

https://dspace.org/

Coping, social support, and needs of grandparents caring for children orphaned by Aids : an ecosystemic approach.

Tloubatla, Sibongile

2009-06-17T09:18:33Z
http://hdl.handle.net/10539/7019

Downloaded from a DSpace repository. https://dspace.org/

INTRODUCTION

According to popular reports *(Pretoria News*, 2002) in the absence of meaningful intervention in South Africa, it is projected that nearly one in every three children aged 15-17 will have no mother by 2015. While the AIDS pandemic has affected the lives of millions worldwide and has a particular devastating impact in Sub-Saharan Africa (Whiteside and Sunter, 2000; van Dyk, 2001), much is known about its consequences for children and young adults but little attention has been devoted to the plight of grandparents who invariably become the caregivers of AIDS-bereaved orphans. This study will focus on a growing phenomenon, in the black South African family, which is the increase of families headed by aged individuals who are often dependent on pension pay-outs for their livelihood. More specifically, the researcher intends to establish i) how grandparents cope with the challenges of caring for AIDS orphans, ii) what social support services are available for such grandparents , and iii) the needs of grandparents in the light of these challenges.

The researcher intends to investigate how grandparents deal with the challenges of caring for AIDS orphans and consequently explore the psychosocial impact of HIV and AIDS on grandparent-headed households. In addition, the intended research will also explore the significance and role of the extended family as the traditional social security system in many African countries. However, the impact and contexts of this social security have weakened because parents, aunts and uncles – in short, those who are sexually and economically active – are dying of HIV and AIDS-related diseases. As a result, the extended family is under severe strain due to the burden of caring for orphans which has fallen disproportionately on elderly women who constitute the majority of caregivers (Matshalaga, 2002). HIV and AIDS literature in psychology has predominantly focused on the impact and contexts of child-headed-households to the neglect of grandparents-headed-households. The research aims to fill this gap.

Chapter One of this study is the literature review. This section explains the background and context of the study. Relevant research done by South African researchers and other researchers outside South Africa will be critically reviewed. Chapter Two explains the theoretical framework chosen for this study. Chapter Three is divided into two parts. Part One of this reflects on the research method, presentation of general data and explores the participants' specific data relating to their experiences as caregivers. Part Two presents the research findings of this study. The findings are discussed in Chapter Four. The interpretation of the findings is integrated with relevant evidence from the selected reviewed literature and theoretical framework. Lastly, conclusions and limitations of the study are discussed.

CHAPTER 1
LITERATURE REVIEW

1.1 Introduction

The global HIV/AIDS pandemic has spread radically, fundamentally changing the economic and social lives of individuals living in heavily infected regions such as Sub-Saharan Africa, Asia, Latin America and the Caribbean (Family Health International, (2001, cited in Van Dyk, 2005). According to the revised statistics from 2000, there were 34.7 million children under age 15 in 34 countries who were orphans, most of them having lost one or both parents to HIV/AIDS and this figure is growing annually (UNICEF, 2004; World Health Organization, 2002). In one study report (UNAIDS et al., 2004; UNAIDS, 2002 cited in Heymann, Earle, Rajaraman, Miller, & Bogen, 2007) it is estimated that twenty percent (120 000) of all children aged 0-17 years in Botswana are orphans, and 77% of these children have lost their parents to AIDS. A similarly worrying trend obtains in South Africa because of the legacy of apartheid, migrant labour and modernization which have all broken down the family structure to a point where the death of just one parent can often make the child an orphan (Streak, 2003).

There are many long-term dilemmas (to be discussed in detail later in this report) faced by those assuming the responsibility of caring for these orphaned children (UNICEF, 2004 cited in van Dyk, 2005). The extended family support system has been particularly strained as fewer and economically able adult family members are available to care for the children. In many instances elderly, widowed grandmothers are taking over the responsibility of seeing to the needs of the children despite facing dire financial, health and economic problems of their own (*Family Health International*, 2001; UNICEF, 2004). Jacques (1999, cited in Heymann et al, 2007), argues that orphan care policy strongly favours strengthening the capacity of the extended family to care for orphans as opposed to institutional care which is still viewed as the worst of all possible alternatives and recommendations for orphan care. Nhongo (2004) reported that in South Africa, 40% of orphaned children are living with their grandparents. Nhongo (2004) further argues that it is apparent that the HIV / AIDS epidemic has immense ramifications for the

structure of the household. Uys & Cameron (2003) add that for a grandmother, the pressures of old age along with the financial and economic constraints regarding child rearing may impact on her ability to cope and to find adequate support from the community. This view is supported by Guest (2001) who argues that although the extended family is a safe place for orphans, AIDS is so rampant that the wider community needs to step in because orphanages are not the answer.

In the context of the foregoing, the focus of this study was the grandparents' role in the lives of these orphans. Lewis and Arndt (2005) states that the seldom told experiences of grandparents who care for children orphaned by AIDS (amongst other things), reveal the enormous burden that orphaning is exerting on grandmothers. According to a report by UNICEF (2007), women are more likely to head the household and take care of orphaned children irrespective of whether the children have lost one or both parents. Therefore this study focussed exclusively on the challenges of caring for AIDS orphaned children by grandmothers in particular. Their ability and means of coping with the demands of being the primary caregiver are dealt with in extensive detail. Furthermore, a critical evaluation of the availability of support systems within the South African context for these grandmothers is undertaken. The ensuing discussions will consequently focus on how grandparents cope with the demands of caring for the AIDS orphaned children.

1.2 Elderly caregivers and coping

1.2.1 Definition of coping

Baron and Byrne (1991) define coping as the response to stress, including what a person does, feels or thinks in order to master, tolerate or decrease the negative effects of a threatening situation. Baron and Byrne (1991) point out that stress occurs when the demands placed on the person exceed his /her ability to adjust. In addition, Hamburg, Hamburg & DeGoza (1953, cited in Rutter et al., 1983) describe coping as the term utilized by an individual to deal with significant threats to his/her psychological stability and to enable him/her to function more effectively.

The inability to cope with a stressful situation by the grandparents may consequently predispose them to reflect symptoms of stress as they are older and more vulnerable to developing health related problems (UNICEF, 2007). Therefore, the challenge facing grandmothers, that of becoming parents again, usually involves a great deal of stress and this can impact negatively on their coping abilities (Heymann, Earle, Bajaraman, Miller & Rogen, 2007). The following discussion will focus on the economic, health, emotional and psychosocial effects that caring for AIDS orphans may have on the lives of grandmothers.

1.2.1.1 Economic conditions and coping

a) Unemployment, Income and Discriminatory Laws

In many poor countries, elderly women are amongst the most vulnerable and marginalized members of society (UNICEF, 2007), yet as Lewis (2007) observes, grandparents have the extra burden of caring for children orphaned by AIDS and face challenges of raising traumatised children and teenagers in extreme impoverished conditions. In addition, in some instances unequal employment opportunities and discriminatory inheritance and property laws force many women to continue working well into old age. Following the deaths of husbands, many elderly women manage to survive on low wages earned in physically strenuous jobs in the informal sector. For instance, in Uganda, a study by the UN Food and Agricultural Organization found that widows were working two to four hours more each day to make up for reduced income following their husbands' deaths (UNICEF, 2007). According to Nhongo (2004) it is not surprising that older people, especially elderly women are impoverished and remain one of the poorest groups in Africa.

b) Poverty and nutrition

According to Hunter (2000, cited in Defilippi, 2000 in Uys & Cameron, 2003) there are several dimensions of poverty namely, income poverty (lack of food, goods, services and opportunities), moral poverty (lack of physical wellbeing, lack of energy and lack of space, lack of time and lack of power) and a spiritual dimension to poverty (lack of hope for change or meaning in the midst of suffering).

The malnutrition associated with poverty implies a compromised immune status and exposes people to infections such as TB and AIDS. Lack of basic services such as water, shelter, food and so on, also predisposes a person to infections like TB. People walk long distances to fetch water that is not even clean enough to drink or cook with and this may further exacerbate vulnerability to infection. Furthermore, according to Defilippi (2000, cited in Uys & Cameron, 2003) the consequences of poverty are not just physical but poverty also impacts on social and economic relationships. In parts of sub-Saharan Africa, the unemployment rate is as high as 70 per cent and consequently people feel trapped in a vicious cycle of hopelessness. Defilippi (2000, cited in Uys & Cameron, 2003) argues that to escape their dreary existence, alcohol and substance abuse as well as promiscuity become rife amongst these poor people. In some home environments, there is also evidence of domestic violence and sexual abuse that may lead to the death of a spouse, thus leaving the children in the care of relatives and mainly the elderly people. Poverty, abuse, and domestic violence have the most devastating impact on children. Hunter (2000, cited in Uys & Cameron, 2003) argues that the HIV and AIDS pandemic have greatly intensified the suffering endured by destitute children and consequently, led to these children being placed in the care of elderly women. Therefore, it is not surprising that grandmothers face challenges of increasing impoverishment and its attendant risks. Rearing a child is not an easy task, particularly for an elderly woman, because there are needs and demands that should be met. Barnett and Blaikie (1992, cited by Ntozi and others, 1999, cited in Subbarao & Couty, 2004) argue that a study conducted in Uganda revealed that young orphans were malnourished because of the inability of the extended family to cope with the increasing number of orphans. According to Ainsworth and Semali (2000, cited in Subbarao & Couty, 2004) a similar finding was observed in Tanzania.

In many instances, grandmothers do not have the basic essentials that are required to care for the AIDS orphans. In South Africa, older women caring for children affected by HIV/ AIDS cited scarcity of food and a day to day struggle to get enough food to feed the family (Ferreira, 2002). It is thought that although extended family members may be able to care for one orphan, the demands of caring for any additional orphan undermines the nutritional

well-being of all the children in the household (UNICEF, 2007). Furthermore, Heymann et al. (2007) observed in a study that nearly half of all caregivers had difficulty meeting the needs of children. This implies that many more children will not receive adequate nutrition in order to develop and grow (Burnette, 1999). The costs of feeding, clothing and paying school fees have proven to be a major concern for older people across the continent. The repercussions of financial problems mean that many grandmothers sacrifice a lot to raise the children and to restore the weakening family as a haven for orphans. In addition, as was stated before, the grandmothers either stop working or continue to work well past the age of retirement in order to support their extended family (Burnette, 1999).

c) Inadequate Housing

In the South African context, according to Mashabela (1990) inadequate housing and shack settlements are as a result of the legacy of the apartheid government's policy which did not provide adequate houses. Mashabela (1990) further argues that shack settlements are today a common feature of African township life within South Africa's industrial heartland. The problem of inadequate housing is one of the serious challenges faced by grandparents living with orphaned grandchildren. The grandparents sometimes share the same inadequate accommodation with their own children and grandchildren. Some grandparents face the challenge of trying to accommodate one or more orphaned children in their state-provided housing namely, the Reconstruction and Development Programme (RDP) houses. This becomes a problem as the children grow older and need their own space and privacy. Some grandparents who live in shacks or informal settlements on the outskirts of the cities live in areas without electricity, running water and a sewerage system – basic primary needs for survival in a city. Some grandmothers ended up in these settlements because as stated earlier on, they lost their houses due to discriminatory laws that forced the grandmothers to live with their relatives or saw them taken to 'homes' after the death of their spouse.

1.2.1.2 Health and coping

Elderly women who have worked hard to eke out a living in difficult conditions are being forced to assume the responsibility of caring for their dying children while also caring for

their soon-to-be orphaned grandchildren. Defilippi (2000, cited in Uys & Cameron, 2003, p164) argues that the elderly are "the very segment of society that ought to be receiving protection and care but instead these grandmothers attempt to stretch their meagre pension to be able to provide food and schooling for their orphaned grandchildren." It is not surprising that these elderly grandmothers are vulnerable to certain types of illnesses as they try to cope with the family trauma.

The elderly caregivers are usually at risk not only of chronic illnesses, such as arthritis, high blood pressure, cardiovascular and respiratory conditions but also of neglected health if these conditions are not treated (Hughes & Waite, 2002; Minkler & Fuller-Thornson, 1999). This situation may exacerbate poor health and impact on coping abilities (Joslin & Harrison, 1998). According to Gerdes (1988), although poor health is not inevitable in old persons, there is a high incidence of chronic conditions among them. Arthritis, rheumatism and other cardiovascular and respiratory conditions may vary from mild to severe and may be influenced by the past socio-economic status of the elderly. In addition, grandparents experience numerous psycho-emotional difficulties in trying to cope with the demands of caring for the AIDS orphans. These will be dealt with in the following discussion.

1.2.1.3 Psycho-emotional coping

1.2.1.3.1 Stress, Anxiety and Coping

According to Joslin and Harrison (1998) and van Dyk (2001) elderly caregivers of AIDS orphans experience physical and emotional health related illnesses that impact on their psychological wellbeing. Elderly people often complain about problems such as depression, stress and burnout, feelings of inadequacy, helplessness, guilt and loss of self-esteem and confidence. Grandparents may also deny their health problems and possibly their stressful situation. They may be anxious that their grandchildren might die if the parent died of AIDS related illnesses. They may make an effort to look strong for the sake of their grandchildren and hence lead a very stressful life.

According to Paul (1998), stress is experienced when the personal and situational demands exceed resources. According to Lazarus (1976, cited in Paul, 1998), there are physical stressors (environmental conditions) and psychosocial stressors (for example, the social and psychological conditions that may be harmful to the self). While grandparents may derive pleasure from grandchildren, according to Minkler, (1999) and Burton (1992), studies have constantly showed that grandparents experience social isolation, financial, physical and emotional hardship. Similarly, while grandparents may provide a secure and loving environment that helps children to socialise, they may find it difficult to respond to children's psychological, legal, economic, and basic needs. These may have a negative impact on the family but most particularly on the grandparent caring for the orphans, who may be unable to adjust to the demands made upon him or her.

In addition, grandparents may be too old to take care of the grandchildren and they may themselves be sick and fatigued (Subbarao & Coury, 2004). Some grandparents may experience chronic stress which could create greater chances of contracting diseases such as flu, depression and even dementia (van Dyk, 2005). In addition, trying hard to cope with the limited resources may be distressful to the grandparents. Van Dyk (2005) states that stress can lead to psychological and physical illness, anxiety, conflict, and so forth. Cannon (1932, cited in Paul, 1998) believes that illness may occur if the stress is continuous and exerts a strain on a specific physiological system which may be compounded by genetic predispositions to specific illnesses such as heart disease, cancer, osteoporosis and so forth.

1.2.1.3.2 Loss, depression and coping

The previous sections discussed various factors that may precipitate and predispose a person to physical and psycho-emotional problems. Stress and depression, among other things, is seen as one of the factors that is experienced by grandparents with symptoms such as loss of energy, low self-esteem, loss of hope, and so forth. Ford (1975, cited in Gerdes et al, 1988, p419) mentions "the loss of social and economic status and becoming physically, financially and emotionally dependent on others" as one of the three stress-producing situations peculiar to older persons in Western society. Gerdes et al (1988)

argue that the theme of 'loss' dominates the lives of older people (for example, loss of health, independence, status, family roles, income, friends and a spouse). According to Gerdes et al, (1988), the person suffering such losses is likely to manifest certain signs of stress, such as depression, fear and anxiety, confusion, indecision, hostility and frustration, and so on.

Gerdes et al, (1988) argue that many old people suffer from 'reactive depression' (that is, a reaction to certain conditions) with loss as its basis. Depression manifests itself in sadness, despair, hopelessness, poor self-esteem and feelings of helplessness and a loss of interest in life (Gerdes et al, 1988). Grandparents who have lost more than one child to HIV related illnesses and/or AIDS may mourn the loss of life itself. They may fear the loss of their ability to care for themselves and their families (van Dyk, 2005). According to Kaufman (1995) depression can be an extremely difficult and prolonged condition where feelings of tiredness, loss of energy and low self-esteem are common. In a study by Guest (2001) on grandmothers caring for AIDS orphans, conducted in Zambia, one grandmother sadly explained that she had always thought that by raising her eight children, she would insure herself against hardship in old age. However, this did not materialise as she stated that she "buried her children year after year for five years and now she has a throng of new dependants with no income" (Guest, 2001, p22). In the same study, the grandmother further commented, "I never thought such cruel things could happen. When I think about it, I pray and cry …" (p22). According to Guest (2001) these grandparents usually face strong material, emotional and psychological constraints and receive little external support.

The following discussion will unveil some of the reasons why grandparents do not receive adequate support from external sources while they care for children orphaned by AIDS. This will be done by discussing the issues surrounding discrimination against HIV- related illnesses and AIDS, and the grandparents' ability to cope with these.

1.2.1.3.3. Stigmatisation and denial in coping

Guest (2001) agues that few HIV and AIDS cases are being diagnosed because of the stigma surrounding the disease. According to the same scholar, doctors keep silent about the cause of death in trying to protect families from extra pain. Other researchers have constantly demonstrated that HIV and AIDS are stigmatising illnesses (Bor & Elford, 1998; Herek & Glunt, 1988). These researchers have argued that people living with HIV and AIDS and their support networks experience a particular and intense type of stigmatisation as compared to people with other medical conditions. For example, people suffering from cancer, high blood pressure, sugar diabetes are treated differently from those with HIV or AIDS. Mason et al. (2001) and Sontag (1988) concur that various illnesses are associated with varying degrees of stigmatisation. Studies have demonstrated the pervasive effects of stigmatisation on the lives of those with schizophrenia (Finlay, Dinos & Lyons, 2001) and Alzheimer's disease (MacRac, 1999), for example. The intensity of stigmatisation regarding HIV/AIDS is greater. According to Kaufmann (1995) for many people telling their loved ones they are HIV positive also involves disclosure about how they got the virus, which normally is through sex. The infected may feel that they are bringing into the open some aspect of their lifestyle they had rather hide.

In addition, people living with AIDS according to Blumenfield et al. (1987) and Crawford et al. (1991) have been more negatively evaluated by health workers and mental health professionals than persons with other diseases. These negative feelings towards people living with AIDS were also echoed in a survey done in the United States (Blendon & Donelan, 1988; Blendon, Donelan & Knox, 1992; Herek & Capitanio, 1993). The parents of the deceased found it difficult to come to terms with the cause of their child's death and as a result resorted to isolating themselves in their house and only came out to do some shopping at night. This behaviour was as a result of the stigma attached to HIV and AIDS. In addition, Kaufmann (1995) states that research has found that infected victims are highly selective about the disclosure of their HIV status. The infected victims may, inter alia, try to protect their families and children in particular, from a further distressful situation.

Kaufmann (1995) points out that even the most unprejudiced and accepting of families may fear the stigma surrounding HIV and AIDS. There is still a widespread attitude that AIDS is a self-inflicted disease and the victims are sometimes subject to verbal and physical harassment at the hands of others. What impact will this have on the grandparents who take care of their dying children? Kaufmann (1995) argues that over a period of time people go through multiple episodes of fear, exhaustion, grieving and bereavement. Because of secrecy and silence about HIV and AIDS within families, Kaufmann (1995) argues that this may lead to older people isolating themselves from, and shutting themselves away in their homes in order to avoid questioning by neighbours, friends and the community.

From the above, it can be argued that the family of the deceased may be experiencing denial related to stigma. Van Dyk (2005) explains 'denial' as an important and protective defence mechanism because it temporarily reduces emotional stress. This view is supported by Lazarus (1979, cited in Sue, Sue & Sue, 1994) who contends that people use emotion-focused responses to cope with stress. Lazarus (1979, cited in Sue et al, 1994) labels these defences 'intra or cognitive' means of coping. This was the case with one grandmother in Zambia who related, in the study by Guest (2001, p19), that her "five children were all struck down by witchcraft because they were successful." Although the grandmothers believed that the disease was common in Zambia and that it had lost much of its social stigma, they revealed that people did not talk about it in public places. Guest (2001, p22) mentions that individuals working with the grandmothers stated that people in Zambia were reluctant to call AIDS by its name even in clear cases of the disease having caused death. Guest gives the reason for this scenario as the overwhelming stigma attached to AIDS. According to Guest (2001) the Zambians instead, preferred to use another language or euphemism such as "this disease" and so on.

1.2.1.3.4 Grief, Loss and coping

Bowlby (1975, cited in Gerdes et al, 1988) defines four psychological phases of grief namely, a phase of numbness (lasting several hours to a week), a phase of yearning for the

lost person (may last for months or years), a phase of disorganisation and despair, and a phase of reorganisation. Bowlby (1979, cited in Uys & Cameron, 2003); Glick, Weiss & Parkes (1974 cited in Gerdes et al, 1988) add that generally a person may require more than a year to come to terms with grief. Gerdes et al (1988) observes that recently, grief has come to be recognised and allied with a range of negative feelings which are part of general emotional turmoil. Elderly people may as a result of the negative feelings become angry and blame fate, self, others and God for the loss of a loved one.

In a study on "Grief and Loss" conducted by Winston (2002) with ten African-American grandmothers parenting AIDS orphans, the findings revealed that participants maintained strong bonds with the deceased through the conscious decision to remember their unique qualities and through parenting their children. These grandmothers maintained that there was a spiritual relationship with God which they said was a source of their strength that made it possible for them to be able to parent while mourning.

1.2.1.4 Psychosocial impact and coping

Grandparents seem to be forced by circumstances mentioned previously to become parents again. As already discussed, the loss of the traditional grandparent roles may cause grandmothers to feel overwhelmed by having their personal freedom taken away by the demands of caring for children. In addition, the constant stress that is involved in caring for adolescent children such as detention or failing classes is difficult for grandmothers to control (Kolomer & McCallion, 2005). Some grandparents worry about the orphans using drugs, going to prison and the instability of the children or grandchildren as they change jobs, boyfriends and living arrangements (Musil & Standing, 2005; Nhongo, 2004).

Therefore, research reveals the disproportionate burden that grandmothers face as heads of households (UNICEF, 2007; Heymann et al, 2007). There is an urgent need to provide grandmothers with assistance in order for them to adequately care for the AIDS orphans. The following section will discuss the support systems that may be available to

grandmothers and whether these systems are adequate and effective in dealing with the specific needs of grandmothers who care for AIDS orphans.

1.2.2 Support systems for grandmothers caring for AIDS orphans

1.2.2.1 Definition and explanation of social support

Baron and Byrne (1991, p607) define social support as "help provided by friends and relatives who give physical and psychological comfort to an individual facing a stressful experience." This means that the individuals that obtain social support tend to be relatively better in terms of physical health, emotional and psychological adjustment and consequently, dealing with stress. Harcombe (1993) and Demaray & Malecki (2003) contend that social support systems play a buffering role in helping individuals cope with undesirable life events. In addition, the findings of Thurton's study (cited in Harcombe, 1993) of disadvantaged black South African adults showed that social support acted as a buffer between the person and stressful events. These findings suggested that unsupported individuals were more adversely affected by stressful life events than those who had ample social support.

Erikson (1963, cited in Maier, 1969) suggested that there is a need to reform the social programmes, services and policies intended to affect adults, given that children are the primary benefactors of such change. By improving the social support services to elderly caregivers, the sustainability of being the surrogate parent can be effectively maintained. Therefore, the following discussion will provide an overview of the various support systems that are, or may be, in place to assist grandmothers and the relative effectiveness of these systems to meet the challenging demands of the grandmother caregivers.

.

1.2.2.2 Governmental organizations

The HIV and AIDS epidemic has crippled the socioeconomic structures of the African continent in general and that of South African society in particular, leading to millions of orphans worldwide either being absorbed by their extended families, and/or placed in institutions. Some orphaned children often have to migrate to new homes and

communities (Ansell & Young, 2004). The burden of care rests upon the extended family households, the siblings, and so on, but mostly upon the grandparents, a very poor elderly group. Nduru (1992) argues that the burden is made heavier by the fact that government departments sometimes appear ill-equipped to assist elderly people in meeting the new demands that are placed on them. South Africa is no exception to this trend.

According to Nduru (1992) while some of the continent's senior citizens may have enjoyed a relatively quiet retirement, this prospect has been largely wiped out by the responsibility of caring for grandchildren who have been orphaned by AIDS. Eckley of the South African Council for the Aged in Pretoria argues that the scars of apartheid seem to be disproportionate on elderly people as the South African government and its structures continue to discriminate against older people (*ANC Daily News*, 30 June 2004). Grandparents continue to struggle to gain entry to support services such as disability grants, child support grants, and pension grants promised to them by the government. However, Nduru (1992) states that the problem faced by senior citizens in South Africa, also occurs in neighbouring countries. Grandparents continue to be discriminated against and they have no say in issues pertaining to their lives in general.

Grandparents struggle to receive medical treatment at the clinics and state hospitals as they have to travel long distances to obtain medical services for themselves and their grandchildren. Eckley, in the article cited above, warns that if grandparents stop giving care to these children, the streets and children's homes will be full of AIDS orphans. Nhongo, (2002) argues that many older people in Africa and other parts of the world have no option but to become 'Africa's Newest Mothers'.

Beales (2002) suggests that there is little support for grandparents who care for AIDS orphans. As a result, grandchildren opt out of school in order to support themselves and their aged carers. Older people also have difficulty getting access to scarce resources which are often not available when needed most. This means that elderly people, mainly women, care for and support orphans with very limited resources or support from the state and they remain the poorest group in every community of Africa (Nhongo, 2002). A

study commissioned by the Minister of Gender, Labour and Social Development in South Africa to analyse the available data in relation to the poor and vulnerable groups, found that 64 percent of older persons (60 years and above) fell below the poverty datum line. According to research carried out in South Africa, older women caring for children affected by HIV and AIDS "referred to a scarcity of food, and a daily struggle to procure food to feed the family" and Ferreira (2002, p56) commented that grandmothers walk a tight rope between survival and starvation.

In South Africa, older people may be eligible for child support grants but very few of these grants are accessible. The primary reason is that there are stringent eligibility requirements placed on these grants and often grandmothers are perceived as too old to care for children (Beales, 2002). However, there is much dissatisfaction over the actual amounts given to the caregivers as figures were calculated in 1992 and do not take into account the rise of inflation (Malefane, 2006). Furthermore, many elderly people and caregivers do not have access to basic water and are still on a waiting list for housing and for the education of their grandchildren (Malefane, 2006). According to a document by the Social Development and Grants (Reconstruction & Development Programme, 1994) the SA government promised to build affordable houses for the poor, to combat poverty, to find a strategy to promote sustainable development, to avail social grants, and to roll out a food support programme for impoverished families. However, these promises have not materialised for the elderly.

1.2.2.3 Non-Governmental Organizations (NGO's)

There is evidence that grandparents are trying hard to gain access to services provided by Non-Governmental Organisations (Beales, 2002). Misguided beliefs and attitudes serve to exclude older people from developmental programmes that could help them and the children they support. In some communities in South Africa and other parts of Africa, social workers provide temporary support to people by distributing food or money. This has not been the case in most poverty stricken areas.

According to van Dyk (2005: 78) while the Non-Governmental Organisations work hard to alleviate poverty in the communities, such as speeding up the foster care grants process, assisting with education of the children, offering emotional and psychological support to families, it is 'a drop in the ocean' because the country's leaders appear to be busy with other agendas. Seedat et al. (2001) argue that funding difficulties for the Non-Governmental Organisations can cause uncertainty in the planning of specific mental health programmes. The same scholars add that the financing of these non-governmental organisations needs attention in order to incorporate their valuable resources into child mental health policy and structures in South Africa.

Guest's (2001) study in Zambia mentions that the Non-Governmental Organisation called 'Children in Distress' formulated branches called 'windows' in the form of support groups through which the community began to recognise the importance of working collectively to help needy people to cope better. In South Africa, there are similar organisations to those of Zambia that cater for the needs of families in distress, trauma, abuse, and violence among other issues (Seedat, et al., 2001). However, as it was stated earlier, funding for these organisations is a major concern. At the same time, the majority of grandparents are unable to gain access to most of these resources.

1.2.2.4 Community support

The South African government is advocating community based care rather than orphanages to care for AIDS orphans (Larkin, 2005). It is believed that the extended family and other community members can care for orphans in the spirit of *ubuntu*, a humanist philosophy that emphasises caring for each other. However, according to Larkin (2005) there will be enormous gaps in orphan care if the responsibility rests solely with community members to care for these children. It is essential that organizations, government agencies, and NGOs support the community members as they care for the AIDS orphans (Larkin, 2005). In South Africa, the community-based initiatives developed by Seepamore and Nkgatho (2000, cited in van Dyk, 2005) in Alexandra Township, include an AIDS Orphans Project that caters for orphaned babies and children. This project also caters for the 'Go-Go Grannies' which is a group of grandmothers who

have lost their own children to Aids and are now raising their orphaned grandchildren. The project assists the grandmothers with care and support for the orphans by providing psychosocial, financial and material support. UNAIDS (2004, cited in van Dyk, 2005) states that these grandmothers are also given a one-time building grant to ensure adequate shelter, seeds to start their own gardens for income generation and feeding their families. Van Dyk (2005) cautions that in order for the project to be sustainable the family and community-based caregivers need support from the government or outside organisations.

1.2.2.5. Religious support

The church and other religious organizations have a crucial role in providing support, faith and hope to the elderly care givers. The Church, through its practices, can provide a climate of love, acceptance and support by reflecting on the issues raised by the AIDS pandemic. Van Dyk (2005) suggests that religious organizations should be actively involved in HIV care and prevention. By listening to comforting words of compassion from religious institutions, elderly caregivers may get the inner strength to endure their difficult situation (van Dyk, 2005).

1.2.3 Conclusion

In the light of literature reviewed about coping, social support and the needs of grandparents caring for the AIDS orphans, it is clear that the HIV and AIDS pandemic has had a negative impact on the lives of individuals, families, community, and societies across the continent and globally. This literature review revealed the worrying statistics AIDS orphaned children. These children are mostly cared for by the extended family, grandmothers in particular. It is however, important not to ignore the importance of the role played by elder orphaned siblings in the lives of their younger siblings. The grandparents are seen in this review as playing prominent roles after the death of grandchildren's parents.

This review also indicated the coping abilities and/or mechanisms for the grandparents. Research has shown that challenges can lead to grandmothers experiencing physical and psycho-emotional difficulties in the absence of coping abilities and social support

systems. However, while much research has focussed on grandparents and their coping ability as well as social support systems available, the social support system offered by government was found to be lacking or slow in some instances.

To explain the complex nature of the impact of caring for children in old age, it is necessary to have a theoretical framework that takes the multi-faceted nature of the phenomenon into account. Thus, the next part of this report will be devoted to an exposition of the Ecosytemic theoretical framework to explain the coping, social support and the needs of grandparents caring for their AIDS orphaned grandchildren.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 Introduction

The purpose of this chapter is to explain the need for a theoretical framework that will provide a logical explanation of the issues pertaining to this study. Using the Ecosystemic theoretical framework, the interconnected assumptions, concepts and relationships between the components of this framework will be explained. The intention is also to link and explain the relevance of the events and issues through the Ecosystemic approach. The following section explains the importance of a theoretical framework in conducting research.

Engelbrecht and Green (2001) state that using a theory to understand certain phenomena promotes knowledge construction and offers frameworks for understanding and interpreting experiences. Neuman (2003) points out that a theoretical framework is used to guide how research should be conducted. Neuman (2003) believes that frameworks also guide the design of a study and the interpretation of the results. Following these pointers, I will show in this chapter the appropriateness of the Ecosystemic theoretical framework to this study which was conducted in a South African context. An explanation of the Ecosystemic theoretical framework follows.

2.2 The Ecosystemic Theoretical Framework

Harcombe (1993; 2001) argues that there is a need to move away from theoretical underpinnings such as the psycho-medical (which categorises people in terms of deficits within themselves) towards a complex politico-socio-economic developmental framework or what has often been called a Marxian critical analysis framework. Donald et al. (2006, p35) describe and explain the ecosystemic perspective as “a blend of ecological views and systems views of interaction between different levels of the social context and the individuals within them.” This view is supported by Bronfenbrenner’s

(1977; 1979; 1986 cited in Donald et al., 2006) ecological model of child development which is based on interdependent and interacting relationships between different organisms and their physical environment. Central to Bronfenbrenner's (1977; 1979; 1986, cited in Donald et al.,(2006) model are the four interacting dimensions namely, the person factors (for example, the temperament of a person), the process factors (for example, the forms of interaction that occur in a family, and so on), the context (for example, families, schools, local communities, and so on) and time (for example, changes over time in the child or the environment).

The strength of the ecological perspective is that it is composed of parts of a system that work together for the survival of the whole. For the ecological perspective, the sum is greater than its individual parts. As it works as a system, this means that whatever happens in one part of the system can affect other parts. Bronfenbrenner (1977, cited in Donald et al., 2006) further explains that maintaining the balance in this ecological system is vital for the system to be sustained. Failure to maintain equilibrium within the ecological system will cause a major disturbance in the whole system as it will be now threatened. For example, poverty and unemployment are major problems threatening the survival of the family. Consequently, the family functioning as a system and its various subsystems will be disturbed as a whole. This, in turn might affect the community and society as well.

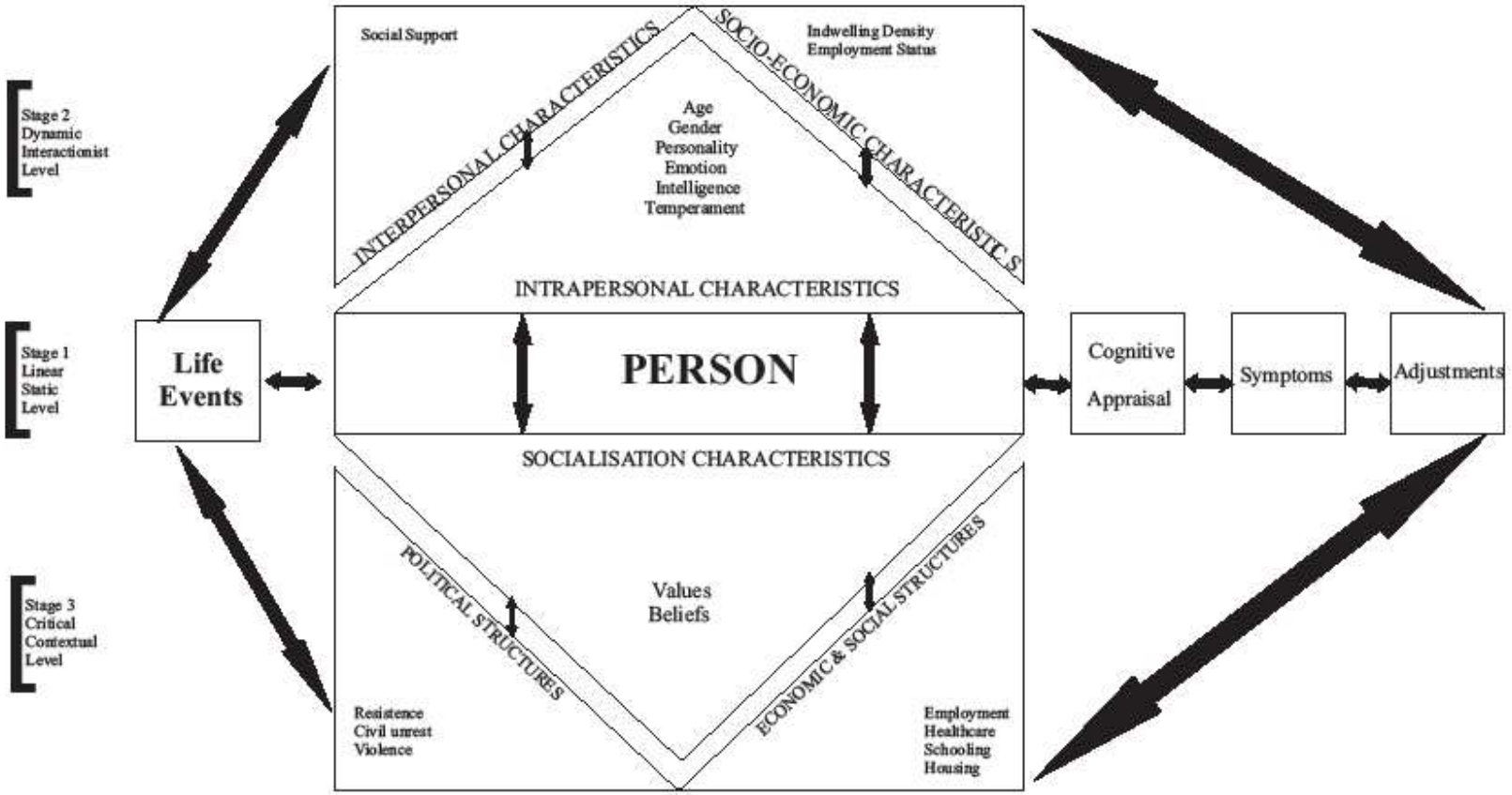
Plas (1986) and Broderick (1993 cited in Donald et al., 2006) state that systems theories are applicable to the study and understanding of different fields such as the family, school, economics, the relationships within them, between them, and their relation to their social contexts. Like the ecological perspective, systems theories emphasise the different levels and groups of people as interactive systems where the functioning of the whole is dependent on the interaction between all the parts of the system (Donald et al., 2006). However, in this interaction, if there is a part or subsystem that is not functioning effectively, the whole system will be affected. For example, this study tries to explore and explain coping, social support and the needs of the grandparents caring for AIDS orphans. If severe financial difficulty exists in these households and the grandchildren are

unable to survive adequately in terms of their primary basic needs (for example, food, clothing, and so forth) then this means that the whole family will be unable to adjust in such living conditions.

Also relevant to this study is the psychoanalytic view point which provides an understanding of how negative or positive representations are experienced emotionally and the attempts by those affected to protect themselves from anxiety associated with it. For example, Guest (2001) mentioned that the Zambians avoided the use of the word "AIDS" because of the overwhelming stigma attached to, and the trauma that comes with it. This means that, there is a link between the psychoanalytic views and the Ecosystemic ones regarding the "intrapersonal characteristics" (such as, cognition, emotion, behaviour, and so forth) that predispose a person to stressful life events (to be discussed later). In addition, Joffe (1999, cited in Rohleder & Gibson, 2006) uses psychoanalytic theory to show how the stigma of AIDS can be understood as a defence against threats to the self. The same scholar further shows how people have constructed AIDS as foreign and associated with deviant malpractices and as such try to protect themselves against possible discrimination.

The Ecosystemic framework is vital for this study as it is seen as 'umbrella or meta-approaches' (Harcombe, 1993) which incorporate many theories in an all-encompassing, coherent whole. Harcombe (1993, 2003) has taken many of the previous concepts and theories, for example, from Turton, Gibson, Donald, Engelbrecht (in Harcombe, 1993, 2003) and combined them into a more integrative and comprehensive framework. She used the Ecosystemic model in understanding stress. The present researcher opted to use this model as it is relevant to the context of this research report. A graphic representation of the Ecosystemic model adapted from Harcombe (1993, 2003) is presented below in Figure 1. This model allows for the examination of the issues presented in the study at three levels and it will allow for the integration and examination of previous findings in this area of study.

Figure 1: Ecosystemic Model adapted from Harcombe (1993, 2003)



However, due to the level of detail contained in this diagram, the researcher will only focus on aspects relevant to this research study. This will enable the researcher to understand and explain the challenges faced by grandparents in terms of their needs, coping and social support systems available to them.

Thus when a particular level of functioning of a grandparent is examined, it is necessary not to lose sight of the larger whole and the complexity of the interactional patterns between systems. According to Harcombe (1993, 2003) these systems are interrelated and operate at different stages and levels. Each dimension will be examined separately before relationships are brought in.

2.3 THE FOUR LEVELS OF THE ECOSYSTEMIC FRAMEWORK

2.3.1 Level 1: History/ Life Events

Level 1 of the Ecosystemic model (see Figure 1) refers to the history or events occurring in the life of an individual's struggle to cope with undesirable life events. At this level the history of the individual is examined. The life events could be any trauma such as abuse, death, divorce, lack of shelter, food and so forth. According to Harcombe (1993) this level includes events relating to disturbances of interpersonal relationships and environmental influences emanating from outside the family circle. Harcombe (1993, 2003) argues that these life events/stressors are considered as predictors (causes) of any problems, symptoms or maladjustment a person may evidence. Becvar and Becvar (1996) concur with Harcombe (1993), in pointing out that at this level, a "pure" cause and effect approach is used. This means that a person can be classified according to his or her difficulty presented at a particular time. Lerner (1993) underlines the importance of the cause and effect approach in citing that it has influenced pervasively some fields of practice and generated considerable research.

Lazarus (1976 cited in Paul, 1998) argues that environmental conditions and their related psychosocial stressors may be harmful to the person trying to adjust to these conditions.

An individual may be classified or labelled in some way as having a disorder. Minkler (1999) and Burton (1992) argue that studies have constantly shown that grandparents experience social isolation, financial, physical and emotional hardship. These life events may be stressful for the elderly and they may, for example, be labelled "inadequate."

2.3.2 Level 2: Intrapersonal Characteristics

This level of the Ecosystemic model (see Figure1) focuses on the intrapersonal characteristics of an individual and the characteristics unique to the person. This means any aspect that comes from within a person that is genetically predetermined and not learnt. This includes the individual's motivational level, learning ability, physical attributes, personality, emotional level, intelligence and temperament (Harcombe, 1993, 2003). According to Harcombe (2003) intrapersonal factors together with other levels of the Ecosystemic model influence the way a person develops and may have an impact on the nature of the adjustment to these. Intrapersonal variables may consist of biological predispositions, which may include obvious differences relating to gender and physical development. However, this section will focus on only three such predispositions which are emotional characteristics, gender and age. These characteristics will be discussed in detail below.

i) Emotional characteristics

This sub-system of the intrapersonal dimension of the Ecosystemic model deals with individual differences regarding emotional levels. According to Wolff (1981) and Strelau (1989) the use of defence mechanisms to deal with a stressful situation may be evident. In this regard, Allport (1961 cited in Gerdes et al., 1988, p104) argued that a person who over-reacts emotionally may be preoccupied with disconnected items of earlier emotional experiences, whereas, a self-accepting person is seen as a person who has a sense of proportion. The latter is able to control his/her emotions through the ability to express his or her feelings openly, taking into consideration the beliefs and feelings of others.

ii) Gender characteristics

According to Turton (1986), Thoits (1984), Dawes and Tredoux (cited in Harcombe, 1993) studies suggest that women and girls experience more undesirable life events than males, and they display a higher proportion of stress reactions than males do. Guest (2001) argues that most of the children, who have lost both parents, are taken in by their extended family, usually an elderly and widowed female. In addition, research by the United Nations Children's Fund revealed that nearly forty per cent of the orphans are cared for by grandparents usually grandmothers (Guest, 2001) and another thirty per cent are looked after by aunts or uncles. This study focused on grandmothers as caregivers of orphans because most of the studies done so far reveal that grandmothers and elder female siblings become caregivers to orphans after the death of the parent(s).

iii) Age

Age is another sub-system of the intrapersonal dimension of the Ecosystemic model. The researcher will focus on late adulthood development in particular. Rodin (1980, cited in Garmezy and Rutter, 1983, p114) presented a series of studies on the importance of control in aged individuals. The findings suggested that the transition from adulthood to old age may represent loss of control both physiologically and psychologically. In the same publication, Rodin argues further that the ability to sustain a sense of personal control in old age may be influenced by societal factors and this may affect the physical well-being of the aged individual.

The present study focused on elderly females in their late adulthood (between ages 60 and above). This is the retirement stage. Challenging life events can be stressful for the elderly persons taking into account their age and many roles they need to play in the life of the child. Blythe (1979), Butler (1982), Kennedy and Scheidt (1979) and Saul (1983 cited in Gerdes et al., 1988, p393) demystify some of the stereotypes and myths of ageing such as "old age is a period of tranquillity and serenity." Elderly people may also be influenced by environments that exert distress and painful feelings as they try to

understand their situation. For example, elderly people may struggle to cope with challenges like health, physical signs of ageing such as sensory deterioration, lack of stamina, loss of cognitive abilities, social roles, and so on. Richter (1989, cited in Harcombe, 1993) points out that children in South Africa appear to be vulnerable to both household density and family size and this in turn will have an impact on the elderly person who has no resources to deal with challenges such as household density.

2.3.3 Level 3: Interpersonal Characteristics

This level refers to the role of significant others in the individual's life. More specifically it refers to the social support systems surrounding the individual such as family, friends, community and so forth. Harcombe (1993) and Demaray & Malecki (2003) contend that social support systems play a buffering role in helping individuals cope with undesirable life events. Harcombe (1993) reviewed the Thurton study which dealt with disadvantaged black South African adults and concluded that social support acted as a buffer between the person and stressful events. The findings of the Thurton study suggested that individuals who were unsupported were more adversely affected by stressful life events than those who had ample social support.

2.3.4 Level 4: Political And Socio-Economic Status Characteristics

At this level of the Ecosystemic model the political and socio-economic structures of the South African society are reviewed. The influence of apartheid policies on the political and socio-economic structures impacted on the lives of the people from 1948 to date (Kallaway, 1994; Wilson & Ramphele, 1989, cited in Harcombe, 2007). These structures included laws and policies that were implemented to undermine certain races, cultural and ethnic groups. According to Kallaway (1984), Wilson & Ramphele (1989, cited in Harcombe, 2007), the interaction of all these systems (that is, the political, social and economic systems) produced civil unrest, unemployment, intimidation, violence and crime, minimal or no health care facilities and so forth. The apartheid South African government policies and legislation resulted in forced removals and a chronic shortage of housing. According to Turton (1986) and Richter (1989 cited in Harcombe, 2007) the shortage of housing has resulted in high household density and squatter settlements. The

most affected groups are black South Africans. Most of the elderly people, if not all, were victims of violence and civil unrest that obtained during the apartheid era. Some of the grandparents are unable to obtain identity documents due to lost documentation during the civil unrest that left many houses burnt and/or destroyed and saw many individuals lose their lives.

It is not surprising to realise that these elderly people became resilient to these adverse conditions and this largely explains their capability to cope, to some extent, with the adverse conditions they live in at the moment. Masten (2001 cited in Kralik, van Loon & Visentin, 2006, p189) proposed that "resilience refers to a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development." Harcombe (2003) maintains that political and socio-economic structures affected the way households lived, developed and learned to cope with, or adjusted to stressful life events. Harcombe (2003) further argues that the integration of contextual aspects into the ecosystemic model enables practitioners and other adults to think about the influence that political and socio-economic structures have on the interacting systems. The same author further argues that all this dynamic interplay could affect the individual's adjustment and development.

2.4 Conclusion

Four levels of the Ecosystemic model were presented in this section. These levels of the Ecosystemic model were used to explain the interactions of life events, the intrapersonal, the interpersonal, as well as the political and the socio-economic structures that have an impact on the lives of people. In addition, a study by Thurton (Harcombe, 1993) revealed that the role of social support systems in the life of the individual is important and acted as a buffer in helping individuals cope with undesirable life events. This study also suggested that unsupported individuals were more adversely affected by stressful life events than those with ample social support. The Ecosystemic model is better placed to account for an individual's challenges because of its multifaceted approach. Furthermore, the Ecosystemic model, it emerged from this exposition, is able to explain and explore

coping ability, social support services and the needs of grandparents without necessarily blaming an individual.

CHAPTER 3
THE STUDY

3.1 Introduction

This study takes a qualitative approach and attempts to explore the experiential dimensions of grandparents' coping, social support and needs in caring for their AIDS orphaned grandchildren. The following brief discussion restates the research aim and rationale of this study. This chapter is divided into two parts. Part One reflects on the research method, presentation of the general data, and explores the participants' specific data relating to experiences of caring for their orphaned grandchildren. Part Two focuses on the research findings of this study.

3.2 Research Aim

The aim of the proposed research is to explore and identify challenges facing grandparents caring for AIDS orphans. This entails understanding the impact of caring for AIDS orphaned children, how grandparents deal with the challenges they face in caring for orphans, and lastly, exploring the availability or non-availability of resources and social support structures to caregivers. In order to understand the nature of experiences of grandparents as caregivers, the following questions were asked during interviews: How old are you? How long have you been living in this house? Do you have any children? Are they still alive? If not, how long have they been dead? Do you know the cause of death? How many children did they have? Are these children living with you? What are the ages of these children? Are you receiving any social grant (old age or child support grants?). Furthermore, questions pertaining to coping mechanisms and social support were asked. These were: How are you coping in terms of: physical heath, emotional wellbeing, financially, socially and mentally? In addition, the grandparents were also asked about support in terms of the above coping questions. Lastly, in relation to the above questions, they were also asked about their needs as caregivers.

3.3 Rationale

This study arose from the researcher's day-to-day interaction with the wider community of Kathorus, in the outskirts of Johannesburg, who needed different types of services. The grandparents seemed to be the most neglected group in the community. Their role as caregivers appeared ignored. At their retirement stage, they became parents again to their orphaned grandchildren left behind by parents who had of AIDS. It is for this reason that the researcher was inspired to explore and investigate this problem.

Guest (2001) states that the extended family is traditionally a safe place for orphans. She further argues that the extended family alone is not adequate to deal with the challenge of the increasing number of AIDS orphans. Guest (2001) is of the opinion that the wider community has to step in because orphanages do not have the capacity to deal with the problem. This is true in African communities since the extended family has a tradition of taking on the responsibility of caring for children once their parents die. However, AIDS related deaths are accelerating the breakdown of the traditional African family. Grandparents have always been involved in the socialization of their grandchildren, enabling many mothers to leave their children for long periods in order to find work and support all three generations. But as the "middle generation[1]" dies, grandmothers are left holding the baby (Guest: 2001).

Due to limited research on the issues of coping, social support and the needs of grandparents as caregivers for AIDS orphans in South Africa, the intention of this study is to explore the challenges facing the grandparents. It also endeavours to identify the nature of these challenges in a limited way and review them with reference to other countries.

[1] "Middle generation" refers to the grandparents' children in this study.

3.4 Part One: Research Method

3.4.1. The Research Design

As the study is exploratory, qualitative research methods of collecting data were employed to address the research aim in this study. This approach deals with data that is primarily verbal and which derives meaning from the participant's perspective. It also intends to understand the meaning that people attach to everyday life (De Vos, 1998). The design of this study included interviews as well as the researcher's observations.

3.4.2. Participants

A purposive sampling strategy was utilized to draw up a sample of participants who would provide adequate information for the study. Purposive sampling is a method whereby the researcher purposefully selects participants that the researcher deems appropriate for the study. Ezzy (2002) contends that appropriate participants would be those that are knowledgeable. In other words, the purposive sampling method is entirely based on the judgment of the researcher. This method also enabled the researcher to obtain a sample from a "hard to reach" population. The grandparents caring for AIDS orphans are a difficult to reach population given the stigma attached to AIDS, hence purposive sampling was appropriate. The idea behind purposive sampling was also to identify access points where participants could be found and selected to best answer the research questions (Ezzy, 2002).

3.4.3. Procedure

a) The sample consisted of ten grandmothers from the ages of sixty-four to eighty-six (mean age of 69,4). The grandmothers live in Katlehong, a historically 'black' township created by the former apartheid South African government. There is high prevalence of crime, poverty, poor education facilities and HIV related infections in this area. The grandparents were individually interviewed in their homes to explore their challenges as caregivers. All these participants were caregivers to AIDS orphaned grandchildren and the majority of them lived in informal settlements. The participants for this study were selected based on the following additional criteria: that they are South African, registered

members of the grandparents-headed-household (both sexes taken into account) support group at Khanya Family Centre, and live within the Kathorus region, and lastly, are from the ages of sixty-four and above.

b) Khanya Family Centre: A Non-Governmental Organization

Khanya Family Centre, a Non-Governmental Organization situated in Katlehong, West of Ekurhuleni, was used as a source to identify willing participants for this study. The participants were approached by the Director of Khanya Family Centre who had links with the members of the support groups. The organization formed several support groups such as the grandparents' headed-household, the child-headed households and the HIV/AIDS support groups. This organization was intended to provide support for children and families infected and/or affected by HIV and AIDS. Members of the support groups met once a week at Khanya to share their daily experiences. There was social, emotional and moral support provided by group members and also the professionals. In addition, information about the latest developments pertaining to their AIDS orphaned grandchildren and their own challenges was offered by the professionals and paraprofessionals respectively.

Thus, adopting a purposive sampling strategy allowed the researcher to identify and select appropriate and knowledgeable participants for the study. When prospective participants were identified, the researcher approached them and invited them to participate in the research project. They were then presented with the information sheet, (that is, a document that states the purpose, reasons for the study, and so forth) which was read to them due to their level of education (see Appendix 2).

3.4.4. Data collection method and instruments used

A rapport was developed with the grandmothers before the interviews began as some of the issues under investigation were likely to evoke emotional difficulty for the participants. Mutual trust was built to ensure cooperation of the interviewees (De Vos, 1998) and also to improve the quality of the data collected. As the sessions were

recorded, the participants were informed beforehand about the tape recording and their consent sought in advance. The grandparents signed both consent forms (see Appendix 2 & Appendix 3).

Scheduled face-to-face individual interviews were used to gather data. The interviews were semi-structured, that is, a list of questions and issues to be discussed was prepared prior to the interview. However, provision was made to probe for clarification and discussion of vital and relevant issues that arose during the interview. The research questions were written in English. However, the interviews were conducted in the grandmothers' first languages namely, the Southern-Sotho and isiZulu languages. The researcher herself speaks these languages. Each interview lasted about one-and-a-half to two hours. The face-to-face interview enabled the researcher to read the non-verbal communication of the grandmothers which was helpful in the study. The interviews were tape-recorded and the transcripts were translated and transcribed verbatim into English.

The responses were analyzed using the thematic content analysis method, which is a technique for gathering and analyzing content (that is, words, meanings, themes or any messages that can be communicated) of the text (Neuman, 2003). Certain themes or content relating to variation and common experiences of coping, social support structures, and the needs of the participants as caregivers were explored.

3.5 Ethical Considerations

All ethical considerations were adhered to. The ethical clearance certificate was obtained from the University in this regard (protocol number HO81001). Confidentiality was maintained with regard to the participants' responses and identities. Pseudonyms or codes were used to ensure anonymity. The researcher noticed that some of the material discussed during the interviews was often distressing for some participants. As a result, the interviewer needed to use her counseling skills to help the participants talk through some of these distressing emotions. Respect for the participants was ensured. These interventions were conducted discreetly and some participants were further referred for psycho-emotional support at Khanya Family Centre.

3.6 Part-Two: The Results

3.6.1 Introduction

The following presentation of the results is based on the findings of this study based on the broad themes of coping, social support and their sub-themes. The needs of grandmothers as caregivers for the AIDS orphaned grandchildren will also be presented in this chapter. But first the demographic information of all the participants in this study is presented below:

3.6.1.1 Table 1: Demographic Information.

Number of Participants=10. Key codes: A to J codes used.

(P=pension grants; CS=Child Support grants; FC= Foster Care grants)

Participants	Age	Residence	No. of dependants	Ages of Orphans	Own children	Grants
A	64 years	RDP	5	13 yrs; 9yrs	3	P = 0 CS=2xR190 Total income R380.00
B	65 years	Shack	7	5yrs; 4yrs; 3yrs; 1yrs-2moths	3	P=0 CS=IxR190 FC=2XR580 Total income R1350.00
C	67 years	Mortgage	4	14yrs; 12yrs; 8yrs; 7yrs	0	P=0 CS=0 Total income NIL
D	70 years	RDP	4	22yrs; 19yrs; 16yrs; 13yrs	0	P=R820 CS=0 Total income R820.00
E	76 years	RDP	2	18yrs	1	P=R820.00 FC=R850 Total income R1400.00
F	70 years	Standard house	4	17yrs; 15yrs; 10yrs; 8yrs	0	P=R820 CS=2xR180 Total income R1180.00
G	64 years	Standard house	4	4 yrs	1	P=R820.00 CS=R190.00 Total income R1010.00
H	86 years	Standard house	2	14yrs; 5yrs	0	P=R820.00 CS=IxR190 Total income R1010.00
I	64years	RDP	4	18yrs; 15yrs	2	P=0 FC=2xR500 Total income R1000.00
J	68years	Standard house	5	22yrs; 16yrs; 13yrs; 10yrs; 6yrs	0	P=R640.00 CS= R680.00 Total income R1320.00

Table 1 represents seven columns of the demographic data. The first column shows the pseudo-names of the participants. Column-two shows the ages of the participants. In column three, the type of dwelling/ residence of the participants is reflected. Column four is the number of dependants. In column five the ages of the orphaned grandchildren are indicated. The number of participants' own children is indicated in column six. Lastly, in column seven, an indication of the amounts and total income per household is indicated.

From the interviews and data presented in this chapter, certain themes or content relating to common experiences of the grandmothers as caregivers of the AIDS orphans were noticed when the grandmothers talked about certain challenges that impacted on their lives as caregivers. However, the researcher also noticed during the one-to-one interviews with the grandmothers the diversity among them. This meant that although the participants may have had common experiences, their lived experiences and perceptions varied regarding the caring for the orphaned grandchildren. It is also vital to note that this study presents only part of the grandmothers' experiences and what is not included are the voices of the grandchildren, relatives, friends, neighbours and Khanya Family Centre's support group organisers.

A number of themes were selected to explain the challenges the grandmothers faced in caring for the AIDS orphans. It appeared to the researcher that certain themes that emerged among the ten participants occurred more often than others. As a result, the presentation of the findings will be focused on the themes that were most common in the study. The presentation focuses first on sub-themes under the first category namely, "coping", followed by the sub-themes of the category "social support" and lastly, "the needs" of the grandmothers as reflected in the interviews.

3.6.2 Coping with Psycho-emotional Challenges

a) Anxiety and Stress-related Illnesses

Anxiety is a fundamental human emotion that is as old as human beings have been alive. The grandparents not only experienced anxiety in terms of overload at home as a result of the burden of caring for their grandchildren, but also reported experiencing stressful lives

in coping with the children's day-to-day needs. In addition, the grandmothers seemed to experience a range of anxieties from mild to severe forms. They stated that they felt helpless and had no hope under their circumstances. It also can be inferred that lack of control over their situation and its stressors appeared to impact on their health and emotional states. As a result of their conditions, the grandmothers stated that they worry a lot and that causes them to panic as they think about the children and were concerned about the children's conditions. Some of the comments included the following:

"My heart is pounding…this breaks my heart because it is like I am on and off."
"My chest hurts and it was getting harder to breathe….I thought I was going to die."
"There is other times when I cannot sleep…I think when you are stressed out this pain comes back."
"I don't sleep at night until morning thinking…."

The grandmothers also seemed to experience anxiety triggered by thoughts of dealing with their stressful situations. They expressed concern over financial issues, the death of their own children, their own impending mortality and an uncertain future for their grandchildren. Feelings of inadequacy seemed to overwhelm and cause them distress. They also felt that misfortune had befallen them and they would rather be with their grandchildren at home than risk the possibility of exposing their grandchildren to public abuse. The grandmothers also displayed some signs of restlessness and seemed to have difficulty in concentrating. They reported that they were tired most of the time from doing house chores. Two grandmothers stated:

"Lately it's getting worse. Sometimes I think I'm going crazy especially at night. I can't sleep for fear of what has to be done the next day".
"I thought I would die …my neck…I was so scared."

Some of the grandmothers reported experiencing pains in their limbs and that they were unable to carry on with their lives as before. They seemed to worry about their ability to function effectively and reported that their sleep patterns had changed. They explained that they did not know what could be the cause of their problems.

b) The Impact of Stress on Physical Health (Psycho-physiological effects)

The grandmothers were faced with the challenges of bringing up their orphaned grandchildren. The ages of the grandchildren varied per household. This appeared stressful for the grandmothers had to deal with the problems of discipline, teenage problems such as drinking, drugs, partying, smoking and so forth. On top of these problems, the grandmothers were faced with the burden of dealing with their personal problems associated with aging.

Sue et al., (1994) argue that there is a relationship between stress and illness. They further explain the role of emotional and psychological states in influencing the disease process. The participants (grandmothers) in the study complained about health issues such as pains in the chest and body. They also spoke of a lack of medication after the deaths of their children who had been the breadwinners. Grandmothers also reported constant thoughts about the deaths of their children and the concomitant insomnia. Additional problems included elevated high blood pressure, diabetes, migraines, muscle pains, arthritis, sore back, and so forth. Their responses on physical wellbeing were:

> "Stress and arthritis. I get disturbed by children's behaviour. I was sick during my daughter's death and I also have high blood, and sugar …the doctor told me to take it easy…"
> "Eish! …even now I go for my treatment for high blood pressure…it is stress…I don't know how to explain .." ; "I don't have energy anymore…this year is hard for me. I have a sore back and waist…" ; " I have high blood and knee problem. I take medication for high blood."
> "I struggle a lot and I need lots of medical attention and I forget what I say now"

From these responses it may be inferred that all the grandmothers in this study struggle with the impact of stressors on their physical wellbeing. Sue et al. (1994) argue that prolonged stress resulting from social or psychological stressors, may make a person more susceptible to illness and may also alter the course of a disease. Most of the grandmothers stated that they were not taking medication for their conditions. They cited transport and money problems as obstacles to obtain help as there was nobody to offer free transport. Others cited a shortage and non-availability of needed medication at the

clinic. The lack of intervention in this regard could only exacerbate the physical and emotional illnesses of the grandmothers.

c) Coping with Socio-Economic Demands

All the grandmothers in this study seemed to struggle with basic essentials such as food, clothing, school uniforms and transport money. This extended generally to poor household conditions such as disrepair. It was also observed that these grandmothers were involved in a daily struggle to fend for their grandchildren. They expressed their feelings about their current state of living as helpless, painful, hard, and a burden on their shoulders. The grandmothers sounded resigned to their misery as they did not believe anything could be done to overcome their situation. Their responses in terms of coping with the orphaned grandchildren under difficult conditions were:

> "It's painful my child …it is difficult, a burden on my shoulders" , "Oh…Oh…you don't know', "I try everything else, I don't have the energy now to go far", "There is nothing… we sleep in one room and I use sponges so that they can sleep". "Like now, these RDP houses they talk about or there will be time for them to build for us…if you don't have an ID…". "We need to pay R120.00 per month for transport…and the children also need pocket money as well…" "Thinking …when I wake up thinking", "My child I cannot stop thinking, because sometimes..."

Poverty was a significant factor that seemed to contribute to the existing stressful lives of these households. Most of the children and some grandmothers in these households were not receiving child support grants. Some of the reasons given by the grandmothers to account for this situation included the lack of documentation, the government's policy on the issue of grants, and the age of the older orphans who did not qualify according to government regulations for obtaining grants. Some families survived on the good will of some relatives or neighbours. Others stated that they went without food on some occasions. This problem was further compounded by the fact that the older grandchildren in some households were unemployed and thus depended on their grandparent's pension grants.

It appeared to the researcher that the grandmothers were under a lot of stress and pain. As a result, they became anxious to obtain help. Hunter (2000, cited in Uys & Cameron 2003, p162) argues that dealing with poverty is not just physical; it also impacts on social and economic relationships. It can be inferred that the families in these households were suffering from malnutrition as a result of poverty. This also implies a compromised immune system and exposure to infections. Lack of basic services was reported by some grandmothers in this study as causing them a stressful life.

d) Coping with Fear, Grief and Loss associated with HIV and AIDS

The grandmothers mentioned that they had lost one or more children to HIV and AIDS related illnesses. It seemed that the grandmothers not only had to deal with the loss of their children to HIV and AIDS but also had to deal with bringing up their orphaned grandchildren. The grandmothers dealt with these losses differently. Some seemed to mourn the loss of life itself and as a result they seemed depressed. Gerdes et al. (1988) argue that "loss" dominates the lives of older people and that a person suffering such losses is likely to manifest signs of stress of which depression, anxiety and defensive reactions are common. Some of the grandmothers in this study stated that they have vivid memories of their deceased children when they were sick and after they had died. Some of their responses included:

> "You know, when I think …[tears] …I miss her a lot such that I remember that her name means Gift…", " and then you start to think about the past and wonder why did my child die?"[tears]
> "I have suffered a lot in my life as a result …I feel sad when seeing children like this…I cannot throw them away… there is no one to go to… You know it feels like it happened yesterday" [tears] "I feel sad, these children don't have parents anymore and yet so young"
> "Now I see if I get sick…[tears] with stress as I don't want them to roam about at night because they can get into problems that will affect my health…", "I do get disturbed a lot…"[tears]

From these responses, it can be inferred that these elderly women were dealing with two issues regarding the death of their loved ones. They seemed to be dealing with the loss of their children and the task of bringing up the grandchildren, a situation further aggravated by the fact that they are old and helpless with no resources to provide for the household.

Thus, living under such stressful conditions may bring feelings of sadness and the pain of grief which can lead to depression. It is as Bowlby (1997, cited in Uys & Cameron, 2003, p75) cautions that, "people who avoid all conscious grieving will eventually breakdown with some form of depression."

e) Coping with the Defences of Stigma Associated with HIV and AIDS

According to the UNICEF (cited in Uys & Cameron, 2003, p176) "neither words nor statistics can adequately capture the human tragedy of children grieving for dying or dead parents stigmatised by society through association with HIVAIDS." Some grandmothers in this study revealed that their orphaned grandchildren reported that they were teased at school by their mates about the cause of the death of their parent(s) while others were confronted by their friends during play on the streets. These AIDS orphans appeared to face the possibility of stigma relating to their parents' deaths. The grandmothers stated that their grandchildren felt rejected or were treated with scorn by the community. While dealing with their own grief over the loss of their children, the stigma surrounding their deceased children has kept people, friends and relatives away from some grandmothers caring for AIDS orphans

It also appeared from the responses that some of the grandmothers learnt about the cause of painful death(s) of their children afterwards. They also appeared to have developed fears about HIV and AIDS related stories, print (like on T-shirts), and so on, because such symbols brought back sad and painful memories associated with people dying and their children left to suffer. In some households, the grandmothers stated that the children wanted to know about the cause of their parents' death. However, the grandmothers felt that it was better if the children remained ignorant because it was God's will. One grandmother said that she thought her daughter was bewitched. However, her daughter died at a hospice, where AIDS people were hospitalised.

In addition, the grandmothers were initially reluctant to identify the cause of their children's death. Only on prompting did they begin to utter phrases such as the following:

"The way I see it, I think it was this disease that now exists….they call it AIDS."
"It was the same with my second daughter, the same disease…this one…AIDS."
"Her husband also passed away…he had this disease…that is killing people, AIDS."
"The doctors did not say or tell us, but…maybe the siblings were told about HIV."
"But people kept talking while she was sick…had bronchitis …was too thin…on and off
To hospital…until this disease finished her…[tears]."

Hjelle and Ziegler (1981, p440) describe denial as a defence mechanism to protect oneself from unpleasant aspects of reality while Rogers (1959, cited in Hjelle & Ziegler, 1981, p414) refers to denial as a "defensive response whereby an individual preserves the integrity of his/her self-structure by avoiding any conscious recognition of threatening experiences." It can be inferred that the pain of openly revealing and talking about the cause of their children's death (s) to the public proved to be too much for the elderly to handle.

However, two out of ten grandmothers indicated that they knew from the beginning when their daughters were sick that they were suffering from AIDS. One of these grandmothers, whose daughter had died three years previously, related the death in detail as if it had recently occurred.

3.6.3 Social Support Systems

The grandmothers in the study were asked about the nature of social support systems available to help them cope. Specifically, the researcher wanted to know the support the grandmothers may or may not have received from their family members, their neighbours, the community, the church, any cultural organisation and the state. The responses were grouped into themes namely, Psycho-emotional Support, Physical and/or Material Support and Financial Support.

3.6.3.1 Psycho-emotional Support

Earlier in this discussion it was shown that the grandmothers were under a lot of stress and that they suffered from various ailments as a result. From the interview and observations it was evident that these grandmothers needed some form of social support

in order to cope with their day-to-day living and at the same time, be capable caregivers to their AIDS orphaned grandchildren.

Eight out of ten grandmothers stated that they did not get any emotional support from their families, neighbours or the church. Eight out of ten grandmothers said they were not emotionally supported by their families. Some cited a lack of family unity regarding this issue, pointing out that some family members were overwhelmed by problems of their own. Some of the grandmothers reported that their families consciously decided not to help them with the grandchildren, making excuses and so on. This was not the case for two grandmothers in the study. They received some form of emotional support from their families, mostly from their surviving daughters. The grandmothers stated that they usually talked about the behaviour of the older grandchildren and how they could get help from the social workers.

It also emerged that most grandmothers lacked support from their neighbours. The grandmothers' responses on this issue indicated that they were not ready to open up. It also seemed that most grandmothers were preoccupied with their own stress, feelings of sadness, frustration and were not willing to accept any help or talk about sensitive issues surrounding family deaths. Others stated that some neighbours were abusive and as such it was better to stay away from them. Some of their responses were:

> "No help from them. I stay in the house because I don't want to bother them…"
> "We just get along by asking, How are you …?"
> "This one [pointing at neighbour's house]…she started to insult me badly…insulting me like…]
> "I am now stressed…it is now stress and people say maybe I also have this disease, because I am thin…this disease [tears]".

The grandmothers indicated that they lacked the energy to deal with their ordeal and to look after the children too. However, others stated that they used to talk to one or two neighbours about the weather and general matters of no importance to while away time but that does not happen anymore.

The grandmothers' responses about church support varied. Most of them stated that they only went to church to pray. Some stated that they attended church services because they were old and would like to be buried with dignity. Others indicated that they attended church because they had been paying their pledge/ church funds for quite some time and therefore realised that there was no way that they could stop as they were looking forward to their ultimate resting places, their graves. Some of their responses were:

> "I don't get help from them, but I do go there only to pray", "I go to church because it is a chance because I will die and not have people to bury me…I must have mourners…"
> "It will be sadness for the children if I die…", "No support from the church at all."

Two grandmothers reported that they attended church every Sunday and prayer meetings on Thursdays in order to receive spiritual healing particularly when they discussed problems with other grandparents. One grandmother added that she received emotional support from one of the members of the church who was a counsellor and a retired social worker.

All ten grandmothers in the study stated that they had attended a grandparents' support group at Khanya Family Centre**,** a Non-Governmental Organisation, in Katlehong, Ekurhuleni West. In their responses they stated that they received emotional support in their groups. They indicated that counselling sessions were conducted by a health professional and the para-professionals. Some grandmothers pointed out that the Centre had trained volunteers who visited the families at least once or twice a month to check on the family needs and as part of the NGO's programme. The grandmothers appeared to have been involved in discussions with volunteers and seemed to have benefited to some degree. These were some of their responses:

> "They would come and we discussed the children's behaviour and share ideas."
> "We met with other grannies…learn about the disease and share information and give support."
> "It helped us to understand life"
> "They sometimes send me food parcels if there is any left."
> "We used to go to granny's group where we were told not to be stressed."
> "Sometimes my heart becomes better when I'm with other grannies in the group."

"We used to share ideas …children had difficulties."

However, not all the grandparents held the same views about the support group. Some grandmothers were of the opinion that they did not benefit much from the support group because they believed that the sessions were terminated prematurely. It also appeared that some grandmothers were not free to talk about their problems in the group. These were some of their responses:

"We used to go to meetings…in the support group but, recently they did not call me…."
"I could not go there every time, transport money was my main problem."
"And I don't know if I should tell them that there is something that is troubling me…[tears].
"I have a stressful life, I am suffering and that I have problems with the boys, but no group now."
"A lot of other grannies want a group but there is none now, they should have stayed longer."
"You see Khanya is far from my place, we were told that it will be created in our area, but this did not happen…a lot of other grannies want a support group, I don't know now…."

The grandmothers indicated that ever since they left the support group things have changed. They used to have support within a larger group. Most concurred that the group had helped them during difficult times to curb loneliness, relieved their stress to some degree, and that their depression and stress levels during this time were low. The grandmothers appeared to think that the support group had strengthened their sense of self-worth and they had seen a great need to care for their grandchildren the best way they could. But, all that had disappeared since the group at the moment of conducting interviews was defunct. They wished for the Centre to re-call them as promised.

3.6.3.2 Physical/Material Support

In their interview responses the grandmothers revealed that they had benefited materially from attending a support group because they were each offered food parcels twice a month. They seemed disappointed that the Centre had changed the frequency to once a month due to rising demand within the community as a whole. The grandparents further stated that this cut had made life unbearable as they were under pressure to care for their growing grandchildren and other related demands. Other grandparents also indicated that

their grandchildren had once received school uniforms from the Centre, but the grandchildren had since outgrown these and none were being issued out.

In addition, two grandmothers stated that they also worked in the vegetable garden, while others were involved in beadwork at the Centre. Not only did they benefit from the produce, they also were able to keep their hypertension low and their energy levels had improved. They attributed their improved health conditions to among other things, the support received from other group members and that they befriended each other not only at the Centre but their homes as well. Some grandmothers indicated that they had gained confidants and thus felt that they were cared for and valued.

Support from family members and relatives did not feature prominently in these households. Six out of ten grandmothers stated that they were unsupported by their families. They cited difficulties experienced by their relatives in families of the latter. Others indicated that they had nobody to go to in terms of support. Their responses varied as some indicated that initially they were a small family due to early deaths in their families. Other grandmothers revealed that their family numbers were reduced due to political violence and unrest in the community, and some family members were murdered in their teens.

However, four of the grandmothers indicated that they were to some extent, supported by their families. Their responses concerning support by family members varied. Some indicated that their unemployed children and some of their older grandchildren helped with the younger ones and house chores. Nonetheless, they all cited difficulties compounded by their inability to cater and care for their grandchildren effectively. The grandparents stated that they encountered challenges concerning material needs such as food, clothing, school fees and so forth. They seemed frustrated by the fact that they also had their older grandchildren who had completed schooling but were unable to find jobs, while their uncles and aunts were not employed as well. For the grandmothers these were also problems because the out-of-school youngsters were vulnerable to various kinds of

social ills such as mingling with wrong friends, gangsters, and the possibility of getting involved in crime.

As mentioned before, most of the grandmothers in the study suffer from one or multiple conditions related to stress and old age. However, they stated during the interviews that they struggle to gain entry to support services such as healthcare. They seemed to struggle to receive medical treatment at clinics and state hospitals. Some of them indicated that they had no money to buy medication for themselves and/or their grandchildren. Others believed that travelling long distances at their ages had worsened their conditions. Some of their responses were:

> "I went to clinic for my high blood, pains in the body and injured arm…got car accident, you see, now the nurse there told me come next time because the HB pills were finished."
> "I don't go there anymore. I don't have money for transport to take me there. It is far…"
> "This one is coughing but they gave her some medicine but she does not become better… She was even worse when her mother was still alive, I don't have money to take her to the doctors nearby, they will want R200. I don't have…this is difficult for me now…[tears]".

3.6.3.3 Financial Support

a) Child Support Grant

According to the South African Policy of Child Support Grants (Social Development and Grants, 1994) "anyone who is poor and looks after a child of up to 8 years old can apply for a child support grant of R180 per month. In 2004, it was extended to children of up to 10 years of age and in 2005 it was extended to children of up to 13 years of age." This child support grant increased by only R10 to R190.00 as of 2007.

Eight out of ten grandmothers interviewed indicated that their grandchildren received child support grants and these grandchildren were less than 14 years old. In these households however, there were some grandchildren who were dependent on their grandmothers for support as they were still at school but were over aged to qualify for the child support grant under the South African policy on child grants.

b) Foster Care Grant

Three grandmothers in the study stated that they received foster care grants for their grandchildren. However, they indicated that the procedure was extremely tedious and time consuming because of long waiting lists and queues.

c) Retirement Pension

All ten grandmothers in this study were over sixty years old and therefore qualified for a state pension grant. Six out of ten grandmothers stated that they received a state pension grant. Much as the six grandmothers received state pension grants, they made it clear that they could barely survive on them as the money was a paltry figure.

The remaining four grandmothers cited difficulties in obtaining identity documentation. They complained that they had been sent from pillar to post by the Departments of Social Services and Home Affairs. Some of the grandmothers' difficulties resulted from family disputes. These elderly mothers indicated that some family members wanted to have child grant money but were not prepared to take care of the orphans. Some of these grandmothers argued that the procedure for the registration of the grants and their identity documents took too long. They also indicated that they had to go to town for registration which cost a lot of money. These grandmothers argued that the system of grant applications and delivery of grants was not properly managed as they had been promised by the state that the orphans would get first preference in dealing with their conditions and that the grandparent caregivers would be helped to manage the AIDS orphans in their households. The state was said to be either slow or did not deliver on these promises.

One grandmother indicated that she found it frustrating and difficult to manage the child grant she received for her two grandchildren because she had to ask her daughter to apply on her behalf since she had no identity document. Thus she did not have direct access to the grant money and that frustrated her a lot. One grandmother said that unless she did casual jobs (such as ironing clothes) for her neighbour, the family went without food. She also complained of a knee problem saying she had no choice as she was awaiting her application and that of her four grandchildren for identity documents to be approved.

Another grandmother indicated that she was waiting for an application for foster care rights for her two grandchildren who in the meantime were receiving child grant support.

It emerged that most of the grandmothers, because of their responsibilities as caregivers, were less able to supplement their meagre income (social grants and pension in some households) with any physical work due to their age and health condition. In their responses to financial support provided by their families, most of the grandmothers indicated that they did not receive any financial assistance from their families. Only four out of ten stated that their families would help occasionally.

d) Housing and service facilities

The grandmothers lived with their orphaned grandchildren in their homes. From the observations made and interview responses, there was a significant difference in family size amongst these households. Some families lived in a shack, while the majority lived in small houses (one bed-roomed) with all their grandchildren and the grandmothers' own sons or daughters (in some households). Some grandmothers indicated that the state had promised to build affordable houses for the poor but little had been done to alleviate their conditions. Some grandmothers stated that their households had a number of orphans all depending on a very low income and as a result, the grandmothers were aware of higher mental and physical difficulties because of their inability to meet healthcare and household costs. However, three grandmothers who owned upgraded houses complained about the burden of bond payments, a debt left by their deceased spouses and/or their children.

Most of the grandmothers complained about inadequate service delivery in their community. They stated that there was no proper water supply and some of them were without electricity in their households, while some grandmothers complained about school transportation for their grandchildren as there were no higher grade schools nearby.

3.6.3.4 Needs Identified

From the interview responses and observations, it was clear that the grandmothers struggled with various aspects needed to cope with their roles as caregivers for orphaned grandchildren. Some of the difficulties or challenges that prevented them from effectively coping with the day-to-day running of their households will be presented in this chapter.

a) Psycho-emotional Support

The grandmothers appeared to experience stress. They indicated that this was a result of the added responsibilities of looking after the orphans. They seemed to worry about their financial state and were concerned about the future of their grandchildren should the grandmothers die suddenly. Some of the grandmothers appeared to have experienced feelings of helplessness and anxiety, compounded by their inability to understand their situations and as a result seemed vulnerable to illnesses and depression. They appeared to be grieving the loss of their daughter(s) and/or son(s) to HIV and AIDS related illnesses, a subject that is not spoken about openly in their households. Some grandmothers indicated that the children's reactions to their parents' death varied. Some did not know what to tell their grandchildren about the death of their parents. They reported examples such as, "children became withdrawn, confused, afraid, ambivalent, and so on". These reactions seemed to have affected the grandmothers' emotional and psychological wellbeing. They indicated a need for psychological help for the grandchildren. They indicated also that they needed support groups to be able to discuss issues that affected them. Spiritual support was also cited as something the grandmothers really needed. Some regretted that they could not attend church prayer meetings due to their deteriorating health. Most spoke of a need to talk to healthcare professionals for counselling.

b) Socio-economic Support

Inefficiency by state officials in the registering of beneficiaries for child grants and pension grants seemed to have caused severe strain for households. Some households could barely survive the financial constraints that came with these delays. The grandmother caregivers appeared to have carried these burdens alone for quite some time.

Some seemed to have waited too long for their applications to be approved by the state, while those who received financial support from the state felt that the grants were not enough to cover the children's basic needs. The grandmothers also cited a need for exemptions or reduction in all school related fees, particularly for the older school children, since these orphans depended entirely on the grandmothers for support. In addition, the grandmothers expressed a desire to continue with their support groups at Khanya. Those who lived far from Khanya felt that similar support groups could be opened nearer their homes to eliminate travel costs.

c) Social Support Needs

Most of the grandmothers who had older grandchildren in their households indicated that their major concern was to find support for these children since some of them were out of school and jobless. Some of these orphaned grandchildren had passed their matriculation examination but could not find employment. The grandmothers expressed concern over their grandchildren's vulnerability to abuse and vices in their crime ridden environments. They appealed for help in securing the safety and positive development of these older grandchildren.

3.7 Conclusion

This chapter was divided into two parts. The first part was the method section and the second part the findings of the study. In the first part, the research aims, the rationale for the study, the design, participants, and the procedures of data collection were explained. Some ethical considerations were observed during the study.

The second part of this chapter reported the findings. Ten grandmothers who were interviewed in their households seemed to have experienced psycho-emotional, psycho-physiological and socio-economic problems as a result of lack of social support to cope with the day-to-day functioning of their households. There were some commonalities and variations in their responses and these dimensions were reported in this chapter. It was also revealed how the burden of caring for orphaned grandchildren had impacted on their lives as elderly women. Some of their ordeals mentioned in this section were the

difficulties in obtaining children's grants, their pensions and the inefficiency of state officials in the delivery of these services.

Housing, water supply, transport and the cost of running households were among other things that exerted pressure on the grandmothers. In addition, the grandmothers needed support in order to cope with their roles as caregivers. Unless this was realised, their functions and the vital roles they played in the lives of the needy orphans would be stressful and possibly detrimental to their lives.

The following chapter will focus on the discussion of the findings/results of this study. This will be done in relation to the literature reviewed. Furthermore, the Ecosystemic theoretical model described in chapter 2 will used to expatiate on the findings.

CHAPTER 4
DISCUSSION

4.1 Introduction

This chapter explicates the study's findings, in order to communicate an understanding of what the grandmothers were going through. The interpretation of the study aims to capture similarities and differences by means of selected evidence, against the background of the existing theoretical framework, as well as including relevant literature on coping, social support and the needs of grandmothers as caregivers for the AIDS orphans. The descriptions and interpretations of the main factors namely, coping, social support and needs, which may influence the grandmothers' ability to perform as caregivers will then be integrated into a concluding discussion.

4.2 Interpretation of Findings

The descriptions and interpretations of the main categories of the challenges faced by the grandmothers as caregivers are discussed below. From the three main categories namely, coping, social support and the needs of the grandmothers, several sub-categories emerged which were also developed to describe the impact of these categories and the challenges faced by the grandmothers. These include coping with psycho-emotional challenges, the impact of stress on physical health, coping with socio-economic demands, coping with fear, grief and loss associated with HIV and AIDS, and coping with the stigmatisation associated with HIV and AIDS.

From the social support systems category, the sub-categories that emerged were psycho-emotional support, physical or material support, and financial support. The needs identified by the participants included psycho-emotional support, socio-economic support and social support needs. An attempt to answer the research questions will be discussed in conjunction with the results of the study in conjunction with the Ecosystemic theoretical framework mentioned in Chapter 2, and the relevant literature reviewed in Chapter 1.

As noted in Chapter 2, the Ecosystemic theoretical framework allows one to examine more carefully the themes emerging from the study. Therefore, this theoretical framework will be used to interpret the meaning and complexity of the grandmothers' situation. It will be noted that the four levels of the Ecosystemic theoretical framework are interdependent and interact at different levels. But for purposes of clarity, the levels will be discussed individually and then linked to the categories (and sub-categories) of coping, social support systems and the needs of grandmothers as caregivers.

4.2.1 Level 1: History/Life Events

This section discusses the events occurring in the lives of grandmothers struggling to cope with stressors such as death, trauma, illnesses, abuse, divorce, lack of shelter, food, and so on.

All ten participants identified trauma experienced following the death of their loved ones due to HIV and AIDS related illnesses. Some of them had suffered multiple losses as a result of the AIDS pandemic, in some cases murder and township violence. Often during the interviews some of the grandmothers were unable to contain their hurt and distress. This situation became difficult for the researcher as well. In some situations, the interviews were stopped to calm down the grandmothers. The emotional condition of the grandmothers can be described as a phase of yearning for the lost person which may last for months or years. These grandmothers were given some counselling as the researcher is trained in this field. They were later referred to healthcare workers (social workers and psychologists) at Khanya Family Centre for emotional support. It was also noticed that these grandmothers suffered intense and severe emotional pain at losing their children who in some instances had been the sole breadwinners in the family. It also appeared to the researcher that talking about the traumatic events opened wounds that had barely healed. Some of the grandmothers were given the option to withdraw from the interview but they opted to continue talking. In a way the interview became an outlet for their stress and pain. They related the deaths of their children as if they had happened recently.

Participants also mentioned the stress of caring for orphans and that they had no option but to care for their grandchildren. Some participants added that caring for their grandchildren was made difficult by the fact that there was none or little financial support to effectively cope with their situation. The grandmothers stated that the orphaned grandchildren's needs and demands were impossible to meet under such impoverished conditions. While some grandmothers received pension grants, some of their orphaned grandchildren could not be registered for a child support grant due to lack of birth documentation, lack of parent's death certificate, and for reasons not clear to the grandparent. However, situations differed from household to household. Some grandmothers stated that what was more painful was the fact that even the pension they received was insufficient to cover costs of food, clothing, rent, water and electricity.

The grandmothers complained that their financial difficulty was further aggravated by the fact that some of their orphaned grandchildren were excluded from the child grant support system because they were over aged. They stated that this had further negatively affected their health conditions. The majority of grandmothers, if not all, suffered from two or more stress related illnesses, such as hypertension, diabetes, depression, preoccupied thoughts, feelings of sadness, sleep disorders, and fear of their own death. They also feared the worst for their grandchildren as the grandchildren were vulnerable to crime, abuse, maladjusted behaviour, and so on.

Lazarus (1976, cited in Paul, 1998) argues that environmental conditions and their related psychosocial stressors may be harmful to the person trying to adjust to these conditions. This was evident in the situation of these elderly women because they were prone to a variety of illnesses that had negatively affected their health in trying to deal with their situations. Minkler (1999) and Burton (1992) argue that studies have constantly showed that grandparents experience social isolation, financial, physical and emotional hardship. These studies confirm the difficulties faced by the grandmothers in this study as they were faced with hardships of struggling in isolation, having little or no support to alleviate their predicament. The pressure seemed unbearable in their roles as elderly caregivers. Some of the reasons for their frustrations included the fact that they were the

biological grandmothers of these orphans and that the orphaned grandchildren were left in their care.

The grandmothers were also confronted with the challenges of paying off the debts left behind by deceased family members. Two grandmothers indicated that they had to repay exorbitant amounts for house mortgages accrued when their spouses were employed. These grandmothers had no financial income other than their pension grants. They indicated that this was very stressful as they had an added burden of caring for their orphaned grandchildren. Another grandmother in the same situation stated that the family had been ordered by bank authorities to inherit the mortgage bond of the house that is in her son's name, or be faced with the possibility of losing it to another person who would settle the debt. She revealed that this was painful and stressful because she had nowhere to go with her four orphans. This situation contributed to her already existing difficulties. As a result, it affected her physically and emotionally. All these grandmothers stated that if supported, life would be different and bearable to some extent.

Some grandmothers were not only faced with the stressful challenges of caring for the orphans, but also dealing with the traumatic experiences of their personal history. Three grandmothers described their painful past stemming from abusive marital relationships. They were victims of divorce and indicated that they had lost everything they had worked for. For example, they had lost their belongings, houses, relatives, and so forth. It can also be inferred that these grandmothers did not only mourn the loss of their children, but also the loss of material belongings. Some of the added burdens to the grandmothers will be discussed in detail under Level 4 of the Ecosystemic model namely, the political and socioeconomic status characteristics. The next level deals with the external conditions that induce internal conditions of the grandmothers in their roles as caregivers.

4.2.2 Level 2: Intrapersonal Characteristics

In this level of the Ecosystemic theoretical model (described in Chapter 2) in order to understand the grandmothers' unique characteristics that may or may not contribute to their challenges as caregivers of the orphaned grandchildren, intrapersonal characteristics

or predispositions such as age, gender, emotional, motivational level and learning ability are discussed. In addition, this study showed that there is a significant relationship between intrapersonal characteristics unique to the grandmothers in terms of their coping, social support systems availability and their needs as caregivers. As noted in Chapter 2, the intrapersonal characteristics may consist of any aspect that comes from within a person that is genetically predetermined and not learnt. In addition, the research literature (explained in Chapter 1) pertaining to this level will be integrated to shed more light on the grandmothers' situation.

4.2.2.1 Age of the participants

The grandmothers in this study were between the ages of sixty-four and eighty-six (mean age of 69,4). This is the retirement stage where these grandmothers, as in some cultures, could be enjoying life and be taken care of by their offspring. But this was not the case with the grandmothers in this study. They had become parents again of their orphaned grandchildren. They were faced with challenges and demands that come with parenting. It appeared they had no choice as they were forced by circumstances to continue the journey of 'motherhood' until they died. In addition, these elderly women may have been influenced by environments that exerted distress and painful feelings on them. For example, these grandmothers struggled with health issues and physical signs of ageing, such as lack of stamina, loss of cognitive abilities, social roles, and so on.

As discussed in Chapter 2, challenging life events can be stressful for elderly persons taking into account their age and many roles they need to play in the life of the child. Rodin (1980, cited in Garmezy & Rutter, 1983) found that the transition from adulthood to old age may present loss of control both physiologically and psychologically. He further argued that the ability to sustain a sense of personal control in old age may be influenced by societal factors that may eventually affect the physical wellbeing of the aged individual. From this observation, it is clear that the grandmothers' stressful lives are further aggravated by the inability to receive external support.

The grandmothers relied also on their acquired skills and knowledge about childrearing to cope with their demanding roles as caregivers. However, little is known about the painful and stressful lives they led in their roles as caregivers. At this stage of development (that is, late adulthood), they seemed to be vulnerable to various illnesses, and needed support systems in order to meet the challenges of the ever changing modern ways of living in an urban society. As noted in Chapter 1, Defilippi (2000, cited in Uys & Cameron, 2003, p164) argues that the elderly are "the very segment of society that ought to be receiving protection and care but instead these grandmothers attempt to stretch their meagre pension to be able to provide food and schooling for their orphaned grandchildren". One grandmother put it this way in her interview: "*for a person to cope, you need money…money is everything in life for us…"*

4.2.2.2 Gender characteristics

The studies conducted by Turton (1986); Thoits (1984); Dawes and Tredoux (1989, cited in Harcombe, 1993) suggest that women and girls experience more undesirable life events than males, and display a higher proportion of stress reactions than males do. This finding was also evident in the present study. UNICEF (2007) supports this view that, elderly women are among the most vulnerable and marginalised members of society. In this regard Lewis (2007) states that the seldom told experiences of grandparents who care for children orphaned by AIDS reveal the enormous burden that orphaning is exerting on them. The majority of these elderly women were not receiving treatment or support for stress. There is no doubt then why these grandmothers experienced pain and stress in their roles as caregivers. In addition, studies conducted by Bor and Elford (1998); Herek and Glunt (1988) demonstrated that HIV and AIDS are stigmatising illnesses. These two scholars argue that people living with HIV and AIDS and their support networks experience a particular and intense type of stigmatisation as compared to people with other medical conditions. These findings support the present study of grandmothers in particular because of the nature of the death(s) of their daughter(s) and/or son(s). In some of these grandmothers' households the number of AIDS orphans was found to be

between one and five. Some grandmothers felt that their grandchildren were discriminated against by their peers, school and society.

The following section will discuss the grandmothers' emotional status in dealing with the challenges of caring for these orphaned grandchildren.

4.2.2.3 Emotional characteristics

This section is the sub-system of the intrapersonal dimension of the Ecosystemic model (see Figure 1 in Chapter 1) that deals with the individual differences in emotional levels. According to Wolff (1981) and Strelau (1989), the use of defence mechanisms to deal with anxiety is evident which may connect the characteristics (of this level) to coping with stressful life events. The above statement supports the findings of this study in that the use of defence mechanisms appeared to be present in the ways the grandmothers responded in interviews. Some of the grandmothers tried to hide their feelings of pain and sadness. They stated that there was nothing wrong with caring for their grandchildren and that they were happy in their roles. This behaviour could be attributed to the fact that the researcher was an outsider and that they were not ready to disclose their emotions. After prompting, these grandmothers began to shed tears and there was sadness and pain in their expressions. They started to open up, revealing their painful experiences. Six of the grandmothers received emotional support from the researcher (as she was trained in this field). They were later referred for further counselling sessions. It was clear to the researcher that these grandmothers had lived their lives under unbearable conditions. Most of these grandmothers stated that they were struggling to cope with day-to-day psychosocial demands. This experience was traumatic for the grandmothers and was accompanied by feelings of distress, forgetfulness, denial, inadequacy, and so on.

In addition, while the grandmothers continued to endure the pain of being caregivers, what became interesting to the researcher was their resilience in the face of these unfavourable conditions. Two additional characteristics that could have played a part in some of the grandmothers' internal and external adaptation under challenging conditions

emerged from the interviews. These were: motivation and learning ability. These will be discussed in the following sub-section.

4.2.2.4 Additional discussion: motivation and learning ability

There is no doubt that the grandmothers in this study suffered the hardships of caring for their orphaned grandchildren. It was noted that all these grandmothers were motivated by the desire to be with their grandchildren during their (orphans') difficult times. They could have abandoned them but opted to be their 'mothers.' Two grandmothers shared this view: "*she now calls me mother because she has never seen her mother before. Her mother passed away during the birth of this child" ; "I am happy because I am here for him, I'm his mother and I will do my best to see to that he gets the best in life even if I'm struggling, but I will struggle with him".*

The elderly women stated that they had learnt a variety of skills at Khanya Family Centre during their support group sessions. For example, they had been trained to be creative in bead-making, card-making, and to work with AIDS infected people. While other grandmothers did not feel free to talk about HIV and AIDS related issues, two grandmothers indicated that they were able to transfer the skills learnt about the disease to other members in their communities. It was also interesting to note that there were grandmothers who played an advocacy role in supporting those infected and affected by HIV and AIDS or those who suffered from other chronic illnesses, such as cancer and diabetes. However, the community seemed not to acknowledge elderly people as useful and knowledgeable. These findings are supported by Blythe (1979); Butler (1982); Kennedy and Scheidt (1979, cited in Gerdes et al, 1988) who expose some of the stereotypes and myths of ageing such as "old age is a period of tranquillity and serenity." It was not the case with the grandmothers in this study as some of them continued to do some work for the community.

From the above discussion, it is evident that there is a strong relationship between the grandmothers' stressors and their differences in emotional levels in coping with the challenging situations.

It is therefore necessary to discuss their means of coping in the face of their challenges as carers. The following discussion will be based on the interpersonal characteristics, that is, the social support systems available to these grandmothers as caregivers.

4.2.3 Level 3: Interpersonal Characteristics

This level refers to the role of significant others in the individual's life. More specifically it refers to the social support systems surrounding the individual such as family, friends, community, church, government, and so forth.

The grandmothers in this study struggled to obtain support from their families. They indicated that some or most of their family members were unable to financially support them due to socio-economic difficulties affecting the country as a whole. However, some grandmothers indicated that they had no-one to support them due to tragedies that had befallen their families. Others stated that their relatives and friends occasionally assisted wherever they could. They indicated however, that this support was not enough to meet the demands for food, clothing, and school-uniforms for the grandchildren.

The grandmothers indicated that they did not receive support from their neighbours. This behaviour was rare in the past, as the neighbours were the second best source of support when the family was destitute. But, this is not the case in contemporary society where poverty and unemployment are rife. It can be inferred that the cost of living, as one grandmother indicated in this study, contributed to a lack of support by neighbours. Some grandmothers stated that they had received some form of support from neighbours, but that it had since stopped because the neighbours had lost their jobs. Other grandmothers reported that they were verbally abused by their neighbours who constantly reminded them of the cause of their children's death(s). According to the grandmothers, such behaviours by their neighbours exacerbated their emotional pain. Ferreira (2002) supports this study's findings that in South Africa, older women caring for children affected by HIV and AIDS referred to a scarcity of food and a day-to-day struggle to get enough food to feed the family. In addition, to support the findings of this study, Harcombe (1993)

reviewed the Thurton study dealing with disadvantaged black South African adults and showed that social support acted as a buffer between the person and stressful events. This study also suggested that individuals who were unsupported were more adversely affected by stressful life events than those who had some social support.

It is interesting also to note that even the church was unable to support these destitute families. While it was historically part of the church's duties to take care of the poor, sick, orphans and their families, this seemed not to happen anymore. While some grandmothers indicated that they only went to church to pray, to receive spiritual healing, some were preoccupied with death as they indicated that they would like to have decent burials. In this regard van Dyk's (2005) idea that by listening to comforting words of compassion and relief from suffering through religious institutions, elderly caregivers may get the inner strength to endure difficult situations. Some felt no need to attend church sermons anymore because there was nothing to gain from them. It should be noted that it seemed that these grandmothers had lost hope in faith due to their painful and stressful lives and poor living conditions.

All the grandmothers in this study attended a grandparent-headed-household support group at Khanya Family Centre, a Non-Governmental Organisation, west of Ekurhuleni, on the outskirts of Johannesburg. They pointed out that they received emotional, physical and material support at the centre. They also indicated that they were offered school uniforms, food parcels, and were assisted with applications for grants for their AIDS orphaned grandchildren. The support group met once or twice a month and after sessions, the grandmothers were given food parcels, that is, groceries. Some grandmothers were also involved in a vegetable garden, beadwork, and card designing project for income generation. Some of these grandmothers stated that working in the vegetable garden helped them to stay emotionally and physically fit. This work also helped them to alleviate stress levels as they would concentrate on positive things rather than worrying about their desperate situations.

However, all the grandmothers were concerned about their support group that had been prematurely terminated, resulting in feelings of sadness and abandonment. They indicated that they had already adjusted to this situation but had nobody to relate to in terms of the needs of the orphans. They also indicated that they had made friends and supported one another in the group and all of this had been lost. The reduction of the frequency and quantity of food parcels was another added factor to their stressful lives. Food parcels according to the grandmothers were only issued once a month, from twice over the same period, which seemed to have affected these families drastically. They indicated that they would like to continue to be part of the support group which they were promised by the Centre would be reinstated. The grandmothers said that they were physically unfit to travel long distances to the Centre. As a result, some grandmothers could not attend support group sessions anymore. Some of them reported that financial difficulty contributed to a lack of attendance at Khanya Family Centre. During the interviews, some of these grandmothers were referred to Khanya Family Centre for emotional support as it became difficult for them to handle some aspects of the interview.

While the grandmothers had concerns about their terminated support group, they had to face yet another burden of dealing with the discriminatory laws of South Africa. While various support systems are a necessity for these elderly people to function effectively in their roles as caregivers to orphaned grandchildren, some of South Africa's political and socio-economic structures from the past must be discussed in order to understand the impact these structures had on these grandmothers. The following discussion attempts to elucidate this point.

4.2.4 Level 4: Political and Socio-Economic Status Characteristics

The grandmothers in this study are victims of the legacy of apartheid policies. These political and socio-economic policies impacted on the lives of the people and the elderly in particular. Laws and policies were implemented to undermine certain races (blacks in particular), cultural and ethnic groups. The grandmothers reported that they had suffered from civil unrest during apartheid, which had left many houses burnt, and/or destroyed and many lives lost. Some of their documents got lost during civil unrest. This resulted in

some of them failing to obtain pension grants and applying for child support grants for their orphaned grandchildren. Their grandchildren were unemployed and lived a life of fear in the townships. Their children and older grandchildren were victims of violence and crime that saw the closing of many schools caused by faction fighting before independence in 1994.

The grandmothers added that they did not have proper medication for their ailments and their communities lacked health facilities. These grandmothers suffered from various conditions such as high blood pressure, diabetes, headaches, arthritis, and so forth. They were among a group of women discriminated against under apartheid policies regarding health care service delivery. The grandmothers reported that they were sent back home without medication by the healthcare workers on several occasions even in independent South Africa. They also pointed out that they could not seek employment even if they wanted to due to their ageing and poor physical condition. Some of them were forced to occasionally do house-work like ironing and washing clothes for their neighbours, in spite of their poor health, in order to survive.

Some of the grandmothers had lost their houses due to forced removals and had been placed in areas that were not conducive or habitable. Others lived in small shelters. Still, others lived in informal settlements, referred to as shacks. These elderly women were promised houses by the government, but the government had not delivered its promise.

Regardless of their difficulties, the grandmothers continued to live, adapt and attempt to cope. This finding is supported by Masten (2001, cited in Kralik, van Loon & Visentin, 2006) who states that resilience refers to good outcomes in spite of serious threats to adaptation. In addition, it should be kept in mind that, intrapersonal characteristics, history of life events, the social and economic backgrounds can predispose elderly women to an inability to cope with the demands of caring for their orphaned grandchildren. However, how they deal with these, may depend on their individual level of resilience and their social support systems.

From the above discussion, it is evident that the grandmothers required a significant amount of support in order to effectively realise their roles as caregivers. Their needs will be discussed next.

4.2.5 The Needs Identified by grandmothers

Some of the needs identified by the grandmothers from the main category 'needs' included, psycho-emotional support, socio-economic support and social support needs.

4.2.5.1 Psycho-emotional support

The grandmothers were under a lot of stress. They obviously grieved and mourned the deaths of their children to HIV and AIDS related illnesses. Their feelings of helplessness and anxiety were aggravated by their inability to understand the situation in which they found themselves. They reported various illnesses such as hypertension, diabetes, arthritis, sleep disturbances, feelings of distress, indiscriminate pain in their bodies, and so forth. These conditions affected their physical wellbeing as they reported that they had no energy to carry out household duties that they had done with ease before. These grandmothers stated that they needed individual and/or familial emotional support (family counselling, individual therapy) for their grandchildren to deal with the death of their parents and other challenges.

The grandmothers felt that they had benefited emotionally, physically and socially from attending a grandparents' support group at Khanya Family Centre in the past. They reported that they would like Khanya Family Centre to reconsider opening another group as promised by the Centre. This was understandable as some of these grandmothers stated that they had built relationships with some members in the support group. They had benefited from socialising with other grandparents in the group by talking, working in the vegetable gardens, designing cards and learning about HIV and AIDS. They also would like to see a revision of the food parcels system because they could not cope without them.

4.2.5.2 Socio-Economic Support

The grandmothers struggled with the lack of child grants. Those who received child support grants felt that the amounts were insufficient to meet basic needs. The grandmothers indicated that government should help them by exempting their charges from school fees. They also needed support for the older children who were then beneficiaries of the grant system to be included in the grants policies since they were dependent on them (grandmothers) for support. The women also struggled with applications for their pension and some with child grants. They expressed a desire that the government put in place structures that would effectively assist them. Some could not afford to wait longer for the applications to be processed. Other needs and requests included the speeding up of affordable houses they were promised by the government and accessibility to health care facilities.

4.3 Conclusion

In this chapter, a discussion of the findings of this study was integrated with the research literature and also the use of the Ecosystemic theoretical model was used in order to discuss and integrate the various factors that impacted on the lives of the grandmothers as caregivers of their AIDS orphaned grandchildren. The categories and sub-categories of coping and social support from the interviews were discussed using this model to assess the grandmothers' situation.

It is evident from the findings of this study and the discussion in this chapter and other studies mentioned in this report that there is considerable amount of empirical evidence to suggest that elderly women caring for AIDS orphaned grandchildren face substantial obstacles in meeting their care-giving responsibilities.

This chapter also discussed the needs identified by the grandmothers in trying to cope with their situation. These were psycho-emotional support and socioeconomic support. In addition, lack of financial stability emerged as an added burden to these grandmothers as they were unable to meet the challenges they faced. They reported shortages of basic

needs such as proper shelter, food, transportation, and so on, all of which presented challenges for them. These elderly women experienced stressful lives, compounded by the imperative to care for their grandchildren in their late adulthood when they were expected to be enjoying their retirement.

CONCLUSIONS

This study involved a survey of ten grandmothers who were caregivers of AIDS orphaned grandchildren. The participants were selected from a list of a grandparents-headed households support group that they attended at Khanya Family Centre, a non-governmental-organisation, in Katlehong west, on the outskirts of Johannesburg and where the researcher was employed as an intern psychologist. These participants lived within an area called Kathorus, a collective of different communities.

The study attempted to explore the experiential dimensions of the participants' coping, social support and needs in caring for their AIDS orphaned grandchildren. The participants were individually and separately interviewed in their households using a semi-structured open-ended questionnaire. The researcher used her knowledge the languages spoken by the participants to conduct the interviews. Some ethical considerations were observed during the study. The participants voluntarily signed consent forms. The interviews were translated from Sesotho and isiZulu languages into English.

This research report included a description of the existing literature on the phenomenon of elderly people's coping ability and the social support availability in their roles as caregivers of AIDS orphans. Apart from other countries in the sub-Saharan regions such as Botswana, Zambia, Zimbabwe and Uganda, there appeared to be little or no research done on the black South African society on the elderly female caregivers of AIDS orphaned grandchildren. As a result of limited research done in this area, the researcher found it difficult to obtain a larger range of views and perceptions on the subject. However, this calls for further research studies on the South African society as the HIV and AIDS epidemic has infected and/or affected millions of households and made elderly people and orphans vulnerable to abuse, stress, and so on.

This study intended to provide further insight into the roles and experiences of the elderly grandmothers as caregivers in coping with their challenges of parenting again. The

Ecosystemic theoretical framework was utilized to further understand the complexity of the grandmothers' the situation. This model was used to direct the researcher's study and to explore the individual grandmothers' challenges. In addition, the four levels of the Ecosystemic model namely, the history or life events/stressors, intrapersonal characteristics, interpersonal characteristics, and political and socio-economic status characteristics were described in detail.

The results and the findings of this study revealed that most of the participants had experienced psycho-emotional, physiological and socio-economic challenges due to past stressful life experiences. They reported that they had lost one or more children to HIV and AIDS related illnesses. Other family deaths were as a result of township violence and/or murder. The participants seemed to be under a lot of stress, compounded by the fact that they were ageing and yet had a critical role to play in the lives of orphaned grandchildren. The findings revealed also that lack of social support, in the face of poverty, poor health, poor housing conditions, lack of health facilities, and so forth, had a negative impact on these participants' coping ability. Some of the participants' concerns included difficulty to obtain child grants and/or retirement pension grants. Lack of government support in accessing grants and retirement pensions by the participants was an added burden. In addition, the participants' needs as caregivers were discussed in this report.

The findings of this research study were then presented, discussed and analysed. The interpretation of findings was integrated in a concluding discussion.

LIMITATIONS OF THE STUDY

A significant aspect of this study is that the results cannot be generalised to other settings. The nature of the sample accounted for this limitation. Firstly, the size was relatively small. It was a non-random selection and thus did not include other organizations within the Gauteng Province which provided similar services as Khanya Family Centre. Hence this exclusion of such organizations affected the "representativity" of the sample.

Secondly, the sample consisted of ten female elderly people representing an organization rather than organizations. In addition, only grandmothers participated in this study and as such, grandfathers were not represented. The researcher relied on the accuracy of participants' explanations, beliefs, and experiences in coping as caregivers. In addition, the possibility that some of participants might have provided desirable responses to please the researcher may not be ignored. However, the participants' genuine responses were expressed as seen through the genuine feelings of some participants particularly as HIV and AIDS-related issues pertaining to their children's deaths brought back painful feelings.

Furthermore, one cannot ignore cultural and religious values and beliefs related to sex and HIV/AIDS-related issues that may have been a major obstacle to individuals dealing with the reality of their children' deaths. The elderly women as participants might have felt disrespected and possibly embarrassed by some questions. Most of these elderly women were reluctant to openly discuss issues surrounding HIV and AIDS. This should be seen as a limitation because even for the researcher it was not easy to openly discuss such issues with the elderly because she was socialised to respect and observe certain cultural boundaries. In spite of this, the participants' experiences as caregivers were gathered.

Another limitation of the study could be the choice of the age of the participants. This study excluded grandparents of a different age group (for example, 40-60 year olds) that could have influenced this study. Therefore this study cannot be generalised to all grandmothers.

Only the voices of the participants in this study were heard. This further limits the study considering that the orphaned grandchildren's voices and those of other family members and the caregivers at Khanya Family Centre were not heard or included in this study.

Lastly, the languages used in the interview were those of the participants. However, the interview questions and transcripts were translated and written in English. This limits the study because the meaning of some of the original expressions, tone, and so on, could have been lost during translation.

REFERENCES

ANC Daily News, "No Rest in Twilight Years", 30 June 2004. Retrieved 20 September 2007 from http//70.84.17/10-etools/newsbrief/index/html.

Ansell, N., & Young, L. (2004). Enabling households to support successful migration of AIDS orphans in southern Africa. *Department of Geography and Earth Sciences, Brunel University, Uxbridge*, UK. AIDS CARE (January 2004), VOL. 16, NO 1, 3-10.

Baron, R.A., & Byrne, D. (1991). *Social Psychology: Understanding Human Interaction. (*6th edition). Boston: Allyn & Bacon.

Beales, S. (2002). Why we should invest in older women and men: the experience of HelpAge International. *Gender and Development*, 8(2), 9-18.

Becvar, D.S., & Becvar, R.J. (1996). *Family therapy: A systemic integration* (3rd edition). Boston: Allyn & Bacon.

Blackburn, M.L. (2000). America's Grandchildren Living in Grandparent Households. *Journal of Family and Consumer Sciences*. 92, 30-36.

Blendon, R. J., & Donelan, K. (1988). Discrimination against people with AIDS: The public perspective. *New England Journal of Medicine,* 319, 1022-1026.

Blendon, R. J., Donelan, K. & Knox, R. (1992). Public opinion and AIDS: Lessons for the second decade. *Journal of the American Medical Association,* 267, 981-986.

Blumenfield, M., Smith, P. J., Milazzo, J., Seropian, S. & Wormser, G. P. (1987). Survey of attitudes of nurses working with AIDS patients. *General Hospital Psychiatry,* 9, 58-63.

Bor, R.J. & Elford, J. (1998). *The family and HIV today: Recent research and practice.* London: Cassell.

Burnette, D. (1999). Social relationships of Latino grandparent caregivers: A role theory perspective. *The Gerontologist*, 39(1), 49-58.

Burton, L. (1992). Black grandmothers rearing children of drug-addicted parents: stressors outcomes and social service needs. *Gerontologist, 32, 744-751.*

Burton, L.M., Allison, K.W. & Obeidallah, D. (1995). Social Context and Adolescence: Alternative Perspectives on Developmental Pathways for African-American Teenagers.

Crawford, I., Humfleet, G., Ribordy, S., Ho, F. & Vickers, V. (1991). Stigmatisation of AIDS patients by mental health professionals Psychology: *Research and Practice,* 22, 357-361.

Cross, S. & Whiteside, A. (1993). *Facing Up To AIDS: The Socio-Economic Impact in Southern Africa*. New York: St. Martin's Press, Inc.

De Vos, A.S. (1998). *Research at grass roots.* Pretoria: Van Schalk.

Demaray M.K., & Malecki, C.K. (2003). Perceptions of the frequency and importance of social support in an urban area. *A Journal of School Psychology, 32,(3), 471-489.*

Donald, D., Lazarus, S., & Lolwana, P. (2006). *Educational Psychology in Social Context. (3RD Ed.).* Oxford: University Press. Southern Africa.

Drew, R.S., Makufa, C. & Foster, G. (1998). Strategies for Providing Care and Support to Children Orphaned by AIDS*: AIDS Care Abingdon*, 10, 9-15.

Engelbrecht, P. & Green, L. (2001). *Promoting learner development: Preventing and working with barriers to learning*. Pretoria: Van Schaik Publishers.

Ezzy, D. (2002*). Qualitative Analysis: practice and innovation*. Melbourne: Routledge.

Ferreira, M. (2002). The impact of South Africa's social pension system on traditional support systems: more generally, should we be looking backwards or forwards in Africa?

In Sustainable Social Structures in a Society for All Ages. United Nations, Department of Economic and Social Affairs Program on Ageing. New York: Report ST/ESA/275, 57-66.

Finlay, W. M. L., Dinos, S. & Lyons, E. (2001). Stigma and multiple social comparisons in people with schizophrenia. *European Journal of Social Psychology,* 31 (5), 579-592.

Garmezy, N., & Rutter, M. (Eds.) (1983). *Stress, Coping, and Development in Children.* Baltimore: Johns Hopkins University Press.

Gerdes, L.C., Moore, C., Ochse, R., & van Ede, D. (1988). *The Developing Adult* (2nd Ed*).* Durban: Butterworths Publishers (Pty) Ltd.

Government Policies (1994). Combating Poverty: Social Development and Grants. Retrieved: September 22, 2006 from

Guest, E. (2001). *Children of AIDS: Africa's Orphan Crisis- South Africa:* University of Natal Press. Pietermaritzburg.

Hamburg,D. A., Hamburg, B. & DeGoza, S. (1953). In Rutter et al. (1983). *Stress, Coping, and Development in Children.* New York: McGraw-Hill Book Company.

Harcombe, E.J. (1993). *The Interaction Effects of Intrapersonal, Interpersonal and Socioeconomic Variables on Stress Adjustment of Disadvantaged Children.* Unpublished masters thesis, University of Witwatersrand.

Harcombe, E.J. (2003, 2007). *Inclusive Education: Learning Support 1. Development and Learning Support in the Inclusive Context.* Sections 1 and 2. Course Material. The Wits School of Education. University of the Witwatersrand.

Herek, G. & Glunt, E. (1988). An epidemic of stigma: public reaction to AIDS. *American Psychologist*, 43(11), 886-891.

Herek, G.M. & Capitanio, J. P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health,* 83, 574-577.

Heymann, J., Earle, A., Rajaraman, D., Miller, C. & Bogen, K. (2007). Extended family caring for children orphaned by AIDS: balancing essential work and caregiving in high HIV prevalence nations. *Journal AIDS care,* 19 (3): 337-345.

Hjelle, L.A. & Ziegler, D.J. (1981). *Personality Theories*: *Basic Assumptions, Research, and Applications* (2nd Edition). Johannesburg: McGraw-Hill International Book Company.
http://www.etu.org.za/toolbox/docs/government/grants.html

Hughes, & Waite, (2002). Health in household context: Living arrangements and health in late middle age. *Journal of Health and Social Behaviour*, 43, 1-21.
In L.J. Crockett and A.C. Crouter (Eds.) *Pathways Through Adolescence* (141-162). Hillsdale, N.J. Erlbaum.

Joslin, D. & Harrison, R. (1998). "The hidden patient" Older relatives raising children orphaned by AIDS. *American Journal of Women's Medical Association.* 53, 65-71.

Kallaway, P. (Ed.) (1984). *Apartheid and education: The education of black South Africans*, Johannesburg: Ravan Press.

Kaufman, T. (1995*). HIV & AIDS and Older People:* London.

Kethusegile, B. M., Kwaramba, A., & Lopi, B. (2000). *Beyond Inequalities: Women in Southern Africa.* Harare.

King, S. (2002). Children of AIDS: Africa's Orphan Crisis*. British Medical Journ*al, 324, 245.

Kolomer, S.R., & McCallion, P. (2005). Depression and caregiver mastery in grandfathers caring for their grandchildren. *International Journal of Ageing and Human Development, 60,283-294.*

Kralik, D., van Loon, A. & Visentin, K. (2006). Resilience in the chronic illness experience. *Journal of Advanced Nursing, 55(3), 320-329.*

Larkin, (2005). Grandparents Raising Children: Health and Wellness Issues. In E. Larkin, D. Friedlander, S. Newman and R. Goff (Eds.), *Intergenerational Relationships* (106-120). Philadelphia: Haworth Press.

Lee, S., Colditz, G., Berkman, L., & Kawachi, I. (2003). Caregiving to Children and Grandchildren and Risks of Coronary Heart Disease in Women. *American Journal of Public Health November; 93(11): 1939-1944.*

Lerner, J. (1993). *Learning Disabilities: Theories, Diagnosis and Teaching Strategies* (6th ed.). Boston: Houghton Miffin.

Lewis, J. D. and Arndt, C. (2005). The Macro Implications of HIV/AIDS in South Africa: A Preliminary Assessment. *African Journal of Economics*, 68 (5), 380-392.

Lewis, S. (2007). *Grandmothers to Grandmothers:* The Dawn of a New Movement. Toronto: Canada.
www.stephenlewisfoundation.org

MacRac, H. (1999). Managing courtesy stigma: The case of Alzheimer's Disease. *Sociology of Health and Illness*, 21(1) 54-70.

Maier, H.W. (1969). *Three Theories of Child Development: Contributions of Erik H. Erikson, Jean Piaget and Robert R. Sears, and their Applications* (Revised Ed.). New York, Evanston and London: Harper & Row, Publishers.

Malefane, M. (2006). Skweyiya ready for big fight to have social grants hiked. Minister wants to reflect reality of South Africa's 10 million needy. *Sunday Times*, 10 September, p.7.

Mashabela, H. (1990). *Mekhukhu: urban African cities of the future*. Unpublished master's thesis, University of the Witwatersrand.

Matshalaga, N.R. (2002). Mass Orphaned in the Era of HIV/AIDS. British Medical Journal, 324, 185-186.

Mason, T., Carliste, C. Watkins, C. & Whitehead, E. (2001). *Stigma and social exclusion in healthcare.* London: Routledge.

Minkler, M. & Fuller-Thornson, E. (1999). The Health of Grandparents Raising Grandchildren: Results of a National Survey. *American Journal of Public Health, 89(9): 1384-1389.*

Minkler, M. (1999). Intergenerational Households Headed by Grandparents: Context, Realities, and Implications for Policy. *Journal of Ageing studies, 13(2) 199-218.*

Munting, C. (2004). Children First: *A Journal On Issues Affecting Children And Their Carers*, 8,(55).

Musil, C. M., & Standing, T. (2005). Grandmothers' Diaries: A glimpse at diary lives. *International Journal of Ageing and Human Development, 60, 317-329.*

Nduru, M. (1992). Rights-Southern Africa: AIDS Orphans Keep Grandpa Busy Till Old Age. New York: *Global Information Network*. Retrieved 22 May 2007 from http://0-proquest.umi.com.raulib.rau.ac.za/pqdweb.p.g.1-3.

Neuman, W.L. (2000). *Social Research Methods: Qualitative and Quantitative Approaches (*4th edition). *Boston:* Allyn & Bacon.

Neuman, W.L. (2003). *Social Research Methods: Qualitative and Quantitative Approaches* (5th edition). Boston: Allyn & Bacon.

Nhongo, T. (2002). Paper presented at the 2002 East and Southern Africa Conference on Children affected by HIV/AIDS, Namibia, 2002.

Nhongo, T.M. (2004). The Changing Role of Older People in African Households and the Impact of Ageing on African Family Structures. Unpublished paper given at The Ageing Conference, Johannesburg 18th-20th August 2004. Retrieved 15 March 2007 from http://www.uaps.org/confageing/tavengwa.

Paul, A.M. (1998). The cost of coping. *Psychology Today*, 31(6),12.

Pretoria News, (2002). "AIDS: Ticking Time Bomb," 4 April, p.5.

Richter, L. M. (1989). Household density, family size and the growth and development of black children- A cross-sectional study from infancy to middle childhood. *South African Journal of Psychology,* 19, 191-198.

Rohleder, P. & Gibson, K. (2006). "We are not fresh": HIV-positive women talk of their experience of living with their 'spoiled identity.' *South African Journal of Psychology, 36(1), 25-44.*

Seedat, M., Duncan, N. & Lazarus, S. (Eds.). (2001). *Community Psychology: Theory, Method and Practice: South African and Other Perspectives* .Oxford: Oxford University Press.

Silverman, D. (2004). *Qualitative Research: Theory, Method and Practice* (2nd Edition*).* London: Sage Publications.

Sontag, S. (1988). *AIDS and its metaphors.* London: Penguin Press.

Streak, (2003). Child Poverty, child socio-economic rights and Budget 2003 – The "right thing" or a small step in the "right direction"? Budget Brief Nr 125. In L. Berry and T. Guthrie (Eds.), *The Analysis of the October Household Survey Data (1995 & 1999).* Capetown: IDASA.

Strelau, J. (1989). Individual differences in tolerance to stress: the role of reactivity. In Spielberger, C.D., Sarason, I.G. & Strelau, J. (Eds.), *Stress and anxiety,* 12,155-156.

Subbarao, K. & Coury, D. (2004). *Reaching Out to Africa's Orphans: A Framework for Public Action*. Washington: The International Bank for Reconstruction and Development/ The World Bank.

Sue, D., Sue, D., & Sue, S. (1994). *Understanding Abnormal Behaviour.* (4th Edition). Boston: Houghton Mifflin.

Thoits, P. A. (1984). Explaining distributions of psychological vulnerability: Lack of social support in the face of life stress. *Social Forces,* 63, 453-48.

Turton, R. W. (1986). *Stressful life events and illness among urban blacks.* Unpublished master's thesis, University of the Witwatersrand.

UNICEF, (2007). Third South African AIDS Conference, 5-8 June. Retrieved 22 August 2007 from www.unicef.org/southafrica/resources.

Uys, L., & Cameron, S. (2003). *Home-based HIV & AIDS Care.* Cape Town: Oxford University Press. Southern Africa.

Van Dyk, A. (2001). *HIV/AIDS Care and Counseling*. Cape Town: Pearson Education.

Van Dyk, A. (2005). *HIV/AIDS Care & Counseling. A Multidisciplinary Approach* (3rd Edition). Cape Town: Pearson Education.

Weiss, R. (2001). *AIDS*: Unbeatable 20 Years On. *The Lancet*, …pp357, 2073-2074.

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

Wilson, F. & Ramphele, M. (1989). *Uprooting poverty: The South African challenge.*Cape Town: David Philip.

Winston, C. (2002). African American grandmothers parenting grandchild orphaned by AIDS: Grieving and coping with loss. *Illness, crisis and loss*, 11, 350-361.

Wolff, C. J. (1981). *Conflicts and Contradictions: Work Psychologists in Europe*. New York: Academic Press.

APPENDIX 1

Appendix B: Subject Information Sheet (Questionnaire Based Research)

Special Educational Needs/Educational Psychology
School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg, South Africa
Tel: (011) 717-8325 Fax: (011) 339-3844

Hello! My name is Sibongile Tloubatla. I am conducting a study on grandparents who care for AIDS orphaned grandchildren. The research is a part of the requirements for a Masters in Educational Psychology at the University of the Witwatersrand. I invite you to participate in this study.

The research aims to investigate among other things, the challenges you are faced with in caring for AIDS orphaned children, to understand how this affects you physically, mentally and psychologically. In addition, the study aims to explore ways in which you deal with the challenges you face and the kind of support you have, and how these affect you in your role as caregivers of children orphaned by HIV and AIDS in general.

If you agree to participate in this study, your participation will involve taking part in an audio-taped interview which will take approximately an hour and a half of your time. Participation is voluntary, and no grandparent will be advantaged or disadvantaged in any way for agreeing or refusing to take part in this interview. While questions are asked about your personal circumstances, no identifying information, such as your name is asked for, and as such you will remain anonymous. Your responses to interview questions and the recorded tapes will be kept safe at a confidential place. They will not be seen by any person in this organisation at any time, and will only be processed by my supervisor and myself. Confidentiality will be ensured. Your responses will only be looked at in relation to all other responses. This means that feedback that will be given to the organisation will be in the form of group

responses and not individual perceptions. I will personally be available to help you during the interview that will be conducted either in your own language or English.

Your participation in this study will be greatly appreciated. This research will contribute to the understanding of the impact of caring for AIDS orphaned children in your families, community and to the society as a whole.

In case you experience negative reaction(s) from participating in this study, you will be referred to Khanya Family Centre counselling team for counselling.

If you have any queries concerning the study, please feel free to ask questions.
My phone numbers are: (011) 905-0915 (work)
076 436 2629 (cell).

APPENDIX 2

CONSENT FORM

I …….(full name), voluntary agree to participate in the study of grandparents caring for AIDS orphans. I have been fully informed and understand the procedures in this study. I am aware of the purpose of the study. I understand that the information I shall have given will be treated with confidentiality. I am also aware of my rights to withdraw from the study at any time without negative consequences to me whatsoever. Should I require emotional and psychological help that can be arranged at no cost to me.

I have been given an opportunity to ask questions which have been answered adequately.

Sign……... Date……

Witness…….. Date…….

APPENDIX 3

TAPE RECORDING CONSENT FORM

I ……(full name), voluntarily give consent for my interview to be tape-recorded. I have read, understood and fully agree to conditions of this interview. I am also aware of how the recorded information will be utilised.

Sign……..Date……..

Witness…….Date…….