

**THE BURDEN OF GRANDPARENTING: CARING FOR AIDS-ORPHANED  
GRANDCHILDREN IN LEPHALALE, SOUTH AFRICA**

**by**

**NTOMBIFUTHI FORTUNATE MOHALE**

**DISSERTATION**

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**SUPERVISOR: PROF S MASHEGOANE**

**CO-SUPERVISOR: DR S MORIPE**

**2013**

## **DECLARATION**

I, Ntombifuthi Fortunate Mohale, declare that this dissertation hereby submitted to the University of Limpopo for the degree of Master of Arts in Research Psychology contains my own original work, that I am the owner of the copyright and that I have not previously submitted it for obtaining any qualification. I also certify that all material contained herein has been duly acknowledged.

Signed at the University of Limpopo on the ..... 2013.

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Mohale N.F.

## **DEDICATION**

I dedicate this study to all grandmothers who have taken on the new carer role for their AIDS-orphaned grandchildren. Regardless of the concomitant odds, they have embraced it and ensured that their grandchildren are reared with adoration and kindness. I respect and admire their courage.

## ACKNOWLEDGEMENTS

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## **ABSTRACT**

HIV/AIDS is devastating and fatal to working adults in the prime of their lives, thus leaving the responsibility of caring for the orphans to their grandparents. This study explored the experiences of grandparents assuming the role of parenting their AIDS-orphaned grandchildren in Lephalale, South Africa. Phenomenological face-face interviews were conducted with ten elderly, black African grandmothers between the ages of 55 and 71. The participating women were self-identified as carers for their AIDS-orphaned grandchildren. The challenges the participant grandmothers faced in caring for their grandchildren were identified as the following: recurrent experiences of loss and grief, lack of social support, fear of stigmatization, financial constraints, mental health and physical strain, difficulty in acquiring state social grants, emotional distress, the caring role being divinely ordained and the rejection of orphans by their biological fathers. Recommendations are advanced on the basis of the findings.

## **KEY CONCEPTS**

Psychosocial sequelae, carer, AIDS-orphaned grandchildren

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## CHAPTER1: GENERAL INTRODUCTION

### 1.1 INTRODUCTION

Acquired Immunodeficiency Syndrome (AIDS) and the virus that causes it, namely, the Human Immunodeficiency Virus Type 1 (HIV-1) have challenged the world's scientists, health care systems and public health policies more than any other medical problem in recorded history. This, according to Temoshok and Baum (1990), may be due to the fact that the pandemic constitutes more than a medical problem; or rather, it is concurrently enmeshed in psychological, cultural, political, social and economic contexts. HIV/AIDS was first identified in the early eighties in Los Angeles and has since then been considered to be deadly (Nattrass, 2002). The pandemic has since spread all over the world with South Africa not being spared in this regard.

Limpopo as a province lies in the northernmost part of South Africa, and it shares international borders with Botswana, Mozambique and Zimbabwe. The province is ranked the seventh in the prevalence of the AIDS pandemic at 11, 0%, whereas holistically in South Africa is at 14, 2% (Dorrington, Bradshaw, & Budlender, 2002). Boon, Ruiter, James, Van Den Borne, Williams and Reddy (2009) assert that the province as perceived is challenged by the pandemic's fatalities felt among adults of child-bearing age, in their economically active years. In their report on the estimates of the provincial mortality rates, Bradshaw et al. (2000) considered HIV/AIDS the main leading cause of death amongst the working generation. Dorrington et al. (2002) corroborated the outcome and further indicated that in 2000 alone mortality rate due to the pandemic in Limpopo Province was estimated at 53 815. Of these, 26 404 (49.1%) were in females and slightly more, 27 410 (50.9%) in males. Further the Department of Health and Social Development observed that in the Limpopo Province mortality rates due to

the epidemic have risen from 6.8% in 2006 to 7.3% in 2010 within the age group of 15-44 years (Bradshaw et al., 2000).

Statistical analysis indicates that most HIV infected partners die in succession (Schatz, & Ogunmefun, 2007). That is, when one spouse dies of AIDS, the remaining one is also often living with the disease and dies shortly afterwards, thereby creating a parenting crisis in most societies. The reality of this statement is explored for Lephalale, Limpopo Province, South Africa. As compared to other areas in the province, the Lephalale Integrated Development Plan (IDP) (2010/2011) rates the HIV/AIDS epidemic as the leading cause of death in the area. Not only HIV/AIDS, but also secondary causes such as Tuberculosis (TB), pneumonia, gastroenteritis, lung infection and meningitis contribute to mortality rates. As such the epidemic is creating a generation of orphans, and with parents being wiped out in their most productive years, leaving extended families, in particular the elderly, struggling with the responsibility of caring for the orphans (Schatz, & Ogunmefun, 2007).

Increasingly, the extended families and communities are finding it more difficult to care for orphaned children, due to their responsibility towards their own children and the high costs of basic family needs. The responsibility of caring then automatically shifts to older generation, commonly the maternal grandmothers. These grandmothers are likely to be unemployed and living in areas highly affected by AIDS rendering their resources inadequate to provide for the basic needs of all the needy children (Lincoln, 2006). Hence, the study's focus on the stress of older people caring for their AIDS-orphaned grandchildren, with an emphasis on the psychosocial sequelae of caregiving them. Emphasis is placed on the stress of caring for the terminally ill adult child before death, fear of the impending death, an uncertain future in terms of financing the funeral and the subsequent day to day care and discipline of the grandchildren. The study seeks

to explore the subjective experiences of older caregivers in this regard, as well as the impact of their role as caregivers.

## 1.2 BACKGROUND OF THE STUDY

The silent legacy of HIV is a generation of motherless children and a generation of grandparents and other older relatives who have become their surrogate parents (Joslin, & Harrison, 1998). Coombe (2001) maintains that sub-Saharan Africa has the fastest-growing HIV/AIDS epidemic in the world: about 10% of those infected world-wide live in South Africa. Further stated is the fact that HIV/AIDS pandemic is reducing life expectancy and raising mortality in the sub-Saharan Africa. In 2001, at least 4.7 million South Africans were reported to be HIV positive, 56% of them women (Bradshaw et al., 2000).

The infection rate that varied provincially in Southern Africa indicated that: 8.7% infected individuals are in the Western Cape, 29.3% in Gauteng, 36.2% in Kwa-Zulu-Natal and 24.1% in Limpopo Province. While millions of South Africans are infected by the virus, almost is directly and/or indirectly affected by the pandemic as productivity declines, public services cost more, family structures threaten to collapse, child mortality increases and poverty deepens. Other studies noted that the pandemic brought reduced opportunities, decreased nurturing support and socialisation, therefore increasing petty or violent crimes, along with increased morbidity and mortality (Coombe, & Kelly, 2001). Coombe and Kelly say that these will however mark South African society for at least the next century.

Focusing on the Limpopo Province, the infection and affection of the pandemic resulted in an increasing orphan population (approximately 3.4% as compared to 2.1% in 2001) which is the most tragic and long term legacy of the pandemic (Coombe, & Kelly, 2001). The steady increasing number of elderly families caring for maternal/or paternal or double orphans in the vicinity of Lephalale area also

contributed. The ability of these caregivers need to be explored specifically within the under resourced homes.

### **1.3 STATEMENT OF THE PROBLEM**

The UNICEF (2003) maintains that the number of older persons (60+ years) in sub-Saharan Africa, currently estimated at 43 million and with a projected annual growth rate of 3%, has attracted social researchers to investigate and explore their living conditions. This was triggered by the impact of HIV/AIDS as it has affected every aspect of life in sub-Saharan Africa. The pandemic has not spared the effective caregiving patterns in this regard. Grandparents, especially maternal grandmothers, have always been available to carry on the role of surrogacy when, parents migrate to urban areas to seek employment or, rather, when they divorce or separate. However, this role was often temporary, unlike the current situation of HIV/AIDS, where they are often left with no choice or alternative in caregiving.

It is not clear whether grandparents are coping with their new, AIDS imposed caregiver role. This study analyses and describes the experiences of grandparents who care for their AIDS-orphaned grandchildren. The study uses a phenomenological approach to unearth personal experiences of Lephalale's elderly persons, currently giving care to their AIDS-orphaned grandchildren. This study's theoretical development emanates from the gerontological concept of Carretero, Garcés, Ródenas and Sanjosé (2009) of theory of burden on caregivers with limited resources.

### **1.4 AIM OF THE STUDY**

The aim of this study was to explore, analyse and describe the experiences of grandparents who care for their AIDS-orphaned grandchildren.

## **1.5 OBJECTIVE OF THE STUDY**

To identify experiences of grandparents of black African descent who provide care for AIDS-orphaned grandchildren in Lephalale, South Africa.

## **1.6 RESEARCH QUESTION**

What are the subjective experiences of grandparents caring for their AIDS-orphaned grandchildren?

## **1.7 SIGNIFICANCE OF THE STUDY**

The demographic landscape of Limpopo Province, South Africa is not likely to change in the near future due to the number and ages of orphaned children. Therefore, it is hoped that the findings of this study will provide a basis for developing guidelines in training and/guiding the elderly in caring for orphaned children in Lephalale. Freeman's (2004) study on HIV/AIDS in developing countries acknowledges that while research in developed countries is quite advanced in this era, and while some of this research is relevant and important in developing countries, understanding and dealing with a disease of relatively low prevalence and which is mostly under control is vastly different from the considerations required of a growing epidemic which seems likely to kill a significant proportion of the population. The implications of HIV/AIDS are felt by immediate families, communities and the society as a whole, mainly by the vulnerable and orphaned children. There are exorbitant medical and funeral expenses for the infected, incurred by the affected, as well as the burden carried by those who have to play a role in giving care to those remaining behind. This study will assist in policy development regarding the caregiving role of grandparents who provide care and support to their AIDS-orphaned

grandchildren. Significant measures in coping strategies for dealing with this stigmatising disease are also developed.

## **1.8 DEFINITION OF TERMS<sup>1</sup>**

### **1.8.1 Caring**

Pindani (2008) defines caring as any form of physical, emotional, social or spiritual assistance provided which aims to reduce suffering, facilitate healing, and promote dignity or to support people with chronic or terminal illnesses and or their orphans. For the purpose of this study, caring means looking after orphans left in the custody of grandparents who in turn attend to their physical, psychological, social, emotional and spiritual needs. Kaufman, Kosberg, Leeper and Tang (2010) compare caring to informal support, which is defined as assistance provided by family members based on feelings of affection or personal obligation towards the recipient(s) of the assistance. Informal social support or caring may take many forms, such as concrete assistance with personal or household tasks, the provision of monetary assistance or other resources, advice or guidance, companionship and emotional encouragement. Care also occurs through relationships; between human beings who try to join together for that purpose. It is in the context of these relationships that the stresses in the role of caring needs to be understood (Kahn, 2005).

### **1.8.2 Old age**

The South African Social Security Agency (SASSA) and the World Health Organisation (WHO) (2002) both define an older person as one being 60 years of age or more. Wilson and Ramphela (1989) corroborate the WHO's definition when they describe a grandparent as an older person, male or female, at the age

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<sup>1</sup> A list of colloquial and non-English words is included as appendix C.



of 60 or more, who may be feeble and, at times, can no longer provide for him- or herself, and whose children have borne children either in or out of wedlock. It should, however, be noted that older people do not form a homogenous group, for no other age group shows as much diversity as does this age group. This may be due to the fact that their increased and varied experiences of life decrease the possibility of uniformity (Stevens-Long, 1979). According to May (2003), an older person or grandparent is anyone who has a grandchild irrespective of age. In this study, a similar reason for early grandparenthood is applied (May, 2003), as early childbirth forces parents to become grandparents at an earlier age.

### **1.8.3 AIDS-orphaned children**

The Oxford dictionary defines an orphan as someone whose mother, father or both parents have died. However, with respect to HIV/AIDS and orphanhood, UNAIDS (2004), UNICEF (2003) and the World Health Organization (WHO) (2011) define HIV/AIDS orphans as children who lose their mother due to AIDS before reaching the age of fifteen. There is a tendency to emphasize the age of the children. Fouad (1990) describes an orphan as a child below the age of eighteen who has lost a parent or both parents to death. Following the joint United Nations Programme on HIV/AIDS (UNAIDS) convention Zarit (2002) maintains that maternal, paternal and double orphans are defined as children under 15 years of age whose mother, father or both have died from AIDS and residing with one or both grandparents. Children thus defined are the focus of this study.

### **1.8.4 Psychosocial sequelae of caring**

Psychosocial sequelae in this study are basically the personal consequences of caring for an AIDS-orphaned child, which have a social bearing. For instance,

reduced experiences of social support and financial difficulties are some of the consequences.

### 1.8.5 **Grandchild**

A grandchild is, in simpler terms, a child of one's son or daughter (Longman Dictionary of Contemporary English, 2003). However, within African culture, Wilson and Ramphela (1989) observe, a grandchild is not only a son or daughter's child, but that nephews and nieces who may be a brother or sister's child are also included.

### 1.8.6 **Caregiver**

Bates (2004) defines a caregiver as a person who cares for others, a spouse, parent or child and offers assistance either in activities such as grocery shopping, cooking, administering medication, bathing, toileting, dressing, housework, transporting, and feeding. Additional tasks may include decision making on behalf of the care recipient, addressing financial matters pertaining to resident nursing care, living wills, durable powers of attorney and probate (Bates, 2004). Marais and Eigelaar-Meets (2007) say that caregiving applies when it is given to a person suffering from any illness that persists for three months or longer. Carretero et al. (2009) as well as Malonebeach and Zarit (1995) define informal caregivers as people from the immediate environment of the dependent person (family, neighbour and friends) who do not possess any training about care and do not receive any economic remuneration for the task. This study will use the term caregiver and carer changeably.

In South Africa, the responsibility of caring for the sick adult child, and later for the double or single orphans is often carried by their grandparents, particularly the grandmothers (Lombard, & Kruger, 2009; Help Age International, 2003;

Schatz, 2007; cf. UNAIDS, 2010/2006; UNGASS, 2011; UNICEF, 2003). Some grandmothers function within a structure dubbed a “skip-generation” household or family, where parents and other older children are absent for some reason or another (usually due to death or migration), and these grandmothers have the obligation to tend to and lead the family (Chazan, 2008). The present study focuses on grandmothers as caregivers.

## 1.9 **SUMMARY OF THE CHAPTER**

This chapter presented an overview of the problem of HIV/AIDS in Lephalale and a brief mention of its existence. Various factors leading to grandparents becoming caregivers for their orphaned grandchildren were highlighted. The next chapter presents a review of the literature relevant to the study.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 THEORETICAL PERSPECTIVE**

The role played by the elderly caregivers in the lives of HIV/AIDS orphaned children is of particular significance in this study. A child who is terminally ill from HIV/AIDS causes different types of hardships to his/her parents. When he/she eventually dies, she leaves behind bereaved children of his/her own and parents. The repercussions of HIV/AIDS death according to Ainsworth and Filmer (2006) are poverty and psychosocial burden. This suggests that the theory of burden which refers to the carer's burden as shown by the physical and emotional stress of an informal carer is appropriate in studying this phenomenon (Carretero et al., 2009; Zarit, 2002).

However, there are issues of loss of important persons in one's life, and attempts to replace them. Thus, the theory of attachment (Block, 2012) is also applicable. Although the present study is empirical, and explores issues that happen due to HIV/AIDS, the theories of burden and attachment are used in the background to guide the study. The applied theories will highlight the relationship that exists between the terminally-ill adult, orphans and their elderly caregivers.

### **2.2 THE GROWING ROLE OF GRANDPARENTS AS CAREGIVERS FOR THEIR AIDS-ORPHANED GRANDCHILDREN**

*"In a perfect world, parents raise their children in their own homes and grandparents have the privilege and joy of spoiling their grandchildren, and then sending them back home to their parents! Well, it's not a perfect world that we live in, and more and more grandparents find themselves in the position of part-time, temporary, full-time, or permanent primary caregivers and/or guardians of their grandchildren" (Safman, 2004, p.13).*

The above quote aptly describes the current situation in HIV/AIDS ravaged countries where grandparents are assuming a new role of raising their orphaned grandchildren, rather than spoiling them. Within different societies Bates (2004) reports that for immediate relatives to assume the caregiving role in the past, it had been due to employment in the CBD far from home, incarceration, separation, divorce, substance abuse, etc. of their parents. Even though a family did not possess sufficient resources to care for the existing family members, those less fortunate were still taken in. (Mudavanhu, 2008) agrees and further infer that in the past, a sense of duty and responsibility of extended families towards their family members was almost without limits. As if not enough, the pandemic (HIV/AIDS) is showing its dire and fatal strain within communities, ensuring that the elderly be ultimately involved in the caregiving role (Foster, 2000). The described situation however is not restricted to a certain geographical area or a particular population, but it is rapidly becoming a reality in many societies. Thus, every year, more grandparents of all ages and from all ethnic and socio-economic groups become primary caregivers as stated to their grandchildren (Tasamane, & Head, 2010; Rembe, 2006).

In Chazan's (2008) study on the socio-economic impact on rural grandparents who care for AIDS-orphaned grandchildren, the harsh reality of surviving on the meagre pensions received by grandparents was highlighted. To bridge the gap between the above mentioned studies, this study on the psychosocial sequelae of grand-parenting AIDS-orphaned grandchildren was conducted in order to explore their experiences in this regard. This study focuses on: a) exploring the phenomenon of psychosocial sequelae; b) through the perspective of attachment theory and the theory of burden; c) developing coping strategies; and d) recommending the strategic ways that would best aid grandparents in nurturing their AIDS-orphaned grandchildren.

In the new millennium laws, social services and resources, education, medical care, insurance coverage and childcare have all undergone significant changes; hence the statement that child rearing has changed significantly. Regardless of the psychosocial, socio-economic and psychological burden that grandparents experience while raising their grandchildren, and whatever their specific needs may be, they all have one thing in common: they seek to provide a loving, safe, and stable environment for their grandchildren, a solid foundation upon which their grandchildren can grow, and they are willing to make the necessary sacrifices to do just that (Newman, & Grauerholz, 2002).

Richter (2002) suggests that the proportion of children living in grandparent-headed households is rapidly growing. Consequently these children may be forced to immigrate to the grandparent's place and face changes in caregiver and family composition. South Africa, where the demographic transformation is evident in the burgeoning number of older people (Oleke, Blystad, & Rekdal, 2005), is not spared. According to Lalthapersad-Pillay (2008) the HIV pandemic has dramatically changed societies, leaving large numbers of orphans in the care of their grandparents. Freeman (2004) maintains that over and above the affected, the pandemic will also have massive implications for mental health within the given societies.

Further research is required so as to find ways of obviating even greater consequences arising from the pandemic. In South Africa and Uganda, it is estimated that over 40% of orphans are cared for by their grandparents. In the rural areas of Tanzania, Uganda and Zambia, grandparents are the primary caregivers for over one-third of the orphans (UNGASS, 2006). In other sub-Saharan African countries, studies estimate that grandmothers take care of 50% of the orphans in Kenya and more than 60% of the orphans in Namibia and Zimbabwe (UNICEF, 2006). A study of eight rural areas in South Africa found

that, in 2002, 39% of the orphans lived with their grandparents, while 16% lived with a parent in a grandparent's house.

In May's (2003) opinion, the devastation of AIDS also indicates that many of the grand-parents, who had cared for their terminally ill children and experienced their deaths, were now looking after their grandchildren. This act is carried out even when their own pensions are severely depleted due to medical and funeral costs. The outcome of the caring role of grandparents is such that it overwhelms their livelihoods, forcing them to contend with a number of different demands in terms of meeting transport costs, food costs, medical costs, and paying for school fees (Gurnessa, 1999). The harsh reality is that they struggle to provide care for their AIDS-orphaned grandchildren and when confronted with such situations they are overwhelmed by uncertainty about the future.

Townsend and Dawes (2004) concur with May (2003) that the safety net of the extended family caring for AIDS-orphans in South Africa is fast becoming overwhelmed. Foster (2000) further stated that the safety net is reaching a saturation point, with a growing proportion of orphans being cared for by their grandparents rather than by aunts and uncles who were traditionally the ones who took care of the orphans (Foster, 2000). Grandparents often experience financial difficulties as their savings are often depleted by the costs of caring for sons and daughters who are suffering from or have died of AIDS, as well as from catering for their anticipated deaths (Chipfupa, 2005). Many older people can no longer be employed, but instead of spending time cultivating crops, their time is consumed by caring for their sick children (Chipfupa, 2005). It is further argued that unemployment, migration and AIDS gradually reduce income (i.e., when employed sick child had to cease work due to ill-health). Despite the attempt of the new government to ease poverty with pension grant, many rural and urban households still live below the poverty line and struggle to make ends meet (Schatz, & Ogunmefun, 2007). In summary, some relatives in particular the

elderly may be faced with the responsibility of caring for their own children, while having to add orphaned grandchildren to their burden, which may have negative financial repercussions (Nhongo, 2004).

### **2.3 PSYCHOSOCIAL SEQUELAE OF CAREGIVING**

Parks and Novielli (2000) define psychosocial sequel in the context of HIV/AIDS as the burden and stress experienced by the caregiver caring for a terminally or chronically ill recipient. The term psychosocial sequel focuses on the strain or stress endured by caregivers. Additionally, care is an all-encompassing term utilised to describe the physical, emotional and financial toll exacted from providing care (Parks, & Novielli, 2000). Poehlmann and Kinderman (2001) as well as Bates (2004) share the same sentiments noting that burden connotes a multidimensional reaction to the physical, emotional, psychological, social and financial stressors associated with providing care. A caregiver's burden, according to Pruncho and Mckenny (2002), is affected by several factors which include: the constant supervision required; the disruption of family relationships; the large amounts of physical care required; role conflict stemming from many obligations, emotional problems, and the demands placed on the caregiver's time and attention; and the unmet needs of the caregiver.

Tennstedt (1999) on the other hand confirms that psychological aspects like depression and anxiety appear to be significant problems experienced by most caregivers. Added to the emotional aspect is the manifestation of physical complaints such as lack of sleep, intense sadness, and tearfulness aggravated by grief. The increasing or decreasing of family structure may cause additional stress (either financially and/ or in grieving) for the grandparents (Mouton, 2004). The issue of financial difficulty which was emphasized by Townsend and Dawes (2004) in their study may play a role as the province is composed of rural areas inhabited by the highest percentage of the population living with HIV/AIDS. In



most cases illiteracy is high and most child bearing females depend on their partners or spouses for survival (Foster, 2000). Practising safe sex is taboo as most women fear rejection. Considering that partners do die one after the other as commented in Barnett (2000) and Whitley's (2000) who maintain that the crisis in caring for those infected with and affected by the virus is unique to caregivers owing to the following reasons:

- (a) The scale of the problem: More children have been orphaned by AIDS in Africa than anywhere else. The deep-rooted kinship systems that exist in African countries, that is, the extended-family networks of aunts and uncles, cousins and grandparents, offer an age-old social safety net for orphaned children have long been proved to be resilient, even during major social change. Capacity and resources are stretched to breaking point, and those providing the necessary care are in many cases already impoverished; often the elderly themselves might have depended financially and physically on the support of the very son or daughter who has died.
  
- (b) An AIDS-weakened infrastructure: Zeenat (2003) asserts that the impact of the epidemic is felt throughout communities and societies as teachers and farmers, trained health care personnel and workers from all sectors of the economy have died and continue to die in vast numbers. The effects also reach deeply into the daily lives of families caring for someone with the disease, where resources rapidly diminish. This study focuses on exploring the care needs of older people as these needs pertain to their psychological sequel as caregivers, and the interventions required in assisting them to cope with their newly acquired roles. Savings are soon depleted and caregivers often accumulate debt in order to care for their sick. Food consumption has been found to drop by 41%. The drain on virtually all segments of communities and nations means that very few resources or services remain and fewer can be produced or provided to sustain those in the front line of orphan care.

- (c) The vulnerability of orphans: Zeenat (2003) contends that of the many vulnerable members of society, young people who have lost one or both parents, and the elderly who grieve long before the actual death of their children, are among the most exposed to grief and being vulnerable. This is particularly true in sub-Saharan Africa, where few social support systems exist outside of families and where basic social services are largely inadequate.
  
- (d) Grieving before death and the tragedy of losing a child and or both parents: A child whose mother or father has HIV begins to experience loss, sorrow, and suffering long before the death of the parents. The grandparents experience this loss as well, as they had never anticipated this kind of disease and its consequences. Casale (2011) emphasises that since HIV could spread sexually between father and mother, once AIDS has claimed the mother or father, the children are far more likely to lose the remaining parent. Further, it is stated that although there are adversities and challenges reflected in the caring role as a consequence of the pandemic, positive responses, perspectives, and experiences do need to be explored. Bates (2004) complements this statement by asserting that after or even during this ordeal, the grandmother will care for her adult child, and after his or her demise, simply assume the parenting role of caring for the orphaned grandchildren.
  
- (e) The AIDS stigma: The distress and social isolation experienced by both children and their caregiver(s) before and after the death of their parent or parents are strongly exacerbated by the shame, fear, and rejection that often surround people affected by HIV/AIDS. Zeenat (2003) shares similar sentiments with Gaugler et al. (2000) maintaining; caregivers in their role of caring often suffer from depression, stress and anxiety due to their grief and pain, exacerbated by the lack of effective social support systems in sub-Saharan Africa.

In their study of the devastations of AIDS in Africa, McNair, Airhihenbuwa and Iwelunmor (2011) reported that in 2007 approximately 350,000 adults and children died of HIV/AIDS, while an estimated 140,000 children lost their mothers, fathers, or both parents to the pandemic. In the Limpopo Province, South Africa, 396,800 people were infected with HIV, and most are likely to die from AIDS-related diseases (Lincoln, 2006). The pandemic places tremendous pressure on HIV affected households in South Africa. It is predicted that the pandemic is the fastest way for families to move from relative wealth to adverse poverty as the pandemic affects the productive working age group leaving behind orphaned and vulnerable children as well as the aged (Rotheram-Borus, Flannery, Rice, & Lester, 2005).

The in-migration aspect plays a major role in this study as Lephalale is a mining industrial area, thus inviting migrants in search of employment from afar. In support of all the studies mentioned above, Goodman, Tan, Ernandes, and Silverstein (2008) agree that grandparent caregivers are particularly sensitive to their family and household environments; hence, they will be there for their grandchildren against all odds. However, the caring role, according to Almeida, Neupert, Banks and Serido (2005), may impact negatively on the health of grandparents in different ways, depending on their income, ethnicity, marital status, age, and mental health condition. For example, a lower socio-economic status has been systematically related to worse health owing to a lack of access to medical care and stresses associated with power. It should, however, be realised that in other studies such as that of Linsk and Mason (2004), it was revealed that some elderly caregivers described the care task as rewarding; they expressed relief and happiness at being able to provide a good home for their grandchildren (Burton, & Minkler, 1992).

## 2.4 PARENTAL BEREAVEMENT

Grieve, according to Winston (2006), is a normal reaction to loss and is usually intertwined with bereavement. In this study focus is on loss of a child which may be severe as compared to other grief, as maternal grief is felt forever. Usually the grief is not resolved as the mother has not reached the stage in her grief called acceptance, but instead has reached the stage of recognition that she will live the rest of her life without one of her children. The mother adapts to living without her child (that is, the mother reaches a stage of recognition that she will live the rest of her life without one of her children). Schatz (2007) argues that when a loved one dies, a man or woman may remarry, but when a child dies, it is difficult to substitute the child. Maternal grief is particularly intense and lengthy given the unique relationship between a mother and her child that begins before birth. When an adult child dies, the grief work must not only deal with lost hopes, but with the reservoir of memories created over the years. Schatz (2007) and Silverman (1981) suggest that parents who grieve the loss of an adult working child are also grieving losses relating to adjusting to life stage transitions. This may however result in the ability to achieve a sense of continuity being compromised.

Dane and Miller (1992) adapted Peppers and Knapp's (1980) concept of shadow grief in describing some AIDS survivors. They define shadow grief as a form of chronic grief experienced by mothers, which does not manifest itself overtly. Winston (2006) asserts that when AIDS causes a child's death, the likelihood that the mourning process will be hindered is increased, specifically because of its association with antisocial and or stigmatising behaviours, including promiscuity, drug abuse, bisexuality and homosexuality. Death due to AIDS may create such shame, guilt, and embarrassment that survivors do not seek the traditional social support to sustain them during their grieving period (Doka, 1989). Walker (1991) argues that the secrecy that routinely surrounds death may hinder the family's

mourning process, while it offers a thin veil of protection from social ostracism, discrimination, and ridicule. At the same time, in cases where death occurs due to AIDS, bereavement may commence while the child is still ill. This may be aggravated by the added task of caring for grandchildren (Johnson-Moore, & Phillips, 1994; Osterweis, 1987).

According to Kubler-Ross (1975), there are five stages in grieving, which apply to both the grieving process after the loss of a loved one and the grief following the diagnosis of a chronic illness. However, the stages do not follow a consecutive constituent, are not absolute, and not everyone goes through every stage in the same sequence or at the same predictable pace. The first stage is most often denial, where, in the current scenario, the grieving older person learns that her child is terminally ill, but cannot accept the fact. This is usually followed by anger, during which the bereaved resents the fact that the offspring of other people are healthy when theirs must die. Their anger and resentment is often directed towards God if they are Christians, as He is viewed as imposing the death sentence arbitrarily, while others may look at it differently, believing that superstitious powers prevailed for their children to die. Others do normally need someone to blame for their child's death.

The bargaining process forms the third stage of grieving. The mourning older person usually bargains with God to give the dying child more time in exchange for good behaviour. This would, however, occur or be distinguished amongst Christians and non-Christians. With non-Christians the reaction might vary. Depression constitutes the fourth stage where the victim of grief awaits the patient's death. The final phase in grieving, which is at most a time viewed as the acceptance stage, is neither a happy nor an unhappy one, but the bereaved finally accepts that death is inevitable and has to adapt to surviving without the deceased. Boon et al. (2009); Knodel, (2005); Ndaba-Mbata, & Seloilwe, 2000; Nyambedha, Wandibba, & Aagaar-Hansen, 2003; Reddy, 2005 and Ssengozi,

2007 suggests that the repercussions of death may be anxiety, distress, depression, helplessness and hopelessness. This will however be compared with the outcomes of this study.

## **2.5 CHALLENGES FACED IN CARING FOR AIDS ORPHANED GRANDCHILDREN**

### **2.5.1 Socio-economic factors**

In accordance with Hallanhan's (1994) description of the concept of socio-economic factors, this study acknowledges the role of the caregivers' environment and community in determining their quality of life, as well as the types of livelihoods that they depend on for their basic needs. More than any other disease, HIV/AIDS has proved its ability to disrupt the economic and social fabric of society as it affects adults of working and child-bearing age (Fouad, 1990; Johnson-Moort, 2006). In most instances it also takes a toll on elderly parents, who then carry the burden of financially supporting the household once their children lose their ability to work, or die and leave behind off-spring who must be cared for.

The study carried out by Safman (2004) revealed that with regard to HIV/AIDS orphans and their caregivers in Thailand, the dominant concern of caregivers of orphaned and vulnerable grandchildren was the costs associated with child rearing in an increasingly market-based society. Safman (2004) further indicates that these concerns arise because the continuation of formal education through to these levels is viewed as a necessity, given the prevailing trends in the labour markets. Therefore, older people are faced with economic burdens, which may aggravate the issue of poverty if their grandchildren do not receive formal education, coupled with stress because they cannot find any solutions to most of their difficulties.

Although stigmatisation is another factor or stressor that may aggravate the caregiver's role, Caliandro and Hughes (1998) believe that some caregivers manage the effects of stigma on HIV by maintaining the secret. Lesar, Gerber, and Semmel (1995) reported that in addition to the stigma and secrecy, caregivers often face the problem of other orphans within the same family becoming HIV infected, resulting in special health and mental health needs. It is further maintained that because of the stigma attached to HIV/AIDS, the family lives with a "conspiracy of silence", which prevents the healing process and isolates the family from traditional forms of support (Fanos, & Wiener, 1994; Levine-Perkell, 1996). The needs of an infected family member may compete with the demands from other family members, leading to feelings of inadequacy and strained family relations (Mellins, & Ehrhardt, 1994). Joslin and Harrison (2002) describe the unique strains of family caregivers as: shame, fear of rejection, caring for an adult infected child while parenting grandchildren, death of an adult child or several family members, and guilt owing to the inability to protect family members from the HIV.

Owing to the hardships faced by grandparents, living with the infected child and/or grandchild places them in a potentially vulnerable situation because as the HIV/AIDS epidemic spreads, they are robbed of one of their main sources of economic support: their sons and daughters. Foster, Makufa, Drew, Mashumba, and Kambeu (1996) add that older people who expected to receive assistance from their children now struggle to find ways to support and care for their orphaned grandchildren. Foster (2000) suggests that once HIV infection begins to deteriorate into chronic illness (AIDS), its economic impact is felt. The grim reality is that the breadwinner, as an infected adult member of the family, can no longer continue to earn a living. This according to Wilson and Adamchak (2000) may be due to the fact that in the African culture, older Africans historically relied on informal support in the form of cash transfers from their children, while

practising some small scale agriculture and trading in order to sell their produce for additional income.

### 2.5.2 Physical strain

According to Hailey (2003), stress may have a negative effect on the functioning of the immune system, blood pressure, and lipid profiles of caregivers, while high levels of stress in older caregivers may constitute a risk factor for an earlier death. The limitation of age may also contribute negatively to the role of aged caregivers as noted in a study carried out by Hailey (2003), who indicated that travelling long distances to a health facility such as a clinic, was also burdensome. Another aspect relating to physical health is burnout, which, according to Gilliland and James (1993), Mitchell and Resnik (1981), as well as Pines and Aronson (1988), is viewed as the result of prolonged work stress and the final step in the progression of unsuccessful attempts to cope with various negative stressful working conditions, demands or environments of caring. Schaufeli and Enzmann (1998, p. 67) define burnout as a persistent, negative, work-related state of mind in normal individuals that is primarily characterised by exhaustion, which is accompanied by distress, a sense of reduced effectiveness, decreased motivation and the development of dysfunctional attitudes and behaviours towards caring, especially when working with problematic teenagers.

Naude and Rothmann (2006) as well as Lincoln (2006) found that occupational stress due to job demands and a lack of job resources contributes to emotional exhaustion and depersonalisation. Older people may be feeble, have no basic resources and have to work overtime, especially with children who are also infected with HIV.



### 2.5.3 Changing lifestyle

Byram (1996) defines culture as constituting the customs and shared values of a given group. It embodies the knowledge and practices of people belonging to a particular social group. In African culture, while older people offer wisdom regarding life skills and problem solving techniques, children are raised to offer support to their elderly during old age. However, HIV/AIDS has inevitably altered the family structure (Wilson, & Ramphela, 1989). It transports its victims into an environment of turmoil, confusion and anxiety. In the study conducted by Meursing (1997) on the social development of older people, none of them ever anticipated a chronic illness like the HIV/AIDS pandemic in their families, nor did they foresee its devastating repercussions. Davey (2005) concur with Meursing (1997) that older indicated that raising grandchildren altered their dreams, new tensions and struggles emerged when the parents die. On the other hand others appreciate being able to provide for their grandchildren and being alive to care for them.

Ferreira (2004) maintains that planned and hoped dreams could not be realised, and thus resulted in despair over the paths their lives had taken. Hosegood, Floyd, Marston, Hill, McGrath, and Isingo (2007) added that many older people find themselves losing touch with friends because their daily activities are different from those of their peers and they grieve this loss at a time when they should be deepening their friendships, which causes further incongruence (Lever, & Wilson, 2005). In a study conducted by Lever and Wilson (2005), it was observed that some older people had raised expectations of being in the “empty nest” and “retirement” phase at this age. Bodily aches, pains and constant fatigue were issues that were raised and they related how these issues interfered with their parenting skills in the home.

From gender perspective, Lund (2006) suggests that, changes in social status occur when a wife is widowed. Friends and family members may respond to this alteration in such a manner that it results in social deprivation for the widow. Therefore, besides the loneliness that arises from the lack of friends, Ansell and Young (2004) link poverty and changed lifestyle to the economic burdens faced by older people. They argue that although they would appear to provide more sustainable situations than other close relatives, they are sometimes unable to accept orphan children on account of their poverty. Thus, from a financial perspective, older people raising grandchildren often experience parenting stress and financial difficulties. Orb and Davey (2005) found that the elderly are often confused about their entitlements and overwhelmed by the required paper work when approaching government departments. This finding may be based on the fact that some of them are illiterate. Confusion may therefore result owing to a lack of appropriate information and resources available to them.

Cook and Oltjenbruns (1989) believe that older females may view this sense of continuity differently as they may question why their lives are being spared when their offspring are taken in the prime of their lives. Studies indicate that experiences of stress serve as a function of breaches in a normal life course, widespread deaths of the middle generation, and role overload among elderly caregivers and their families (Gatz, Bengtson, & Blum, 1990). It is further emphasised that the precipitating stressful events result in the assumption of caring responsibilities due to the deaths of children's biological parents, family resources, the perception of the crisis and the outcome, a sense of strain, or number of crises, and maybe the accumulation of additional problems secondary to the initial stressor, which may all serve as a breach of life expectations. These events may also constitute competing or secondary stressors (changes in the caregiver's life course) besides the precipitating stressor (the role overload) which contribute to the experienced stress of the caregiver (Gatz, et al., 1990).

Lalthapersad-Pillay (2008) shares the same sentiments, that is, that HIV/AIDS has caused adult mortality rates to soar and has ushered in a large number of orphans and vulnerable children. Globally, in 2005, the number of children orphaned by AIDS stood at 15 million, and the greater share of these orphans (namely, more than 12 million) were located in sub-Saharan Africa. Estimates indicate that in sub-Saharan Africa approximately 9 % of children under the age of fifteen have suffered the loss of at least one parent to AIDS and that one in six households with children had taken in at least one orphan. In South Africa, this situation could be attributed to the labour migration system under the apartheid regime which forced black men to seek jobs in the mines and in urban areas, resulting in lengthy spousal separation, child fostering, and other family configurations that negatively affected the welfare of family members (Houghton, 2001). While the demise of apartheid lifted all restrictions on movement and residence, the challenge of finding employment still remains today and migration continues to be a very important means of connecting to people, places and resources (Posel, 2006).

According to Cohen (2000) and Schoepf (2001), poverty, related to structural conditions has fuelled the spread of AIDS in recent years to unprecedented levels, while limited access to health services has resulted in families undertaking much of the necessary burden of care, further increasing household poverty levels. Much has been written about the impact of the epidemic on AIDS orphans. However, less research has been conducted on elderly caregivers and those who will care for them when they are frail and ill (Knodel, & Van Landingham, 2002).

#### **2.5.4 Poverty within the older person's household**

Poverty was found to be a more manifest feature of households headed by maternal rather than paternal kin, and a large majority of the paternal orphans

interviewed in other studies were highly conscious of the relative poverty in their households. Freeman and Nkomo (2006) also report that poverty is the primary barrier to fostering. Nyambedha et al. (2003), in their study on retirement of grandparents within their household, did not cover the basics of caring for their orphaned grandchildren; they mentioned that escalating poverty reinforces the AIDS epidemic and that the epidemic intensifies poverty. This is happening at a time when, as mentioned earlier, many African families are experiencing increasing difficulties in living up to the traditional ideals of sharing and mutual assistance in a context of widespread poverty, food shortage, geographic dispersion of families, and change of lifestyles. These are factors which among others have been attributed to the continent's incorporation into the global political economy (Barnett, & Whiteside, 2000; Cattell, 1993).

In a study conducted by Oleke et al. (2005), the women who cared for orphans were said to constantly do their utmost to ensure that none of the children spent a day without a meal, irrespective of how little that meal may be. In emphasis Aliber (2001) suggests that perhaps more meaningfully, poverty could be understood as the inability, or lack of opportunity in a household or individual to improve its circumstances over time or to sustain it through difficult times. As a result, poverty could constitute a function of the individual's characteristics based on being old or disabled; or of the environment (e.g., sustained periods of high unemployment, landlessness), or very likely both (Cattell, 1997, p. 124).

Orner (2006) supports other studies that argue that caring places considerable demands and strains on caregivers, which may be exacerbated by insufficient support, dire poverty and the added responsibilities of caring for other household members. Concurring with Orner (2006) Nyambedha et al. (2003) maintain lack of basic needs unemployment and the HIV pandemic impact negatively on the social life of the elderly. Stigma and prejudice towards caregivers are common and exacerbate their stress levels. Other studies stipulate various factors that

may be regarded as the causes of poverty being the changing nature of work and income generation, changing roles within the household and community, and the exclusion of access to networks and opportunities.

All the above mentioned external factors affect one's mental well-being. These aspects are also associated with the burden of the task of caregiving, as mental health implies not only the absence of any illness, but to the contrary, a state of emotional and mental well-being that allows an individual to enjoy life and cope with everyday situations. These daily situations specifically include happiness, peace of mind, enjoyment, or satisfaction. The manner in which one copes with emotions such as anger, grief, demands of life, and how one gets along with family members and one's community, is of great importance.

## **2.6 SUMMARY OF THE CHAPTER**

In this chapter, literature on the psychosocial sequelae that older people face when they resume parenting role to their AIDS-orphaned grandchildren is reviewed. The literature indicates how older people are recruited into caring for their orphaned grandchildren by circumstances beyond their control, in particular, the HIV pandemic. This occurs at a developmental stage that, according to their psychosocial level of development, is punctuated by either integrity or despair. In a nutshell, the challenges that older people face as a consequence of their caring task and losing their adult children are manifold. Financially, older people struggle as their adult children due to ill-health are no longer able to provide them with support (Moore, 2008). Furthermore, their pension income and child support grants are the only source of household income and are unfortunately not sufficient to cover all the living, medical, and schooling expenses for themselves and their grandchildren, irrespective of what the cause of death of the adult child might have been.

The next chapter outlines the research design and methodology of the study in detail.

## **CHAPTER 3: RESEARCH METHOD**

### **3.1 INTRODUCTION**

This chapter outlines the research method employed in gathering data in this study. This is a phenomenological study utilising one-to-one interviews to gather data, as it is based on the lived experiences of the participant grandmothers (Groenewald, 2004). This method is appropriate for this study as it enables participating grandmothers to better understand their role as carers.

### **3.2 SELECTION OF PARTICIPANT GRANDMOTHERS**

In this study ten females currently caring for their AIDS-orphaned grandchildren were recruited from a hospital-based Wellness Clinic in the Lephalale, Limpopo area. These women were unknown to the researcher. During the selection process, the coordinator in the Wellness Clinic who routinely interacts with people living with HIV/AIDS, after approval from the chief executive officer (CEO) of the hospital as well as the hospital board, described the research to 30 randomly selected, prospective individual participant grandmothers. The names of those who agreed to partake in the research were handed to the researcher. Hospital numbers were used rather than actual names of prospective participant grandmothers to protect their identity. The researcher was kept in the dark about the names of those who declined and those who agreed to participate. The researcher then randomly selected ten hospital numbers in order to interact with the owners. The persons whose numbers were not selected were given written communication to explain that they were not included in the study, and were each given a hamper of vegetables as a token of appreciation for their availability for inclusion.

The clinic where the study was conducted is part of a hospital which specializes in offering medical, social and psychological care for HIV infected patients. Its staff complement includes a variety of health caregivers (doctor, nursing staff, social worker, counsellor, dietician, speech and hearing therapist, optometrist, physiotherapist, dietician, and occupational therapist) who offer medical attention, counselling, support and adherence within the Wellness Clinic. The participating grandparents are considered a critical element in the chain of care. They were interviewed for this study on their personal experiences of caring for these orphans, and also requested to describe their experiences of caring for their adult children who had died from the pandemic. The smaller number of participant grandmothers allowed for an in-depth analysis of the raw data provided in the participant grandmothers' descriptions. Groenewald (2004) critically agrees with Boyd (2001) that two to ten participants or research subjects are regarded as sufficient to reach saturation for a phenomenological study; hence the selection adopted.

The same institution serves these grandmothers and their grandchildren with HAART (Highly Active Antiretroviral Treatment) or ARVs, as young children are to be seen by the doctor on a monthly basis. The participant grandmothers as indicated were selected based on the criteria of caring for children who died from AIDS, and sheltering infected and affected grandchildren. Each of them cared for 4 grandchildren on average, and one also had two great-grandchildren. The grandmothers' ages ranged from 55 to 71 years, with an average of 60 years. The reason for this selection was to gather the core experiences regarding the topic of study and to enable the participant grandmothers to be articulate in communicating about their experiences (Bailey, 1996; Leipert, 1996).

After the selection process, the actual research process took place, immediately establishing rapport with the selected participant grandmothers and highlighting the ethical aspects pertaining to the study. The assistant, who herself was well



conversant with applicable research ethics, was introduced to the participant grandmothers. Her primary role was to assist with translations and interpretation with regards to participant grandmothers who spoke a specialized dialect of Setswana (whose language was highly influenced by the Botswana accent of the language). A quiet room was used for interviews. Almost all data was collected by means of a tape recorder, and hand-written notes were also taken during the course of each interview and immediately thereafter.

### **3.3 THE STUDY SITE**

The Wellness clinic is situated within the structures of the district hospital in Lephalale. It is a clinic that attends to people living with AIDS. The clinic also partners with the TB ward in the hospital, thus caring for in- and out-patients. Attendees of the clinic are drawn from nearby villages, the semi-urban townships and urban areas of Lephalale.

### **3.4 PROCEDURE**

First and foremost, the research was approved by the University of Limpopo Research Ethics Committee. Subsequently, permission to access potential participants was granted by the chief executive officer (CEO) of the hospital together with the hospital board. The specific phenomenon focused on is the psychosocial issues and more particularly the burden experienced by the elderly caregivers to their AIDS-orphaned grandchildren. Participant grandmothers were selected, highlighted about their research rights and consent forms were distributed for signing. Phenomenological research methods were applied, yet an attempt was also made to gain full knowledge of the grandmothers. Instead of 'analysing data' as is commonly done in research, the researcher worked within the concept of 'explicitation of data'. Groenewald (2004) cautions that the idea of 'analysis' has dangerous connotations for phenomenological research. On the

other hand, 'explicitation' implies an investigation of the constituents of a phenomenon while maintaining the integrity of the whole. Observations included the emotional aspect, that is, the body language of the participant during the interview. Participant grandmothers' experiences and descriptions entailed the raw data for the study. The data obtained were analysed and reduced into meaningful structures using the phenomenological and qualitative psychological method (Giorgi, 1985).

### **3.5 DATA COLLECTION**

With the permission of interviewees, all face-to-face interviews were audio-recorded. A quiet room was utilised to avoid interruptions. The researcher was cautious not to interrupt the participant grandmothers while they described their experiences so as not to disrupt their flow of ideas as they accessed information from memory. At the beginning of the interview, the researcher introduced herself to the interviewee and further explained the aim of the study. The participant grandmothers were highlighted about the procedures, risks and benefits of the study. They were also informed about the voluntary nature of their participation, and their right to withdraw from the research if they subsequently felt uncomfortable at any time. They were made aware that it is within their right to make sure that they understood the nature of their participation before signing the consent form. Those who agreed to participate signed their consent forms, and those who did not were not pressured to participate in the study. Once participant grandmothers agreed to take part in the study, procedures were put in place to protect their identities. The confidentiality aspect was emphasised as a norm throughout the study.

Following the transcription of the recorded information into verbatim text, the researcher scheduled follow-up interviews with each of the participant grandmothers in order to clarify any information that seemed unclear. The follow-

up data were transcribed into text and added to the transcribed interviews verbatim. To ensure anonymity even during the storage of data, pseudonyms were assigned to each participant. The assigned pseudonyms are the names that will also be used during the presentation and discussion of the data in this study. The main questions of the study included the following: “How did/do you experience the role of giving care to your grand-child(ren)?”, “What are the challenges you experience in caring for your grand-child(ren)?”, and “What kind of support do you receive as you care for your grand-child(ren)?” Further questions were asked to capture a rich description of the phenomenon (see appendix B). Where responses were not clear or provided in an unresponsive manner, the participant grandmother was encouraged to elaborate further.

### **3.6 SUMMARY OF THE CHAPTER**

This chapter focused on the research methodology in terms of data gathering through interviews and observations. The merits and demerits of methodology were discussed as well as data gathering and analysis. Ethical considerations were also considered, to ensure that the participant grandmothers’ rights were not violated. The next chapter focuses on the findings of the research. Stories of some participant grandmothers and an outline of the themes that emerged during data analysis are included.

## **CHAPTER 4: RESEARCH FINDINGS**

### **4.1 INTRODUCTION**

While research in developed countries is quite advanced in the area, and while some of this research is relevant and important in developing countries, understanding and dealing with a disease of relatively low prevalence and which is mostly under control is vastly different from the considerations required of a widespread epidemic which seems likely to kill a significant proportion of the population. The statement is supported by the findings of this study. The research findings are presented in two sections: the biographical profile of the selected participant grandmothers, followed by a presentation of the themes that emerged from the data analysis. The presentation is supported by extracts or brief information from the participant grandmothers' stories. Two of the stories are presented in appendix A for illustration purposes.

### **4.2 FINDINGS**

Instead of 'analysing data' as is commonly done in research, the researcher worked within the concept of 'explicitation of data'. Groenewald (2004) cautions that the idea of 'analysis' has dangerous connotations for phenomenological research. Data itself was analysed using the method of extracting units of meaning from the interviews and creating general themes (Braun, & Clarke, 2006). The researcher first familiarized herself with each of the interviews and field notes by reading them over and over. Coding was then systematically accomplished, identifying and classifying units of meaning. The meanings were then grouped into logical, unified themes, or thematic categories. These were confirmed by the researcher's academic dissertation supervisor (Prof. S Mashegoane). The themes were later presented to the participant grandmothers, to have them express their opinion on them, before finalization.

### 4.3 DEMOGRAPHIC PROFILE OF PARTICIPANT GRANDMOTHERS CARING FOR THEIR AIDS-ORPHANED GRANDCHILDREN

All ten participant grandmothers came from the vicinity of Lephalale, Limpopo Province (South Africa). Table 1 below furnishes their demographic details, including the number of their own children who died from AIDS as well as the number of HIV/AIDS-orphaned grandchildren for whom they are caring. The average age of the participant grandmothers was 62 years (SD = 5.70, range = 55-71 years). Four (40%) of them were married, two were divorced, one never married and the other three (30%) were widowed. The grandparents had an average of 6.20 children (2.66) of their own, and an average of 2 (SD = 1.05) of them died from AIDS. The average number of grandchildren they cared for was 4, with a minimum of 1 and a maximum of 11 grandchildren. Their average age was 8.70 years (SD = 4.05), with the ages ranging from 3 to 21 years.

According to table 1 (below), six (60%) of the ten participant grandmothers resided in so-called "RDP" houses. The government-supplied houses consisted of a single bedroom and a toilet, as well as an open plan dining room and a kitchenette. Occupants commonly used linen to partition the dining room area, so as to create a separate sleeping area for the grandchildren. Another two (20%) of the participant grandmothers lived in three bed-roomed houses, while the remaining two (20%) lived in two-roomed shacks.

Three (30%) participant grandmothers lived with their own children and their grandchildren, in other cases a sibling and an elderly relative (see table 1). Five (50%) of them reported that some of their children were living elsewhere. For instance, in two families, two of the adult children from each family were residing with their partners while another three adult children from these respective families were tenants nearer to their working places, who sometimes visited home at the end of the month. Two (20%) of the participant grandmothers stated

that their children mostly resided elsewhere and returned home only when they ran out of money to make ends meet. One of these two participant grandmothers reported that her son was an alcoholic who roamed around like a nomad. Regarding the other seven (70%) participant grandmothers, their children did not reside with them permanently, and the other three (30%) participant grandmothers, left their own homes and migrated to where their ailing children resided. The other three (30%) participant grandmothers stated that their children returned home to reside with them, bringing along the grandchildren.

Although all the participant grandmothers suffered from various ailments, they all reported backache (see table 2) emanating from the caregiving task of frequently bending. All the youngest grandchildren they cared for had HIV.

**Table 1:**  
**Demographics of participant grandmothers**

| <b>Participant grandmother*</b> | <b>Participant's age</b> | <b>Marital status</b> | <b>No. of participant's own children</b> | <b>No. of deceased own children</b> | <b>No. of orphaned grandchildren cared for</b> | <b>Age in years of orphaned grandchildren</b> | <b>No. of household members (and their description)</b>   |
|---------------------------------|--------------------------|-----------------------|--|-------------------------------------|--|---|---|
| Mama Kejaeng                    | 67                       | Divorced              | 3  | 1                                   | 1  | 6   | 6 (2 children with 1 child each, & AIDS- orphaned grandchild)   |
| Grandma Modiegi                 | 71                       | Widowed               | 10                                       | 4                                   | 11   | 15, 11, 10, 9, 8, 7, 6, 5, 4, 4 & 3           | 19 (11 AIDS-orphaned grandchildren, son & his child, sibling & 2 children, 2 other children)            |
| Grandma Leitlhorang             | 70                       | Widowed               | 7  | 2                                   | 6*   | 21, 19, 13, 13, 10 & 8**                      | 10 (Son, 6 AIDS-orphaned grandchildren, & 2 great grandchildren)  |
| Mama Rulani                     | 59                       | Married               | 5  | 2                                   | 3  | 12, 9 & 4                                     | 8 (Spouse, 3 children, 3 AIDS-orphaned grandchildren)   |
| Mama Angela                     | 60                       | Married               | 6  | 3                                   | 6  | 14, 9, 7, 6, 5 & 4                            | 15 (Spouse, brother with 2 children, divorced daughter with 3 children & 6 Aids-orphaned grandchildren) |

| <b>Participant grandmother*</b> | <b>Participant's age</b> | <b>Marital status</b> | <b>No. of participant's own children</b> | <b>No. of deceased own children</b> | <b>No. of orphaned grandchildren cared for</b> | <b>Age in years of orphaned grandchildren</b> | <b>No. of household members (and their description)</b>                          |
|---------------------------------|--------------------------|-----------------------|--|-------------------------------------|--|---|--|
| Mama Kentse                     | 56                       | Married               | 4  | 1                                   | 2  | 7 & 10  | 4 (Spouse, 2 AIDS-orphaned grandchildren)  |
| Mama Rebone                     | 60                       | Widowed               | 7  | 2                                   | 4  | 12, 9, 8, & 5                                 | 7 (2 children, 4 AIDS-orphaned grandchildren)                                    |
| Mama Mothibi                    | 55                       | Single                | 5  | 1                                   | 2  | 9 & 6   | 5 (Child with 1 off-spring & 2 AIDS-orphaned grandchildren)                      |
| Mama Morongwe                   | 58                       | Divorced              | 4  | 1                                   | 2  | 5 & 6   | 10 (Partner, 2 children with 2 off-springs each & 2 AIDS-orphaned grandchildren) |
| Mama Seithati                   | 64                       | Married               | 11                                       | 3                                   | 6  | 13, 12, 11, 10, 5 & 4                         | 14 (Spouse, 2 other children with a child each, & 6 AIDS-orphaned grandchildren) |

Note: \* = two great-grandchildren in addition, \*\* = additional great grandchildren aged 4 and 5



**Table 2:**  
**Household size and major illnesses within the household**

| <b>Participant grandmother</b> | <b>Age of participant</b> | <b>Household size</b>   | <b>Ailment of participant grandmother</b>        | <b>Major illness of child or parent</b>     | <b>HIV status of partner, child, or grandchild</b> | <b>Migration to child due to child's illness</b> |
|--------------------------------|---------------------------|-------------------------|--|---|--|--|
| Mama Kejaeng                   | 67                        | Decreased from 8 to 6   | Backache, arthritis, Hypertension                |   | 6yrs, old-HIV+                                     |  |
| Grandma Modiegi                | 71                        | Increased from 11 to 19 | Backache, muscle pains, General Body pains (GBP) |   | Son-HIV+ 3yrs, old-HIV+, PTB                       | Yes  |
| Grandma Leitlhorang            | 70                        | Decreased from 17 to 10 | Backache, muscles pains, GBP                     |   | 8yrs, old—HIV+                                     |  |
| Mama Rulani                    | 59                        | Decreased from 10-8     | Backache, muscles pains                          |   | 4yrs, old—HIV+, TB                                 |  |
| Mama Angela                    | 60                        | Decreased from 17-12    | Backache, muscle pains                           | Arthritis, Spouse-gangrene, prostate cancer | Brother—HIV+ 4yrs.old—HIV+ TB                      |  |
| Mama Kentse                    | 56                        | Decreased from 5-4      | Backache, Hypertension                           | TB, Spouse-Diabetes                         | 7yrs,old HIV+, TB                                  |  |

| Participant grandmother | Age of participant | Household size      | Ailment of participant grandmother | Major illness of child or parent | HIV status of partner, child, or grandchild | Migration to child due to child's illness |
|-------------------------|--------------------|---------------------|------------------------------------|----------------------------------|---|---|
|                         |                    |                     |                                    | Mellitus Type 1                  |   |   |
| Mama Rebone             | 60                 | Decreased from 9-7  | Backache, HIV+                     | Arthritis,                       |   |   |
| Mama Mothibi            | 55                 | Decreased from 6-5  | Backache, Hypertension             |                                  | 6yrs, old –HIV+, TB                         | Yes                                       |
| Mama Morongwe           | 58                 | Increased to 12     | Backache, muscle pains             | Arthritis,                       | 5yrs, old—HIV+                              |   |
| Mama Seithati           | 64                 | Increased from 8-12 | Backache, TB, muscle pains         |                                  | 5yrs, old – HIV+, TB                        | Yes                                       |

Note: PTB = Pulmonary TB

## 4.4 THEMES THAT EMERGED FROM THE INTERVIEWS

The following themes emerged from the interviews: recurrent experience of loss and grief relating to parental grieving and emotional distress; lack of social support, fear of stigmatisation, financial constraints, difficulty in acquiring state support grants, mental health, physical strain, change of household size, emotional distress, caring role being divinely ordained, rejection of orphans by their biological fathers, and child disciplinary methods.

### 4.4.1 Recurrent experiences and images of loss, grief, and their relation to care-giver burden

In narratives where participant grandmothers' distress was related to parental death some hid their distress for they did not want to stress their grandchildren. Mama Mothibi's (55, single) son died after a long undisclosed illness. Subsequent to this loss she struggled to meet her grandchildren's basic and medical needs. Mama Mothibi described her household as characterized by regular intense conflicts that according to her suggested that her other children resented looking after their sibling's orphans. When asked if she ever discussed this with her children and come up with other strategies of dealing with the problem at hand, she was adamant that:

*"They will not care. They accuse me of treating them unequally. My son was working at the mine. He provided food and helped with his siblings' education fees. While working as a contractor we were "people" (of worth). Now I am nothing, left with nothing to raise his children from different mothers. Life is hard now, my other two children are roaming around and do nothing to help me with these children..."*

Mama Mothibi further reported that she was unable to forget the picture of his wasted body. She said:

*"He was only skin and bone. Nothing (no clothing) fitted him"*

Mama Mothibi reported that her son drew his last breath in her arms when she was trying to feed him. He had sores in his mouth which inhibited eating, resulting in poor appetite. She kept repeating the phrase

*“How does God allow these children to suffer like this?”*

The most touching statement Mama Mothibi made, filled with tears in her eyes, was how devastating it was for her to bathe her son, remembering him as a child and seeing him now as a man: *“How do you raise a child to be a man, and then you have to bath him like a small child?”*

When asked if coping with her current responsibility of caring for her grandchild, mama Mothibi said:

*“It pains me when my grandchild asks me where her father is. My uncles and aunts advised me to whisper in her ear while asleep that her father has passed on. It didn’t help. I don’t have a simpler way to address this.”*

Mama Seithati (64, married) expressed herself as follows:

*“I wish my children were still alive to raise their own children as they would want. Things today are different and children demand so much. I feel so alone; I ask myself why God did (sic) this to me”.*

Mama Rulani (59, married) reported her loss being unbearable. She mentioned that her brother has been molesting her youngest daughter. Mama Rulani suggested that sharing her difficulty with her brother or any member of the family was impossible because it would bring shame to her family. Mama Rulani was also asked if she told her husband about the sexual molestation she said:

*“I could not tell my husband anything. I never wanted him to know as he would have looked at my family in a negative way... I did not want to cause conflict in my own family...”*

Mama Rulani reported that she did not lay any charges as her brother was sick and eventually died a few months later. Asked about coping with the death of her child she said:

*“I failed my child... I did not protect her. Now she is gone.”*

A health professional was contacted to help mama Rulani in this regard. Mama Seithati compared her sadness to a feeling of emptiness. When grandma Modiegi (71, widowed) related her ordeal, she was tearful. She complained about her loss of sleep as her youngest grandchild has a persistent cough due to pulmonary tuberculosis (PTB) and her ailment kept her up for most part of the night. Another concern was her other grandchild who would go play without thinking about the time to take his medication, takes money without asking and problems with his general conduct.

#### **4.4.2 Lack of social support**

At least five (50%) of the participant grandmothers did not receive any assistance from relatives. They also reported not receiving sufficient financial, emotional or physical support. They struggled to put food on the table and meet their grandchildren's and other family members' basic needs. However, throughout all their experiences, they still all believed that no one could have done a better job than they had.

*“Mama Seithati says: “Every time I mention that there is no food then the little happiness that was there fades away...my husband becomes angry and being in that state you can never say anything else to him.”*

Mama Angela (60, married; see Appendix A) fears her husband and described him as hard headed, meaning that he was stubborn. She said that:

*“When one of the orphans needs medical attention I go to my neighbour and pretend to need money for a society. If my husband knows he will be so angry.”*

When asked about her daily chores in her home, she further report that:

*“I don’t know what to do. I have a husband but I feel like I am alone. My husband does nothing for me. He blames me for everything that goes wrong. If I ever ask him to give me money to buy bread, then I know I won’t sleep for the whole night. Asking for money while my sister is living with us is a daily problem. I cannot send her away as she has nowhere to stay. Pocket money is an issue on its own. I know that we are struggling but giving these children some coins once in a while will do no harm. I look at my grandchild and I can’t help it, I just cry. Feeding time is a nightmare as nothing settles in the small tummy. She was recently admitted at hospital. To visit her I had to go borrow money. I constantly think about my two children as it is difficult to go on with life, but what can I do I have to be strong for every one family”.*

Grandma Modiegi’s youngest grandchild who has HIV visits the hospital monthly for check-ups. Grandma Modiegi receives a child support grant. A support grant refers to the R290 that is supplied for children below the age of 18 to alleviate poverty. On the other hand the foster-care grants amounting to R900 and is supplied to orphans whose parent(s) have died. She reported that she has to borrow money from neighbours and micro lenders to take her grandchild for monthly check-ups because not one of her relatives is willing to assist her. She reasons that maybe it is because they also have their own social and financial problems. When asked if the relatives know about her experiences she reported that she would not even think about it. When asked why she felt she could not share anything with relatives, she added that she feared being discriminated against.

*“How will people look at me if they knew? They will be laughing behind my back. I cannot do that to my children.”*

The micro lenders reclaimed her television set and refrigerator as she was unable to repay her loan. Yet, despite these kinds of incidents, none of the grandmothers bore any resentment towards their role as carers.

Mama Seithati reported that she received food parcels from SASSA in her area because her youngest daughter was diagnosed as HIV positive and received ARTs. Her CD4 count during the interview was 32 and the food parcels provided in order to help improve her condition.

On the other hand, Mama Morongwe requested an orphan grant in 2008 but has since received neither money nor food parcels. Without the grant her grandchild who is only 5 years old is thus unable to keep up with her HAART. This is mainly owing to there being no one within the family willing to assist her in either accompanying her to the hospital or looking after her while carrying out other responsibilities. Participant grandmothers were asked about how their marital status played a role in their task as caregivers. Their responses were evident that there was no difference in obtaining social and instrumental support as they all faced similar difficulties. Being married did not bring any difference in the difficulties experienced in caring for their grandchildren. Two (20%) of the other married participant grandmothers indicated that their spouses did not play any role in caring for the sick child(ren). One indicated that she never told her spouse about their daughter's infection as she feared being blamed for leniency in disciplining the children. The other two (20%) indicated that they could not receive social support from their spouses as they too were ill. One spouse suffered from gangrene and prostate cancer while the other had diabetes mellitus type 1 and was partially blind in one eye due to the advanced stage of the disease.

#### 4.4.3 Fear of stigmatisation

In this study the main reason for maintaining the silence about their children's' status was due to fear of stigmatization. Participant grandmothers spoke about fear of harsh circumstances surrounding the infection of HIV, fear of being rejected by relatives and the community, orphanhood and financial hardships. A sense of isolation, desolation, disconnection and distress was narrated by some participant grandmothers when talking about being discriminated against about the suspicion of that their children may have died from AIDS.

At least two participant grandmothers indicated that they were afraid to disclose their children's status to the community as they feared being discriminated against as a family; therefore, they avoided talking about the affliction affecting their children. Another reason pertaining to their non-disclosure was fear that their children may be discriminated against and judged as immoral individuals, thus being considered promiscuous. The fear was so widespread that it even included non-disclosure to close relatives. When mama Seithati was asked on what she thought was the problem with her daughter she responded in this way:

*“She was suffering from the sickness of today; the fashion disease.” (“Fashion disease” refers to HIV/AIDS; also see appendix c).*

She further indicated that she avoided disclosing to her husband their daughter's illness, as she feared being blamed for being too lenient on the children. Concealing her daughter's sickness enabled her to cope with the day-to-day caregiving. In this study, at least five (50%) participant grandmothers indicated that they believed that neighbours were not aware of their children's health status or ailment.

However, some participant grandmothers did not report being stigmatised, but only the fear thereof was mentioned. Three (30%) participant grandmothers indicated that their neighbours knew about their children's HIV status but did not treat them



harshly. This may have been due to the particular neighbours' knowledge of the pandemic's transmission and their change of attitude towards the infected and affected.

#### 4.4.4 Financial constraints and difficulty in acquiring state support grants

According to clinic records, 23.3% of orphans between the ages of three and eight were found to have been born with the virus. None of them ever knew their mothers. Their health status put an enormous strain on some of the participant grandmothers. Added was the fact that some of the participant grandmothers who have not reached the age of 60 were not granted pension grant. Mama Leitthorang has been advising her granddaughters to put more effort on their school work and avoid intimate relationships. Each of the two granddaughters has a baby and it is mama Leitthorang who has to shoulder the responsibility of caring for her great-grandchildren.

*"How do I buy food and clothes for these children when their mothers are playing with it? There is nothing to prepare. I am consoled that they get pap and soup at school."*

The great-grandchildren each receive a support grant as well but their mothers demand it to buy things they desire for themselves, which is quite upsetting for mama Leitthorang. A professional nurse was requested to intervene in this regard to discuss contraception and Voluntary Counselling Test (VCT) for HIV testing with her granddaughters.

Of the ten participant grandmothers interviewed, only one is employed. The others indicated that being unemployed hindered their day to day activities of taking care of their grandchildren and carrying the costs of taking them to the hospital for their monthly check ups, which are obligatory as the requirements of their treatment differ from adult patients. Meeting the family's basic needs from the little money available

was, therefore a challenge, especially in families where there were other children and extended family members to care for besides the orphans.

During the interviews, some of the participant grandmothers indicated that they found it difficult to obtain an orphan grant as they were told by government personnel to declare who the biological fathers of the children were. Grandmothers often did not know who their grandchildren's fathers was/were as they were mostly born to single mothers who returned home ill to be cared for by their mothers.

*“She only came back when the sickness worsened. How could I ask who the father was? She was my child and I could not give her away. God will punish me for that. They will eat what I have.”*

Two of the participant grandmothers have not yet applied for child support grants as they do not understand the procedures involved. In other instances the financial implication due to legal battles left a disturbing mark. For example mama Rulani had to apply to the court in order to obtain custody of her grandchildren, as their paternal grandmother tried to obtain their custody for financial gain. When the latter found it difficult to take the sick grandchild to the hospital for regular monthly check ups, she would call mama Rulani and either demand money or force her to take the child to the doctor. Through the social workers' intervention the matter was resolved and mama Rulani was granted sole custody.

Obtaining support grant for orphans has had a detrimental effect on some participant grandmothers. Some of them (participant grandmothers) indicated that when they visited the South African Social Security Agency (SASSA) within the Department of Social Development they returned empty handed as they discovered that their grandchildren's particulars were not yet captured on the SASSA database. This was discouraging news as most of them had to borrow money to visit the offices and could not afford the wasted efforts. On the other hand, mama Kentse and mama Rulani faced the problem that their deceased children were also the

breadwinners in their families. Their chronic illness meant a loss of income and increased hospital bills. They survived on the social support grant for the two grandchildren. Mama Rulani has been visiting the SASSA offices to no avail trying to obtain an orphan grant. Tears filled her eyes when she explained how the personnel advised her to trace the children's biological fathers. This troubled her immensely as she had never approached the fathers' family for the so-called "damages" (according to custom, compensation demanded from a man who has impregnated a woman).

Lephalale has no orphanages, but drop centres. SASSA relies on Polokwane centres for orphans to cater for orphaned and vulnerable children who have no one to care for them. Those willing to care for the orphans are immediate families.

#### **4.4.5 Mental health and physical strain**

In this section their external and internal barriers to self-care during the era of surrogacy to their AIDS-orphaned grandchildren were explored. Participant grandmothers' responses in relating to their health-status reported financial difficulties and their age which according to them represented time to relax and watch their own lives rather than caregiving (economic and familial strains associated with late-life surrogate parenthood). The listed are stresses imposed by HIV diagnosis and disease progression, including the stigmatizing of infected and affected family members; social withdrawal and isolation, and the eventual death of children, siblings, parents and other family members' disenfranchised grief (which refers to grief associated with a death whose circumstances must be hidden). Thus child rearing often occurs in the context of grieving the loss of (multiple) family members, including grandchildren and own adult children.

Participant grandmothers reported feeling mentally drained (stressed out). Four (40%) of them complained of experiencing migraine, uncontrolled hypertension and

shortness of breath from their task of caring. They also reported being saddened by the frequent mood changes of their sick adult children. Other symptoms reported were: inability to maintain sleep, feeling helpless and hopeless over their children's health condition. This is backed up by Freeman and Nkomo (2006) who maintain that there is a relationship between HIV/AIDS and depression. Amongst other causes they further indicated that depression may arise due to psychological stress. If untreated depression may result in lower quality of life, high-risk behaviour (of concern to HIV prevention efforts) and higher mortality to mention a few. The findings noted are similar with regard to the following:

Six (60%) of the participating mothers indicated that they had to go to the clinic or hospital for the treatment of muscle pain and arthritis. All the participant grandmothers complained of backache which was triggered by constant bending in order to bath the patient and lift them either to change their sitting or sleeping position. Age and in certain instances chronic medical situation were also a contributory aspect to their burden, especially considering their frail physique. Grandmothers Leitlhorang and Modiegi are 70 and 71 respectively, which made it difficult to carry out all the chores without assistance. Grandmother Leitlhorang reported receiving chronic medication for High Blood Pressure (HBP) and other ailments. When asked how she was coping with the task she responded that:

*"I am no longer young. Going to the fields to collect wood is difficult. When I send the young ones to fetch wood, they take forever to return. If my bones were not this painful, I would do it myself."*

Ten (23%) of the orphans were infected with HIV and were on HAART treatment, while thirty-three (77%) were not infected. Their ages ranged between three and eight. Some of them (14%) also suffered from TB. One of the participant grandmothers is also HIV infected from caring for her daughter, while the other was diagnosed with TB. They both did not use gloves or any protective measure like wearing a mask during the caring period, which lasted for seven months for one of

them. She also suffered from hypertension and diabetes. The period of caring for a terminally ill person aggravated the circumstances with grandmothers developing ailments such as high blood pressure and other ailments due to the enormous stress they experienced. Apparently participant grandmothers never used protective measures when caring for their sick children as they felt it may be an indication that they discriminate against their children or are ashamed of them. When asked about the routinely chores of caregiving the sick mama Seithati said:

*“It’s like you are ashamed of your child when you put the rubber things on (rubber things in this study meant latent gloves). My back is killing me as I could not afford to get someone to help with laundry. I used my bear hands”.*

Another aspect that aggravated the poor health condition of the participant grandmothers is the length of time it took to care for their ill children as well as the number of deaths that occurred. About six (60%) of the grandmother participant grandmothers who lost more than one child, cared for their children over a longer period, with the maximum period being two years. The other 40 % lost one child each and the duration of care provided for their dead offspring ranged from one year and six months; with an average of eight months. This section needs further investigation in acquiring the difference between HIV/AIDS and mental health. The relationship between the pandemic and mental health also need further investigation especially in South Africa.

#### 4.4.6 **Disciplinary Problems**

Other issues raised by the other participant grandmothers were the poverty, emotional and behavioural problems presented by their grandchildren. In certain instances it was not only the grandchildren who presented disciplinary issues. One grandmother reported that her divorced daughter came back home with her three children for whom she hardly cared. She would take the support grant money and disappear for weeks. This frustrated the grandmother as she had other orphaned

grandchildren to care for as well. Most young grandchildren suffered from pneumonia, pulmonary tuberculosis (PTB), weight loss and flu symptoms, diseases that are regarded as opportunistic diseases; these children are sometimes withdrawn and isolated and thus treated badly by their healthy immediate relatives because of their weakness. Peer pressure activities were also reported as the teenagers engaged in general misconduct associated with behavioural problems, such as smoking cigarettes, dagga and other illegal substances. Furthermore, they were impulsive and hyperactive. These issues were described as being stressful to their grandmothers. Mama Angela and Seithati (see appendix D) indicated that their teenage grandchildren were uncooperative. Mama Seithati's nephew demanded all the money his mother had left, after she died. He also took the support grant that mama Seithati was saving for his education. She indicated how this distressed her, especially when he came back home after having spent all the money with his friends and could not even buy himself a T-shirt.

#### 4.4.7 Emotional distress

Eight (80%) of the participant grandmothers indicated that they experienced the strain of living or caring for people living with HIV/AIDS. Taking care of their chronically sick adult children drained their energy, especially when they refused to eat owing to oral thrush. Seeing them vomiting up the little that they tried to swallow and the constant diarrhoea made it difficult for the grandmothers to cope with the pain their children were suffering.

Mama Mothibi who was never married indicated how her daughter's death devastated her. Seeing the deterioration of their children's bodies, their loss of cognitive functioning and their children being aggressive during their sick period towards them (parents) troubled the participant grandmothers. Two (20%) of them reported feeling the strain but at the same time felt that they were coping with the situation.

The level of stress experienced may be based on the lengths of the period they had taken in caring for their sick children. These 20% indicated that they had cared for their daughters for four to five months respectively. Of the eight (80%) participant grandmothers, one (10%) indicated that her emotional distress was aggravated by her granddaughter's school work that had deteriorated as she had difficulties coming to terms with her loss. A health worker was involved in this matter for assistance.

Grandmother Modiegi lost four of her children to AIDS. As she relates, tears fill her eyes and she starts crying. The researcher had to stop the interview to give her time to recuperate. However, she assured the researcher that she will be fine.

*"I never talk openly about my bad luck. How do you go on with life as if nothing happened? I buried my four children with my own hands. Who is going to bury me when your children die like flies?"*

When asked what that if there was a situation she could change, what would it be? Her response was:

*"I will ask God to bring them back and they be available to look after their children. I am old to be going up and down with these children. I myself am not well. Who will teach them to be there for each other? Who is going to fend for them in their troubles?"*

#### **4.4.8 Change of household size**

All the participant grandmothers cared for their HIV infected adult children and parented their orphaned-grandchildren with limited resources. They reported that the role of caregiving was their responsibility because there was no other option. This may be due to the fact that Lephalale has no orphanage homes. According to the Department of Social Development, for removal of the orphan they check

Polokwane has space for acceptance. Rather than sending them away they reported feeling like they are rejecting their grandchildren. Three (30%) of the participant grandmothers reported that they had to migrate to their sick adult children's homes in order to care for them, as travelling costs were too high. These participant grandmothers found the living conditions to be very difficult as they had other members of the family to care for. Adding to their frustrations, spouses would sometimes accuse them of infidelity and that they enjoyed being far from them. This led them in other instances to bring the ill child home.

For example, grandma Modiegi a widow in her early seventies had ten children. At least four of them passed away leaving eleven of their children respectively in her care. The grandchildren's ages ranges from 15, 11, 10, 9, 8, 7, 6, 5, 4, 4 & 3 years respectively. The youngest orphaned-grandchild is HIV+ and also suffers from TB. Her household comprises of three of her own children, the 11 orphaned grandchildren; her sibling along with two of her children. Amongst her children, one is HIV+ and has a child. This brings the total of household members to 19.

She migrated to her son's place due to his health status of being HIV infected. She reported that: "Going to my child's house to take care of him was difficult. When I am there, then here at home my grandchildren don't have anyone to do things properly as I want. You know the eldest is trying to cook, but she just is not good with task." We laugh at that. How do you give birth to a child, rear him while in diapers and end up repeating the same task when he is fully grown?" it is not good. I look at him and see that he also does not enjoy that. But what can I do, I have to help him' I am his mother." After her son's spouse died she took him with her back home, increasing the household size from 17 to 19. Grandma Modiegi believe that the other two may have also died from this "fashion disease" as it is called but her other daughters told her they had makgoma. The members' number renders the living space very small as they have to share a two-roomed shack between nineteen people. The participant grandmothers experienced a role shift from grandmother to primary carer. Even as they cared for a terminally ill adult child, they also cared for



their grandchildren, often under duress and in other cases immediate relatives residing with them. Financial constrain is hard felt in households that depends only on the support grant for survival.

Mama Mothibi has been staying with two of her children, included, the deceased, her two AIDS-orphaned grandchildren, her partner, and the other grandchild. Mama Mothibi was asked about her challenges in the role of caregiving and she reported that she is worried by the fact that her youngest granddaughter is infected with HIV. She is sickly as she also suffers from Pulmonary Tuberculosis (PTB), with a constant cough. Further on she states that she feels the void and emptiness of her child's room; especially when her grandchildren refuse to play with other children as they feel like outcasts when other children talk about their mothers.

*“When their mother died, “I just cried. The house was so quiet. The waking up during the night to turn her, cooking earlier meals to feed her, making sure that there is enough water to wash her linen and bath her, had all gone.”*

Her house hold number has decreased and the loud noises had ceased.

#### **4.4.9 Caring role being divinely ordained**

All the participant grandmothers expressed the belief that their children's death was God's will. They indicated that the Lord saw how their children suffered, not being able to bath or feed themselves. They reported that everything happened for a reason. That God's will was not viewed in a passive sense; instead, their belief was that God had personally intervened and made a decision to release the son or daughter from suffering and pain here on earth. All the participant grandmothers reported that singing to the Lord eased their pain. They also reported that they gave God all their troubles and meeting in prayer or listening to a religious program on the radio soothed their pain. They further indicated that their faith kept them going.

Grandmother Leitlhorang when asked what kind of support she received, she responded that she could not be where she is if God was not in her life.

*“My child in all you do, believe the Lord to help you through. On Sundays I force these children to go to church.”*

She starts a Sepedi chorus and we sing along.

*“Di thuša eng dipelaelo le ona masetlapelo? Mookamedi ya renang o tseba se re se hlokang”.*

In translation the meaning of the chorus is: what is the use of moaning or complaining and concentrating on our disasters? The Lord we serve knows what we don't have (See appendix F)

#### **4.4.10 Rejection of orphans by their fathers**

About four (40%) grandmothers did not know the biological fathers of their grandchildren. They never tried to look for them as they had nowhere to start. Three (30%) of the participant grandmothers reported that the fathers of their orphaned grandchildren stated that they were not ill and denied paternity of these children. Mama Mothibi went to the youngest granddaughter's family to seek financial assistance, but the father of the young child denied ever being involved with her daughter. She explains as follows:

*“My neighbours used to talk about Lesenya (the supposed biological father of her youngest granddaughter), that they saw them together in many instances, my daughter never spoke to me about him. I was not expecting her to die, so I never asked who the father was. My mind was on helping her get well. I tried to involve my brother to go speak to them, he refused.”*

Mama Kejaeng and mama Kentse also experienced the same rejection. With regards to mama Kentse, the father asserted that he was not the only man in the life of her daughter. He unfortunately died before paternity tests could be conducted. Mama Kentse's problem is that she does not know the father of her first grandchild. She said:

*"...I don't even know the man she was with. I don't know who impregnated her. ... Other people think we know these things and our children never discuss this with us". It is a taboo to talk about sex matters with your child".*

Mama Kejaeng reported that her daughter's boyfriend denied paternity claiming that he was now married and this could bring problems into his marriage. He promised to help in any way he could, but never did anything. Mama Kejaeng explains:

*"He said he would help, but there is nothing happening. I don't want to be blamed for his marital problems so I keep quiet and believe the Lord will provide."*

The other three (30%) fathers stated that they could not afford to care for their children due to unemployment and the fact that their children would constantly need more money to cover transport costs for hospital visitations and health issues. They also claimed to be sick and unemployed. Mama Rebone reports that:

*"I asked him to at least help me with money for the child to go see a doctor for her monthly check-ups. He just said Mama I am sick too and have no money. This brought more frustration than understanding to me".*

According to the responses made by the participant grandmothers, most fathers rejected their responsibility of caring for their offspring, thereby leaving the responsibility entirely to them. As a way of ventilating their frustration, they pray and sing gospel songs.

#### 4.4.11 Supernatural belief and Western medicine

There were participant grandmothers who did not believe in Western explanations of their children's ailments. Two (20%) participant grandmothers reported that they believed that their children were bewitched, through the medium of *seješo* (meaning bewitchment poured into an unsuspecting victim's food). For instance, mama Rulani believed that her daughter was given *seješo* by those who were jealous that she was renovating and improving her house. Mama Rebone's daughter told her she had *makgoma* and *Mogatišo*, cultural ailments; with the latter meaning that someone poured *muti* where she was likely to pass. For medical purposes mama Rebone took him to their local traditional healer. The hospital was also involved but it was done in the final phase or the advanced stage of the disease. The general pattern was that the sick children just never disclosed their illness to their parents. However, participant grandmothers later came to know that their children were HIV positive. However, they too also failed to disclose to their grandchildren the type of ailment that their parent(s) were suffering from.

#### 4.5 SUMMARY OF THE CHAPTER

The chapter outlined the personal experiences of the elderly caring for their AIDS-orphaned grandchildren. Their experiences were classified into themes. First, a demographic profile of the participant grandmothers was provided. Thereafter, the themes were covered, ranging from issues of loss and grief, to supernatural beliefs. The next chapter discusses the findings.

## **CHAPTER 5: DISCUSSION OF THE FINDINGS, CONCLUSION, RECOMMENDATIONS AND STUDY LIMITATIONS**

### **5.1 INTRODUCTION**

This chapter discusses the various themes that emerged from the interviews. An attempt is made to relate the findings of the study to the existing literature on the topic of care, especially as it relates to the care of children and grandchildren by grandmothers.

### **5.2 DEATH, GRIEF AND CHANGE OF FAMILY AND LIFE CIRCUMSTANCES**

The burden of caring for people infected by AIDS has a number of consequences on grandmothers, who are frequently cited as the principal carers. A number of the themes in this study emerged in the verbalisations of the grandmothers. One of the obvious outcomes is the structural changes imposed by HIV/AIDS infection and mortality. Unlike the situation in other African countries, it is comparatively uncommon for most South African men to live with their offspring whether the mothers are alive or not (Hosegood et al., 2007). Research showed that maternal and double orphans are cared for by grandmothers subsequent to the maternal death. In this study, most of the grandmothers took in their sick children along with their grandchildren.

Studies showed that people living with HIV/AIDS tend to return to their place of birth to live with their relatives and presumably receive better care there (Ssenigozi, 2009; Clark, Collinson, Kahn, Drullinger, & Tollman, 2007). This study echoes the same results. The finding about or on altered family size in this study does not bring advantages such as intergenerational sharing of resources and parenting responsibilities, but rather adds burdens to the recipient grandmothers. Some of them migrated to settle with their daughters and grandchildren, so as to minimise

the costs of frequent commuting between their own homes and that of the care recipients.

The deaths of their own children appear to have been expected by most of the grandmothers. They attributed their deaths to divine intervention in the apparent suffering of the children as consequence of a debilitating disease. However, grief and heartache from their loss were quite obvious. Feeling intense sadness, worthless, hopeless and helpless as well as being hysterical; were common when some of the grandmothers touched on the subject of their children's death. They reported that these deaths left them lonely and feeling empty. It was not unusual for their loss to be expressed in the context of ensuing economic deprivation, particularly in the cases where the children who died were the primary sources of income for the household (Schatz, & Ogunmefun, 2007).

Repeated deaths compounded the situation. Some of the grandmothers lost more than one child to AIDS-related diseases or illnesses. The children were cared for when they were ill, and their deaths led to unexpected and unplanned expenditure, for instance, unaffordable funeral expenses. Some of the deceased adult children also left behind children who were also HIV infected and ill. Emotionally and psychologically, they suffered from feelings of distress, anxiety, depression, helplessness, and hopelessness as a result of their caring responsibilities and loss of loved ones. This finding is backed up by Freeman (2004), who reported that high levels of depression have been found in studies of the wellbeing of HIV/AIDS patient carers. Freeman (2004) however further indicates that depression is not an automatic or expected reaction of being an HIV/AIDS carer.

Mudavanhu, Segalo and Fourie (2008) slightly differ with the outcome of this study with regard to the spirituality aspect. They indicate that although grandmothers used prayer, song and faith as assistance in the challenging demands of parenting at an advanced age and grieving the loss of a child to death, with other grandmothers, faith was shaken.

The fathers of some of the maternal orphans did not help the situation. They disputed paternity, pleaded poverty and defaulted on the maintenance of the children, while others indicated that due to being in wedlock bringing the orphan would spark marital problems. In some cases, the grandmothers either did not know the fathers or were reluctant to approach them for assistance following the death of the children's birth mothers. That their fathers were alive was not an automatic guarantee of safety for maternal orphans, as in most cases they never avail themselves for the maintenance to their children. Losada, Márquez-Gonzalez, Knight, Yanguas, Sayegh and Romero-Moreno (2010) indicated that caregivers do experience emotional distress during loss.

The participation of male figures in the provision of care for AIDS-orphaned children remains questionable. Even though participant grandmothers in this study were few, but they reconfirmed some of the stereotypes about carers of AIDS orphans in South Africa. The women relatives who took in AIDS-orphaned children and provided care were more likely to be single, widowed, unemployed, poor and/or elderly. Coincidentally, grandmothers who were married faced similar problems as those who did not have a spouse. Participant grandmothers who were not married in other instances indicated that they felt that should they have been married, their spouses would have helped in this regard. Comparing their thoughts to those who were married, there was no difference. Moreover, they appeared to experience comparable emotional strains. For instance, they also complained about loneliness. Some of the husbands suffered from debilitating ailments like gangrene and prostate cancer adding to the care burden of the married carers. The role of males in caring was that of absence or lack of care (Datta, 2007; Montgomery, Hosegood, Busza, & Timaeus, 2006; Schaltz, & Gilbert, 2012, p. 21).

However, reaching conclusions with regards to male participation in the care of AIDS-orphans should be dealt with cautiously. Responding to the interview question on the support role offered by their husbands and partners, the participant grandmothers did not highlight the role of the fathers in caring. Yet, some of the men

may actually have been engaged in certain care activities that are considered non-traditional and therefore unreported or unrecognised (Montgomery et al., 2006). Even though the matter was not pursued in this study, it calls for a separate investigation (Nyasani, Sterberg, & Smith, 2009).

### **5.3 LACK OF SOCIAL SUPPORT AND CONSEQUENT PSYCHOLOGICAL AND PHYSICAL STRAIN**

Lack of functional and structural social support was also common among the grandmothers. Other studies indicated that they appeared to lack social support in several of its functional manifestations, namely emotional concern, information, appraisal and instrumental aspects (House, 1981). Freeman (2004) maintains that the stress that emanates from caregiving an ill adult child and later the AIDS-orphaned grandchild is due to the following aspects: a) knowing that a loved one is going to die is painful in any circumstances. When this individual is in the prime of his or her life or is a child (which is generally the case with HIV-infected people), the tragedy tends to be greater than if the person has lived a long and fulfilled life. b) The community ostracism because of the AIDS stigma puts added stress. c) As the HIV-positive person becomes more ill, family responsibilities are forced to shift. d) The physical care of a person often becomes extremely stressful psychologically. Likewise, the grandmothers specified a limited range of support networks. Marital conflict was apparent among some of those who were married. This would hint at the lack of emotional support from spouses. Relatives seemed to distance themselves from the grandmothers, leaving them to their own devices with regards to their caring role. Professional help was available to some; however, it did not cover all aspects of need. Medical and social work services were available, but the interventions were limited in scope. All this suggests that the grandmothers did not benefit from the stress-buffering effects of social support (Cohen, & Willis, 1985; Pearlin, Mullan, Semple, & Skaff, 1995). Unsurprisingly, they were susceptible to various kinds of physical and emotional strain.



Physical and emotional strains were not measured in any systematic way in this study. However, indications are that they were present. Emotional strain emanating from the grandmothers' loss of children has already been alluded to. Financial difficulties and conflicts with their spouses or husbands over trips to their children's place, added to their emotional costs. Beyond that, grandmothers complained about the physical strain of caring. The tasks involved in caring for an individual debilitated by AIDS are enormous (Schatz, 2007). Grandmothers referred to backaches, which they attributed to constant bending when bathing and carrying care recipients to change their sitting or sleeping positions, and engaging in numerous chores related to assisting the sick person. It could be that a backache is just one of the many health-related problems common among young and old carers (Schatz, & Gilbert, 2012). There were also self-reports of high blood pressure and diabetes. The reports were typical of this developmental stage in local and international studies, respectively (Schatz, & Gilbert, 2012; Whitney, Kelley, & Sipe, 2001). According to Whitney et al. (2001) most of the affected children (and people who care for them) do not get the grants they have a right to get. This may be due to ignorance of their rights, lack of access and lack of the right documents.

Similarly to the findings by Mudavanhu (2008), this study found that the challenges that grandmothers, caring for their AIDS-orphaned grandchildren, face are extensive and often involve emotional stressors. Most participant grandmothers endured the on-going struggles relating to emotional, physical and financial adjustments they had to make. This theme needs further exploration considering the vulnerability of the elderly generation and the knowledge they impart on the young generation. They need to be taken into consideration offering them the necessary assistance they require in the caring of their AIDS-orphaned grandchildren. They also need to be educated about the pandemic taking into consideration that HIV/AIDS can be treated.

#### 5.4 **STIGMATIZATION**

It is only the enacted HIV/AIDS stigma that should be a matter of concern. People associated with HIV/AIDS, as exemplified by grandmothers and their children in this study, could also feel insecure due to their fear of stigmatisation and social rejection. Their actions, while understandable, simultaneously impede potential social support. Some of the children failed to disclose their HIV status to their parents, and the grandmothers failed to divulge the HIV situation in their homes to their neighbours. In one case, the veil of secrecy was also maintained at home, where a grandmother did not disclose the HIV status of her daughter to her husband for fear of being blamed for laxity and poor maintenance of discipline. Disclosure to their immediate relatives may have helped to improve prospective social support. In this study, participant grandmothers could not share the health status with relatives or other community members due fear of being stigmatized.

From Freeman's (2004) perspective, the HIV/AIDS pandemic will have massive implications for mental health in sub-Saharan Africa, and the burden of mental health on society will be immense, increasing from 12% to 15% by 2020. Isolated by the demands of caregiving, child care, and the stigma of AIDS on even uninfected family members, the elderly caregivers are at risk not only for chronic conditions and stress-related somatic complaints, but for neglected health as well.

#### 5.5 **CAREGIVERS' HIV TRAUMATIZATION**

Another aspect of stigma emerged from the study. Grandparent carers did not use any protective clothing when they cared for their children. For instance, they did not wear gloves when they bathed their sick children, nor did they do so when handling body fluids. As a result, one of them is known to have been infected with HIV. The grandmothers were of the view that wearing protective clothing when handling their sick children, could have made them (sick children) feel rejected.

## 5.6 SOCIAL GRANTS

South Africa is one of the few countries in southern Africa that operates a number of social grants to alleviate poverty among children and the elderly. Entire households, especially in impoverished rural backgrounds and some townships, have been found to depend on the non-contributory, means-tested monthly pension (old age grants), or child support schemes such as foster care or child support grants (Schatz, Madhavan, & Williams, 2011).

Freeman and Nkomo (2006) in their study on guardianship of orphans and vulnerable children reported that most prospective caregivers identified significant additional stressors (most importantly financial) and expressed a strong need for assistance if they were to take in additional children. In this study as compared to Freeman and Nkomo (2006) although they faced or experienced financial constrain, they however reported that no one could have done a better job on these children than they did. Nevertheless, results from this study confirm that it is difficult to access social grants (Help Age International and International HIV/AIDS Alliance, 2003), and those who receive them have to extend their use to feed and care for more people rather than what the social grant was intended to do (Nyasani et al., 2009; Schatz, & Ogunmefun, 2007).

Like most skipped-generation or grandparent-led families in South Africa, families in this study were characterised by poverty and mounting responsibilities (Chazan, 2008). A number of grandmothers could not access pensions because of being ineligible, yet they were unemployed, lacked alternative and regular sources of financial help, and their life situation ruled out full time employment. Others were told to go find the children's fathers. Those who received the grant, it just was not enough.

This study highlighted the interrelations between stressors and strains experienced by grandmothers caring for AIDS-orphaned grandchildren. Providing care to a child

who is ill or dying from AIDS is daunting and stressful to both younger and elderly carers (Oburu, & Palmeru, 2005). Material resources were limited and the health of the elderly carers could not cope with the physical demands of the tasks involved (Boon et al., 2009; Kelly, 1993; van Dongen, 2005). The stress was compounded by the existence of grandchildren who were also tended and parented. Despite the stress endured in this role, the participant grandmothers did not support the idea of sending their grandchildren to be cared for elsewhere. This may be due to their traditional background believing that “*tlou ga e šitwe ke mmogo wa yona*” (meaning whatever the challenge they will somehow survive). Older grandparents took on the care task at a life stage when they were vulnerable in many ways (Joslin, & Harrison, 2002; Patel et al., 2000; Schatz, & Gilbert, 2012). They were compelled to direct resources to the health of their grandchildren and neglect their own, perpetuating their status as “hidden patients” (Joslin, & Harrison, 2002).

On the issue of not obtaining social grant, the researcher asked from the Social Development the legibility of the grandmothers’ claims. The explanation given was that social workers are faced with the challenge of placing children whose mothers have died in foster care. A child is an offspring of two people and they expect that when one dies, the one who is left behind should continue with his responsibility towards the child. All that is required is enough data about the father and his financial circumstances so that the department and social workers can indicate that in their reports. Social workers reports are returned from court with comments from magistrates that they don’t believe that the child’s father is unknown. In most cases the fathers are known and contribute although not enough to the upbringing of their children. However the caregivers are more concerned about the funds provided by the state than anything else.

## 5.7 DISCIPLINE

The grandmothers in this study also contended with issues of discipline. Intergenerational conflicts were not uncommon between grandmothers and the

grandchildren under their care (Nyasani et al., 2009). The common disciplinary challenges that were evident in this sample are: peer pressure, early initiation into sexual activity and teenage pregnancy, disinterest in school, poor academic performance, and wastefulness of the meagre financial resources. These children were reluctant to receive any psychological intervention. Coming to the centre was also costly for other grandmothers. The counsellor at the Wellness Clinic did offer group therapy as well as individual therapy to these children. The main concern of the grandmothers, as in the other studies citing disciplinary concerns, was that the grandchildren do not seem to appreciate their situation and its causes, making them likely to repeat the cycle of poverty and HIV/AIDS burden in their own lives (Nyasani et al., 2009; Schatz, & Gilbert, 2012).

Coombe (2002) maintains that the nature of relationships between boys and girls is only one of many elements in South Africa's complex social mix which determine the thrust and spread of HIV/AIDS. According to Smart (1999), many adolescents are sexually active when they are young. Further emphasised is the report that HIV/AIDS is not alone the cause and effect of problems experienced within communities. What constitutes the HIV/AIDS problem is the fact that South Africa is described as a racially divided, traumatized, dehumanised and child welfare negligent society. This may be associated with leaving morality and discipline to schools only. Further indicated is the rare communication skill adolescents have with their parent/guardians or other adults about sexual and reproductive health issues, and too many receive conflicting messages about sex and sexuality from various sources. Most adolescents make decisions about sex in the absence of accurate information, and access to support and service. They further lack confidence and the skill to negotiate sexual issues, contraception and prevention of infection (Smart, 1999).

According to Richter (2000) the intersection between HIV/AIDS and poverty necessitates a shift in perspective in approaches to meeting the needs of orphaned children. This emanates from the fact that poverty is the undeniable background to

the HIV/AIDS epidemic and the pandemic itself deepens the poverty already felt and or experienced by orphaned children (Richter, 2000). This outcome does not necessarily mean or imply that these children will lack critical socialising experiences, or that they will become alienated, disturbed or pose a potential threat to social stability even on a massive scale (Johnson, & Dorrington, 2001). However, an intense investigation is required.

## **5.8 CONCLUSION AND RECOMMENDATIONS**

### **5.8.1 CONCLUSION**

The aim of this study was to explore, analyse and describe the experiences of grandparents who care for their AIDS-orphaned grandchildren. The outcomes of this study correlates with other studies (Howard et al., 2006) in various themes reported. For instance, poverty is the most primary barrier in caregiving with financial, physical, and high emotional stress level high among potential carers. Fear of stigmatization and responsibility of fathers in the role of their children's upbringing needs attention and further investigation.

Grandmothers go through a number of negative experiences commonly found among carers of AIDS-orphaned grandchildren. Social agencies need to pay particular attention to their situation by helping the grandmothers irrespective of age to obtain support grants in order to assist in rearing and nurturing these orphans. As also stated by Orner (2006) in her study on psychosocial impact on caregivers, carers were able to identify the support they wanted and would find useful. The kind of support envisaged is the support that will make a difference, including sufficient food and maintaining order in their households. Social workers and other health workers should create ample time in discussing social matters like teenage pregnancy, sexual transmitted infection including HIV and testing, facts on adoption agencies and orphanage homes.

Added to the curriculum should be guidance period whereby educators as well as school counsellors organize seminars for teenagers in various communities that they learn from a tender age about these social issues and behavioural change. All participant grandparents are committed to their role of caring and endorse their caring with love and the belief that no other person could do a better job besides them. From the findings it was indicated that carers need social and financial support, and the orphans' mental health as well as that of their carers need to be taken into consideration. For further investigation the role of fathers, mental health and stigmatization should be prioritized.

### 5.8.2 RECOMMENDATIONS

Due to the impact of HIV/AIDS in Limpopo Province, South Africa, a broad range of interventions, including improved access to health care, promotion of a healthy lifestyle and ensuring that basic needs are met is required. The grandmothers in their roles as carers of AIDS-orphaned children should be supported through advocating for age sensitive HIV prevention messages developed with and provided by older people themselves. They should be included in programmes that provide access to HIV testing and treatment and receive guidance from trained health workers who understand their specific needs. As reported by Boon et al. (2009), grandmothers who attend a health education intervention comprising skills and HIV/AIDS knowledge, effective intergenerational communication, home-based basic nursing care, accessing social services and grants as well as relaxation techniques. From the above-mentioned techniques, grandmothers would apply them in their caregiving task.

There should be an increased recognition of the vital contributions that older carers are making, and they should be supported as they carry out this vital role. For example, they have the right to income security, access to health care and to dignity. Global HIV/AIDS indicators should include older people, in describing cutting-edge development to improve HIV service delivery in highly affected areas.

As suggested by UNAIDS (2004) to introduce the HIV Core which is a task order under USAID's Project Search that conducts research to improve other programs for HIV and AIDS treatment, care and support, as well as prevention of mother-to-child transmission (PMTCT) of HIV. The substantial gaps that may occur should be covered and government should strengthen its involvement in this regard. Carers should be involved in programs that educate them on recommended standard of care. Added the resources should not be constrained, or the constraints should be minimised significantly. Operations research and program evaluation can play a significant role in ensuring efficient and effective service delivery, scaling up to reach more clients on a broader geographical scope and enhancing quality of care, and improving the health outcomes and health systems in the country's settings. Service delivery problems and programmatic solutions to overcome these issues through the application of systematic research methods should be identified. The President's Emergency Plan for AIDS Relief (PEPFAR) that supported the scale up of services should be adopted and revised.

The main reasons for including them is to enable them to acquire more where there is lack of access, lack of relevant documents and in some instances where the older people were told to trace their grandchildren's biological fathers, as these stressors impacted directly on the needs of the elderly. SASSA should thus assist carers in rearing these AIDS-orphaned children rather than shaming them. Social workers and other health workers should also aim at helping them cope with their ordeal. Home-based carers should at least be compensated to make their calling easy especially in rural and semi-urban areas.

Added should be the economic strengthening of carers and AIDS-orphaned children by forming and training savings and loan circles as well as organic farming groups. Additionally increased school performance and decreased school dropout rate by the AIDS-orphans due to psychosocial support to deal with the trauma and loss according to needs individually as well as in groups. Special and regular health



issues related to groups for HIV-positive orphans where they learn about HIV and adherence should be administered.

Appropriate government policies are essential for the protection and well-being of orphaned and vulnerable children; and their families are enmeshed in the country's constitution. It is thus recommended that all public personnel implement the policies to assist those in need. These policies must contain clauses to prohibit discrimination on access of medical services, education, employment, housing, and protect the rights of carers and orphans. These policies should also ensure the existing residential care meets children's developmental, psychosocial, and material needs of orphans as well as the carers. At risk generation (vulnerable and orphaned children) should be targeted by HIV counsellors, school programs be endorsed on the prevention or delay of teenage pregnancies. Male learners should also be included that they learn their responsibility towards other children as well as the responsibility of being a father. This recommendation will hopefully reduce the rate of becoming a young grandmother. Their eminent role of carers in their caring task should be acknowledged.

It is also of utmost importance that carers have access to appropriate preventive and curative medical care including access to HAART treatment for those who are infected with HIV. By improving the living conditions of carers, orphan hood will be reduced or postponed and other interventions to prepare children for a transition can be implemented to prevent the long-term issues AIDS-orphans and carers face. The elderly, however, should be educated about the disease in order to be in a position to help out in the initial stages of the pandemic, thereby providing immediate treatment.

## **5.9 STUDY LIMITATIONS**

Although the sample size was adequate for purposes of the study, care must be taken to extend the findings to groupings that were not part of the study. This means

that it is risky to generalize the findings before replication studies have been conducted. Also, the study included grandmothers who had not reached the retirement age as prescribed by the law in South Africa. Grandmothers below the mandatory retirement age will of course not be entitled to access pension. Combining grandmothers who received pension and those who did not is problematic. The grant goes a long way in alleviating poverty and increasing the family's income. So, the condition of grandmothers who accessed pension and those who did not are not the same. Ideally, the access to pension element should have been controlled in this study.

#### 5.10 **SUMMARY OF THE CHAPTER**

Discussion and explication of data was given in this chapter. Also, the chapter provided a conclusion and recommendations regarding the study, and possible intervention uses of the research. Furthermore, the chapter explored some of the possible limitations of the study.

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## **APPENDICES**

### **APPENDIX A**

#### **NARRATIVES OF TWO PARTICIPANT GRANDMOTHERS**

Although ten participant grandmothers were introduced, I include the narrative accounts of only two participant grandmothers' life stories so as to augment chapter 4. These stories were selected randomly for inclusion in this dissertation. Names appearing in the stories (marked with asterisks) are pseudo-names, used for the protection of the participant grandmothers' identities.

##### Mama Angela's narrative:

Mama Angela is a 60 year old married woman who gave birth to six children. Three of her children died from AIDS related diseases, leaving their off-springs in her care. She resides with her ailing husband, who suffers from gangrene and prostate cancer, her brother who is HIV positive, and a negligent divorced daughter who arrived with her three children, and six AIDS-orphaned children. Her husband is currently working but does not earn much. Most days he fails to go to work, due to ill-health. Her family has been despoiled by AIDS. The first AIDS death in her family was that of her second child (Mulano; not her real name) who passed on in 2005, leaving behind a six weeks old baby of her own. Mama Angela cared for Mulano during her illness. She also cared for her third daughter, Puseletso. They (the second and third daughters) both came home when the disease was in its final phase. She cared for them for one year, six months, and eight months, respectively. They died two months after each other.

Five months later after the death of Puseletso, Mama Angela's son had to be brought home as well to be cared for after his spouse's death. She cared for him for only three months after which he also died of AIDS. His off-spring also came to reside with Mama

Angela as they still attended school and could not manage to care for their then sick father. His wife died earlier before the husband was bedridden, she was also cared for by Mama Angela. She would walk to their house to help in whatever way possible, doing laundry, cooking and bathing her daughter in law. Her youngest daughter, Amanda,\* who is still at school, also has a baby and the young one is Mama Angela's responsibility, as she (Amanda) is unemployed. She depends on her child's support grant which does not do much as it is too little.

All her children died in her household and entering the room fills her eyes with tears due to the pain that she endured.

The youngest grandchild, a four year old, is infected and recently developed tuberculosis (TB). Mama Angela does not even know the man who impregnated her daughter (the girl's mother), as she was working around Tshwane before she fell ill.

Two of her other children have their own families outside Shongoane, a township within the Lephalale local municipality area. Lelemang,\* her first born is in a polygamous marriage with five children. The fourth born, Rantsona,\* is divorced and four of his children are residing with his estranged wife. He is somewhere in Thabazimbi and Mama Angela cannot help but worry about him, since he never visits, he may be dead or sick. It has been years since she last spoke to him. He last came home in December 2005 to bury his sibling. Mama Angela reported that seeing him that day nearly killed her as he was wasted and looked ill. On asking him, he reassured her that he was fine. He also reported that he has a "wife" and three children and promised to bring them along on the next visit; he has never kept his promise.

Mama Angela consequently cares for her 6 AIDS-orphaned grandchildren, her husband, HIV+ brother + his 2 off-springs, and her divorced daughter and 3 children. In addition to her dilemma, her husband is unwell, and does not instrumentally support her due to his ill-health. Mama Angela grew a garden to support the family. The amount of money including the money she receives from her husband for maintenance and the little for support grant is very little. She does not receive the grant issued for orphans. She reported that the

reason she does not get the money is that she was told to look for the children's biological father or fathers. "Where will I find him? I don't even know even know him." She asks with tears in her eyes.

Some of the challenges she meets are:

She faces economic challenges like seeing to it that fees are paid as required by her youngest daughter's school, covering transport costs to school and some pocket money, which is inadequate. Her daughter cannot help as she herself is a drunkard and a gambler. She sometimes uses the entire support grant for gambling (playing cards). A social worker was called in to attend to this issue; she now receives counselling from the hospital and Mama Angela has become the sole guardian of the child. Her daughter was adamant to go for counselling at first, but later agreed to get help. She was also of the opinion that her grandchild should leave her current school and attend the local institution where no school fees are paid and the children are fed at school. Another challenge experienced is taking the youngest orphan for monthly check ups at the hospital. As if she does not have to cope with enough troubles, she also has to bath and feed her brother.

Given all these demands on her, her heart is troubled every time the other orphan needs something invaluable for school like education excursions and she thus wishes his parents were alive to fend for him. Her household size has increased, yet she is staying in a two bed roomed shelter.

#### Mama Seithati's narrative:

Mama Seithati is a 64 year married woman, residing with her husband, her youngest child who is HIV+ and six grandchildren. In her marriage she bore eleven children and lost three of them to AIDS. Her daughter left behind two children; her son died in January 2011 and her first born Bongwe (not his real name) passed on in October 2011. It was difficult for her to accept Bongwe's death, as she believes that he was turned into a zombie so as to work for the old witch in their village. What also troubles her is the issue of his green identity



book which was never obtained as well as his clothing and assets that he had accumulated while working. She sees herself as having bad luck losing her children to AIDS and leaving such young children who needed their mothers so much. During her caregiving role she contracted TB as she wore no mask when tending for her sick child, avoiding being perceived as discriminating against. A social worker was called in to visit her home with mobile nurses to immunise the whole family to avoid infection as the disease is airborne. This was also done to alleviate financial implications as it would have been difficult to pay for them all to be treated.

Mama Seithati reported having problems with her husband's infidelity. In order to alleviate her financial problem she claimed child support, which amounted to R500 in 2007 and now R1000, after reporting to the maintenance court that the R500 was insufficient. She never disclosed her children's ailments to her husband in fear of being criticised for being too lenient in disciplining them.

## APPENDIX B

### INTERVIEW QUESTIONS

- When and where were you born? Please tell me about yourself?
- How many children do/did you have?
- How did they grow up?
- Can you give your history of the events that led to your caring role to your grandchildren?
- In which physical state was the deceased child before his or her ultimate illness?
- How and when did you realise that your child was not in a good state of health?
- What steps did you take in trying to deal with your child's situation?
- How long was/were your child/children ill?
- How did/do you experience the role of giving care to your child?
- How did/do you experience the role of giving care to your grand-child (ren)?
- What are the challenges you experience in caring for your grand-child (ren)?
- What kind of support do you receive as you care for your grand-child (ren)?
- If there was a situation you could change now, what would it be and why?

## APPENDIX C

### DEFINITION OF COLLOQUIAL AND NON-ENGLISH WORDS

**Makgoma:** Among the Pedi of South Africa the word refers to indigestion and constipation. The person feels bloated and suffers discomfort, especially after attending a funeral.

**Mogatišo:** It is a concept from Sepedi, a type of witchcraft act, whereby a jealous person(s) snatches the soil where a target person passed, and put a curse on it. In other cases it may be muti placed where the target person is likely to pass by and the person then suffers from chronic leg pains, which no doctor is able to treat.

**Muti:** A Zulu word commonly used to refer portions prepared by a traditional healer, sometimes used malevolently against enemies or rivals.

**Seješo:** A Sepedi concept implying food poisoning using traditional medicine from a traditional healer.

**Mashonisa:** A Zulu word for loan sharks. These are people who loan out money. When they loan you the money your bank card is retained so that they are in a position to withdraw the loaned amount including interests. This practice is considered illegal in South Africa.

**Fashion disease:** A colloquial name for HIV/AIDS used in Lephalale, South Africa.