicide. Society may turn away from these types of deaths because of the high stigma attached to them and because the complexities of these deaths are not well understood (Corr, 1999). Many of the emotions associated with normal grief (like sadness, depression, anger and numbness) are intensified and this occurs in a social context where the bereaved individual is not accorded the right to grieve or mourn (Demmer, 2005).

3.4 Conclusion

The loss of a loved one is a very stressful experience and can at times leads to psychological or mental morbidity. The intensity of the grief varies from person to person and between cultures. Bereavement may be prolonged or it could be of a short duration.

People who grieve losses that are stigmatized are susceptible to grief- related problems. While each stage of the process of mourning is important to reach, this time can be cut short because of the plethora of people dying in communities. Once death is imminent, discussing it with the child prevents anxiety and distress that builds once the child perceives that something is wrong. Discussion can allow children to prepare for what lies ahead and give them confidence to manage the grief. Allowing the child to say goodbye and exchange wishes and thoughts is healing for the child and leaves less unfinished business to complicate grief. Creating a supportive environment can allow the child to positively begin the grieving process before the actual death.

In this chapter I presented the main theoretical anchor of the study. The concepts derived from the Bronfenbrenner's ecological model and the perspectives in understanding grief and bereavement was used to illuminate the data and provided insight into the various factors and relationships that have affected the children orphaned on the account of HIV and AIDS.

In the next chapter, I describe the research methodology utilized.

CHAPTER 4

METHODOLOGY

Though there be madness, yet there is method!

*We shall not cease from exploration
And at the end of all our exploring
Will be to arrive where we started
And to know the place for the first time*
T.S Elliot

4.1 Introduction

This chapter serves to document my role as researcher as well as outline the research methodology that was utilized to answer the critical research questions of this study. This chapter describes the research methodology used in the study and my rationale for the selection of the qualitative paradigm. This is followed by a discussion on the sampling process, data collection and analysis procedures, ethical considerations as well as challenges presented by this type of study.

Recall that the main research questions are:-

- *What are the experiences of children orphaned on account of HIV and AIDS?*
- *What consequences does the HIV and AIDS pandemic have on children?*
- *How do children cope with AIDS-related loss and grief?*
- *What are the caregiver's roles, experiences and perceptions regarding children orphaned on the account of HIV and AIDS?*
- *What resources and support systems are available to caregivers in fulfilling their roles in relation to children?*

This chapter consists of three sections, namely:-

In Section One of this chapter: *Setting up the research design*, I provide a narrative account of how the research design of this study unfolded.

In Section Two, *Data collection plan*: I focus on how the research choices I made attempted to answer the critical research questions of the study. I present a description of the sources of data, the sample, the design and the kinds of instruments that were utilized to access the data. I provided details of the strategy employed to answer the critical questions as well as the methods employed to enhance the validity of my data.

In Section Three, *Analyzing the data*, I present decisions made on how the data was analyzed and presented.

4.2 Rationale for this Study

My interest in exploring the life experiences of children orphaned on account of HIV and AIDS arises from my vocation. As a social worker in a child welfare setting, where there is a high prevalence of children orphaned on account of HIV and AIDS, I assist children on a daily basis. Due to heavy workloads, poor service conditions, high staff turnover and limited time, children orphaned on account of HIV and AIDS are barely given the attention that they deserve.

Despite the high AIDS- related mortality rate in South Africa, very little attention has been given to the impact AIDS has on children and the concrete responses and experiences of children, especially children orphaned on account of AIDS. The research literature on HIV and AIDS generally focuses on HIV and AIDS prevention, treatment and the community's responsibility for the pandemic. Also most studies on

HIV and AIDS have focused at the macro-level within a quantitative research approach. Little attention has been given to micro-level analysis of the impact of AIDS on children using a qualitative approach.

Having identified the gaps in the literature in Chapter Two, I decided that it was important to explore the life experiences of children orphaned on account of HIV and AIDS. The study is different from other studies in that it has given ‘voice to children and their experiences’. In this study all participants were on my caseload and the cause of death of either one or both parents has been documented as HIV and AIDS related. The study hoped to make a contribution to the existing literature by examining how children respond to and cope with AIDS- related loss. The study combined the practitioner- researcher role. Each participant already has a case file at the organization where I am employed. Hence, the researcher was familiar to the participants.

4.3.1 The Research Design

The changes and adaptations in the research process were due mainly to various contextual factors, which emerged during setting up the research process and specifically the execution of the data collection and analysis. This is different from the “emergent design” methodology of research where there is a deliberate decision to allow the process of research methodology to unfold in the course of doing the research (Valero & Vithal, 1998). I entered the research field with pre-formulated key questions and research strategies that I intended using in my study. I had also commenced with a clearly formulated plan for data collection. Nevertheless, I was open to the possibility of being influenced by the specifics of enacting the research design and modifying and re-modifying my research plan along the way.

I decided to employ qualitative methods for this study and the research is located in the interpretive paradigm. Qualitative research, according to Uys (2003: 118), refers to “a collection of data that reflects the quality or nature of a particular phenomenon,

in the form of description". Henwood and Pidgeon (1995) suggested using qualitative methods when exploring a new area of enquiry and when there is a need to be sensitive to people's own understandings as seen from their local frames of reference. Generally qualitative methods are used when depth is required.

Qualitative researchers are interested in understanding the issues being researched from the perspective of the research participants. In other words, you are trying to see through the eyes of the participants. It is for the researcher to analyze and interpret the research in association with the participants. Qualitative research is interested in process rather than outcomes. The researcher is concerned with meaning. Qualitative researchers believe that you cannot be unbiased and neutral and each researcher brings his/her own biases, views, personal opinions and attitudes to the research process (Struwig and Stead, 2001).

4.3.2 The Use of Self in the Research Process

Postmodern feminist methodology concerns itself with the interviewer qua human being/person in the research process and the researcher as the instrument of data collection (Janesick, cited in Denzin & Lincoln, 2000). This applies equally to other types of qualitative research. Although the emphasis is on the participant's interpretation of social reality, the potential influence of the researcher and the introduction of researcher bias cannot be dismissed.

As qualitative researchers are aware of the researcher as a person in the research process, there is a greater preoccupation with *reflexivity* (Sewpaul, 1995). The researcher pays particular attention to the ways in which he/she influences the study, in both the methods of data collection and in the techniques of data reporting. The concern with reflexivity contributes to new ways of minimizing the influence of the researcher. One way of doing this where the voices of the subjects are recorded with minimal influence from the researcher and are not collapsed together and reported as one, through the interpretation of the researcher. However, as Sewpaul (1995) points out, one must remember that there are different levels of complexities involved

simply with the researcher as an instrument of data collection in the interview process. Furthermore, the eventual interpretation is that of the researcher (Sewpaul, 1995). Although the use of myself as person and therapist was evident in this study, all data obtained from both the primary sample was recorded and transcribed. The transcripts reflected the voices of participants and not my interpretations. However, in view of my sensitivity to the ethical considerations of the issues studied, I was aware of my involvement in the research interviewing, in the interpretation of the data and the documentation of the results. Rubin and Babbie (1989:388) asserted that “as with all such problems, sensitivity and awareness may provide sufficient safeguards. Merely by being aware of the problem, you may be able to avoid it.”

Oakley (1994) rejected the hierarchical, objective stance of the neutral, impersonal researcher as neither possible nor desirable. Successful qualitative research depends on the development of rapport with participants and on empathy and mutuality. Mies (1983) asserted that the value-free and value-neutral notions of research need to be replaced by that of *conscious partiality*. This is opposite of spectator-knowledge where the researcher remains detached from the research subjects. Conscious partiality is more than mere subjectivity and empathy. It creates, according to Mies (1983:68) “a critical and dialectical distance between the researcher and his “objects”. It enables the correction of distortions of perception on both sides and widens the consciousness of both, the researcher and the “researched.” Conscious partiality might help us prevent both, what Rubin and Babbie (1993, pages: 389-390) termed, *provincialism* and *going native*. Provincialism refers to the tendency to interpret behaviour primarily from the researcher’s world view. Going native, on the other hand, refers to the tendency to over-identify with research subjects, with a consequent loss of one’s own identity and analytic stance (Sewpaul, 1995).

Qualitative researchers focus primarily on the depth and richness of the data and therefore researchers generally select samples purposefully rather than randomly. Qualitative research emphasis is on studying human action in its natural setting and through the eyes of the actors themselves together with the emphasis on detailed

description and understanding phenomenon within the appropriate context. Typically, qualitative research shares the following features:-

- A detailed engagement with the object of the study.
- A focus on process rather than outcome
- An openness to multiple sources of data.
- Flexible design features that allow the researcher to adapt and make changes to the study.
- The primary aim is in-depth descriptions and understanding of actions and events.
- The main concern is to understand social actions in terms of its specific context rather than attempting to generalize it to some theoretical population (Babbie & Mouton, 2001)

According to Struwig and Stead (2001) qualitative research generally attempts to:-

- Understand the issues from the viewpoint of the participants.
- Describe the social setting of the participants so that the participants' views are not isolated from their contexts.
- Understand the participant's thoughts, feelings and behaviour.
- Conduct research in a relatively unstructured manner.
- The researcher cannot be completely neutral.

From an interpretivist point of view, what distinguishes human action from the movement of physical objects is that human action is inherently meaningful. To say that human action is meaningful is to claim either that it has certain intentional content that indicates the kind of action it is or what an action means can be grasped only in terms of the system of meanings in which it belongs (Fay & Outhwaite, cited in Denzin & Lincoln, 2000).

To find meaning in an action or to say one understands what a particular action means, requires that one interprets, in a particular way, what the actors are doing (Denzin and Lincoln, 2000). The central endeavour in the context of the interpretative

paradigm is to understand the subjective world of the human experience. Efforts are made to get inside the person and understand from within. Interpretative approaches focus on action. This may be thought of as behaviour with meaning. Actions are only meaningful to us in so far as we are able to ascertain the intention of actors to share their experiences. A large number of our everyday interactions with one another rely on such shared experiences (Cohen, Manion & Morrison, 2000).

For the interpretive researcher, reality is based on people's definition of it rather than being something externally present. The subjective experience is what needs to be studied rather than an objective one. The researcher and the participant create a reality through their interaction. Instead of being research-driven, the research process is subject -driven. They are primarily interested in description rather than explanation.

In this study I sought to explore the meanings children orphaned on account of HIV and AIDS make of their lives, the reality they experience and their caregivers' experiences. The participant is at the centre of discussions and the research agenda becomes driven by the participants' experiences rather than a rigidly structured research focus.

The United Nations Convention on the Rights of the Child, (UNICEF, 1989) advocate strongly for children's rights to participate in research and intervention endeavours, recognizing them as fully- fledged individuals with the potential to have their perspectives and the right to express their views in matters affecting them in accordance with their age and maturity. I attempted to design this study so that these principles would be evident for both children and the significant others. Like much qualitative research, it is interpretative in that it deals with the perceptions of ordinary people in their daily lives (Mc Bride, 2002). I decided to utilize this methodology as I believed that it would provide a better understanding of the life experiences of children orphaned on account of HIV and AIDS and their caregivers.

Padgett (1998) described qualitative research as a journey of discovery. The opportunity of listening and observing participants in their environment can produce amazing insights. As I began to gather data, I realized that I made the right choice in selecting this methodology and I was particularly gratified to obtain rich, meaningful data from participants. My choice to utilize qualitative methodology was primarily determined by my research topic. The purpose of my study was to investigate the life experiences of children orphaned on account of AIDS. I felt that qualitative methods would facilitate a process of introspection and enable participants to tell their stories in their own words. The choice of qualitative methodology reflected my interest in gathering data from the participant's perspective and my belief that this type of design would elicit deeper, richer information about the lived experiences of children and caregivers than quantitative research could.

In this study, I employed the collective case study methodology. The case study is an intensive investigation of a single unit (Yin, 1994). Most case studies involve the examination of multiple variables. Thickly described case studies take multiple perspectives into account and attempt to understand the influences of multi-level social systems on the participant's perspectives and behaviour (Denzin & Lincoln, 2000).

The defining characteristic of a case study is its emphasis on an individual unit. Case studies can also be done with other units. A holistic case study on each child was conducted.

I utilized triangulation in order to obtain data from different sources. Using multiple sources of data is important in case studies. I used more than one method to collect data, namely, multiple interviews with nine children and extended interviews with the other two children. Separate interviews were conducted with their caregivers (key informant); observation techniques, and existing case files. This assisted to strengthen and enhance the quality of my data and increased validity and reliability of data. Hitchcock and Hughes (cited in Denzin & Lincoln, 2000) suggest that case studies are concerned with rich and vivid description of events relevant to the case. It

blends a description of events with the analysis of them. It highlights specific events that are relevant to the case. As a qualitative researcher, I was interested in description rather than explanation. Qualitative researchers usually collect qualitative information using words instead of numbers and focuses on underlying meanings and patterns of relationships. The sample was small because the focus was on collecting in-depth information from each participant so as to understand the participant's subjective experience (Marlow, 1998).

4.4 Section Two: Data Collection Plan

4.4.1 Sampling

I utilized the purposive sampling strategy for my study. Purposive sampling is concerned with providing a sample of information-rich participants. The participants manifest certain characteristics that the researcher is interested in. The interviewing process relies strongly on the questioning and listening capabilities of the researcher. The researcher is more interested in whether the information from the sample is rich in data and thick in description than the extent to which the sample's data can generalize to the population (Babbie & Mouton, 2001) .

Drawing a sample for this study was indeed a challenge. Given the stigma associated with the pandemic, identifying participants who would be comfortable to share their lived experiences, proved difficult. A sample of eleven children was recruited from my caseload. The child participants were between the ages of thirteen and seventeen years and had lost one or both parents to HIV/AIDS. There was a combination of male and female participants. The study comprised of three male and eight female children participants, two being a sibling pair, and ten adult participants that acted as primary caregivers of the orphan participants. The caregivers of all eleven children were also interviewed. A total of thirty interviewing sessions were conducted with the participants.

The reason for the choice of that particular age category was that the older children were usually more willing to express their feelings and emotions.

Qualitative studies usually consist of small samples since the aim is to interview participants in-depth. The researcher was also of the view that the size of the sample in this study was sufficient to provide for contextually rich narratives that would deepen our understanding of the grief response and coping strategies of people bereaved by AIDS.

Before I commenced with the research, I described the study to the prospective participants and what their involvement would entail. An interview was then scheduled at my offices at a mutually agreed time. On a few occasions, I experienced difficulty in scheduling appointments as the participants were writing examinations or tests, involved in extra-curricular activities or were away on holiday. Some of the caregivers were either sick or working. Also time constraints on the part of the researcher was a significant limitation as I was either busy at work or had to attend other conferences and workshops. When things did not always go as planned, this naturally created some anxiety for me, as I scheduled a certain time frame to complete my interviews and I was afraid that I wouldn't complete these interviews on time.

Gaining access to talk about sensitive issues around HIV and AIDS is not easy. All the participants were not at the same level. Sometimes I had to thoroughly explain the process and repeat questions. Because of the stigma and secrecy surrounding HIV/AIDS in South Africa, I was concerned about my ability to recruit participants who would be willing to share their experience. I also had to consider the emotionally draining nature of the data collection process and the psychological reactions of the participants. Although I am English-speaking, I have basic proficiency in isiZulu. However due to the nature of my study that required in-depth information and description of feelings, I utilized my colleague, who is an IsiZulu-speaking social worker, to assist me with the interpretation. He was briefed on the entire process. However, he did not sit in for all the interviews.

4.4.2 In-depth Interviews

Initial appointments were made with children and their caregivers, telephonically. During the initial interview, the purpose of the research study was explained to the child participants and their caregivers, in English and IsiZulu. The consent form (Appendix I) was discussed with them which were written in IsiZulu. At this stage, it was explained to participants that their participation was voluntary and they could withdraw from the study at any stage if they were uncomfortable.

Data collection took place over a period of 18 months. Due to the subject matter and the potential emotional strain on children, the duration of each interview was between thirty minutes to an hour. Interviews were communicated in English and isiZulu, to ensure maximum and complete access to all participants. Most interviews were conducted in the presence of the translator. Some interviews took place in the setting with only the researcher and participant present. I had two interviews with nine child participants and extended interviews with the other two child participants.

I used semi-structured interviews in my study because meanings, understandings, and interpretations cannot be standardized and, therefore, cannot be obtained with a formal, fixed choice questionnaire (Denzin, 1989). To guide me, I designed a semi- structured interview schedule (See Appendix II). Firstly, I engaged in a focused literature study to determine the overall issues to be tackled in the interview. I listed a broad range of themes and designed questions within these themes. I arranged the questions from simple to complex and from broad to more specific, in order to allow the participants to gradually adjust to the pattern of the research schedule. Initial questions entailed the personal details of the participants, their family details, household membership, and sources of income, health and nutrition, school and community issues. Finally, I arranged the themes into the most appropriate sequence. The use of open-ended questions ensured a conversational dialogue and participants were able to talk freely about their experiences and feelings. This kind of interview is needed when in-depth information is required as in a qualitative study (Denzin, 1989). The objective is to keep the interview as open-ended

as possible, in order for children to create their own stories. My colleague and I utilized probes to elicit further responses to encourage participants to provide detailed information on feelings and behaviour. Using less structured forms of questioning enables researchers to obtain information that cannot be expected using a more structured format (Denzin & Lincoln, 2000).

I recorded the interviews on audio tapes and transcribed each interview verbatim.

This helped to capture non-verbal communication; the feelings, texture, tone, silences and hesitation of the participants. Patton(1990) states that a tape recorder is 'indispensable'. I also maintained a journal to record my thoughts, feelings and reactions and my on-site experiences. This would supplement and assist in the analysis of the data. The interviews lasted for between thirty to sixty minutes allowing me to probe to sufficient depth on particular issues and at the same time being cautious of the comfort and well-being of the respondent.

The children and caregivers were from my caseload and were known to me, at a superficial level. Both were well prepared for the process prior to the interviews. Consent in writing was obtained from each participant (See Appendix I). The consent form included permission to audiotape the interviews as well as transcribing the interviews for analysis.

4.4.3 Observation

I conducted visits to the homes of each participant and observed them in their natural environment. This assisted to strengthen and enhance the quality of my data and increased validity and reliability of the data.

4.4.4 Secondary Analysis of Case Files/Records

Henning (2004) states that any document, whether old or new, whether in printed format, handwritten or in electronic format and which relates to the research question may be of value. Each participant already had a case file at our offices. The case file was utilized as

an additional data source. Pertinent information, like biographic and background information on the participants was retrieved from the case files. Each file contains vital information on the participants. Without compromising the integrity of my vocation, I utilized information from the case file to obtain richer insight into the experiences of the participants, with the approval from the organization I am employed at.

4.5 Data Analysis

Qualitative research depends on the presentation of solid, descriptive data, so that the researcher leads the reader to an understanding of the meaning of experience or phenomenon being studied (Denzin and Lincoln, 2000).

In this study, qualitative data was collected through personal interviews with the children and their caregivers and secondary analysis of case files. All the individual interviews were recorded on audio-tape. The interviews lent itself to content analysis. De Vos (2002) recommends that the content of interviews be analyzed while they are still fresh and preliminary coding which is characteristic of content analysis may be useful. De Vos (2002), states that employing qualitative analysis in interviews will attempt to capture the richness of the themes emerging from the participants' responses.

The data was analyzed according to the steps described in De Vos (2002). The steps that De Vos (2002) described are managing the data; familiarizing yourself with the data; coding the data; elaboration and interpretation. Lincoln and Guba's (2001) approach was employed in order to evaluate the validity of the findings. Credibility, transferability, dependability and confirmability were evaluated.

Data was managed by transcribing the interviews via the computer (voice editing). Both my colleague and I jointly listened to the audiotapes that were in isiZulu and transcribed them; read my field notes and the transcripts simultaneously. We checked and re-checked them against the audio-tapes. This was done several times in order to obtain accurate data. In keeping with the qualitative nature of the study, data was analyzed thematically. I began by reading line-by-line and identified codes that I wrote at the end of the sentences

wherever possible. Coding helped me identify underlying meanings in the text. I then identified salient themes, patterns and categories that emerged (Boyatzis, 1998). I grouped the topics that related to each other. I then found the most descriptive wording for the topics and turned them into themes or categories. Two types of categories emerged; ones that I developed and ones that developed naturally from the participant's responses. These gave rise to a thematic storyline which I present in the chapters to follow. My final step was to create links to established theory. I did this by examining the works of other researchers in the context of established knowledge to find literature to support my findings.

4.6 Ethical considerations

Research into HIV and AIDS involves participants volunteering highly personal and sensitive information. Researchers, therefore, need to exercise respect and circumspection when engaging with participants. Gray, Lyons and Melton (1995) make the point that respect for persons and their privacy are key ethical issues in HIV and AIDS research. Given the stigma and discrimination associated with the pandemic, I was extremely sensitive to issues around participation in this study, confidentiality and anonymity in the reporting of data. In conducting any kind of research, it is necessary to obtain informed consent from the research participants. In order to achieve informed consent, by the participants, the following four elements must be practiced: The subjects must be competent, meaning they are responsible and mature to make correct decisions when given the relevant information. They are voluntarily participating in the research. They have received full information regarding the research and what the data will be used for. The subjects must fully comprehend the research project, even when risks are involved (Cohen & Manion, 2001).

Ethical clearance was secured from the University of KwaZulu-Natal's Ethics Committee. The details pertaining to the ethical issues in this study are contained below:

Confidentiality

Participants were assured that all information would remain confidential. I attempted to create a therapeutic environment, where interruptions were minimized and privacy was ensured so that the participants were free to express their feelings openly. Reporting of data has been done by utilizing pseudo names and the participants were informed that all the necessary demographic data, audiotapes and transcripts would be destroyed upon completion of the study. In the subsequent dissemination of the research findings, participants' identities were concealed at all times. No reference was made to any specific child or their caregiver.

Anonymity

Working with disempowered participants on highly sensitive and potentially stigmatizing issues, required careful ethical consideration. Since the study involved entry into the private spaces of the participants, I was particularly sensitive to issues around anonymity and confidentiality, when reporting data. It was essential to afford the participants anonymity and to ensure that the participants understood the reasons for being identified to participate in the study. Agreements were reached with the participants about the limits to accessibility of records and documents and to the process of dissemination of the findings. The research consent form was specifically designed, through the guaranteeing of anonymity and confidentiality when reporting data to enable open and honest participation without fear of any repercussions. The identity of the participants had been concealed and anonymity was guaranteed in the consent agreement.

Informed Consent

According to Mark (1996), the principle of informed consent is at the heart of efforts to ensure that participation is voluntary. All role-players were made fully aware of the nature of the research content, the process and the ethics of the study so that they could make informed decisions about their participation. Permission was obtained prior to the

interviews and appointments had to be made to conduct the interviews. Participants were made aware that their participation was voluntary and they could voluntarily withdraw at anytime from the research process. They were made to understand that there would be no negative consequences should they not participate.

The participants were also made aware that the data gathered would be used for research purposes only.

In my study, receiving consent was a four-fold process: I received consent from:

- my Board of Management to analyze case files and utilize the participants, that were existing service recipients of the organization.
- the child participants
- and their caregivers
- ethical clearance from UKZN, Faculty of HDSS Higher Degrees.

Not all participants were in a position to read the consent forms due to their literacy level. Hence the aims and nature of the study was explained verbally to the children and adult participants in isiZulu and English.

Psychological Discomfort

Research on sensitive topics like HIV and AIDS and death may lead to distress, even resulting in a child crying. There is a need for care and skill on the part of the researcher not to pressurize the child to talk. It is important to heed the warning by Fratter (1996) that researchers should be careful not to open up painful or distressing areas, especially in one-off contacts, unless it is clear that follow-up support is available to the child (Greene, 2005).

The interviews did produce varying degrees of psychological discomfort for participants. However, the expression of such discomfort was, in itself, therapeutic for the participants.

I attempted to make the child participants to feel comfortable at all times during the research process.

When exploring feelings, emotions and experiences around AIDS- related loss, it is imperative to identify this and understand how to help participants cope with their grief.

The children forming the sample of this study were known to be vulnerable and in engaging children in a study of this nature, I expected children to share painful past life experiences. These were dealt with by me appropriately, being a qualified social worker. Appropriate counseling and supportive services were provided as well as referrals for specialized services, when necessary.

4.7. Data collection and Storage

The research data was secured as follows:

- Data was audio-taped, electronically and manually recorded. Data was kept in a locked up cabinet, when not in use and will be destroyed five years after the completion of the study.
- Electronic data was password secured.
- All information was confidential and none of the participants were identifiable.

4.8. Funding

This research was not supported by funding that is likely to inform or impact in any way on the design, outcome or dissemination of the research.

4.9 Research Instruments

The following draft instruments are attached as Appendices.

- Appendix I : Consent Forms
- Appendix II: Semi- structured interview schedules

4. 10 Reliability and Validity

According to Babbie and Mouton (2001), a qualitative study may strive towards objectivity, validity and reliability but may never truly attain this. De Vos (2002) indicates that in quantitative studies the assumption is that the universe is unchanging and an inquiry could quite logically be replicated. This assumption is however, in direct contrast to the qualitative assumption that the social world is always being constructed, and the concept of replication itself is problematic. The generalization (validity) of qualitative findings is challenging and it is therefore imperative for the researcher to employ other methods such as triangulating multiple sources to enhance the study's generalizability.

In this study, in depth interviews with children and their caregivers, visits to the homes of the participants, as well as analysis of case files, enabled triangulation to take place by allowing the researcher to corroborate, elaborate and illuminate the same phenomenon, thereby enhancing the contents and methods validity of this study (De Vos, 2002). Triangulation further enables one to be sure that the findings are reflective of the participants and the inquiry itself, rather than a creation of the researcher's biases or prejudices (Marshall & Rossman, cited in de Vos, 2002).

Since the foregoing suggests that the reliability and validity is challenging to outline in qualitative research, trustworthiness appeared to be more appropriate to use in qualitative studies (Babbie & Mouton, 2001).

Lincoln & Guba (cited in Babbie and Mouton, 2001), base trustworthiness on four constructs:

- Credibility
- Dependability
- Transferability
- Confirmability

Credibility and Dependability

In this study, credibility was addressed through triangulating multiple sources of information to corroborate, illuminate and elaborate children's experiences. To this end, caregivers participated in the study. This was seen to further add to the study's dependability. If a study is credible then it will be dependable, drawing a comparison to quantitative studies where validity cannot exist without reliability (Lincoln & Guba, cited in Babbie & Mouton, 2001).

Transferability

Transferability refers to the extent to which findings can be applied to other contexts or with other respondents. The qualitative researcher is not primarily interested in generalizations and does not claim that knowledge gained from one context will necessarily have relevance for other contexts or for the same context in another time frame (Lincoln and Guba, in Babbie and Mouton, 2001). Therefore in this study, the researcher attempted to provide a thick description of children's experiences orphaned on account of AIDS and reported it with sufficient detail and precision to allow judgements about transferability to be made by the reader.

Confirmability

According to Lincoln & Guba (cited in Babbie and Mouton, 2001) confirmability relates to leaving an adequate trail to enable the reader to determine whether the conclusions, interpretations and recommendations can be traced to their sources. In this study, this was easily achieved by various sources of data which included the field notes, tape recordings of all interviews, transcripts, semi- structured interview schedules, notes from the analysis of case files. The qualitative content of this study may be useful to other practitioners or service providers.

Marshall (cited in Sewpaul, 1995) offered the following reflective checklist that may be used in our assessment of validity:-

Questions pertaining to how the research was conducted:

- Was the researcher aware of his/her own perspective and influence?
- How did the researcher handle himself/herself?
- Did he/she challenge himself/herself to accept challenges from others?
- Was he/she open to new encounters?
- Did he/she tolerate and work on the chaos and confusion?
- Has the researcher grown personally through the experience?

Questions pertaining to relationship with data:

- Is the level of theorizing appropriate to the study and to the data?
- Is the theorizing of sufficient complexity to reflect the phenomena being studied?
- Are alternative interpretations explored?

Questions pertaining to contextual validity:

- How do the conclusions relate to other work in the area?
- Is the researcher aware of relevant contexts for the phenomena studied?
- Is the material useful?
- The reliability of qualitative information may be questioned as there are no statistical checks and figures. The use of self in the research process means that should someone else conduct the same study the results and the conclusions may differ (Sewpaul, 1995). One way of overcoming this is by developing an intimacy with one's data so that there is some assurance that the ideas or meanings have wider salience. The reliability of data may also be enhanced through proper documentation of the methods of data collection and through reliable recording of data. Reliability, in qualitative research, may also be enhanced by presenting as much of the original data as possible in the research document. As meaning is

paramount in qualitative research, the researcher seeks to achieve depth and richness rather than any widely applicable or replicable simplified statements.

All these measures to ensure reliability have been considered in this study.

4.11 Challenges presented by the Study

A research study is subject to possible limitations and problems, which could have a negative effect on validity and reliability of the data collection.

The following factors could be seen as a limitation of the study:

Firstly, I utilized the purposive sampling strategy for my study. Not all participants chosen in the initial sample were available to be interviewed due to unforeseen circumstances. Two participants re-located, one fell ill and one caregiver died during the research process

Second, getting the participants to participate was a challenging task because data could only be gathered over weekends, school vacations and after school, so as not to disrupt the schooling of child participants. It was also difficult to conduct interviews as scheduled, as there were times when schools were on strike and the whole curriculum had to be accommodated within a limited time frame. Hence child participants were finishing school late and their school vacation was also limited. It was also difficult to schedule appointments during the school vacation as most children went to visit relatives that lived away from home.

Third, most of the interviews were conducted in isiZulu. This prolonged the interviews and transcribing the interviews took longer than planned. In addition, I had to enlist the assistance of my colleague, who is fluent in IsiZulu, to assist in transcribing and unfortunately, I had to rely on his availability.

Fourth, I attempted to create a therapeutic environment, where interruptions were minimized and privacy was ensured so that the participants were free to express their feelings openly. I considered my office to be a private setting. This was not always possible as I am also a practitioner and supervising social worker and was sometimes interrupted by telephone calls and other emergencies. Hence it was not always possible to fully immerse myself in the research context.

Fifth, the community hall which was identified as a venue to conduct interview were not always available. Participants had to travel to my office, which is quite a distance away from their homes, for scheduled interviews. Time was always a factor and the researcher was always concerned about their safety and was afraid to detain the participants too late, especially in the afternoons.

Sixth, this aspect of research has enabled us to hear the voices of children and their caregivers. Because my study intended to obtain qualitative data, the sample was relatively small and was conveniently selected. Hence, owing to the small size of the sample and the specific geographical area selected for this study, the findings cannot be generalized to the population as a whole. If a large sample was utilized, we would have had more data to work with and offered a fuller picture of the lived experiences of children orphaned on account of HIV and AIDS.

Seventh, language, race and cultural differences in the South African context created particular dynamics amongst myself as a researcher and the participants. One of the key features of participatory methodologies is about being an insider and being in the situation of participation. Muthukrishna (2006) explains that because of language, in most instances, the researcher is very much like an outsider to the process.

Most of the participants were isiZulu speaking and this meant that the data had to be translated and transcribed. This raised issues about lack of equivalence of concepts across English and isiZulu, and practical difficulties in having to train a translator to engage in translation of the transcriptions.

Eighth, Alderson (2004) outlines three main ways of thinking about what is ‘good’ research related to good ethics in working with children. Firstly, the principles of respect and justice recognise that children have views that researchers cannot take for granted. Ethical research includes sensitive methods for discovering children’s own views and meaning. Secondly, rights based research involves respect and children’s rights have been listed under the ‘3Ps’, namely: - providing for basic needs; *protection* from harm, abuse, neglect, discrimination; and *participation* (Franklin, 2002). Participation rights include children being well informed and having their own views, being listened to and respected by adults. Finally, best outcomes based ethics means working out how to avoid or reduce harms and costs, and to promote benefits.

Article 13 of the Convention on the Rights of the Child (1980) states that children have a right to freedom of expression, which includes seeking, receiving and giving information and ideas through speaking, writing or in print, through art or any other media of the child’s choice. Their participation is not a mere formality: children must be fully informed and must understand the consequences and impact of expressing their opinions. The corollary is that children are free not to participate, and should not be pressured. Participation is a right, not an obligation (UNICEF, 1998).

The challenge was to find ways of accessing credible data and facilitating the expression of children’s voices.

Ninth, the dual position of researcher and practitioner lends an element of subjectivity. Challenges of power imbalances were evident in issues such as differing world views between adults and children and researchers seen as experts by children, race of researcher and children’s wishes to please adults.

Tenth, due to work commitments and heavy workloads, time was always of essence, to implement the study effectively. The study was time-consuming. Other sources of data, like the case files were created by other inexperienced social workers. Hence it did not contain the depth and volume of information I would have preferred for the study.

Eleventh, some child participants shared painful experiences, due to the nature of the study. These experiences were addressed by the researcher immediately. This was time consuming and lengthened the field work involved in the study.

Twelveth, dealing with the introduction of possible respondent bias was another challenge in this study. The face to face contact with me might have tempted some participants to tell me what they thought I wanted to hear.

4.12 Conclusion

In this chapter, I have documented the research design utilized, the sampling technique used, the rationale for the study, the use of in-depth interviews, and the methods of analysis. The ethical concerns and reliability and validity were consolidated and addressed as well. Finally the challenges presented by the study and the efforts made to meet them are elucidated.

In Chapter 5, I begin the first level of analysis.

DATA ANALYSIS

CHAPTER 5

RESEARCH FINDINGS

5.1 Introduction

This chapter focuses on the presentation and the analysis of the data obtained from the research. The purpose of the study was to explore and describe the life experiences of children orphaned by HIV and AIDS - related deaths. This information provided insight into the manner in which these children deal with their situation and how they made sense of their lives. The presentation of the findings of the study is according to the following outline:

- A biographical profile of the research participants.
- Demographic characteristics of the research participants, in the form of a table, reflecting the details of child participants, the number of individuals in the household, the average income and the primary caregiver.

5.2 Profiles of the Research Participants

A brief narrative on the biography and background of each child participant and their caregivers is presented. These profiles serve as a point of reference for the analysis section. The profiles are an initiation of this research study. There were two sample groups, which were drawn from the Child Welfare SA, Margate's clientele population. A sample of eleven children was recruited from the caseload. The child participants were between the ages of thirteen and seventeen years and they lost one or both parents to HIV and AIDS. There was a combination of male and female participants. The study comprised of three male and eight female children participants, two being a sibling pair, and ten adult participants that acted as primary caregivers of the orphan participants.

Data collection took place over a period of eighteen months, in 2006 and 2007. Data was collected for this study by conducting in-depth interviews with each child. All interviews were conducted in the office of the organization that I work in. A total of thirty interviewing sessions were conducted with the participants. Each child participant participated in two interviews, except for two children that were involved in extended individual interviews. All their caregivers were also involved in extended interviews. The interviews were conducted either in English, IsiZulu or both languages. Pseudonyms were utilized to protect the identity of all participants.

Participant One: Nomfundo

Nomfundo was a fifteen year old female at the time of the study. She was in grade seven at School A in the site where the study was conducted. Nomfundo was abandoned by her mother when she was approximately three years old. Subsequently her biological mother died in 1998, when Nomfundo was seven years old. Her father showed little interest in her well being. Since the tender age of three years, Nomfundo has been in the care of her maternal aunt, Dorica. Nomfundo also has a younger sister aged twelve years old. According to her academic records, Nomfundo's school performance was satisfactory. Both Nomfundo and her sister were officially placed in foster care of their maternal aunt, Dorica on the 15th July 2005.

Dorica was thirty nine years old, at the time of the study .She was widowed and had two children, aged twenty one and sixteen years old. She was employed as a housekeeper at a neighbouring hotel and earned R 850-00 per month. The home that they occupied belonged to Dorica. There were two adults and four children occupying the home, at the time of the interviews. The interviews with Nomfundo were held in IsiZulu. Her caregiver was able to converse in English.

Participant Two: Nqobile

Nqobile was a seventeen year old female at the time of the study. She was in grade nine at School A. Her mother died at the age of thirty, in 2003, when Nqobile was thirteen years old. She was officially placed in the foster care of her maternal grandmother,

Akhona, on the 10th December 2004. Akhona was legally married for twenty seven years. She resided with her husband and Nqobile. They have 6 children living independently. She and her husband were in receipt of state disability pensions. She was also in receipt of a foster care grant in respect of Nqobile. In addition, she supplemented her income through weaving and selling baskets at the coastline beaches. Nqobile accompanied her grandmother and assisted her in the selling of weaved baskets. The family also depended on subsistence farming. Religion was significant to them and they attended church services at a local church.

Nqobile had four friends and one special friend that she confided in. Her favourite sport was athletics. Her grandparents attended to all her general needs, including her school requirements, school uniform and pocket money. She loved following the current trends when dressing up. Nqobile's goal was to be a doctor as she wished to help others. She thereafter changed her goal to be policewomen as she reported that "I don't like to see the sick". Nqobile was the only child of her late mother. Nqobile had difficulty conversing in English and was interviewed in IsiZulu. Her caregiver also participated in an IsiZulu interview. There were five members in their household.

Participant three : Aletta

Aletta was fifteen years old at the commencement of the study. She was in grade nine at school A and had performed well academically. Her mother died at the age of twenty eight in 2003. Her father's whereabouts were unknown and he did not contribute towards her upbringing. Her mum was never married. Aletta was the only child for her mum. Aletta was twelve years old when her mum died. Together with her mum, she had been staying with her maternal aunt, Thabisile since birth. On the 10th November 2006, Aletta was officially placed in the foster care of Thabisile. Her aunt had been legally married for three years. She had three minor children, aged eleven years, nine years and three months old. She was employed as a domestic worker and earned R 1200-00 per month. Her husband was a tiler and earned R 800-00 per month. In addition she was in receipt of a foster care grant in respect of Aletta and child support grant in respect of her children. During the Children's Court Inquiry, Aletta was very articulate, well conversant in English and responded readily to the questions posed by the magistrate. However, Aletta

was very shy and emotional during the interviews and she was still traumatized by her mother's untimely demise. She participated in mixed interviews, both English and IsiZulu. Her caregiver participated in an English interview. She was casually dressed in modern clothes. Aletta was self sufficient and attended to all the household chores whilst her caregiver was at work. She also assisted with the care of her caregiver's three month old baby. There were six members in their household.

Participant Four: Basanda

Basanda was a sixteen year old female at the time of the study and was in grade ten at School B. Basanda experienced multiple losses as both her parents were deceased. Her mother died on the 16th June 2004, at the age of forty one and her father died on the 10th March 2006, at the age of forty four years. Her parents were legally married for twenty one years. Basanda was thirteen years old when her mother died. Basanda had three other sisters, aged twenty three, twenty one and ten years old. Despite her circumstances, Basanda was always smiling, bubbly and highly self confident. She was articulate and well conversant in English and participated in an English interview. Her caregiver also participated in an English interview.

Prior to their demise, their mother was residing in Kwa Nzimakwe and their father was in Gauteng for most of his life. Basanda and her sister were officially placed in the foster care of their sister, Primrose, on the 10 November 2006. Primrose struggled financially to provide for her siblings as she did not have a stable income and was employed casually as a domestic worker. Primrose was twenty years old and in matric when her mother died. Primrose had one child aged seven years old at the time of the interview. She fell pregnant when she was in grade ten. Due to conflict between her parents as a result of her pregnancy, she failed grade ten. Her boyfriend provided minimal financial support towards their child as he was unemployed for a long period of time. Together with her three sisters, and her son, she continued to reside in their family home. Hence, there were five members in their household. Primrose was in receipt of foster care grants for both her siblings and a child support grant in respect of her son.

Participant No. 5: Thabiso

Thabiso was a fifteen year old male at the time of the study and was in grade ten at School B. Thabiso was friendly and petite and always wore a mischievous smile. He was well conversant in English and participated in an English interview. He was always well attired in his school uniform. Thabiso's favourite sport was soccer and he played for the school and community team. Thabiso was very self-sufficient and assisted his caregiver with the household chores. He and his younger sister, together with their mum, were residing in Durban. When his mother had taken ill in 2003, they came to reside with his maternal grandparents in Kwa Nzimakwe. Their mother completed her nursing training but was unable to practice due to her illness. His sister was eight years old at the time of the study. Thabiso and his sister had different fathers.

Thabiso's father never played an active role in his life, but Thabiso visited his father occasionally and his father contributed to some of his school requirements. Thabiso's father did not attend his mother's funeral. Thabiso's mother died on the 04th December 2004. Thabiso was thirteen years old at the time of the demise of his mother. On the 28th July 2006, Thabiso and his sister were officially placed in the foster care of their maternal grandparents, Vinah and her husband. Both his grandparents were fifty two years old at the time of the study. The couple had been married for twenty seven years. They have four children; aged twenty seven, a set of twins aged twenty five and twenty two years old. Thabiso's grandmother was unemployed and his grandfather was employed casually. They were also in receipt of foster care grants in respect of both children. Thabiso's grandparents were sometimes financially assisted by their children and their income was supplemented by subsistence farming. There were six members in their household and Thabiso's caregiver participated in an English interview.

Participant Six: Penelope

Penelope was a seventeen year old female at the time of the study. She was in grade eleven at School B. She was polite and had a pleasant disposition. Penelope enjoyed watching movies and listening to music, especially R & B and Rock. She also loved reading and her favourite soapie was Generations. Her best friend was her only brother, Darius, but she also has another school friend. She loved attending school and was

appointed as a prefect. Her mother died on the 26th December 2002, at the age of forty one. At the time of her demise, Penelope was twelve years old and brother was almost eleven years old, when their mother died. Their natural father was unknown to them and did not play any role in their lives.

Whilst their mother was still alive, both children were residing with their maternal aunt, Noxolo. Noxolo assisted with the care of their dying mother and assumed total responsibility for the children after the demise of their mother. On the 15th July 2003, both children were officially placed in the foster care of Noxolo. At the time of this study, Noxolo was thirty four years old. She was a single parent with two children; boys aged twenty one and six years old. Her eldest child lived with his father. Noxolo was employed casually as a domestic worker and a waitress at a local hotel. She also received foster care grants for both children and a child support grant for her own child. There were six members in their household. Both Penelope and her caregiver participated in English interviews.

Participant Seven: Darius

Darius was the brother of Penelope. Darius was fifteen years old at the time of the study and in Grade ten at the same school as his sister. He was performing at an average level and his conduct was excellent. Darius enjoyed reading and art, spending time with friends, playing music and watching movies with them. Darius favourite music was hip-hop and rap. Darius also enjoyed watching Generations and Passions on television and playing soccer. Darius depended on his sister to attend to the household chores and merely attended to the washing and ironing of his own clothing. Darius and his caregiver participated in English interviews. There were six members in their household.

Participant Eight: Sisanda

Sisanda was a chubby, pleasant thirteen year old female at the time of the study. Sisanda did not devote much attention to her general appearance. Sisanda was in grade eight at school C and conversed well in English. Hence, she participated in an English interview.

Sisanda loved reading, dancing and listening to music. Sisanda's most popular music was R & B and her favourite artist was Chris Brown. Sisanda enjoyed playing cricket and volleyball and had already received certificates of achievement for cricket.

Sisanda's mother died on the 04th October 2001, at the age of twenty four. Sisanda was the only child of her parents. At that time, Sisanda was eight years old. Sisanda's mother was working and residing in Gauteng. When she fell sick, she came home to her mother and sister. Sisanda's father was unknown to her and was not responsible for her care and upbringing. Sisanda was living with her maternal aunt, Venice, since birth.

Sisanda was officially placed in the foster care of Venice on the 28th May 2003. Venice was thirty four years old at the time of the study. She got married in 1998 and had no children of her own. Venice dropped out of school when she was in Grade ten, due to ill-health. Venice was a widow and did not re-marry. Venice had no children of her own and she loved children. Venice also assumed responsibility for two of her nieces and her sister. Venice was employed casually as a domestic worker but was not working at the time of the study. Venice received a contribution from her husband's previous company and a foster care grant in respect of two children.

The family had strong religious convictions and attended church services regularly. As a single parent, Venice instilled strong religious values in the children and motivated them to read the bible on a regular basis. There were three members in their household. Both Sisanda and her caregiver participated in English interviews.

Participant Ten: Tsepo

Tsepo was sixteen years at the time of the study. He was in grade eleven at School A. He was performing well academically. Tsepo always appeared neatly attired and well groomed. Tsepo's favourite sport was rugby and he often played for the community team. Tsepo enjoyed listening to music, his favourite music artist being Zola 7. He watched television occasionally and participated in drama at school. Tsepo was very pessimistic about his studies, home circumstances and his future. According to school records, Tsepo was performing well academically, but suddenly declined. Tsepo was self sufficient and assisted with most household chores. During the interview process, Tsepo preferred to communicate both in English and IsiZulu. His caregiver communicated in IsiZulu.

Tsepo experienced multiple losses as both of his parents were deceased. The year 2000 was a traumatic year for the family, as both his parents died less than a month apart from each other. His father died on the 15th June 2000 at the age of thirty seven and his mother died soon after on the 09th of July 2000, at the age of thirty six. Both his parents were married to each other. At the demise of his parents, Tsepo was ten years old. Tsepo had two other brothers, aged fifteen years and thirteen years at the time of the study. Prior to the death of their parents, Tsepo, his siblings and his parents were residing in Umlazi, Durban. Upon the death of their parents, Tsepo and his siblings had to re-locate to Margate as they were no suitable caregivers in Durban.

All three children were placed in the foster care of their paternal uncle and aunt, Anthony and Thoko on the 16th July 2003. The couple was married for twenty four years and was childless.

At the time of the study, Anthony was employed as a Security officer for a local hotel and Thoko was a housewife. They were also in receipt of foster care grants in respect of all three children. Religion played a vital role in their lives and they worshipped at the African Gospel church. There were five members in their household.

Participant No. 9: Mbali

At the time of this study, Mbali was thirteen years old and in grade seven at School D. Mbali was shy, reserved, polite and always smiling. Mbali took pride in her general appearance. She was well conversant in English and attended an English medium school. Hence, Mbali and her caregiver participated in English interviews. Throughout her schooling years, Mbali had been producing excellent academic results. During the previous year she had seven distinctions. Mbali loved reading, watching television, swimming, listening to music and playing board games. Mbali's favourite music was R & B and her favourite artist was Mary Jane Blige. Mbali's caregiver described her as a well behaved and obedient child who was always willing to render assistance.

Mbali's mother died on the 01st December 2001 at the age of forty four. The whereabouts of her father was unknown whilst she was growing up but he had recently established contact with her and had been showing some interest in her welfare. Her

parents were never married. Mbali was eight years old at the time of the demise of her mother. Mbali had an older brother, aged twenty and a half-sister aged twenty four. Prior to the demise of their mother, Mbali and her brother were residing with their mother. When her mother had taken ill, their half sister, Stembile, who was residing in Stanger with her father and doing her matric, was called to assist with the caring of her siblings. Stembile was nineteen years old at the time of the death of her mother.

Stembile had to drop out of school to work and support her siblings. She later studied through correspondence and completed her matric, with the financial assistance of her employer.

Stembile was a single parent and had a six year old child. Stembile's employer owned a holiday cottage, which she maintained and managed. She took care of the tourists that accommodated the cottage. Stembile, her two siblings and her son occupied a one-roomed cottage attached to the main cottage. Stembile was in receipt of a foster care grant in respect of Mbali and a child support grant in respect of her son.

Participant No. 11: Brenda

Brenda was sixteen years old at the time of this study and in grade eight at School B. She was timid but highly self confident, mature and possessed good values. Brenda was always observed to be well groomed and composed. Brenda produced excellent academic results. She was well conversant in English and participated in English interviews. Her caregiver participated in an IsiZulu interview. Brenda's parents were never married. Brenda experienced multiple losses as both her parents were deceased. Her mother died on the 27th October 1997, at the age of thirty seven years old and her father died on the 03rd November 2002, at the age of forty seven years. Brenda was seven years old when her mother died. Her parents never married and were living apart. Prior to their demise, her mother resided in Bizana and her father was in Gauteng. Her father assumed no responsibility for her upbringing. Brenda has three other siblings, two sisters, aged twenty nine and twenty years old and a brother, aged fourteen years old, at the time of the interviews. Prior to the death of their mother, Brenda and her brother came to reside with

their older sister, Sylvia. Sylvia was twenty nine years old at the time of the study and had two children aged twelve and nine years old. At the time of her mother's death Sylvia was twenty years old. Sylvia was married and her husband was employed as a plumber whilst Sylvia was a housewife. Both Brenda and her brother were officially placed in the foster care of their sister, Sylvia on the 07th July 2004. Brenda and Sylvia did not share the same father. Sylvia was in receipt of foster care grants in respect of both her siblings and a child support grant in respect of her two children. There were six members in the household.

5.3 Demographic Profile of Households

The table 5.3.1 below reflects the number of individuals in the household, the average income and the primary caregiver. The table reveals that in all of the eleven cases the primary caregiver is a female with the majority not supported by an adult male. The average size of the household was six and in all cases where siblings were present, they were living together in one household. In six out of the eleven cases, the primary caregiver had child/children of their own without support from the father of the child/children.

Table 2: Profiling the Households

NAME	AGE	GRADE	AGE AT TIME OF DEATH OF MOTHER	NAME OF CAREGIVER	RELATIONSHIP TO CHILD	DATE OF FOSTER PLACEMENT	NO. IN HOUSE-HOLD	ESTIMATE MONTHLY INCOME	MALE ROLE MODEL
Mbali	13	7	8	Stembile	sister	08/05/2003	4	R 1690-00	Nil
Sisanda	13	7	8	Venice	maternal aunt	28/05/2003	3	R 3180-00	Nil
Thabiso	15	10	13	Vinah	maternal grandmother	28/07/2006	6	R 1180-00	husband of caregiver
Aletta	15	9	12	Thabisile	maternal aunt	10/11/2006	6	R 2170-00	husband of caregiver (not always present)
Nomfundo	15	7	7	Dorica	maternal aunt	15/07/2005	6	R 2030-00	Nil
Tsepo	16	11	10	Thoko	paternal uncle & aunt	16/07/2003	5	R 2970-00	caregiver
Darius	16	10	10	Noxolo	maternal aunt	15/07/2003	6	R 1970-00	Nil
Brenda	16	8	7	Sylvia	Sister	07/07/2004	6	R 2760-00	husband of caregiver (not always present)

Basanda	16	10	13	Primrose	Sister	10/11/2006	5	R 1720-00	Nil
Penelope	17	11	12	Noxolo	maternal aunt	15/07/2003	6	R 1970-00	Nil
Nqobile	17	9	13	Akhona	maternal grandmother	10/12/2004	5	R 2330-00	husband of caregiver

5.4 Conclusion

This chapter profiled each of the eleven child participants together with their caregivers to provide a context to the analysis chapters that follow. The profiles present a brief biography of each participant and focused mainly on providing data on age, age of child participant upon the demise of the parent (s) so as to give the reader a sense of how young the child participants were when they experienced loss and trauma. Data on who the caregiver was in relation to the child participant is also presented. In all eleven cases the primary caregiver had a prior established relationship with the child participant. All primary caregivers in the study were female. These trends have also been documented in other studies [Cross (2001); Africa Recovery (2001) & Demmer (2005)]. In communities especially ravished by the HIV and AIDS pandemic, the community response is at the forefront, particularly in poorly resourced, low socio-economic communities. Foster care is the first available option from a social worker's perspective. In rare circumstances and as a last resort, orphans are placed in institutions (Perumal, 2007).

In the next chapter, I provide an in-depth discussion of the factors negatively impacting the lives of these eleven participants, while Chapter 7, deals with factors that contribute to children's resilience.

CHAPTER 6

FACTORS IMPACTING THE LIFE OF THE CHILDREN

6.1 Introduction

In this chapter, factors impacting on the lives of children are discussed. From the data gathered, it was clear that poverty, sickness and death have taken their toll on many of the households. Obviously, being orphaned or abandoned is a highly traumatic experience, and where this has been accompanied by sickness, it is highly likely that children bear deep emotional scars. Having to live with someone else was an added difficulty these children often had to face.

The intention of this chapter is to map the various factors that affect the lives of children and to show how cumulatively they impact on the child's emotional, psychological and physical well being.

6.2 Poverty / Material Deprivation

In this chapter, I focus on the daily living conditions of the participants and the central role that poverty played in their lives. Unlike the United States and other developed countries, people affected by AIDS in South Africa have to deal with extreme economic hardship on a daily basis (Demmer, 2005). In this section I explore how the participants' emotional response to AIDS-related loss was frequently overshadowed by their daily survival needs, a finding similar to that of Demmer's study (2005). In South Africa, many people affected by AIDS live in very impoverished circumstances, which seem to worsen when a family member dies from AIDS. The care and support services that exist in this country to help the poor who are most devastated by AIDS are comparatively meager, and the government is swamped by the demand for welfare support (Ewing, 2002). The

dawn of democracy in South Africa in 1994 brought with it the hopes of many that political transformation would lead to a substantial alleviation of poverty. Fifteen years after this historical transition, millions of South Africans in dire need are still not afforded decent and gainful employment but are provided support in the form of social grants.

The migrant labour system has contributed to the absence of adults in the home and the HIV/AIDS pandemic, in combination with the profound levels of poverty, have led to multiple losses, food insecurity and daily survival strategies (Van der Riet, Hough, .& Killian, 2005). Poverty made the pandemic harder to fight, but it does not absolve the government of the responsibility for not acting faster and more aggressively against it. Most African governments themselves are now weakened by AIDS as the disease lowers productivity and efficiency, undermines the capacity to deliver services, and possibly even threatens democracy itself (Barnett & Whiteside, 2002). Most individuals in South Africa who are grieving AIDS-related deaths face a variety of stresses such as poverty, malnutrition, poor housing conditions and limited formal support services (Demmer, 2005).

As we shall see in this chapter, the primary focus for caregivers was not on addressing their emotional well-being, but rather it was about trying to survive on a daily basis-dealing with health issues, finding money for food and clothing, a place to live in, or figuring out ways to send their children to school. Poverty was experienced as a profound source of hardship that impacted on all spheres of functioning. There are various factors that exacerbate and are exacerbated by poverty. These are discussed below:

6.2.1 Living Conditions

The research context was the rural area of Kwa Nzimakwe, which is approximately 59 km from Port Shepstone and falls within the UGU District Municipality of KwaZulu Natal, South Africa. The community in which the research was undertaken lacked basic infrastructure, proper housing and access to social services. Most participants in this study were very poor and struggled to support themselves and their families. This is not

unusual when one realizes that AIDS primarily affects the poorest, the most disadvantaged groups in this country (Mitton, cited in Demmer, 2005). The majority of poor in South Africa have inadequate provision of water; sanitation, electricity, and more than one third of children less than five years of age are undernourished (Gilbert & Walker, cited in Demmer, 2005).

In this current study of 10 households, the following was found:

- The average monthly household income was R 2000-00, with the state grants forming the majority of this income.
- 10% of the households had piped sewage
- 90% had external ablution facilities in the form of pit latrines
- 90% of the households did not have any bathroom facilities.
Having only one basin in which all family members wash, delayed morning departures and some participants mentioned waking up very early in the morning, so as to be punctual at school.
- 90% of the households utilized a communal tap to retrieve water. Only one household had an in-house water source
- Fortunately all households had electricity installed in the form of the government coupon system. Some participants also spoke of difficulties with doing homework because of the lack of facilities or space. If the elders need to go to sleep, the lights needed to be switched off and everyone were compelled to go to bed, thereby limiting time available to do homework. In addition, some participants expressed the view that the electricity needed to be saved for more important necessities like cooking and could not be “wasted”.
- All households could not afford private medical care and utilized the community health centres, clinics and government hospitals.
- The distance from the selected schools to the homes of the child participants varied from 5 km to approximately 62 km.
- 82% of the children in this study walked to school. Poor access routes to school, both in terms of distance and the quality of the roads, made the journey to school for many children extremely difficult. The majority of the participants walked to school and the roads were dusty or muddy during inclement weather. These unpleasant conditions meant that children arrived at school tired and sometimes dirty.

Given poverty and unemployment, it was not surprising that many of the households lived in housing of a poor quality. In this study, three households (ranging in size from five to six members were living in a two-bed roomed house; one household with four members were living in a single room and the other six households with an average of six occupants occupied a three to four bed roomed house. Only two households were living

in houses that were not their own. The rest bought a piece of land and constructed their own homes. None of the child participants had their own room and all of them shared with other members of the family. Homework had to be completed before nightfall or in the kitchen when others were asleep. Some of the child participants expressed that they were not allowed to study at night as they would have to save the electricity for more pressing needs and also they would be disturbing the sick or elderly at night.

In addition to the poor quality of housing, other infrastructure in the community where the study was conducted was also poor or non-existent. The community complained of a lack of proper sanitation systems, crèches, tarred roads, bridges and hospitals. There was only one clinic/community health care centre available and the nearest provincial hospital was approximately 59 km away. Hence, there was a lack of immediate emergency or after hours care services. Most pre-schools/ crèches were in a poor condition and not easily accessible. Obtaining an income was a constant struggle for many families, resulting in many caregivers being absent from their children's daily lives, due to them being employed in towns and neighbouring cities. Hence, it was expected of all children to perform various household chores, like fetching water, collecting firewood, washing clothing and dishes, cooking, sweeping and shopping. Females were expected to take on more household chores and greater responsibility for the care of their younger siblings or their caregiver's children. They expressed that these chores were time-consuming and tiring and left very little time for themselves.

All the participants did not have access to cars, which further disadvantaged them in terms of access to facilities or resources. All households utilized public transport, mainly in the form of mini bus taxis or buses. Although cell phone access might be seen as a luxury, in areas where resources are constrained, cell phones are the main form of communication. All households had access to cell phones and these households seem to prioritize cell phones over television as a resource. Only one household had a land line facility.

6.2.2 School Environment

Lack of resources within the school environment also impacted negatively on the lives of the children. There was always the shortage of books and stationery and more often than not, learners had to purchase their own books and stationery.

Mbali related:

‘They give us some exercise books and some we buy’.

Penelope responded;

‘There are textbooks and exercise books but it is not enough. My aunt bought us books’.

Not all the rural schools had computers and the participants verbalized that there was also a shortage of maths and science teachers. Some schools did not have basic facilities. In the rural schools, most of the time there were problems with their water supply and toilets were thus not fully functional. Fencing was poor and the schools in this context had experienced burglaries and vandalism. Participants also complained of inadequate sporting equipment and a training coach.

The issue of teacher absenteeism or lateness at school was also raised. No arrangements were made to relieve educators who were absent. Learners were expected to mind themselves. However, three of the child participants complained that educators were often not approachable. All eleven child participants reported on overcrowded classrooms, most classrooms had between fifty to sixty five learners per one educator. Shortage of teachers and teacher overload affected learning at schools. Departmental processes, meetings and funerals also disrupted schooling. Teachers in this context largely resided away from the schools and commuted daily. Distances travelled range from thirty five to seventy kilometres.

When asked about their educators at school, the child participants responded as follows:

Basanda responded:

‘Sometimes the teachers come, sometimes they don’t. Sometimes the teachers come to school but they don’t teach. When they don’t teach, I get frustrated’.

Darius replied:

‘We have a problem. We didn’t have a teacher and we haven’t learnt much since we started this year. Also our health science teacher doesn’t teach very well’.

Sisanda added:

‘Sometimes I didn’t go to school because the teachers were not all there. Some teachers were absent so I decided to stay at home’.

Tsepo responded:

‘It’s alright. Sometimes we learn, sometimes we don’t. The teachers sometimes don’t come to classes and we don’t learn for the whole day’.

Tsepo further added:

‘Even if they are not absent, they sit in the staffroom. They don’t usually come to class’.

Alletta related:

‘At school there is a strike. The Principal took the money and is gone. I changed schools because of the strike’.

It was also revealed that children’s school reports were withheld if school fees were not fully paid or children were punished if they did not have the correct school uniform. Most schools are financially dependant on school fees and are very strict regarding the non-payment of school fees.

Mbali responded:

‘The school is beginning to fuss because most children leave it to the end.’

Tsepo indicated:

We didn’t pay school fees because there was a strike in school.

Participants mentioned the fact that children often have to travel considerable distances to get to school. This has a number of implications, including cost (if transport must be paid for); safety on the route (where rivers without bridges needed to be crossed, and also possible abuse); physical fatigue in children who walk; possible lateness to school (and where school close gates, possibly missing some or all of school on that day).

When the child participants were asked about possible lateness to school, they responded as follows:

Nomfundo responded:

‘I go late to school, only when it rains, because the road is not good’.

Tsepo related:

‘Everyday I go late to school. Even when I wake up early, I get late. I get in trouble, but the security likes me and lets me in’.

Penelope added:

‘I leave home at about six or quarter past six (in the morning). I had to run to school. In winter, it is more difficult. It is dark and cold, but I’ll cope’.

When enquired about school attendance, the child participants responded as follows:

Sisanda responded:

‘Sometimes when my mother doesn’t have money for the ticket, I don’t go to school. I go on the day that she has’.

Two child participants commuted daily with the school bus. They had to rise very early to board the bus and if they missed the bus, they couldn’t attend school, which was approximately sixty two kilometres from home.

When asked about school attendance, Mbali reported:

‘I was absent for four days. Twice the bus left me, once I had flu and once it rained’.

When asked the reason for her lateness, Mbali responded:

‘I woke up late; the alarm clock sometimes doesn’t work’.

6.2.3 Impact of Death on the Household

AIDS impacts households over a long period of time, from the time the person becomes ill until way after their death (Gow and Desmond, 2002). Households tend to experience a longer period of depletion of resources when the household member has the AIDS virus

than any other illness, due to the protracted nature of the disease (Barnett, Whiteside & Desmond, 2001). In a study of HIV-infected adolescents and HIV-infected parents in the North West Province of South Africa, twenty out of the twenty five parents reported negative economic effects on the household stemming from their diagnosis (Strydom & Raath, in Demmer, 2005). Likewise in Demmer's (2005) study, 13 out of the 18 participants made reference to increased economic hardship both before and after the death of a loved one.

In this current study, all the participants made reference to some form of economic hardship. The following narrates to some extent their economic hardship:-

When asked, if there anybody that came to give them food or money, Stembile replied:

'I don't like to sound that I'm bad-mouthing them, but no one really. When I didn't apply for the grant, it was very difficult'.

Clearly there is a dependence on state assistance and resources, however, minimal. Noxolo relates how Darius could not utilize an option of changing schools as he was having a problem with the isiZulu language due to financial constraints. When asked why she didn't change schools, she replied:-

"Because of money, I didn't have any money and I'm not sure of the guarantee of the foster care grant".

When Primrose was asked if she had any money after her mother died? She replied:

"It was very hard; I didn't have any money, not even a cent".

In Sylvia's case she had taken on the responsibility of caring for Brenda even though she was not working at the time. She reported:

"My husband was not working but doing piece jobs (employed casually).I was not working and then I applied for the grant for my child and I was taking care of all the children (her siblings) with my child's grant".

In Sisanda's case lack of money impacted on whether she would be able to attend school regularly:

"Sometimes when my mother doesn't have money for a ticket, I don't go to school. I go on the day that she has".

Typically, a family member became very ill and then lost his/her job, with the result that other members of the household had to scramble to find extra money to fill the void. This has been reflected in the stories of Basanda, Mbali, Thabiso, Tsepo, Aletta and Brenda.

The economic impact of having an HIV-infected member in a household has received some, though not enough attention by researchers. Several studies have examined the impact of AIDS-related illness and death on households in developing countries but there are very few studies done in South Africa. In Cross's (2001) study of poor, rural households in KwaZulu Natal, the burden of incorporating children orphaned on account of AIDS into the household, without additional support, typically pushed households over the edge. The education costs of the orphans were a particular drain on household finances, and this included school fees, transport to school, and school uniforms. With few options for digging their way out of poverty, households fell into a downward spiral where spending for basic needs was drastically curtailed and little money was available for food.

None of the participants in this study complained about medical costs of caring for the deceased. All of them did not have to pay medical costs, because the member of the family that had taken ill was either treated at a public /government hospital or community health care facility or was cared for at home. In this study, the natural mothers of seven child participants were hospitalized, prior to their death. The natural mothers of the other four child participants (two being a sibling pair) died at their home. Only four caregivers had knowledge of the natural mothers being in receipt of ARVs. This contrasts with research done on AIDS impacted households in Free State Province, where health care costs were found to be a significant drain on household resources (Bachman & Booysen, as cited in Demmer, 2005).

Deaths as a result of AIDS places financial demands on families such as funeral and catering expenses, which might divert family resources from schooling. Funerals also sometimes disrupt children's schooling as they may be required to assist with preparations, or travel distances to attend funerals. Participants in Demmer's (2005) study

described how families became splintered upon the death of an individual and family members were re-located to other households. Most of the participants in Demmer's study also discussed the difficulties of trying to keep their family together, whilst some participants experienced no change in living arrangements after their loved one died. This contrasts with the current study, where out of the eleven child participants; only two child participants experienced changes in their living circumstances and had to re-locate upon the death of their parent(s).

6.2.4 Burden Borne by Women

The family has never been a stable social unit in South Africa. In the late nineteenth and twentieth centuries, the African family was invariably a fluid structure, affected by apartheid labour processes, by urbanization and industrialization, and shaped by gendered forces that pressed more heavily upon women than men. In the last two decades, a new trend has emerged with the rise in single-parent households headed by women. This means that a minority of black children live in two-parent households (Posel & Casale, cited in Demmer, 2005).

Therefore the nuclear family cannot be assumed as a norm. A dominant theme in my interviews was the central role women played in caring for the sick as well as dealing with the aftermath of death. But this is not new information. In a qualitative study of the impact of AIDS-related deaths on rural households in KwaZulu Natal, Cross (2001) noted that most of the economic burden of household support was being carried by women. Women headed households were at great risk for sinking even deeper into poverty because of the shock of taking in children orphaned by AIDS as well as the fact that women had greater difficulty applying for assistance from bureaucratic organizations. Barnett, Whiteside, & Desmond (2001) indicated that females in Africa are more harshly affected by the pandemic as they are removed from school to save money for care costs of a sick parent, experienced stigmatization on the death of a husband, and finally a lonely and impoverished widowhood. Also, participants in

Demmer's (2005) study mentioned that they seldom received support from males, either in caring for the deceased or the deceased's children.

In the current study, in all of the 11 cases, the primary caregiver was a female with the majority not supported by an adult male. Out of the eleven child participants, five participants were cared for by their maternal aunt; two by their maternal grandparents, one by his paternal aunt and uncle and three of the eleven cases reflecting the caring done by an older female sibling. The husbands of the caregivers were not always present in the children's lives. Only one child participant, out of the eleven participants was receiving financial support from her father.

Some of the responses of the participants are as follows, Stembile responded:

‘What happened was that I was staying with my father in Stanger, I was doing grade twelve. When she (my mother) was starting to get sick (had taken ill), there was no one to take care of her (Mbali). I had to drop out of school to come and stay with them, we all stayed together.

Sylvia responded:

‘I grew up not going to school. What cause (d) me not to go to school was that my mother was not educated. She (my mother) didn't have time for school. She didn't care about school. My mother would tell me that she was raised not going to school. I went to school when I was very old.’

In addition, rural women in Africa find themselves at the very bottom of the social stratification system. They are denied access to power and to decision-making both within and outside the home and they are denied access to education, land and to credit without collateral (Sewpaul, 1994). Citing a Markinor study (2007), Trevor Manuel, Ex-Minister of Finance in South Africa provided the following data:

- Only 15 per cent of rural women have a school leaving certificate (matriculation) compared to 50 per cent of urban women.
- About 16 per cent of rural women have no schooling relative to 3 per cent for urban women.
- About 36 per cent of urban women are employed compared to only 20 per cent in rural areas.
(Sewpaul, 2008- unpublished article).

Much of women's exclusion from mainstream economic opportunities has led to their involvement in casual, informal and unregulated labour at rates that exceed those of men (Beneria & Feldman, 1992; Brydon & Chant, 1998; Lawson, 1995).

In this study, five of the caregivers were employed on a temporary or informal basis limiting their access to benefits derived from permanent employment. Three caregivers had to leave school prematurely to care for their siblings limiting economic opportunities available to them.

While women are responsible for ensuring the survival needs of the continent, they also assume responsibility for major domestic tasks, including care of children, the sick and the elderly; fetching and purifying water and gathering of firewood. They often do this alone in the absence of their male partners. Female-headed households which are common in rural areas as men migrate to urban areas in search of employment, tend to be poorer than male headed or two-parent households with women prone to food insecurity (Khan, 2000).

6.2.5 The Elderly

In reviewing the literature, I found a scarcity of data/ research on the impact of AIDS-related deaths on the elderly, and this applies to both developed and developing countries. Adults who die of AIDS leave behind parents as well as children and the elderly are affected by AIDS-related loss in profound and consequential ways. In developing countries, the social, economic and health consequences of AIDS on the elderly are magnified. Besides having to endure the pain of losing a child, elderly parents have to take on the responsibility of paying for the medical and living expenses of their sick children, care for them, pay for their funeral costs, as well as assume responsibility for their grandchildren (Knodel & van Landingham, cited in Demmer, 2005). AIDS in Africa has also been called the "grandmother's disease" because older women are expected to care for their grandchildren as they watch their own children die (Moller, cited in Demmer, 2005:136). They are expected to take in children orphaned by AIDS,

care for them as well as educate them, care for them if they are HIV-infected and later bury them. Because of the high number of AIDS-related deaths in Africa, many elderly people are deprived of any support in their old age that their deceased children would have provided (Demmer, 2004).

In their study of the impact of AIDS on households in the Bergville area of KwaZulu Natal, Gow and Desmond (2002) found that in households where both parents had died, it was typically the grandmother who became the primary caregiver and they cautioned:

The reliance on grandparents to provide care after the death of parents is dangerous and will become increasingly so as the epidemic progresses. When the grandparents die, these children face being orphaned again. The question of who will care for them then remains unanswered...The grandparents of the future are dying in the present. Who will care for the children in 15 years time (Gow and Desmond, 2002: 124)?

It is not uncommon for terminally ill urban family members to return to the rural home to die. With AIDS killing the most productive adult members of the households, elderly grandmothers in rural areas often take on the responsibility to care for their orphaned grandchildren.

In the community where the study was conducted, it was not uncommon for grandmothers to assume responsibility for their grandchildren upon the demise of their own children. However, in this current study, out of the eleven child participants, only two were cared for by their grandmothers. Hence the reliance on grandparents to provide care for the children after the death of their parents is not so prominent in this study.

6.2.6 Unemployment

Unemployment is a universal problem with which the political leadership of almost every country has to wrestle. The problem we are faced with is that, not only does unemployment exist in South Africa, but it is so severe that it directly causes poverty. Unemployment has become the prime social and economic issue in South Africa and in a

number of developing countries. It is responsible for poverty and inequality; it erodes human capital and creates social and economic tensions wherever it strikes (Snower & de la Dehesa, cited in Demmer, 2005). More than anything, participants felt obligated to secure employment in order to support their existing households. Unemployment is rife in South Africa, even though South Africa is classified as a middle-income country by the World Bank, about 40% of the workforce is unemployed (Gilbert & Walker, cited in Demmer, 2005).

Thirteen of the eighteen participants in Demmer's (2005) study did not have steady employment. In the current study, five of the caregivers were employed casually; two of them depended on their husbands for financial assistance; two were unemployed and one was in receipt of a state pension. All caregivers relied heavily on state financial assistance in the form of grants, as reflected in Table 5 in Chapter 8. Even those who were employed earned very little. In the community that the study was conducted, many heads of households migrated to urban areas to secure employment. The majority of women traveled long distances to secure some sort of employment in order to sustain their families.

6.3 Absent fathers: Children of deceased mothers and unknown fathers

The provision of care, and the lack of men's involvement in childcare, is by no means a new challenge. The widespread absence of fathers and the lack of support by men for families and children is a major gap in potential resources for affected children in South Africa. Most children are raised by single mothers and seldom see their biological father even if they are lucky enough to know who he is. In this current study, of the eleven child participants, eight participants had no contact with their father. There are numerous factors, particularly poverty, unemployment and more than a century of enforced migrant labour, that have a negative impact on men's ability to fulfill their responsibilities as fathers.

Historically, it had been important for fathers to be responsible and provide for their children. Migrant workers' expectation of themselves included that they would have and support a homestead with a wife and children in the rural areas. Even in the context of men not earning well, men hold the idea that being a good man involves being a good father. But fatherhood patterns are changing as the country and its economy changes. Despite the widely held view that being a father and providing for one's children is important, many South Africans neglect their parental responsibilities (Silberschmidt, 2001).

The table below shows the marked absence of the fathers in the family.

Table 3: Biological Fathers' presence in the family

Fathers' presence in the family	Number	Percentage
Present in the life of their child until death	2	18.18 %
Present after death of natural mother	1	9.09 %
Absent	8	72.73 %
Total	11	100 %

Out of the eleven child participants, only one received support from her father, two received support from their fathers before they died. The child participants reflected on the absence of support from their biological fathers, showing a deep sense of betrayal. When questioned about their father, they related the following:-

Sisanda remarked:

'I have no idea who my father is and I haven't seen him at all'.

Darius stated: 'My father lives in Transkei, but I don't see him. It's just that he didn't do anything for us, so there is nothing I can say. I don't know whether he likes me or not'.

Mbali replied:

‘I think I remember his face, but I don’t know where he stays’.

Nqobile reported:

‘I saw him long ago, when he came to somebody’s house for a funeral. He does not support or visit me now’.

Nqobile added:

‘I grew up knowing my mother and I grew up staying with her...I don’t like my father’.

Penelope displayed a strong sense of betrayal by the absence of her father:

‘I don’t know him and I don’t even think I want to know’.

Sylvia indicated:

‘When he was still alive. He went to Johannesburg and didn’t come back. He didn’t support the children. My mother was assisted by her mom when she was sick. She went there to her family home and would return to her marital home when she is better. Because her husband was not supporting her, she died at her family home; they took her to hospital, where she died. When she died they took her to her marital home but her family was responsible for all funeral costs’.

This absence is not compensated for by an adult male role model in the family. Table 6.1 shows that of the eleven cases, only four have some sort of male presence in the household. When the caregivers and child participants were asked about the role of male role models, they replied as follows:

Noxolo replied:

‘Yes he just come and sees the children once after three or six months, but he doesn’t help me with finances’.

In *Sylvia’s*, *Aletta’s* and *Thabisile’s* cases, the presence of a male role model came with its own set of problems.

When Sylvia was asked if her husband had any problems taking care of the children, she replied:

‘No, not now. Before he had a problem, the reason is that he is a person that is drinking and says, hey Sylvia! These children are using my money; hey these children are using my money. He later understood and he listened to the radio and got information on how to treat people and he changed. Now he is talking more like a father to them’.

Thabisile reported:

He (My husband) is fine, but we got problems, because he is still young, he got lot of girls’.

Aletta also indicated that she was fearful of her uncle. When asked whether she talks to her uncle, she replied:

‘I fright for him, he is old and I respect him’.

When Nqobile was asked whether she had a boyfriend, she replied:

‘No, I am scared of my grandfather.’

By definition, when a father is absent, little is known about him. It is often hard to know whether he is dead or alive. For example, the accounts above demonstrate how little is known about some absent fathers. What the interviews show is that these fathers were absent from the children’s and their caregivers’ discourse. They were, simply, not spoken about. Often they had no name. The mothers of the children probably had some recollections of them, but they preferred to keep silent. From the interviews with some of the child participants, it was apparent that the absence of their fathers caused deep, if repressed pain in these children.

When reviewing the literature, it was apparent that there was no data currently available in South Africa with which we can count and describe all men who are fathers, nor identify changes over time. But we can establish that very high and growing proportions of children, and particularly African children, do not live in their households with their fathers. In fact, children are more likely not to live with their fathers than with them.

Although many fathers desert their children without bothering about what will happen in their absence, the situation is not irredeemable. Fathers who are reported to be absent or deceased may be substituted with social fathers. Other father-figures can be available like a grandfather, an uncle or a teacher. The child participants also have social fathers in the form of their caregivers' live-in lovers, even if it is for a limited period of time (Devey, 2004).

Concerning the relationships between the mothers and the fathers of the children, this study fully confirms Hunter's (cited in Richter & Morel, 2006) conclusions. Among the poor in contemporary KwaZulu-Natal, marriage has ceased to be an option. Even cohabitation has become unusual. An overwhelming majority of children grow up in female-headed households. Their fathers have casual encounters with their mothers or the parents cohabit only for a short time. Children become alienated from relationships and display an over-reliance on self dependency as is shown in Penelope's case.

When asked if her mother was around, how would it be different? Do you think you would have been different?
 She (Penelope) replied: 'No. I think it is all up to me to make myself happy and not to rely on anyone'.

Table 4 : Relationships between Natural Parents

Relationships between parents	Number	Percentage
Marriage	1	9.09 %
Marriage followed by separation	1	9.09 %
Female-headed households	10	90.91 %
No parents	-	
TOTAL	11	109.09 %

As evident in the above table, the number does not total to twelve participants. This is so because upon separation of one couple, the household was headed by a female.

Our overall impression is that, in the families described, marriage no longer governs the relationships between parents. Customary marriage with payment of a bride wealth (lobola) to the bride's family continues to exist. However, in the face of unemployment, many men cannot afford lobola resulting in prolonged courtships or many women remaining single. Only two parents of eleven child participants were or had been married, but one couple subsequently separated at the time of the interview.

Some men were not taking care of their children because they were married to other women with whom they also had children.

Nqobile's case reflects this:

'I was told that he is married and is now staying in Durban, but I am not sure'.

In my sample, the grandparents taking care of two child participants were married and supported their spouses in caring for the children. Only a few single mothers could rely on the support of a loving father or, if he had died, could cherish his memories. In some instances, maternal grandfathers took responsibility for the upbringing of their grandchildren on the death of their daughter. Often, relationships with paternal side of the family were strained.

Nqobile's story is one of disaffection from the paternal side of the family:

'I grew up knowing my mother and I grew up staying with her.... I don't like my father'.

In Sylvia's case all costs were borne by the maternal home:

'He went to Jo'burg and didn't come back. He didn't support the children. My mother was assisted by her mom when she was sick. She went there to her family home and would return to her marital home when she is better. Because her husband was not supporting her, she died at her family home. They took her to hospital where she died. When she died they took her to her marital home but her family was responsible for all the costs'.

Stembile related the distance between her mother and the father's side of her family:

'We are not close (with my paternal family) and we weren't close with my mum before (even when my mum was alive).

Although Devey (cited in Richter & Morrell, 2006) indicated earlier on that fathers who are reported absent or deceased may be substituted with social fathers, Preston-Whyte (1989) argues that these social fathers do not replace the natural fathers of children, at least not permanently. For children, the real issue is not the crisis of marriage but the fact that often their fathers and sometimes their mothers leave them to live with relatives or desert them. In addition, paternal uncles or other significant male adults do not replace their fathers. There may be stepfathers of sorts- their mother's boyfriend, but these rarely play a meaningful role in the lives of the children. Men are seldom completely absent from the household since adult women may have lovers who visit them regularly and even live with them for long periods of time. Many of these men may be married to other women and eventually move away. Hence, their role in the household is usually ill defined and transient (Preston-Whyte, cited in Richter & Morrell, 2006).

On the basis of a small sample of children and their families, this study confirms the findings of other researchers. Among the poor, single mothers raise most children. Their biological fathers play a marginal role in their lives. These men do not see the benefit of establishing a permanent relationship with the mothers of their children. Many women have ceased to pursue the ideal of marriage, and the stigma of single motherhood has receded. Short-term associations between men and women are seen as more convenient. Some children express the pain of not living with their father and sometimes not knowing their father's name.

This section looked at various factors that impacted on and were impacted by poverty. In the next section I examine in depth the impact of stigma and discrimination.

6.4 Stigma and Discrimination

AIDS remains a highly stigmatized disease, causing persons affected as well as persons infected to be victimized by discrimination and to be ostracized by their communities and even their own families (Geballe & Gruendel, 1995). Many parents are reluctant to talk openly and honestly about their infection with their children from a sense of shame.

Infected parents also resist telling children about their condition because the disclosure forces into common awareness the parent's own illness and potential death. As a result, the disease becomes unnamed, unspoken, and often unspeakable to children who then have no name for what they know is happening to their loved ones and to themselves.

Survivors may be forced to keep the nature of the death secret and hide their own grief. Because of their fears of being ostracized by others, survivors may be hesitant to mourn openly in public and to seek support from others. Generally, there is a great deal of secrecy surrounding AIDS and deaths related to AIDS. Several factors account for this atmosphere of secrecy and denial around AIDS and AIDS-related death in South Africa. The main reason for this secrecy is the high level of stigma and discrimination that exists in South Africa with regard to HIV and AIDS. In Demmer's (2005) study, societal stigma determined the extent to which participants were open about their HIV status, whether they revealed the cause of a loved one's death, and whether they were able to share their loss with others. Most participants kept the HIV status of the deceased hidden from others. Participants in this study felt that they could not be open because of issues related to prejudice, shame, gossip, and the lack of understanding. Other factors played a role such as family relationships and not wanting to burden others.

There is no doubt that AIDS stigma is an obstacle to HIV preventive behaviours, voluntary counseling and testing and the perception and treatment of people with HIV and AIDS by people in society. The culture of silence and denial that pervades South African society is perpetuated by the past policies of the government (Demmer, 2005). It is disturbing that even in countries like the US which has made enormous progress in HIV prevention education and treatment, HIV-related stigma is still rampant. According to Kain (1996), the stigma of AIDS applies not only to the deceased but also the survivors and this prevents them from mourning freely. There is no doubt that individuals in South Africa who lose a loved one to AIDS are likely to receive less support and sympathy than if their loved one died a more socially acceptable death such as cancer. The stigmatization of AIDS not only increases the pain and suffering of the bereaved but

also contributes to the social and economic vulnerability of those living in AIDS-affected households (Strode and Grant, 2001).

In this study, a conspiracy of silence pervaded the lives of the caregivers and they played an active role in perpetuating this silence. The main reason for this silence was the stigma associated with HIV and AIDS. Parents and caregivers experienced difficulties openly discussing HIV and AIDS. Prior to their demise, only one parent disclosed to their child that she was HIV positive. Even after their deaths, the caregivers continued to perpetuate this silence. The child participants became aware that their mothers/parents were HIV positive, via other sources, like their extended family members and health personnel. The following are some of the responses of the participants:

Basanda related:

‘I was sad. They didn’t tell me anything (anything) when they were alive. I was young, but I needed to know the truth’.

Nqobile responded:

‘I went to school and left granny at home. When I came back from school, I saw things but I didn’t ask. I noticed that something was wrong. I went to sleep’.

Sisanda reported:

‘My aunt told me that she (my mum) had yaundis’.

Stembile responded:

‘Me and Mbali (Mbali and I) went to the hospital where she (my mum) was and we tried to find out from the nurses but they didn’t tell us. They said we were too young. They said we must come with an adult’.

Penelope indicated:

‘All I remember was that my auntwe were all sitting in the same room and my aunt wrote a letter to the uncle. She didn’t want to speak because we will hear’.

Vinah (Thabiso’s caregiver) responded:

‘Before the funeral when I told him that his mother was sick with this “disease”, I was afraid that he may hang himself’.

Vinah further added:

‘He (Thabiso) wants to be a doctor to see this disease that killed his mother (to find a cure for AIDS)’.

Primrose (Basanda’s caregiver) responded:

‘My mother asked me to come to her bedroom. I come (went) and she tell (told) me that she is (was) sick. She said my father came with this disease’.

Thabisile (Aletta’s caregiver) related:

‘She was sick for long. She didn’t tell me the first time that she was suffering from HIV; she always used to go to the clinic. I think it was after two years (that) she told me’.

Thabisile further added:

‘I talk to my sister in Jo’burg (Johannesburg) and said, your sister is suffering with this thing, but it is too late now to help’.

When Akhona (Nqobile’s caregiver) was asked about the cause of death of her daughter, she responded:

‘I don’t know, the hospital said it was TB’.

6.5 Bereavement

6.5.1 Multiple losses

Because AIDS is so prevalent in South Africa, it is not surprising that most participants experienced multiple AIDS-related deaths among people close to them. There were varied reactions to repeated loss including pain, acceptance and numbness. Being exposed to so much loss required participants to develop ways to deal with the situation.

Several qualitative studies have examined the phenomenon of multiple AIDS-related losses within the gay community in the US. Biller and Rice, (cited in Demmer 2005), conducted interviews with seven participants from California. With the exception of one participant who had AIDS, all the participants were HIV negative or were not tested. The researchers concluded that coping with multiple AIDS deaths was very difficult for the participants. Participants were never able to resolve their feelings about previous losses because they were confronted with new losses (Demmer, 2005).

In Demmer's (2005) study, some participants had experienced staggering losses to AIDS and reactions to so much loss ranged from heightened personal death anxiety to numbness. More research needs to be done to learn about the long-term impact of multiple losses among individuals, especially women, in the local context. The following are some of the narratives by child participants captured reflecting multiple losses:

Basanda indicated:

'The rate of AIDS is high, people are dying, and there is no free weekend. In my community, much people are dying, they are really dying. You saw this one today, she is fat and cute and the other day (on another day), uh! she is like dying'.

Mbali's reaction:

'Oh! There were many deaths. Almost every year. This year, it was my uncle and two grannies'.

Thabiso's responded:

'I think it was in June, my aunty passed. Then in August, my aunt's mother died and after that my mother died. I thought we all going to die'.

The literature on AIDS indicates the destabilizing effect of AIDS-related deaths on the lives of orphaned children. (Barnett & Whiteside, 2002; Gow & Desmond, 2002). Their life circumstances almost invariably deteriorate and they suffer emotional trauma. What this research suggests, however, is that the loss caused by AIDS rarely comes alone. In this current study, out of the eleven child participants, four lost both parents and all suffered multiple losses of some form. Independently of HIV/AIDS, their fathers and, in

some cases, their mothers had deserted them without giving any reason. Added to that was the effect of poverty, which AIDS intensified but did not create. All families could be described as poor, despite some disparity in their levels of income and life circumstances.

AIDS frequently causes illness and death in more than one family member, and often in more than a single generation of the family (Geballe and Gruendel, 1998). The very integrity of the child's family becomes challenged by these multiple and multi-generational death challenges subjecting the children to additional loss and support including changes in residence, of school, of parental figures, separation of siblings and moving away from friends. Out of the eleven child participants, seven had to move residence and change schools.

Primrose related her story of the death of both parents. She was one of the participants that was present at the death of both parents.

Primrose related:

‘Yes, she was sleeping in her bed and Granny asked us to come and tell us that now it is time for your mother to go. We never noticed that. She said you have to take everything from the fridge, because she never eat something strong, she used to eat yoghurt , smooth things.....and we never noticed anything because it was first time to see somebody like that. We take everything and eat, never thought that she was going to die. I was very drowsy at that time and granny told us to go in the bedroom, and asked my father, because he was working and very tired and he was sleeping that time, we wake him, and wait for the time....We saw her passed away, everything’.

She further related the last moments with her father.

“He was at hospital. Yes, we go to visit him and I come to see him and I say ‘Father, it’s me, Primrose’ and he said ‘of course my child, I see you ‘, that’s all, he never mentioned anything. Then I saw his eyes were not fine”.

Crewe (2001:12) comments that children who have lost one or both of their parents to HIV and AIDS, slowly have less and less until eventually “... they’re destitute in every sense: emotionally, economically and in terms of community.” Children respond to the loss of a parent with a heightened sense of vulnerability, “... often marked by fears of

recurrent tragedy” (Siegel & Freund 1994:43). Dane (1994:16) states that children have a “... struggle of living with fear” in reaction to the loss of a parent. In Thabiso’s case with the loss of both parents his story relates his response of vulnerability and fear of the impending death of his mother:

Thabiso related::

‘When my mother passed away, I was in Glenmore beach. When my father passed away, I was at home and he was in Harding. I came back from the beach and my grandmother told me that my mother she is in the hospital, here in Port Shepstone. The next day she asked my aunt to go and see how she was doing. When she came back, she came and told us that she has passed away. My grandmother came and told me that she was bleeding. I was shocked. I was not waiting for that kind of er ... Ya. I was in a good mood but when I heard that I was sad’.

Basanda’s story is one of extreme desolation and depression. When asked how she felt when her parents died, she replied:

‘My mother’sI was still having the hope that there is my father, but now. When my father died ...I was depressed’.

In Sisanda’s case the death of her mother was compounded by not knowing who would be able to support her. She responded:

‘Yes , it did affect me because before my mother died, my aunty told me that she is not my mother, so I asked her then whose my mother and then she showed me my mother and we were very close, when the time that I meet my mother, my real mother.. After she died and I went to my mother, my aunty, and I said that what I’m going to do now if I don’t have a mother. Will I stay with you or will I die too? And she said that no I must stay with her. Sometimes it does affect me’.

Children are exposed to a multitude of stressors when their household is exposed to HIV and AIDS. Griesel-Roux (2004) states that the impact of psychological needs of persons infected and affected by HIV/AIDS are often overshadowed by physical and social needs in a setting with limited resources.

The case of Sylvia (who was twenty years old at the time of her mother's death) exemplifies this:

‘When my mum passed away, I was in hospital about to deliver my baby. They didn't tell me but waited for me to deliver the baby and then I went to my marital home. My husband asked me to go home. I asked why. He said that he got the message that I must go home. When I got home my granny told me that my mother had died. At that I knew that my mother was in hospital but I was shocked. I was not feeling well, I didn't believe it. That time I was not working. I didn't know how to take care of the children. Even though my mother was not working but she was able to take care of the children by doing piece jobs. Even though she was an alcoholic, she was able to care for them. At that time I was thinking and asked my grandmother what to do with the children. She said wait until after the funeral. I took them after the funeral, it was very difficult. My husband was not working but doing piece jobs. I was not working and then I applied for the grant for my child and was taking care of Brenda with my child's grant and then Brenda's grant came after and I was able to manage after that’.

Fear, worry, observing and caring for ill parents in pain, stigmatization, hospital visitations, shattered hope and eventual loss are all experiences shared by these children (Germann, 2004). Children's psychological distress begins with a parent's illness, and they are left emotionally and physically vulnerable from attending to dying parents and seeing parents die (Hunter and Williamson, 2002).

Stembile had to drop out of school to fulfill this responsibility: Stembile related:

‘You see. What happen is that I was staying with my father in Stanger; I was doing grade twelve there, and the same year she died. I was doing grade twelve, when she was starting to get sick, there was no one to take care for her, and she was staying with Loyisa and Mbali. My family was not very close. My mother was staying with Mbali and I was staying with my daddy. And when she was sick, she felt that there was no- one to take care of her. So I had to drop out of school and come to stay (with my siblings and mother), we stayed all together’.

6.5.2 *Getting the News of the Death*

The news of death is always traumatic for the family. The child participants in the study spoke about how they got the news of the death of their parents. In most cases the participants were left to cope with the news on their own. Very little attention was paid to the psychological and long term impact of the news of the death.

Thabiso responded:

‘I came back from the beach and my grandmother told me that my mother is in hospital. The next day, she asked my aunt to go and see how she was doing. When she (aunt) came back, she came and told us that she has passed away. I was shocked. I was not waiting for that kind of news. I was in a good mood but when I heard that I was sad’.

Caregiver of Thabiso says this about him:

‘On the funeral day, he was just shock (in shock) and getting sick. My brother took him to the clinic’.

In Nqobile’s case the news of the death of her parent was delayed even though the activities associated with funeral arrangements was taking place. Nqobile related:

‘I went to school and left granny at home. When I came from school, I saw things but didn’t ask but I noticed that something was wrong. I went to sleep. I noticed that something was wrong. They told me a day after. They told me that I will never see my mother again’.

Basanda’s story indicated how she was excluded from being told that her mother had died:

‘They didn’t told (tell) me. She died in June. Ya, it was really early. I think it was about half past 3. Ya, my other uncle arrived ...he was shouting, everyone came out, the older ones they go. I said I wanted to go with them. They didn’t want me to go. They said I must stay at home. My mother is going to be alright, she was going to be fine .All the night I was crying .So, my aunt came back, to fetch her child, then she told me to wait at gate, then I asked why, she didn’t tell me nothing. They are people who are coming to pray, so I went I was such (very) happy, I was happy, and then I saw my friend by the way, she was crying. When I asked her, she didn’t say nothing, she just looked at me...then we continued, when we arrived people had red eyes, they seem that they were crying a lot. When I came into the kitchen, I asked them, why they didn’t tell me. Ya, then I started crying’.

Penelope reacted maturely on hearing of her parent's death:

'I couldn't believe it. I was shocked...but at the same time, I said it's okay because she was in so much pain, so it was okay for her to die'.

As in Demmer's (2005) study, several child participants felt that the way they were given the news of their loved one's death was not good.

6.5.3 *The Funeral*

The funeral is an emotionally charged event and carries with it financial burden. Funerals have become routine for young people in South Africa, as a result of the rise in AIDS-related deaths in recent years. There is little documentation in the bereavement literature about the therapeutic value of funerals from an African perspective. Overall, the cost of the funeral was not an issue for the participants because in most cases the deceased was covered by an insurance policy. Usually AIDS was not mentioned at funerals and the "understanding" was that the deceased died of other causes.

A study of 74 bereaved individuals by Gamino, Easterling, Stirman & Sewell(cited in Demmer, 2005) provided empirical support that participating in funerals and burial rituals assists in the psychological adjustment of mourners by facilitating social support and helping the mourner gain deeper levels of meaning with which to frame and understand their loss.

Almost all of the child participants were emotional and crying when discussing the death of their parents and the funeral process with me. In Penelope's case she sought comfort in her aunt being available to take care of her. Penelope responded:

'It was horrible. I felt alone but then again I knew there was my aunt and I can also count on her'.

Brenda's caregiver relates a similar experience of comfort. She responded:

'It didn't affect them (Brenda and her brother) because they were small. They grew up knowing that I am their mother. I told them when they were much older that they do not have a mother and I was their sister'.

However, all participants didn't display that level of comfort. In Mbali's case she felt and wanted to be alienated:

'I cried a lot at first but at the funeral I was quiet'.

When asked whether there was somebody to support her, she responded:

'Yes, but I didn't want to be held'.

A funeral is generally a dignified event with family members dealing with practical issues until after the funeral. This was not the case for Stembile (Mbali's caregiver), she responded:

'I was very close to my mum and I am missing her. I was sad on that day; everybody was fighting about who is going to get the money'.

6.5.4 Psychological support to the bereaved

Much has been written about enhancing psychosocial support of children affected by HIV and AIDS through memory work and memory boxes (Huni, 2005). Huni (2005) explains the opportunities created by such memory work:

- opens opportunities for communication with the family, breaking the culture of silence relating to death and dying.
- is seen as a holistic approach that facilitates the child and the family to plan jointly to address their needs.
- enables work on prevention of further HIV transmission, and adherence to anti-retroviral treatment.
- has been instrumental in shifting the hopelessness surrounding HIV and AIDS to a range of possibilities including living positively within a context of adversity.
- strengthens the capacity of families to protect, support and care for children affected by HIV and AIDS.

Wild (2001) claims that despite the potential importance of the topic, the psychosocial adjustment of children orphaned on account of AIDS has often been overlooked by researchers, international AIDS conferences, governments, non-governmental organizations and service providers. Publications have been based largely on practice wisdom and clinical experience. Rigorous and systematic empirical research designed to

explore and test hypotheses derived from these informal sources of knowledge is still relatively rare.

However some authors caution on the importance of acknowledging the powerful discourses playing a role in these HIV and AIDS crises, and comment that the training the State provides to these counsellors ought to bear in mind the African way of thinking (Schoeman, Killian & Hough, 2002). Just as Western ways of trying to inform and prevent the spread of the HIV and AIDS virus are doomed to fail in an African context (Van Dyk, 2003), so too will Western ways of grief counselling fail. What should be remembered is that African people are greatly influenced by their culture, and this has to be kept in mind when attempting to reach out to them emotionally.

Mallman (2002) points out that children cope better with adversity when they have three capabilities:- the capability to understand an adverse event; the capability to believe they can cope with a crisis; and the capability to give deeper meaning to an adverse event.

She suggests that a child's inner resources can be developed in a wide variety of ways.

This includes:

- 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 self-confidence, and
- increasing a child's ability to envision a future.

Under conditions of extreme adversity, none of these development efforts were evident in the child participants of the study.

6.6 The Social System of the Household/ financial support

In the United States, people with HIV and AIDS can qualify for a variety of services and benefits including medical care, monthly financial support (social security), food stamps, and case management services from a variety of community-based organizations, including housing assistance, psychological support and even recreational services. In

contrast, welfare support for people with HIV and AIDS and their families in South Africa is extremely limited. Granted, there are people taking advantage of the system, but to any practitioner working with people affected by HIV and AIDS in South Africa, there is no doubt that there is a lot of unmet need. Up to this point, the South African social welfare system has been unable to adequately meet the basic needs of those affected by the pandemic (Demmer, 2005).

Many individuals, including children, who are trying to cope with their loss, must summon the energy and determination to embark on the often frustrating and draining process of applying for minimal government benefits. It can take an extremely long time, sometimes up to several years, to process welfare applications, and the lack of appropriate documentation prevents many from applying for and receiving welfare support. This can be a life or death situation for some bereaved families who have no food or shelter. However in this study, all child participants and their caregivers were assisted by the social worker to access foster care grants (Demmer, 2005).

One of the other official initiatives that could clearly impact on poverty is the social security system. Many people are eligible for, in particular, Child Support grants, disability grants and old age pensions (often all three are referred to as pension by community members). Many of those who are eligible for these grants are not accessing them. Given the high dependency on social grants, barriers to accessing social welfare grants as a result of the lack of documents (such as birth certificates, death certificates and identity documents) appears to be compounding these problems. Research commissioned by the Finance and Economics Directorate of the Department of Social development (Samson, Lee, Ndlebe, cited in Sewpaul, 2005) and produced by the Economic Policy Research Institute (EPRI) reveal that social grants, even in its means-tested form, play a crucial role in alleviating poverty and in promoting social development. According to the EPRI(cited in Sewpaul, 2005), the partial means-tested grants closed the poverty gap by 23% and it excludes those poorest households that do not have members receiving UIF, state old age pensions, disability grants or children qualifying for grants. Even with full uptake of the existing grants, for those who qualify,

it will reduce the poverty gap by only 36%. With universal coverage a BIG would close the poverty gap by about 74% (EPRI, 2001).

Despite the limitations in the delivery of services the study shows a remarkable dependence on any form of social assistance. All households in this study depended heavily on social grants.

6.7 Disclosure

As in Demmer's (2005) study, participants (informants of helping organizations) commented that it was difficult to get people to share their feelings about loss. One main explanation was that the Zulu culture is such that people are not encouraged to talk. Furthermore, some don't have the luxury of grieving due to multiple losses experienced. What is happening is that instead of grieving, people are worrying about how to bury the next person. Another informant in Demmer's study commented that in the African community, it is very rare for somebody who has lost a loved one to go to an outsider and talk about grief. People often felt guilty that they were still grieving after the funeral but they would not seek help. Another observation was that children are usually kept in the dark about what was going on in the family, in terms of who was sick and even about who had died. Children's feelings are rarely explored. Often, they were not even told that their parent had died.

A key finding is that, while many orphaned teenagers desire direct communication with adults about parental illness and death, adults themselves, whether it is the sick parent, other relatives in the household or a caregiver are often ill-equipped to identify and manage children's distress positively. The reasons given for not talking to children in Marcus's (1999) South African study were that children would be upset, would not understand, would not know how to cope and would not benefit from knowing. that her Children are frequently excluded from discussion about both the imminent and recent death of a parent, on the grounds that death is only an appropriate topic for adults to

discuss. The idea that ‘children are too young to understand’ is almost universally accepted as a valid reason for ongoing silence regarding parental death. In this study, parents never disclosed to their children that they were HIV positive. Only one parent disclosed to her child. Out of the eleven child participants, five were not informed immediately of the death of their mother.

The excerpts below capture the varied reactions of the participants:

Vinah explains this about Thabiso:

‘Before the funeral when I told him that his mother was sick with this disease...HIV. He ran away. I was afraid that he may hang himself as (but) he was there with relatives’.

Basanda responded:

‘They passed away because of AIDS. My aunt told me. I was sad; they didn’t tell me anything when they were alive. I was young but I needed to know the truth’.

When Primrose was questioned whether she was aware of the cause of their parents’ death, she responded:

‘They were HIV positive’.

When asked how she knew, she responded:

‘My mother asked me to come to her bedroom, I come and she tells me that she is sick, and then I said why? She said my father came with this disease. Because my mother was always staying with us everyday’.

When Penelope was asked whether she was notified of her mother’s death, she replied:

‘No one actually. All I remember was that we were all sitting in the same room and my other aunt wrote a letter to the uncle. She didn’t want to speak because we will hear. She wrote a letter and gave to the uncle telling that our mother has died. My brother took the page that she wrote the letter and traced down the words’.

In Sisanda’s case she was not aware of her mother’ death.

‘My granny didn’t tell me that my mother was dead. She called the funeral car, I was playing with my two cousins and they took her away. I went to my granny and asked her what was going on. She was crying and wearing a black thing over her head. I asked her what was going on. She didn’t tell me’.

Nqobile's caregiver did not notice any changes in Nqobile after her mother's death. She indicated:

'She knew her mother died and she knew her mother was sick and going to the doctor'.

Not much attention is given to the child's psycho-social well being as defined in Western terms. In times of dire need as long as the child is cared for physically, it is assumed that that is all the child needs. Nqobile's caregiver related:

'There was no one to care for her. When I got her pension, I put it in the bank in her name. When I die that will be her savings'.

In other cases the caregiver is at a loss of how to comfort the child. Stembile's case is particularly unique in that her siblings were placed in her care. She had to cope with the stress of her own grief of losing her mother and that of comforting her siblings. Her story shows her helplessness: When asked whether the children were affected by the death of the mother, she replied:

'Very much! Mbali she was so young, she cried so much. We were all affected. Even after that, months after that and shame she did (she was infected) and we were staying alone here .It was so difficult, I just told her to stop crying , even at night, she used to wake up .I used to wake up and she was crying, I tried to comfort her like sometimes I didn't know what to say'.

Daniels, (cited in Louw, 2005), argues that the failure to discuss death and dying with children is expedient avoidance behaviour on the part of adults, designed to avoid the difficult and frightening task of explaining death to children. Brouard (quoted in Stein, 2003) also suggests that lack of disclosure has less to do with the need to protect children than the need to protect adult caregivers. Preparing a child for the death of a parent is very painful for everyone concerned. The most important benefit is that it gives the child and parent time to share what they need and want to share. This may well be the basis for healing after the death of the parent (Mallman, 2002).

In none of the eleven cases presented in this study was there any preparation for the death of the parent in respect of parent-child time to share and want to share. In the cases of Penelope, Mbali, Thabiso and Aletta, prior arrangements were made with relatives to care

for the ones remaining behind. It is assumed that designating a caregiver will be all the psycho-social support the orphan will need. In all eleven cases there was no preparation for the death of the dying.

6.8 Conclusion

The findings in this study and my broader working experience in the field reflect that in its intersection with other factors, in particular HIV and AIDS, poverty deepens, entrenches and sustains oppression in this community under study. AIDS-related deaths push many poor households over the edge into deeper poverty, forcing the bereaved to desperately find ways to sustain themselves and other household members while simultaneously coping with the pain of their loss. The high prevalence of AIDS-related deaths has major social and economic consequences for South Africa. On the micro level, individuals, households and communities are being pushed to the limit trying to cope with the economic implications of losing a breadwinner to AIDS, and the government's continued expectation that households and community members take care of one another is unreasonable. Women, children and the elderly are bearing the brunt of AIDS-related mortality and government assistance for these vulnerable groups is inadequate.

Secrecy and stigma dominate the South African landscape and not surprisingly most participants were unable to openly share their grief with others and to disclose the cause of death of their loved one. Because of fears of being ostracized by others, the bereaved in South Africa may have to censor their interactions with others and mask the truth, so that others do not have to deal with the reality of HIV and AIDS. It is indeed unfortunate that we have a culture where both the dying person and their loved ones are commonly denied the opportunity to be honest with one another- even at the end of life.

Despite these factors, the child participants showed resilience in coping with adverse circumstances. Various resilience factors are discussed in the next chapter.

CHAPTER 7

FACTORS CONTRIBUTING TO CHILDREN'S RESILIENCE

7.1 Introduction

HIV and AIDS has impacted severely on children. The difficulties experienced by children are increasing dramatically as the epidemic matures and adult deaths mount. Despite the factors discussed in the previous chapter, the child participants showed resilience in coping with adverse circumstances. Researchers have defined resilience as the human capacity to face, overcome and be strengthened by or even transformed by the adversities of life and the ability to bounce back after stressful and potentially traumatizing events. Resilient children are generally better able to cope with life adversities (Demmer, 2005).

The literature suggests that despite exposure to the major psychological risks, approximately thirty three to fifty percent of children who have grown up in circumstances of substantial disadvantage, appear to have overcome the statistical risks to become adaptive, functional adults (Masten, 2001). Amongst these risks are extreme poverty, experience of parental death, multiple and insecure attachments, and exposure to various forms of violence.

In South Africa AIDS has left many children without parents. The loss of a parent has profound significance for a child. The death of a mother, in particular, has dramatic psychosocial consequences. Children lose love and nurturing, and their households may break up, with siblings sent to live with different members of the extended family. Loss of a father often means loss of income and results in economic deprivation (Hunter and Williamson, 2002). However, as Masten (2001) noted even in circumstances of extreme adversity, many children demonstrate remarkable resilience.

From the data analyzed in the current study, it is evident that of the eleven child participants, ten displayed resilience. This was evident as follows:

- Their ability to express their emotions, sometimes painful emotions during the interviews.
- Objective evidence of good academic performance, in the form of school reports.
- Good social networks in the form of good friendships and peer support.
- Relationship with significant others, like their siblings, aunts or educators.

One child participant displayed resilience to a certain extent. She was performing well at school, had a good social network in the form of friendship and a significant other, but was very emotional and cried during the interviews. Various resilience factors are discussed in this chapter.

7.2 Stability of the Household

A significant source of resilience was having an attachment figure, at least one reliable adult from whom a child could gain security, food, a stable home and a predictable routine. There was a high prevalence of migrant labour and children are often cared for by other family members, other than their caregivers. In this study, all the child participants drew a sense of strength and comfort from knowing that there were family members who would take care of their material needs. If a child has more protective processes, then this child would be less likely to become distressed or dysfunctional despite being in adverse circumstances. The most significant protective processes include access to social support and the ability to seek and receive physical and psychological comfort and support from other people.

The most frequently identified protective processes include those that originate within the child's microsystems (Bronfenbrenner, 1986). These include the child having primary caregivers with whom he or she enjoys positive secure attachments that are characterized by mutual feelings of emotional care and support, firm discipline, predictable routine and general stability. Other features that characterize helpful microsystems are clear, open and honest communication that enables expression of feelings to avoid

misunderstandings and conflict. Beneficial microsystems also offer children good role models and clear value systems.

7.3 Family Support

The family is the first environment in which a child experiences love and affection and makes discoveries. Families provide the basic framework for a child's development and have an enormous impact on a child's resilience. The family provides the child with a sense of belonging and an identity. Families have common roots and ancestors and similar system of values, rules and norms. Families usually share cultures and religions. Most families are bound together by trust, solidarity and support for one another (Mallman, Silke- Andrea, 2003).

Most children make their first social contacts and experience unconditional love in the family. Healthy family relationships are the best environment for a child to develop resilience. Family characteristics that contribute to resilience include a consistent nurturing relationship between at least one parent, older sibling and another adult. Consistent parental supervision tempered by predictable rules and balanced discipline; emphatic understanding of the child as a unique individual; an open system of communication in which problems and planning for the future are shared and cohesiveness amongst family members (Geballe & Gruendel, 1998). Growing up with extended family, especially grandparents have become normalized in the African Black community, not only on account of the death of natural parents. Natural mothers generally leave their children with grandmothers and migrate to urban areas to seek employment.

Effective social support from outside the family is also critical to promote resilience. For children, effective social support means relationships with caring individuals in whom they can trust and feel safe to express their emotions. Such support includes friends, church leaders or teachers (Geballe & Gruendel, 1998). The children's own internal coping abilities can be strengthened, by providing them with opportunities to distance themselves from what is going on in the immediate family and with mental health

support, problem-solving skills, positive outlets for physical energy and emotional expression . Promoting stability and consistency in the child’s environment at every opportunity is of paramount importance (Geballe & Gruendel, 1998).

All the child participants had strong support network mainly in the form of family (aunts, grandparents and siblings) and peers. If linked to the social ecological model, the family can be regarded as the child participants’ microsystem. All the participants also had a good circle of friends and at least one close friend whom they could confide in. The following is an indication of strong family support that is inherent in the lives of every child participant. Thabiso responded:

‘Whenever I am feeling sad, I talk to my granny. I usually do not remember my mother a lot because my grandmother has covered that space’.

Thabiso further related:

‘I can’t feel that my mother had passed away’.

Thabiso had good relations on both sides of his family, maternal and paternal. He spent holidays with his paternal family. He also had a good circle of friends. He responded:

‘They (paternal family) told me that when I finish writing, I must go (come to them); they would teach me to drive’.

‘I got only good friends. When I’m studying, I get help from them. At home, we play soccer. At school, we walk around and buy something to eat’.

Brenda indicated that she considered her sister as assuming the role of her mother and she shared the following:

‘I talk to her like she is my mother...ya she do everything for me and she try to make sure that I got it if she can afford it’.

Brenda had one special friend that she confided in. She also confided in her older sibling. She also had strong peer support in schoolwork. When asked what she did if she didn’t understand anything, she replied:

‘I go to someone else in class and ask him or her if she/he understood what has been taught and then tell them to help me’.

Basanda also had one special friend and was usually in the company of boys from her class. She also confided in and sought advice from her elder sister. During the loss of her parents, she had her relatives comforting her; her aunt and grandmother provided financial support.

Penelope related:

‘I have five friends in school, at home, my brother is my friend’.

Penelope also describes her emotions at the funeral of her mom:

‘ I felt alone but then again there was my aunt and I knew I could count on her’.

Darius also considered Penelope (his sister and one of the child participants) to be his best friend and he confided in her. He also has a lot of male friends with whom he played soccer and music with. He also shared a strong bond with his aunt. He stated:

‘She is like a mother to me. When there is something I need, I go and tell her and she helps me. When I’m sick and sleeping in my room, she would say my sister to wake me, she has some pills to give me’.

Mbali also had one close friend but when asked who she confided in if she had a problem, she replied:

‘I talk to my sister. Sometimes I miss my mother but my sister is nice’.

Mbali considered boys to be rude.

Sisanda related that she had one close friend and replied:

‘She is my best friend who I tell my secrets’.

Sisanda also considered her caregiver as her mother.

‘We are close and I talk to her if something is troubling me’.

Nqobile had a support system in the form of her grandmother, her grandmother’s friend and her cousin.

7.4 Good School Environment

After the family, school is the most important factor in a child's life. As a child grows up, more and more time is spent at school in the company of friends and teachers. Schools do not only teach children about reading, writing and arithmetic. They also look at the whole child and focus on cognitive development (that is, the acquiring of knowledge and skills), while at the same time emphasising the social and emotional development of the child.

It is very important to develop the social and emotional development of students. Many children come from single-parent homes, or homes in which there is no parent. Elderly relatives or siblings may raise children. In homes like these there is often not enough emphasis (if any) on the social and emotional development of the child. In this situation, the development of resilience takes place primarily in the classroom and in the community (Mallman, Silke- Andrea, 2003).

Significantly, in this study, attending school was identified as the most important thing that the children liked about their lives. Most of the child participants reported positively on their schooling experiences and indicated that they had support from their educators. Our data does indicate that some teachers (albeit a minority) showed authentic instances of care and support to some of these vulnerable participants. At times, various demands were made on teachers by the learners, parents and the community around issues of violence, abuse, poverty, orphan hood, teenage pregnancy and child abuse for which they have no formal training. This work is often unrecognized, not credited for or taken for granted.

Several factors were identified by the children as facilitating learning. These included facilitation by the educator (the teacher explaining content and allowing questioning), some learners (child participants) actively asking the teacher for assistance if he/she did not understand. Peer group discussions, reading, reviewing work and doing homework, was also identified as facilitating learning. It would therefore seem that creating an open learning environment in which participation and asking questions are encouraged is

beneficial. The schools also provided opportunities for the children to participate in extra-curricular activities. If adapted to the social ecological model, the school can be regarded as the child's mesosystem.

Some child participants reported that some teachers were aware that they lost their parents and were very supportive. They identified these educators as possible adults who could help them in the absence of their parents.

Thabiso related the following about his class teacher:

‘The teachers sympathized with me and my class teacher told me that I must talk. Even if I didn't have money, she gave me’.

When Thabiso was asked about what he liked about school, he responded:

‘The kids (children) are disciplined. We respect the teachers and they also respect us’.

Two child participants reported that the school also engaged in extra lessons to complete the syllabus. However, two reported of teachers not attending school regularly, or if they were at school, they were not teaching and were just relaxing in the staffroom.

All reported that they enjoyed and looked forward to attending school and all reported on regular school attendance. Of the eleven participants, nine of them walked to school, usually long distances and two of them utilized public transport. Despite their personal circumstances, all the child participants participated in some form of sport or extra-curricular activities. Thabiso was a boy scout and formed part of their debating team and Tsepo participated in drama at school.

Another factor, which was identified as promoting resilience and coping, was having friends who could help one to forget or be distracted from negative experience. The child participants claims about performing well academically, attending school regularly, participating in extra-curricular activities and being respectful was collaborated with recordings and documents (such as certificates of achievements) in their existing case files, regular school records and the views of their respective caregivers.

7.5 Relationship with the Deceased parent(s)

Open communication about the illness and death is essential. The child affected by AIDS will need to communicate thoughts and fantasies about the death of the parent and to express feelings of anger, guilt, sadness and loss. The child needs to receive accurate information in order to dispel misconceptions (Geballe & Gruendel, 1998). As Dane & Miller (cited in Demmer, 2005) noted, the intensity of the grief reaction is directly related to the degree of closeness between the person and the deceased. Most participants drew strength from their lost bonds with the deceased.

In this study, the majority of child participants were excluded from being communicated about the illness and death of their parents. There is the possibility that on death these children idealized their relationship with their natural parents and they constructed very positively after death of their parents. Of the eleven participants, seven participants were residing with their natural parent(s) prior to the demise of the parent(s). Two participants were abandoned by their mother at a very young age; one was neglected and the other was not residing with her mother due to work commitments. What was interesting was that most of the participants talked about their relationship with the deceased not only in terms of the emotional bond they had with them but also how helpful the deceased was, prior to their death, in giving them money, shelter or helping them around the house.

When Sylvia was asked what she missed about her mother, she replied:

‘I miss her shouting. Sometimes she would put you down for something you did, like the clothes that I wear. My mum thought me to behave as a girl, she thought me to cook, and there is nothing I don’t know about work at home’.

Primrose added the following about her parents:

‘Sometimes when I come from work, I feel like I can go and sit at the grave, I feel like talking to them, I miss them so much. It is so painful (to lose them). My mother was like a friend to me, she used to give me advice’.

Penelope said this when talking about her mother:

‘I miss her so much. The emptiness will always be there. I don’t feel it so much now. I accepted that she is gone’.

Darius related:

‘I miss my mother. When I want something, she used to buy it, do everything for me; she would greet me when I go to school. She liked me. She didn’t come home without anything for me’.

When Mbali was asked what she remembered about her mother, she replied:

‘She used to shout a lot. Maybe someone does something wrong especially with my sister, she would defend her’.

When Stembile was asked what she remembered about her mother; she replied:

‘She was strict. If you did something wrong, she would shout for days, she would remind you of what you did. She was caring; she didn’t have enough, but she tried. I do miss her’.

7.6 Future orientation and Goals

The personal goals and aspirations of the child participants also appeared to promote resilience and inner strength. Even at a young age, many were already nursing ambitions about career and employment prospects. Furthering one’s education and getting a job were top priorities.

Thabiso’s caregiver indicated:

‘Thabiso says that he wants to be a doctor. He wants to see this disease (find a cure) for this disease that killed his mother’.

Brenda’s desire was to become a social worker because she wanted to try to help people.

Penelope indicated:

‘I have journalism in mind or maybe I want to be a paramedic. My first choice was to be a radio DJ, but I’m not sure whether I would be able to get a job easily’.

Her brother, Darius, dreamt of being an actor, he responded:

‘When I read about the celebrities and the money that they earn, that encourages me to do more work, my schoolwork (work harder in my schoolwork)’.

When Mbali was asked what her plans were after she finished school, she replied:

‘I like to be an architect, somebody who designs houses’.

Basanda shared the following:

‘I think I want to do acting. I like acting. In fact, I wanted to be a social worker or an electrical engineer, but I changed my mind for some comedy, I like acting’.

When asked what she liked to be when she finished school, Aletta expressed:

‘I want to be a scientist. I want to help people’.

Nomfundo related that she liked to be a teacher, whilst Nqobile indicated that she wanted to be a doctor. Nqobile stated:

‘There a too many people at the hospital, I like to help them’.

Clearly the goals of most child participants were quite grandiose. But it was these dreams and hope for a better life in the future that kept them going each day.

7.8 Conclusion

The participants in this study typically contained their emotions in response to their loss and kept their grief to themselves and tried not to dwell on it. The factors mentioned above assisted the child participants in dealing with the challenges and hardships they encountered. Resilience should be encouraged and developed in all children. All children are born with the potential to be resilient, but resilience has to be developed, like other skills and capacities.

In the next chapter, I discuss the resources available to the participants, the views of the caregivers of the child participants and what motivated the caregivers to take on the care giving role.

CHAPTER 8

COPING AND SUPPORT

8.1.1 Introduction

At its most basic conception, coping implies adaptation by an individual to demands. Coping is framed as a process of interaction between an individual and an environment, each with its own set of resources, vulnerabilities, potential and needs. Coping is what people do when they successfully manage transactions with their environment (Donald, Lazarus & Lolwana, cited in Demmer (2005)]. Most people who experience the loss of a loved one are able to cope with bereavement without major long –term physical and mental health consequences, and only a small portion of the bereaved suffer serious consequences that require assistance from professionals (Parkes & Bonanno et al, cited in Demmer, 2005). But individuals who are bereaved due to AIDS confront additional burdens like stigma, lack of social support and poverty. With so many people bereaved on account of AIDS in South Africa, it is important that we try to understand how they cope psychologically with their loss.

8.1.2 Coping with AIDS-related Loss and Grief

The key question is how did the participants in this study cope? Confronted by poverty and an environment that was unsupportive to those affected by the disease, the participants focused on daily survival needs, suppressing emotions and relying on inner resources (constructing meaning from the loss and relying on religious faith). Caregivers were preoccupied in trying to survive on a daily basis and to feed, clothe and shelter their family, so all their energies were devoted to this challenge. At the same time, another response was to suppress emotions, so that participants could focus on daily survival or alternately because it was too painful or because there was no-one to share their grief with. Because of little help being available, participants obtained comfort by relying on

their religious faith to help them understand their loss as to draw strength from it. The question of whether it is good to suppress one's emotions in response to stress is highly controversial. It seemed to make sense why many participants suppressed their grief to varying degrees so that they could focus on their daily survival needs. Lindstrom (2002) approach was that we should not pressure the bereaved individual to work through their loss nor should we tell them to completely avoid it. There were also some indications from participants in Demmer's (2005) study of AIDS-related bereavement in South Africa that grief and mourning was supposed to end after the funeral. It was difficult to determine to what degree participants suppressed their feelings about their loss because of cultural norms, or to avoid dealing with the pain, or to enable them to focus on more urgent daily stresses. A dominant means of coping for the participants in Demmer's (2005) study was to suppress their emotions, and this was mainly in response to the perceived lack of social support and the daily struggle to survive.

Just as in Demmer's (2005) study, most participants in this study were unemployed and poor. Grief and bereavement took a back seat as the more pressing need was addressing the physical needs of children. In a sense, grief was a "luxury" in marked contrast to studies in the West, middle class bereaved gay men, who lost partners to AIDS. Several participants experienced increased economic hardship both before their loved one died as well as after (Demmer, 2005). When considering all the stresses that participants endured in their lives in a context dominated by multiple loss, lack of support and poverty, one wonders how they and many others like them in South Africa are able to survive and be resilient. Bonanno, cited in Demmer, 2005: 20) defined resilience to loss and trauma as:

‘...the ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially highly disruptive event, such as the death of a close relation, to maintain relatively stable, healthy levels of psychological and physical functioning’.

It is essential that more comprehensive research be done in the future that specifically explores the notion of resilience among people who survive multiple AIDS-related loss in the midst of extreme poverty and a host of other stresses.

In their meetings with me, participants had the opportunity to share their feelings, for most it was the first time in a safe and non-judgmental atmosphere, and it demonstrated to them the value of receiving comfort and support from others. I came to the conclusion that participant's tendency to avoid dealing with their emotions or talking about it to others was a reasonable response considering the context in which they lived, where there were few opportunities to receive kindness and support from others. This was probably the first time that participants were able to talk to someone about their loss. It is important for the bereaved to express their feelings to someone they could trust. Participants felt that if they had the emotional support from others, they would have better able to cope with AIDS-related loss and grief.

8.1.3 The Ecological Framework for Addressing Bereavement

AIDS is the leading cause of death in South Africa and the intent of this study was to shine a spotlight on children who grieve AIDS-related deaths. Among the many issues that social workers are confronted with in the local context is the issue of how to respond to the needs of those bereaved by AIDS. It is imperative that AIDS –related bereavement be understood in terms of the complex social, political, cultural and economic factors inherent in South African society, and the strategies to assist the bereaved address these factors. The social ecological approach provides a useful framework for addressing the needs of individuals bereaved in South Africa. Social ecology is an appropriate framework because of its holistic view of the individual and its emphasis on macro-level changes as well as empowerment, self-help and mutual support.

The concept of ubuntu has become entrenched in the South African government's welfare policies. The White Paper for Social Welfare (Department of Social Welfare, 1997, p. 17) stated that: 'Ubuntu means that people are people through other people'. It also acknowledges both the rights and the responsibilities of every citizen in promoting individual and societal well-being. This means that the person exists in the context of the community and the emphasis is on caring for each other's well-being and fostering

mutual support. This caring ‘stems from as deep a regard for other human beings as for oneself’ (Sewpaul, 1997: 6). The ecological approach embraces a similar view with its “person-in-the-environment” philosophy and its focus on reciprocal relationships between people, with the environment, and with the various systems within the person’s environment.

8.2. LEVELS OF SUPPORT RECEIVED BY ADULT CAREGIVERS

In Demmer’s (2005) study participants felt that there was little help of any kind, financial and emotional, available to those dealing with the consequences of an AIDS-related death. They had minimal expectations of the government and NGOs, and the same was true for the family members, neighbours and others in their community. So basically they were left on their own. Again in comparison to the developed countries like the US, the bereaved could take advantage of a host of social and psychological support services provided by AIDS service organizations, private practitioners and other NGOs.

8.2.1 Social Support

In Demmer’s (2005) study, some participants were fortunate to have somebody who they were able to confide in, whilst some belonged to a support group for people with HIV/AIDS and they gained support from this venue. Whilst other participants felt that they did not get much support for their grief, from family members, friends or neighbours. Most participants reported feeling lonely.

Participants in this study were asked about the extent and quality of social support received from family and friends after the loss of their loved one. Some were fortunate to have people, someone they could confide in.

When the participants were asked if they received any support from family or friends, their responses were as follows:

Dorica responded:

‘If there is a problem, there is my sister I talk to’.

Vinah replied:

‘I talk to my husband and my last born (youngest daughter)’.

Primrose responded:

‘I got an aunt; she likes to help as she doesn’t have children’.

Stembile responded:

‘I talk to a friend; she does help me and give me advice’.

Venice indicated:

‘I have no friends, just neighbours. My friend is my mum’.

On the whole, some participants felt that they did not get much support for their grief, from either family members, friends or neighbours. When the participants were asked if they received any support from family or friends, their responses were as follows:

Noxolo responded:

‘No support, nothing. My sisters are people who are very wild and cruel. Only if I have a nice job, they come to me for help’.

Stembile replied:

‘I don’t like to sound that I’m bad mouthing them (talking ill of them) them, but no-one really supported me....they didn’t really’.

Sylvia responded:

‘None from the family (I received no support from the family)’.

Stajdahr (1997), (as cited in Demmer, 2005), conducted in-depth interviews with family caregivers of people with HIV/AIDS in Canada. A theme that resonated amongst these caregivers was the importance of social support. Participants complained about the unsupportive interactions with other family members as well as professionals such as

physicians, nurses and social workers. The participants felt that supportive networks could have aided them in making sense of their loss.

8.2.2 Spirituality

The majority of participants relied on their faith both as a way to understand their loss experiences as well as draw strength and comfort from it as they coped with life without their loved ones. The participants identified religion as a significant resource. There was a tendency to believe that everything was in God's hands and that He knew what was best. Their religion or faith provided a lens to view the world around them and assist them in dealing with the challenges and hardships they encountered.

In Demmer's (2005) study several participants commented that they could not be angry with God and believed that He did not wish for them to have regrets. Some totally turned off religion upon their loss. Richards and Folkman (cited in Demmer, 2005) conducted a study among 125 gay men using open-ended interviews within a month after the death of their partner. More than half of the bereaved participants made explicit references to spiritual phenomena in their narratives. Just as in Demmer's (2005) study, in this study it was evident in their discussion of spiritual beliefs, experiences, and rituals that participants adopted a spiritual perspective to help deal with the impending death of their loved ones. This spiritual perspective was considered to be a primary source of emotional support for these participants, helping them create positive meaning during a time of intense grief.

All the caregivers in this study revealed that religion played an integral part of their lives and the majority of them were regular churchgoers. Two caregivers could not attend church sometimes due to work commitments. They also read the bible regularly and instilled in the children strong religious values. Some of the child participants were actively involved in Sunday school and church youth camps.

Some of their responses to spirituality were as follows:

Primrose related:

‘I used to cry and ask God why they are doing this to me’.

Vinah expressed:

‘I feel very bad, but I asked God to help me’.

Sylvia reported:

‘We are the people going to church. What I like most is that while she (Brenda) was small she believed in the Lord. What I pray for that she must continue with that’.

Sylvia thereafter added:

‘But it is nice to be a parent, specifically if you believe in the Lord to help you with the children’.

Venice responded:

‘No darling, I have no problems, I pray to God to help me’.

She further added:

‘Sisanda goes to church every Sunday and we also read the bible’.

Vinah revealed the following about Thabiso:

‘He listens to me; he goes to church, Sunday school. He loves Gospel’.

For Brenda, strong religious convictions permeated her choices and beliefs. When asked what her idea was of a good partner, she replied:

‘Someone who loves Jesus, I think I can have a nice life with him. If I chose a Christian, a real Christian, not just a churchgoer, I know that I’m in good hands’.

Celebrations such as special meals at Christmas, spending time on the beach on Christmas Eve, observing rituals were also seen as important times of happiness, celebration, and of building resilience. Often gifts of food or clothing given by the caregivers to the children were seen as the happiest moments in the children’s lives.

8.2.3 The Impact of the Welfare System

In Demmer's (2005) study, participants voiced opinions about the quality of social welfare services provided by NGOs and the state welfare department for people affected by HIV/AIDS. Although they felt that there were enough local organizations available to assist people with HIV/AIDS in Durban and surrounding areas, many participants did not regard them very highly. A common perception was that local organizations were only in it for the money. Most participants felt that organizations did not work together.

According to Demmer (2004) the South African Welfare system was unable to adequately meet the basic needs of those suffering from AIDS and their families. Many individuals, including children, who were trying to cope with their loss, must summon the energy and determination to embark on the often frustrating and draining process of applying for the minimal government benefits. It could take an extremely long time to process welfare applications. This could be a life or death situation for some bereaved families who have no food or shelter (Demmer, 2004). Scarce organizational resources, including inadequate staff, made it extremely difficult for providers to address client's emotional needs and to provide one-on-one services. Some NGOs had no trained mental health professionals like social workers or psychologists. Social workers can become overwhelmed by the plight of individuals and families affected by AIDS and they may experience frustration themselves at not being able to do more for them. A number of voluntary organizations serving those with AIDS and their families have emerged over the last few years, but they are also largely under funded and under staffed.

Fortunately, in this current study and at the time of the interviews, all child participants were in receipt of foster care grants, through the assistance of the social workers of the organization. Although the organization (Child Welfare, Margate) was under-staffed with heavy caseloads, social workers made a concerted effort to expedite the foster care process and ensured that their beneficiaries were assisted to access the necessary social grants. In relation to the social ecological model, Child Welfare, Margate could be seen

as an exosystem, instrumental in assisting caregivers to fulfill the basic needs of the child participants.

8.2.4 Social Security System

In contrast to many other countries in Africa, South Africa has a social support system which provides grants of various types to the people. Sewpaul (2005) in her critique of the Draft National Family Policy states that since 1994, the government has been significant efforts to ensure access to basic education, primary health care, water, sanitation, electricity and infrastructure development. The key anti-poverty strategy adopted by Government include the social security benefits granted on a means-tested basis; Poverty Alleviation Fund where its main purpose is job creation and the Flagship programme for unemployed women with children under five years of age, land distribution and rural development. Of these programmes, social security has been found to have the most significant impact on poverty reduction (Economic Policy Research Institute, cited in Sewpaul, 2005).

The various types of social security provided the main source of income sufficient in many cases to support an entire household (Ziervogel, Mukheiber & Van Niekerk, 2005). A significant proportion of the social security was essentially spent on food. This was followed by transport and medical expenses and for membership fees to various organizations. Five basic types of grants, listed in Table 5 are available.

Table 5: Available Grants from the State

Grant Type	Specification	Amount²	No of participants receiving
Child Support Grant	For children under the age of 14.	R240-00	5 caregivers
Foster care grant	For children who are orphaned or in need of care from caregivers other than their parents	R680-00	All 11 orphans
Disability Grant	For adults suffering from HIV/AIDS and other incapacities. Not all qualifying adults apply for this grant as there is a social stigma when an individual is known to be infected.	R 1010-00	1 caregiver
Old-age Pension	Seniors may receive this grant from the age of 60 for women and the age of 65 for men.	R1010-00	None
Care dependency grant	Awarded to children living with disabilities	R 1010 – 00	None

Unlike many sub-Saharan countries, South Africa has grant schemes for children, orphans, disabled and pensioners as a larger programme for poverty alleviation. Research reported, e.g. in Case , Hoosegood & Lund(2003) ; Triegaardt & Patel (2005) and

² These figures are documented for the South African State grant system as at April 2009.

Ziervogel et al. (2005) provided further insight to the significance of grants in the region. The child grant policy allows grants to be allocated irrespective of the household composition to which the child belongs (Triegaardt, 2005). Although a grant scheme for every child in the household brings opportunities to their families, the amount received is small. In most cases, a household's sole income depended upon the accumulated grant that they received through all of its members. Households had an incentive to accommodate orphans because of the foster care grants to which they are entitled.

In this current study, at the time of the interviews, the caregivers of all eleven participants were in receipt of foster care grants. The caregivers responded as follows, when asked how they were coping with the children:-

Vinah related:

“I’m right now; I’m getting the foster care grant”.

Sylvia indicated:

“My husband was not working but (because) the employer got sick, he had a stroke. My husband was staying at home. Then came the grant and everything was alright”.

Noxolo related:

“It’s better now that I get the foster care grant”.

Stembile responded:

‘When I didn’t apply for the grant, it was very, very difficult’.

Akhona replied:

‘Yes, I manage now, I am getting the grant.’

Dorica responded:

‘Yes, I manage now, before it was very hard.’

Orphans were also more likely than other children to be found living with household heads who had received no school education and/or who were currently unemployed, and were found disproportionately in rural, female, elderly, and adolescent-headed households. In the Kisesa Community Study in Tanzania (Urassa, Boerma, Ng'weshemi, Isingo, Schapink & Kumugola, 1997) households with orphans did not have a lower economic status in terms of off-farm income, household assets and physical structure of the house. Orphans seemed to be absorbed by households already containing children, making the households larger and the dependency ratio less favourable. They were also more likely to be female-headed with jobs in the lower strata of the economic scale. Other studies in sub-Saharan Africa had revealed that fostering households were not necessarily among the poorest in a community (Seaman and Petty, 2005; Senefeld and Polsky, 2005).

There was some evidence, nevertheless, of the increasing burden of orphan care becoming manifested in food security indicators. Of the eleven cases, nine child participants were in secondary schools with no support of the school feeding system at school. While households could manage to absorb one orphan without being impacted significantly, it appeared difficult to take on more orphans without affecting their livelihood. As mortality rates increased and the population of orphans continued to rise, more and more households were faced with the decision to foster more than one orphan or leave him/her to fend for him/her (Muthukrishna, 2006). More often than not, there was no support from the paternal side of the family and whatever little support was present diminished when the foster care grant was received as is evident in Basanda's case below:

Basanda relates:

'Granny give (gave) us food, I got aunty (an aunt) staying in Gamalakhe. She likes to help us because she doesn't have children. Yes, but not now, because we....getting the grant she has stopped'

The problem of financial support was exacerbated by unreasonable expectations by the child participants themselves when they became aware that their caregiver was in receipt of a foster care grant.

The case of Sylvia shows this:

‘Since they know they are receiving the grant, they demand sometimes, sisi, I want this, sisi this. But I talk to them and tell them that if they want something, they must say and then I would budget properly so they started doing that’.

Dorica added:

‘She wants money for everything in school; she wants to eat everything in school, because she knows that she got the money now’.

In Nqobile’s case, as was often the case when grandparents became the caregiver, consideration was given to what happens when the caregiver dies. Nqobile’s grandmother indicated:

‘When I got her pension, I put it in the bank in her name, when I die there will be savings for her’.

8.3 What motivated the caregivers to care for children orphaned?

For most orphans in this study, their fathers are unknown. Hence the death of mothers leaves them without any parent at all. Invariably, these children will need people to care for and support them, and guide them through life until they are old enough to care for themselves. One very important aspect of the care and support of children orphaned is knowing who cares for them after the death of their parents. African cultures have long been characterized by family and kinship networks that function as strong support systems in times of need. It is not uncommon for terminally ill urban family members to return to the rural home to die. With AIDS killing the most productive adult members of the households, elderly grandmothers in rural areas often take on the responsibility to care for their orphaned grandchildren.

In the community where the study was conducted, it was not uncommon for grandmothers to assume responsibility for their grandchildren upon the demise of their own children. However, in this current study, out of the eleven child participants, only two were cared for by their grandmothers. Hence the reliance on grandparents to provide care for the children after the death of their parents is not so prominent in this study.

Kinship care placements enable children to live with people that they know and trust. It supports the transmission of a child's family, cultural and ethnic identity; helps the child stay connected to siblings and helps the child build and retain connections to the extended family (Scannapieco and Hegar, 1996). It can be surmised that many carers care for children who have been emotionally or socially damaged by their circumstances. Kinship carers are expected to care for these traumatized children independently, with little professional assistance.

When Sylvia was asked what made her decide to care for her siblings, she replied:

‘There was uncles and aunty but they got their own families. You know that when you got no parents you may not get the right treatment from the other people who are caring for them. So that is why I had to take them. I stayed with the children who didn't have a mother’.

Noxolo (maternal aunt of child participant) reported:

‘When her mother died, nobody wanted to take her to their home’.

Stembile indicated:

‘You see when my mum was sick, she wrote a letter saying that I should take care and she trusts me to take care of Mbali and Loyisa’.

When Dorica was asked what motivated her to care for Nomfundo and her sibling, she responded:

‘I think it's my children, because her mother was gone when they were too small, so it's like my children’.

Thabisile indicated:

“While I was not got a child (I do not have a child of my own) because she is the first child between me and my sister. She always thinks I'm her mother. When I got money, I take her to the shop and take (buy her) what she wants”.

Akhona responded:

“There was no one to care for her. When I got her pension, I put it in the bank in her name, when I die, there will be savings”.

Noxolo responded:

‘My sister wanted me to care for her, it was her wish’.

8.4 The Views of the Caregivers (adult participants)

Caring for children, whether one’s own children or someone else’s children always comes with its own challenges. Caregivers of orphans have their own setbacks in the provision of care and support for orphans. The ability of caregivers to render effective care and support depends to a large extent on their own wellbeing, status and availability of resources. Just as Demmer (2005) reported, it was women in the current study who bore the burden of caregiving. The dominant feeling among participants was how difficult it was for them to take care of their loved ones with so few resources. Yet, they did so without hesitation. Few participants had any regrets about their role. When participants were asked about her feelings of caregiving, they responded as follows:

Sylvia responded:

‘It’s nice. What’s nice is that they listen and it’s nice to be a parent because usually children don’t listen, they trouble but these children are listening. If I talk to them I have time to talk to them even about relationships, especially the older one. But it’s nice to be a parent, especially if you believe in the Lord to help you with the children’.

Sylvia added:

‘What makes me not having a problem is that they are behaving, the children give me love everyday’.

Noxolo responded:

‘Yes, she is a nice lady. Since I am working, she does everything at the house’.

When Noxolo was asked what her difficulties were as a caregiver, she replied:

‘There is none and I am happy being a caregiver to the children’.

Stembile indicated:

‘I was confused. I know that my mum was sick and I had to come back. I don’t know, I think I was confused’.

When Stembile was asked how it felt being a caregiver to her siblings. She responded:

‘I used to get frustrated, angry all the time. I don’t know, I felt like it was too much for me. It was too much responsibility’.

Primrose responded:

‘Sometimes they are not nice, they don’t listen. I used to cry and ask God why He is doing this to me’.

Vinah replied:

‘Very good, he (Thabiso) is a nice child. He listens to me and goes to church, Sunday school’.

From the responses documented, it was evident that out of the ten adult participants (caregivers), two initially experienced difficulties caregiving. This could be attributed to the fact that they were siblings of the child participants and had to assume the role of a caregiver at a very young age and was unprepared for this role

8.5 Conclusion

Either unconsciously or consciously, caregivers typically contained their emotions in response to their loss, which was understandable considering the context in which they lived. In the face of scarce support of any kind and the struggle to survive, participants kept their grief to themselves and tried not to dwell on it.

On the other hand, this was a purposive sampling study and the participants were recruited from the caseload of the child welfare organization that I am employed at. Generally, social workers have a control function and there is a possibility that the

caregivers did not admit their difficulties for fear of the children being removed from their care or losing the foster care grant. However, I utilized the method of triangulation, where interviews were conducted with the child participants and their caregivers. Observational visits and analysis of case files was also done. All these allowed for a more holistic picture and hence the data was more reliable

A major weakness of research studies in South Africa was that few have paid attention to understanding social, cultural, economic and political factors and how they influence coping among individuals bereaved by AIDS, and this is a crucial area for future research.

It is evident in this study that the caregivers enjoyed their role as caregivers to the children and were happy to care for the children in their care. Whilst there are many positive reasons documented for kinship care placements, there are also drawbacks. Foster care grants is a more viable option and we, as social workers should advocate for foster care grants to be more accessible to more people.

Kinship care raises many challenges for the carers and the professionals that serve them. There are a multitude of factors makes it difficult for kinship carers to positively contribute to the healthy development of children in their care. Whilst economic support is a most pressing need for many kinship carers, support and parenting skills are likely to empower, restore their self-confidence in their roles as carers, and enable them to address these challenges. Kinship carers require educational and support services. This would be discussed in detail in the next chapter.

In the next chapter, I summarize the main themes that emanated from this study and provide recommendations and implications for future research.

CHAPTER 9

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

9.1 Introduction

The purpose of this chapter is to summarize the content of the research report and to make conclusions about the study of the life experiences of children orphaned on account of HIV and AIDS. The researcher would also make recommendations and implications for future research, policy and practice.

9.2 Summary and Conclusion

HIV and AIDS pandemic have devastated this country for the last two decades. South Africa has become synonymous with HIV and AIDS. It has become the HIV and AIDS capital of the world, having the largest number of people infected with HIV and AIDS (Demmer, 2005).

There is no disputing the fact that HIV prevention efforts in South Africa have failed; as evidenced by the increasing infection rate, resistance to condom use and negative attitudes toward those infected by HIV and AIDS. Whilst resources have primarily focused on HIV prevention efforts, comparatively little attention has been devoted to addressing the psychological needs of infected individuals and their loved ones, particularly with regard to bereavement issues. Whilst reviewing the literature, there has been little available research exploring the experiences of adults and children within the South African context with regard to bereavement associated with AIDS.

Although the current study focused on a small sample of children and their caregivers from an impoverished community in KwaZulu-Natal, and thus had limited generalizability, it nevertheless offers a new perspective on what it means to be bereaved by AIDS in the South African context.

In many research studies, the voices of children are silent or marginalized. Using a qualitative approach, this study captured the voices and experiences of children affected by HIV and AIDS and their caregivers.

Given the difficulties in conducting research with children, and in this particular study working with extremely vulnerable children on a particular sensitive topic, this study has enabled us to give voice to the children's perspectives on their lives.

This study created an opportunity for children to ventilate their feelings/ emotions for the first time in their lives. For most of the children, it was the first time that they were able to talk about the death of their parents and the first step towards therapeutic intervention. The study also facilitated the recall of positive memories of the deceased. It was somewhat difficult to get participants to share their feeling about loss and several reasons were offered for this. One explanation was that the culture (for instance, the Zulu culture) is such that people are not encouraged to talk about their feelings.

In this study, the interviews did produce varying degrees of psychological discomfort for participants. Some child participants shared painful experiences, due to the nature of the study. These experiences were addressed by me immediately.

In terms of my study, the ecological model is apt because a child affected by HIV and AIDS does not exist in isolation but in association with a number of other sub-systems within the environment. A parent infected with AIDS impacts on the child because the necessary primary support systems that the child needs may be absent or totally inadequate. The model is however limited in that it identifies what factors and relationships are necessary for the optimal development of the child but does not question what causes the absence or presence of these factors, nor does it delve into the dynamics of power that allows certain factors to prevail. The ecological model takes cognizance of the reciprocity and the mutually reinforcing influences of families and the larger socio-political, economic and cultural systems that surround them. Whilst the draft National Family Policy pays cursory attention to the impact of environmental factors on family life, it stresses that "the family is a powerful agent for political, economic, cultural and

social change”. Families are also subject to the powerful influences of socio-political, cultural and economic factors (Sewpaul, 2005).

In the general literature, when children are not linked to foster care, there are horrific cases of child abuse. The death of a parent is usually mitigated by other factors. Foster care placements involve an intensive procedure. As social work is a scarce skill and due to high staff turnover at non- governmental organizations(NGOs), a child may have to go through several social workers before being placed in foster care and actually receiving the foster care grant. From the findings in this study, it is evident that all child participants were happy and well adjusted in the care of their caregivers/ foster parents. This could be attributed to the social worker, who had a crucial role to play in conducting proper assessments and investigations of the families, expediting the foster care placement process, linking the foster parents to social security and rendering ongoing supervision and supportive services to the children and families concerned. From the findings it was also evident that the children were resilient and were fortunate to have at least one significant other to assist them with their loss and grief. Despite their circumstances, the child participants were achieving academically, in sport and other leadership roles.

On the other hand, this is a purposive sampling study and the participants were recruited from the caseload of the child welfare organization that I am employed at. It can be considered a bias study. There is a possibility that the participants wanted to present to the social worker that the placement was successful for fear of losing the foster care grant. Because they were service users, they reported positively and we may have received different results if an outsider interviewed them.

Most caregivers were unemployed or very poor, and emotional needs tended to take a back seat to the daily struggle to make ends meet. Under circumstances of dire poverty, grief and bereavement opportunity was a “luxury” (Demmer, 2005). Participants subjugated their grief in response to more urgent life stresses. Participants were pre-

occupied with trying to survive on a daily basis and to feed, clothe and shelter their families, so all their energies were devoted to this challenge.

It is now well established that the HIV and AIDS pandemic disproportionately affects women's lives both in terms of rates of infection and the burden of care and support they carry for those with AIDS- related illnesses. In this study, I find the phenomenon of absent fathers so startling. From the eleven child participants, only three participants were fortunate to receive emotional or material support from their father. One of them received financial support recently, after the death of her mother and the other two received support from their fathers prior to the death of the fathers. Hence, the women played a central role in caring for the sick as well as dealing with the aftermath of the death of their loved ones and caring for their children.

Being intimately involved with the community, the overall conclusion is that the plight of the children was not remarkably bad than that of the non-AIDS family. As a service provider in the community, the stories of these children quite reflected of children in other families, where there is death.

9.3 Recommendations

Emanating from the conclusions, I propose the following recommendations:

9.3.1 Addressing Grief and Bereavement

Given the emotional trauma of losing a parent to the pandemic, there is a dire need for bereavement counseling of affected children and their families. Apart from social workers being trained to provide the counseling, schools should become nodal points where such counseling can be accessed. Support groups and children's clubs should be initiated for these children.

9.3.2 Poverty Alleviation and the System of Social Security

As discussed in Chapter 6, poverty overshadows the lives of all the participants and a large portion of the South African population particular those affected by HIV/AIDS. The participant's emotional response to AIDS-related loss was frequently overshadowed by their daily survival needs (Demmer, 2005). Against tremendous odds, caregivers support their families. Poverty is becoming so normalized, it's like accepting abuse and oppression.

As Sewpaul (2005: 318) indicated:

‘ If external socio-economic, political and cultural factors are maintaining families in poor, dispossessed and helpless positions, how are such families expected to move towards independence and self-reliance within the same structural constraints?’

Fifteen years into democracy and there has been little change in the overall level of inequality that exists in South Africa (Nattrass & Seekings, cited in Demmer, 2005). The issue of poverty and unemployment needs to be seriously addressed by the government. Hope (2004) outlined four broad areas of policy for including Africa's poor in efforts to reduce poverty: (a) job creation and removing restrictions on the informal sector, (b) providing increased access to credit to finance small-scale enterprises and farming activities, (c) government need to allocate more money in areas of education and health and improving the access to the poor to health care, education and social services and (d) establish social safety nets through short-term income transfer. The emphasis should be on the creation of more skilled, relatively well- paid jobs and to promote education and training necessary for these jobs. Moutloug and Mears, (cited in Demmer, 2005), stressed the need for creating more employment opportunities. Sewpaul (2005) also makes this recommendation but predicts that increasing gainful employment of people is not likely to happen in the near future. The Draft National Family Policy (2005) relegates job-creation to the corporate sector thus supporting the notion that unemployment is a private issue. The development of infrastructure and the Government's Public Works programme are insufficient to create the required numbers of jobs.

Advocating a structural social justice approach to the problem of poverty in South Africa, Sewpaul (2005) proposes a second option which is a universal social security provision in the form of a basic income grant. In terms of poverty alleviation, focus should be on both, introducing the basic income grant and creating jobs. A BIG that addresses poverty in a developmental manner supports job-creating economic growth and increases efficiency of social service delivery. Research commissioned by the Department of Social Development (Samson et al, cited in Sewpaul, 2005) provides compelling evidence for the developmental benefits of social security, confirming that social security must be seen as an investment in people rather than a drain on the Government.

A BIG would help ensure that: 1) unemployed persons could undertake intensive skills training or education to improve their chances of securing work without worrying about their family's survival for the duration, 2) people could undertake higher risk job search involving expenditure, and 3) people's overall health improves (through better nutrition and the ability to access health services) which would enhance their ability to undertake demanding full-time work and undertake intensive job search (BIG Financing Reference Group, 2004).

I strongly maintain that the implementation of a Basic Income Grant for all citizens and the extension of the Child Support Grant for all children up to the age of eighteen would assist to alleviate poverty to a great extent. The primary purpose of these grants is to provide a regular source of income to caregivers living in poverty to assist them to meet the basic needs of the children in their care.

9.3.3 Encouraging Men to Play an Active Role in Care and Support

There is a need to shift social norms so that men feel more comfortable as well as motivated to play a more active role in the care and support of those that are ill with HIV and AIDS as well as those left behind.

Whilst there has been widespread acknowledgment of the burden placed on women in the HIV and AIDS pandemic, there have been few interventions that actually encourage men to become more involved in care and support activities. Men need to be made to feel more responsible. There may be several reasons why men have remained relatively uninvolved until now, including pressure to conform to traditional gender roles, not having the knowledge and skills and risking appearing ignorant, and being afraid that their involvement in care and support might lead others to think that they were HIV positive themselves (Peacock & Levack, cited in Demmer, 2005).

The Men as Partners (MAP) Programme in South Africa has demonstrated that it is indeed possible to get men involved in social issues. Launched in 1998 in eight of the nine provinces, the MAP works to promote gender equality and to reduce the spread of HIV and AIDS. The programme works to effect change through the following strategies: workshops, mobilizing men to take action within their own communities, lobbying with the media to promote changes in social norms, collaborating with various NGOs and advocating for increased commitment from the government to promote positive male involvement. Thus social workers have an opportunity to develop similar types of community-based interventions that encourage men to become more aware of and be better equipped to assist those infected and affected by HIV and AIDS (Demmer, 2005).

Fathers are a critical resource for children. Many fathers are the primary source of financial support for their children, but they are also an important resource in other ways—through the time and skills they bring into the household, through the support they provide to mothers and through their social networks. In the context of the AIDS pandemic, the father's presence, or at least involvement, is important also prior to either parent's death. If a mother is ill, the presence of the father could be a key supporting factor for the sick adult as well as the children. A more fundamental government intervention would be to take steps to close the income gap between men and women. Desmond (cited in Richter & Morrel, 2006: 230) argues:

‘The greater the income inequality between men and women, the greater the power men have over women. If, as it is assumed, men prefer more sexual partners, the greater the power men have, the more sexual partners they will

have, placing themselves and their partners at greater risk of infection. A distribution of income towards women, while maintaining the same average income for the group, would reduce the risk of the entire group by reducing the power of men within that group’.

Currently the burden of childcare falls on women. Even after a mother’s death it is likely that living fathers will not be present and that the role of caregiver will be taken on by a female relative. HIV and AIDS is worsening an already difficult environment for many children. The involvement of their fathers and other male relatives could go a long way to alleviating the damaging impacts of the HIV and AIDS epidemic on children.

The greater involvement of men brings with it greater access to income and other resources, as men, on average, have higher rates of employment and higher earnings. In addition to greater access to resources, higher rates of involvement by men in childcare, that is by both fathers and other men, in particular male relatives, increases the supply of household labour. There are indications that children who live with their fathers or with their male partners of their mother may be better protected than children who live in single women- headed households (Guma & Henda, cited in Richter & Morrell, 2006).

It is not always easy to reach fathers and men in families, but innovative strategies such as using sport, religious leaders and military can work. Initiatives to create family-friendly workplace include the following:

- Role models in the form of top management in the workplace
- Flexible working hours.
- Pay for performance and not time- employment contracts should be negotiated on an outcomes basis.
- Time-off for fathers to stay with an ill child.
- Father and family enhancement programmes. Such programmes enable fathers to cope better with work-life imbalances by interacting with other fathers and by acquiring coping skills and insights. This assists working fathers to cope in appropriate ways with accommodating work and family demands.
- Paid or unpaid paternity leave.

The time is coming when all responsible employers will develop and implement comprehensive and effective policies to support fathers they employ to benefit both employer and employee. Shared parenting is a child's right and countries need to do more to ensure that this right is fulfilled for every child. It is recommended that the government do their best to support men's roles in gender equity and care for children, and at the same time empower women. Specific actions need to be supported providing men with more opportunities for caring for their children.

9.3.4 Access to Anti-retroviral

Prior to 2004, access to ART was limited mainly to beneficiaries of medical schemes and individuals receiving treatment through workplace treatment programmes. Towards the end of 2003, the Department of Health announced a comprehensive HIV/AIDS care, management and treatment plan, which included the provision of ART to all patients attending public health facilities with a CD4+ count less than 200 or an AIDS-defining illness (Department of Health cited in Child Gauge, 2009). Although great progress has been made in making ART available in the public health sector, there is clearly still a large number of eligible individuals who are not receiving treatment. A wholehearted commitment by the government to a comprehensive roll-out of ARVs would help. Access to ARVs and adopting a healthy lifestyle with proper nutrition could prolong the lives of many infected with HIV.

9.3.5. Kinship /foster care/ cluster foster care

Within the formal child care system in South Africa, foster care is normally considered to be the preferred form of substitute care for children who cannot remain with their biological families and whose parents are deceased. This reflects the belief that the family is normally the environment most suited to the healthy growth and development of the child. Just as the participants in this study, many thousands of South African children have benefited from court-ordered foster care or kinship care. As documented in Chapter

Two, kinship care, foster and cluster foster care is considered as the most cost effective and viable option of care.

Kinship and foster care raises many challenges for the carers and the professionals that serve them. A multitude of factors makes it difficult for kinship carers to positively contribute to the healthy development of children in their care. Caring for vulnerable children is a highly skilled function and as such maximum support needs to be provided to caregivers. However, the State continues to formulate policies such as the White Paper for Welfare and the Draft National family Policy (2005) to foster self-reliance within families without taking into consideration the structural constraints families face (Sewpaul, 2005).

Whilst economic support is a most pressing need for many kinship carers, support and parenting skills are likely to empower, restore their self-confidence in their roles as carers, and enable them to address these challenges. Kinship carers require educational and support service. It is the responsibility of government to support families through appropriate policies. Families are not self-reliant and are dependant on a political, social and economic environment to support their caring functions (Sewpaul, 2007).

It is also recommended that a structurally balanced national family preservation programme be formulated. The programme should contract with foster parents from the outset ensuring commitment to the programme. This programme should embody direct counselling services to foster parents on the micro level, group support from other foster parents on the mezzo level and community awareness on the macro level. One of the core elements of this programme must be parenting skills. However, both foster children and parents need to be engaged as partners in this aspect of the programme to ensure effectiveness (Perumal, 2007).

Another core element of the programme would be to restore the status of families of origin by providing a Basic Income Grant to all poverty stricken families and/or extending the Child Support Grant. This financial aid must be balanced with a basic

finance management course in order to reduce financial stress placed on poverty-stricken families. Self-help projects would spin-off from this financial assistance with community development support to initiate and sustain income generating projects e.g. food gardens, poultry farming, sewing and arts and crafts projects.

Support groups are considered an invaluable source of providing short term emotional, informational and material support for carers. In these support groups, carers can socialize with others and share similar experiences and benefit from each other. Filial therapy is seen to have potential as a valuable intervention for kinship carers and the children in their care as it combines support and education. The kinship carers develop new skills that strengthen the relational ties between themselves and the children in their care. Carers are taught to create opportunities for children, through play, to work through some of their emotional pain (Petty, 2002). Social workers need to be trained in filial therapy in order to implement them with foster parents.

Another viable option of care is cluster foster care. This was discussed in detail in Chapter 2. Pietermaritzburg Child and Family Welfare Society have developed a cluster foster care scheme for children with HIV and AIDS. In terms of this scheme, potential cluster foster care (CFC) parents are recruited, screened and trained in home-based care, universal precautions and the management of AIDS-afflicted children. They are provided with a start-up pack of, *inter alia*, milk formula, clothing, toiletries and, in some instances, material support until the foster care grant is received. CFC parents are also visited monthly to offer support and to ensure that children are well cared for.

The concept of one foster mother caring for several children in a communal setting is used by at least two other CINDI partners, God's Golden Acre and Kenosis.

Colby-Newton, M (2006), conducted an evaluation of the cluster foster care system for orphans and abandoned children as it is implemented at three organizations in KwaZulu Natal, South Africa, including God's Golden Acre, the Kenosis Community, and the Pietermaritzburg SOS Children's Village. The main source of information for this study was provided by personal meetings with members of leadership at God's Golden Acre,

the Kenosis Community and the Pietermaritzburg SOS Children's Village, Through these interactions, it was found that the cluster foster care system is implemented in varying ways at the above three organizations and that there is some disagreement among child care experts in KwaZulu- Natal as to the benefits and validity of the cluster foster care system. This study concludes that further investigation is necessary to determine the value of the cluster foster care system.

Rehoboth children's Villages, situated on the Natal South Coast of KwaZulu Natal intended to initiate cluster foster care scheme. Their objective was to provide love and care for HIV positive babies and toddlers who have been abandoned in the hospitals on the KwaZulu Natal South Coast and who cannot be placed in foster care. The number of HIV positive babies being abandoned with no one to care for them was reaching alarming proportions. Instead of the hospital being their home, they attempted to create architectural designed home units for four children each with a foster mother. The unit would also function as a hospice in the last phase of the child's life. However, their vision did not materialize as the Department of Social Development refused to register them as a cluster foster care scheme. After meeting all the requirements, they were finally registered as a Children's Home, currently accommodating 60 children.

If managed appropriately and supported, cluster foster care is a more viable option where children are allowed an opportunity to grow up in a supportive family structure within their community. It is the role of government to create an enabling environment. Statutory placements must not be compromised. We should not abolish a viable system because of poor Government management systems. Cluster foster care is the most cost effective system and should be recognised and supported.

9.3.6. Models of Intervention

The incidence of HIV and AIDS in South Africa is increasing. The changing demographics of our society with young people, who would otherwise be economically active and productive members of society dying of AIDS, presents a major challenge to

the country as a whole. Of particular concern to the welfare sector is the number of children who are infected by HIV and the number of children being orphaned by the HIV and AIDS pandemic (Sewpaul, 2001).

Despite the well documented psychological and socio-economic consequences of HIV and AIDS, South Africa's government has failed to adopt a comprehensive approach that incorporates both management and prevention of the pandemic. In view of the government's inadequate response to the HIV/AIDS pandemic, it is not surprising that NGOs have taken the lead in responding to the direct needs of those infected and affected by HIV and AIDS, reflecting some innovative local responses to the HIV and AIDS challenge, including support groups for caregivers of HIV positive children (Veerasamy, cited in Sewpaul, 2001), empowering HIV positive women who have babies with AIDS to take on roles of counselors, educators and advocates (Sewpaul & Rollins; Sewpaul & Mahialela; cited in Sewpaul, 2001); and alternative community care models (Nielson, cited in Sewpaul, 2001).

Some of the models identified being implemented by Cape Town Child Welfare ; the Children in Distress (CINDI) project in KwaZulu Natal; Child Care communities, re-defining the role of social work and the use of volunteers, providing support services for caregivers, recruiting foster parents and linking foster parents to relief programmes.

The task of Child Care Committees included identifying vulnerable children within their areas; keeping a register of children orphaned on account of AIDS and child-headed households; identifying potential foster parents; supervising placements to ensure that the children receive adequate standard of care; maintaining a support network for families or foster parents or referring families for assistance.

Another project is the Thandanani Project in the Pietermaritzburg area of KwaZulu Natal, which also operates on the basis of Child Care Committees in each participating community, seeking to facilitate the development of sustainable community-based care for children in distress, particularly children affected by AIDS, by empowering communities to mobilize their own resources and lobby state authorities in their communities.

Although the extended family is seen as the main catch net of care, resources are limited. Communities must increasingly take on the responsibilities of providing care for children in the face of the HIV and AIDS pandemic. The government must facilitate this shift in responsibility developing an enabling and supportive socio-economic environment.

At a CINDI summit in July 1996, a four-catchnet approach was proposed: The first and preferred catchnet was the extended family of the orphaned child; the next best was the neighbourhood or community, based on structure such as the cluster foster care that enables children to remain in familiar environment; the third option was an enterprised-centred collective model, developed by a consortia of government departments , private sector and NGOs, like the SOS Children's Villages and the last option was institutional care. It has been widely understood that institutional care is expensive, generally impersonal and that it should only be used as a short- term emergency care (Sewpaul, 2001).

In the face of increasing number of children being orphaned on account of AIDS, the high costs of traditional residential care facilities and the Department of Social Development's call for the least restrictive forms of care, alternative care models have been developed. Nielson & Somnath, cited in Sewpaul, 2001, described the establishment and maintenance of community family care centres that provide children with a family life experience, in a context similar to that of their community; cater for the physical, social, psychological and spiritual development of children; provide children with a sense of stability and permanency and opportunities to develop long-term relationships within their community. These community family care centers have proved to be more cost effective than places of safety or children's homes.

Child Welfare South Africa also initiated a national programme, called Asibavikele (Let's protect them), to creatively respond to HIV and AIDS pandemic. The programme aims to reach orphans, vulnerable children and their families across the country. The national programme is currently implemented in 82 sites across the country, fourteen being in KwaZulu Natal. The overall goal of the programme is to facilitate and strengthen

community - based structures for the care and support of orphans and vulnerable children affected by HIV and AIDS in under- serviced communities, through the infrastructure of Child Welfare SA. Volunteers from the community are recruited, screened and trained to be deployed in the community to assist orphan and vulnerable children. In light of the scarcity of social workers, the programme has proved to be beneficial. Volunteers in this project are also trained to utilize “memory box”, to help mothers or caregivers to preserve their families, cultural heritage and communicate with their children long after their death. Women make a memory box with their children. It serves as a “keepsake” of family photos, letters, stories and history. Red Cross believes that this helps to diminish the trauma of a parent’s death and keeps the memory of their mother alive (Cheek, 2000). This is a simple and inexpensive strategy and would prove to be valuable in assisting children cope with their loss and grief.

Many valuable and creative models have been developed by NGOs. Many of the programmes were developed and sustained through the passion, commitment and dedication of individuals who believed in investing in individuals, groups and communities (Sewpaul, 2001).

9.3.7. Social Work Services

Social workers are at the forefront of addressing the breakdown of families. Whilst kinship care is not a new phenomenon, it is an ever-increasing one that this profession has to tackle. When kinship care placements are orchestrated with care, they help strengthen the quality of life for the children and carers involved. Social workers need to offer kinship care families opportunities to strengthen their reconstructed families and support to enable them to cope with the challenging issues intrinsic to these placements. Social workers should be trained in the didactic and dynamic model for assisting and empowering families in distress (play therapy/filial therapy). Social workers in South Africa also need to be more involved in policy-making and advocating for socio- political

and economic changes that will improve the lives of those infected and affected by HIV and AIDS.

In South Africa, social work staff turnover is high, especially in the NGO sector. Foster families may therefore be inadequately supported in terms of social services. (Briede and Loffell, 2005) It is not uncommon at an NGO like Margate Child Welfare, in the process of a statutory placement of a child, for that child to be seen by as many as three social workers.

9.3.8. Strengthening the Social Work Profession

These are indeed challenging times for those confronting the HIV/AIDS epidemic in South Africa, including those living with the disease, those who have lost loved ones to it, as well as professionals whose job is to care for those infected and affected by the epidemic. For social workers to be more effective in addressing the concern of those infected or affected by HIV and AIDS, some consideration must also be given to finding ways to increase morale among social workers and to strengthen their collective ability as a profession. Low morale within the social work profession is increasing. Low morale stems from the changed and uncertain role of social work within the new welfare system as well as low salaries and lack of respect from government for the contribution of social work to social development. Mazibuko and Gray (cited in Demmer, 2005) argue that the social work profession lacks professional unity and they recommend the establishment of a national professional association, which was subsequently launched in September 2007. The profession would then be in a stronger position to form alliances with other groups to achieve social change, to formulate positions on development, social welfare and social work issues on both a national and global level, and to advance the interests of social workers in matters relating to salaries, work conditions and benefits.

In South Africa there exists the South African Council for Social Services Professions. Social workers are also affiliates of various worker unions. The National Association of Social Workers in South Africa was established in 2007 but it is still in its infant stages.

Membership needs to be increased in order to have strong bargaining power to lobby for social workers and matters relating to the social service profession.

Social Development Minister Zola Skweyiya said the government declared social work a “scarce skill” profession with the country facing an acute shortage of social service professionals. Social workers were not appreciated and recognized as much as their teacher and nurse counterparts. Margot Davids of the National Association of Social Workers in South Africa said most social workers were operating in difficult conditions and their contributions were less recognized. The Department of Social Development has launched a rigorous campaign to retain and make social work the career of choice for SA’s youth. Hence the department of Social Development had allocated R210 million to the social work bursary scheme for students who wanted to pursue social work (Article from Business Day, 18 March 2009). The Department of Social Development have attempted to attract prospective students to the Profession by offering bursaries to study at a tertiary level, but still there is a need for more social workers to cope especially with the orphan pandemic.

Iveda Smith, chief executive of SA Council for Social Service Professions, noted that “while government was making strides to stop the poaching of social workers by overseas countries, something needed to be done to stop government from taking non-governmental organizations’ staff. The NGOs are doing a great job in training our social workers and we cannot afford to lose them”. She goes on further to report that “Government needed to either to increase the subsidies allocated to NGOs for salaries, or find a way of working together because at the end of day we are all working towards a common goal, serving our people in the best way possible” (City Press, 22 March 2009, page 12).

A National March was also conducted on the 26th August 2009, by the NGO sector to express their grievances in service conditions and remuneration. The march was a national effort, happening in all major centres. The march in Durban was co-ordinated by the National Welfare, Social Service and Development Forum and the Network of

Directors for Subsidized Welfare. A memorandum was handed to the Minister of Social Development and the NGOs are awaiting a response.

It is recommended that the social work profession be restored. Social work should be a market related profession where salaries commensurate with qualifications and experiences in order to restore the dignity of the profession and keep social workers in our country.

9.3.9. Care for Carers

In South Africa presently, caregivers as well as social workers are faced with caring for and working with vulnerable children, who have been abused and/or terminally ill. Terminally ill children often die in alternative care. This experience is traumatizing for caregivers. It is therefore recommended that trauma debriefing be built into a respite care programme for caregivers and social workers, e.g. a wellness centre where caregivers and social workers could retreat to. A respite programme will allow caregivers and social workers “time out” following traumatic experiences, to rejuvenate. The “time out” will further restore the human element to caregivers’ roles as opposed to simply building resilience to trauma (Perumal, 2007).

Another initiative in the KwaZulu Natal South Coast is a forum for social workers. All social workers meet on a quarterly basis, relax and de-stress in a friendly, conducive environment.

9.4 Implication for Future Research

- i. It is recommended that this study should be utilized as a basis for similar studies throughout the province and/or in other provinces so that generalization may be possible.
- ii. It would be interesting to follow up on these child participants and their levels of adjustment on a longitudinal level.

- iii. Given the bias nature of the study, a comparative study is recommended between this sample and a sample with children orphaned but not placed in foster care.
- iv. Develop and evaluate appropriate interventions to address the needs of children and adults bereaved by AIDS.
- v. Explore the short-term and long –term impact of AIDS-related bereavement on children.
- vi. Future research is also needed to assess the role of social workers in addressing AIDS-related bereavement in South Africa:-
 - Investigate current AIDS- related education for social workers, specifically training on death and dying and grief and bereavement.
 - Determine what types of practices and interventions are effective in helping individuals bereaved by AIDS in the South African context.

9.5 Conclusion

While research conducted in developed countries has shown weak relationships between the availability of informal social support and the degree of bereavement distress amongst those that have lost loved ones to AIDS, it is unclear if similar findings would be obtained in the local context, considering that the availability and the degree of both formal and informal support services in the local context are so much less.

Death is a normal part of life and so is grief. However, grief stemming from an AIDS-related death may be exacerbated because of a number of factors such as greater social stigma, less social support, greater reluctance to disclose the cause of death and multiple losses (Demmer, 2005).

The future role of social work in addressing the HIV and AIDS pandemic in South Africa is daunting, yet promising. In recent years, social workers and NGOs have taken the initiative and developed innovative community-based programmes (Sewpaul, 2001). But a challenge facing social workers is finding the 'time, energy and skills to focus on issues directly relating to AIDS bereavement and finding the funds to do so. It is hoped that this study will provide an impetus for more comprehensive attention to the issue of AIDS-related bereavement, both in terms of addressing the needs of the bereaved as well as research. AIDS is a disease that affects us all and we will be judged not only by what we did to address the epidemic but more importantly what we did not do even though we had the capacity. I believe that the more we give voice to those children infected and affected by HIV and AIDS, the more likely governments will be pressured to respond more effectively.

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CONSENT TO PARTICIPATE IN RESEARCH

NAME OF RESEARCHER: SHAMITHA RAMSURAN

**ADDRESS : P.O BOX 13
MARGATE
4275**

TELEPHONE 039-3122015

The purpose of this research is to learn more about the needs and experiences of children orphaned on account of HIV/AIDS. I would like to give children an opportunity to express their feelings and emotions.

The study would concentrate on children from my caseload between the ages of 10-18 years old. They would include both males and females.

I am currently a Master's student at the University of Natal and employed as a Senior Social worker at Child Welfare: Margate. I am working independently on this research project, with the permission and supervision of Child Welfare: Margate and the School of Social Work of the University of Natal. We do appreciate your willingness to be interviewed and your participation in this project.

- Your involvement in this project is voluntary, you do not have to divulge information you would prefer to remain private. You may also withdraw from the project at any time.
- The information provided by you will be treated as confidential. You will not be identified in any documents by your name or surname. You will be referred to in the documents under a code name.
- The sessions with you may be audio - taped and video- taped.
- The information gathered from the project would be used to compile a research report and may be used to assist other children.
- The researcher plans to share the results of this study with other professionals through presentations and publications.
- Every effort would be made to minimize possible risks.
- Should you have any queries, you are welcome to contact the Researcher.

I understand the contents of this document and agree to participate in this research.

.....
SIGNATURE OF CHILD

.....
NAME OF CHILD

.....
SIGNATURE OF CAREGIVER

.....
NAME OF CAREGIVER

.....
DATE

UKUVUMA UKUZIBANDAKANYA KULOLUCWANINGO

IGAMA LOMHLELI : **SHAMITHA RAMSURAN**
IDILESI : **P.O BOX 13**
 MARGATE
 4275
INOMBOLO YOCINGO **039-3122015**

Inhloso yalolu cwaningo ukufunda okuningi ngezidingo nangezehlakalo ezenzeka kubantwana abayizintandane ezenziwa yisifo Sengculazi (HIV/AIDS). Ngifisa ukunikeza izingane ithuba lokuveza imibono nemizwa yabo.

Isifundo lesi sizogxila kakhulu kulezo zingane ezineminyaka esuka kweyi- 8-18 ubudala. Kuhlangu abesilisa nabesifazane.

Okwamanje ngiwumfundi weziqu ze- Masters ENyunivesi yase- Natali futhi ngisebenza njengo Nonhlalakahle Ophezulu, esikhungweni Sezenhlakahe Sezingane e- Margate (Child Welfare: Margate). Ngisebenza ngokuzimela kuloluhlelo, ngemvume nokwengamelwa yi- Child Welfare: Margate and the School of Social Work of the University of Natal.

Siyakwamukela ukuzimisela kwenu ukuba niphendule imibuzo nokuzibandakanya kuloluhlelo

- Ukuzibandakanya kwenu kuloluhlelo nikwenza ngokuthada kwenu, akumele niveze ulwazi uwazi enilunikezile luzohlala luyimfihlo. Amagama enu angeke avezwe. Nizonikezwa amakhodi ngokwezincwadi ngamunye.
- Ingxoxo esizobanayo kungenzeka iqoshwe
- Ulwazi olutholakele kuloluhlelo luzosetshenziselwa ukuhlanganisa i- ripoti yaloluhlelo(research report) olungasetshenziselwa ukusiza ezinye izingane.
- Umhleli ulungiselela ukushiyelana ngemiphumela yalesisifundo nabanye ongcweti ngokuthi kwziswe emaphepheni nokuthi lwethulwe.
- Kuzozanywa ngakho konke ukuthi kuvikelwe umonakalo ungenzeki.
- Uma kokhona onemibuzo, makathintane nomhleli.

Ngiyakwazi okuqukethwe yilelibhukwana futhi ngiyavuma ukuzibandakanya kuloluhlelo.

.....
ISINYATHELO SENGANE

.....
IGAMA LENGANE

.....
ISINYATHELO SONGCINA INGANE

.....
IGAMA LOGCINA INGANE

.....
USUKU

Appendix II (a)

INTERVIEW SCHEDULE (CHILD PARTICIPANTS)

1. Explain the research process.
2. Reason for the research.
3. Reason for choice of participants
4. Confidentiality
5. Use of Research material
6. Consent forms
7. Choice of code names.

8. Identifying details of participants
 - Date of birth
 - Age
 - Gender
 - Grade, school
 - Hobbies
 - Friends and social circle
 - How would you describe a friend?
 - Do you have friends outside of school?
 - Are they the same friends you have in school?
 - If no, why do you have different friends in school and different friends at home
 - With the friends you have in school what are some of the things you do with them
 - How many hours do you spend with you friends in school?
 - Do you have friends from the opposite sex i.e. if you are female do you have friends who are male and if you are male do you have friends who are female
 - What is special about being friends with boys
 - What is special about being friends with girls?
 - How is your friendship with members from the opposite sex different to that of the same sex
 - What are some of the things you like to talk about?
 - Are you able to talk about the same things that you do with friends from the same sex than you do with the opposite sex? Why?
 - If you need advice who would you go to – the boys or the girls? Why?
 - What sort of advice do you ask your girl friends
 - What sort of advice do you ask your boy friends?
 - Do you share secrets with your friends from the opposite sex? Why?
 - Are there boys or girls who you want to be friends with but they don't want to be friends with you?
 - What kinds of arguments do you have with the people in your friendship group

- Problematic behaviour
- Favourite artist- music
- Favourite sport

9. Family composition

- Parents
- If deceased, when.
- Siblings and ages
- Relation to Caregiver
- Who lives at home with them?
- How many people in total live at home?
- Ages of occupants.
- How many go to school?
- Whom do they see often at home
- Whom do they hardly see?
- Who is the owner of the house?
- Lost family members through death
- Cause of death.

10. Financial Sources

- Who is working at home?
- Who attends to the household expenses?
- Does anyone get state pension/grants
- Any income- generating projects.
- Anyone self employed.

11. Housing

- Type of housing
- Shack, single room attached, traditional mud and daub hut, brick building.
- Composition
- Ablution: internal/external. Flush or bucket/pit toilet
- Electricity- any supplements
- Water: internal, external or communal.
- Land telephone/ cell phone
- Mode of transport.

12 Nutrition

- What meals did you have yesterday
- What did you eat
- Do you take lunch to school?

- If not, why not.
- Do you take money to school
- Who gives you money
- Do you ever go without eating food? How often.
- Is there a feeding scheme programme at school
- If so, are you part of the programme?
- What do you think are the problems in our community?

13. General Health

- Do you get ill
- How often
- Common ailments
- Do you visit the clinic/ doctor
- Any major operations.

14. Schooling.

- Academic performance.
- Skills/ excel in anything
- General barriers.
- How many days were you absent last term/ this year
- Reason for absenteeism.
- Are you sometimes late for school.
- Reason.
- How much is your school fees.
- Is payment completed?
- If not, why not.
- What has the school done about this?
- Who pays your school fees?
- Who buys your books/school uniform, etc.
- Did you get exercise books
- Did you get text books?
- Outside support.
- Did the school provide you with school requirements or did you buy
- Availability of school uniform/ school bag/shoes
- Is there a library at school
- Do you have your own desk and chair
- How many children in your class.
- How many teachers do you have
- Are your teachers ever absent?
- How often are they absent
- What do you like about school?

Appendix II (b)

INTERVIEW SCHEDULE- CAREGIVERS

1. Name – where do you live
2. Age
3. Occupation
4. Marital status
5. Family composition
6. Relationship to child concerned
7. Relationship to deceased parents
8. Do you receive any contact from natural father
9. Do you receive any support from the maternal /paternal family
10. Is there any conflict amongst family members?
11. When did you start caring for the child
12. Why did you decide to care for the child
13. Relationship between your children and the child concerned
14. Problems experienced with child
15. Difficulties- personal, financial or emotional
16. Do you have time for yourself?
17. How did you cope or are coping with the demise of the natural parents.
18. Upon assuming responsibility over the child, how is your relationship with your husband/partner/children/in-laws
19. Share with me your usual routine/ on an ordinary day
20. Roles and responsibilities
21. Have they notice any changes in the children since the death of their parent(s)
22. Any physiological or psychological impact
23. School performance and behaviour patterns regarding the children.
24. Is there anything else you would like to share?