

HIV/AIDS and elderly health: The experiences of caregivers living in HIV affected households.

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College of Humanities

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Abstract

More than three decades after the outbreak of the AIDS pandemic, sub-Saharan Africa is home to the largest epidemic in the world. Over 70% of infected people live in this region and are aged 15–49 years. Given that it is at this age that young adults are more likely to start families, their death as a result of AIDS gives rise to the crisis of AIDS-orphaned children. Several studies show that the number of AIDS orphans is on the rise and can reach up to 18 million throughout the continent. Generally, patients expect to be admitted in formal health care facilities for adequate treatment but the absence of cure and an increasing number of infected make it difficult for them to be treated as in-patients. In order to fill the gap, the elderly care for AIDS patients and take on the parenting role of AIDS orphans. However, there is not much information on the implications of caregiving on the well-being of the elderly. This dissertation aims at shedding light on this issue – using data from an informal settlement in the province of KwaZulu-Natal – in order to highlight the risks to the health of elderly caregivers.

The elderly are the primary caregivers to thousands of AIDS patients and AIDS-orphaned children across sub-Saharan Africa. Their caregiving activities are strenuous and repetitive on a daily basis. Through qualitative data collected from 14 elderly caregivers, this project found that their well-being was compromised by several caregiving activities and the expectations placed upon them were unbearable. The vulnerability of caregivers was emphasized by the high number of dependents that resulted in lowered standard of living. There was also the risk of contracting HIV during caregiving since the elderly were not able to afford protective equipment.

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Acronyms and abbreviations

AIDS:	Acquired Immunodeficiency Syndrome
ANC:	African National Congress
ARV:	Antiretroviral
HDR:	Human Development Report
HIV:	Human Immunodeficiency Virus
HSRC:	Human Sciences Research Council
IFP:	Inkhata Freedom Party
KZN:	KwaZulu-Natal
NGO:	Non-Governmental Organisation
STATS SA:	Statistics South Africa
UN:	United Nations
UNAIDS:	Joint United Nations Programme on HIV/AIDS
VCT:	Voluntary Counselling and Testing
WHO:	World Health Organisation

Chapter one

INTRODUCTION

1.1. Introduction

Traditionally, “parents” were expected to care for children who should in turn look after them in their old age. Children were viewed as old age assets. The extent of support expected by parents was dependent on the number of children they had. At present, these expectations are challenged by a various set of issues. Over the years African societies have witnessed significant changes in the role played by the elderly at the household level. In fact, in the past, older people had an important role to play in guiding their families and communities. They were concerned with the socialization of the society and ensured that the values, knowledge and norms are passed on from one generation to the next. The elderly were the guardians of tradition, they had to ensure that the “ancestral” knowledge and know-how were preserved from older generations to the young ones (Nhongo, 2004).

However, the rise in importance of formal educational institutions and the increasing influence of the church and a modern lifestyle have reduced the influence of older people on households and families. These institutions replaced the elderly in the role of socialization and as a result their prestige and contributions are often overlooked (Nhongo, 2004). Over the years, the involvement of the elderly in family life has again gained momentum. The onset of the AIDS epidemic has placed the elderly in the spotlight since they are being increasingly involved in the upbringing of their grandchildren and in the care of AIDS patients. They often provide economic, psychological and social support to AIDS orphans and AIDS patients. This caregiving could go beyond the one that was previously exerted by the extended family since it is submitted that, traditionally, family members were expected to care for widows and orphaned children (ibid). Unlike the support provided by the extended family, the issue of secrecy surrounding AIDS imposes restrictions on the number of caregivers. In contrast, in the past, “the whole community” could be involved in assisting the affected family. Since the AIDS epidemic deprives

communities of young adults in the prime of their life, it has become difficult to provide necessary support to all needy members of the society. Older people are then at the forefront of caregiving in the era of AIDS.

1.2. Older people

According to the United Nations (UN), older people refer to those who are 60 and above. Nevertheless, this chronological definition does not hold true in the African context since it leaves out very important realities (Nhongo, 2004). Firstly, in Africa many older people are unable to provide their exact dates of birth and they have to remember events that might have occurred in the year of birth to determine their ages. Their ages are either under-estimated or over-estimated. Secondly, the concept of older people varies across societies. In some communities, the term ‘older people’ is associated with the extent of achievement in life, assets, the size of family in terms of number of wives and children, as well as grandchildren, etc. Thirdly, criteria like physical appearances (such as grey hair, wrinkled face, etc.) are put forward as signs of age or seniority. Fourthly, the extent of knowledge that some people in the community can have of major events, history, initiations, rituals as well as other traditional processes. Finally, using the retirement ages as criteria is flawed since these ages vary from 45 to 65 years. The UN definition seems to be the most “practical” since it helps to get rid of operational issues but is more likely to leave out some of the people that should be classified as senior, while their identity papers deny them this “attribute”. However, for operational purposes, a person aged 60 years and above can be classified as elderly.

1.3. Ailing health

Old age can negatively impact on the quality of life which can in turn be worsened by the extent of expectations placed upon the elderly. Despite this perceived risk that looking after others might represent to the elderly, their contribution to the relief of the suffering of their loved ones is truly a major breakthrough. It is argued that old age is associated with a given set of changes in

the elderly that might impede their perceived competence and abilities (Bengtson, 1973; Butler, 1967; Lewis, 1982). According to Deci and Ryan (1985), the concept of control can be viewed as the ability to commit intended acts and avoid those that are not. This notion of control seems very essential since it is proven that the ability to exert control over one's decisions has strong implications for physical and emotional health (Schmale and Engel, 1967; Glass, 1977). Moreover, looking after AIDS patients and taking on the parenting role of AIDS orphans might result in challenges that the elderly are implicitly obliged to live up to, and they are expected to exert more control. This is to say that older people, especially the heads of households, are responsible for making major decisions.

1.4. Caregiving and HIV/AIDS

The AIDS pandemic has challenged the medical landscape (Richman et al., 2009), raised concerns over its impact on world peace and stability (Mann, 1987), and thoroughly affected social relationships because of the issue of stigma and discrimination (Marks, 2002). The effects of this epidemic are also felt at the family level since it has resulted in an increase in the number of caregivers. This situation is more acute in countries where the prevalence is very high (van Dyk, 2008). The high proportion of AIDS patients has forced non-professional caregivers to come to the rescue of the sick. Sub-Saharan Africa is by far the most affected region. Most of AIDS patients living in this region are either out-patients who receive some kind of treatment through formal health care institutions or home-based programmes or are not on any formal health care, and rely solely on family members (Kipp et al., 2007). This is to say that the extent of prevalence impacts on the level of reliance on "informal caregivers". It can therefore be argued that this reliance goes beyond the expectations placed on formal caregivers.

The outbreak of HIV/AIDS has profoundly changed the concept of caregiving. According to van Dyk (2008), a caregiver can be defined as every person involved in psychological, emotional, physical and spiritual care of people affected or infected by HIV/AIDS. The increasing number of people living with HIV/AIDS has led non-professional caregivers to assist. It goes without saying

that the caregivers looking after these patients in formal and informal health sectors are made up of the following groups: professional health providers (nurses and doctors, from formal health care facilities such as clinics, hospitals, hospices and home-based care programmes); voluntary counselling and testing (VCT) caregivers; social workers based in hospitals or public organisations; educators targeting vulnerable populations; psychologists and special counsellors for people living with AIDS and volunteers working for organisations that provide various AIDS services. Another category is made of people without formal training such as traditional healers and herbalists. Besides the groups of formal and informal caregivers, family members have also stepped in to take care of their loved ones (ibid).

Prior to the onset of HIV/AIDS, orphaned children existed in Africa but the steep increase in the number of orphans is recent. According to UNAIDS (2004) there are 18 million affected children in sub-Saharan Africa. The death of parents as a result of AIDS has led to changes in household composition and structure. It is submitted that the proportion of grandparents heading up households is on the rise as a direct outcome of the increasing influence and role that older people play in the upbringing of their grandchildren (Zimmer and Dayton, 2005). In other words, the elderly are more involved in the parenting of orphaned children in countries with high HIV prevalence (Beegle *et al.*, 2009). The children that fit into the category of orphans are those under the age of 18 and who have lost at least one parent.

The death of parents as a result of AIDS, in particular, can make children more vulnerable since some end up living in child-headed households while others are cared for by family members, especially grandparents (Ntozi and Nakayiwa, 1999). It is poignant to realise that other children are more vulnerable than these two groups as they end up living on the street and are exposed to several challenges common to homeless people such as lacking shelter and food.

In many countries severely affected by the AIDS epidemic, there is up to now limited access to antiretroviral (ARV) treatment (UNAIDS, 2010), and as a consequence in these settings,

contracting HIV is synonymous with a death sentence. The loss of young adults deprives children of main breadwinners and may force the extended family to step in to fill the gap. The elderly members of the affected family are more likely to deal with the “collateral damage” of AIDS. The contribution of the elderly to this effect is very substantial throughout the continent, especially in the hardest hit countries (Jazdowska, 1992).

The role played by the elderly is crucial for the survival of the household and the well-being of AIDS patients. In other words, the elderly seem to be well-motivated to care for their infected loved ones, because most AIDS patients return to their parents’ homes when they are no longer able to take care of themselves (Ntozi and Nakayiwa, 1999). The disruption caused by the AIDS epidemic is so disastrous at the family level since many of the infected adults are afflicted at the age that they are likely to have started a family. The loss of young adults in the prime of their lives leads to changes in family structures such as increasing older people-headed and “skipped-generation” households.

South Africa is home to the largest AIDS epidemic in the world, it can be termed as the “world’s AIDS capital city”. This country alone accounts for 5,6 million people living with AIDS (Department of Health, 2010). In contrast, South Africa accounts for less than 0,8% of the world’s population while AIDS prevalence is slightly above 3% of 34 million people living with AIDS recorded at the end of 2010 (UNAIDS, 2011). It is reported that one million people have died annually as a result of AIDS in sub-Saharan Africa since 1998. One in two AIDS deaths was recorded in Southern Africa (ibid).

Though there is a significant decline in AIDS incidence in South Africa from a high of 2,4% in 2001 to a low of 1,5% in 2009, this figure is still high and varies across the country (ibid). The decline in the number of new HIV infections occurs simultaneously with that of AIDS mortality which went down by 21% between 2001 and 2010 (ibid). This synchronized shift in terms of death and new infections is explained by the amount of investment made by the government of

South Africa to stabilize the incidence rate around 500 000 cases per year. It is also possible to bring this statistic below 250 000 per year if current efforts are maintained (UNAIDS, 2011).

The decrease in the number of new infections is offset by an increase in the proportion of AIDS patients that are currently on ARVs; this figure shows that the burden of disease is still huge. Despite the scaling up of ARVs, it is reasonable to argue that the burden of caregiving is expected to continue for several years. A significant proportion of these caregivers are older people who are expected to be accommodating in this situation. There is a large body of research that focuses on the contribution of the elderly caring for AIDS patients, especially during the last stages of terminally ill life. This research also provides insights into the commitment of the elderly looking after AIDS-orphaned children (Knodel, 2005; Agyarko *et al.*, 2000). Regardless of sex and age, being a caregiver is a difficult task as it requires commitment, discipline, self-control, enough time and physical strength. Though it is possible that some elderly can manage to live up to these challenges, and view their caregiving activities as part of their family obligation or duties, it should be made clear that most of them do not have sufficient education, have minimum training, and lack some key information that could help them to handle some particular tasks (Makiwane *et al.*, 2004). This takes place at a time when a significant proportion of these elderly are part of the poorest, since their working ability has diminished as a direct outcome of years of hardship. Further, being elderly is already a challenge in itself. In Africa, the elderly end up falling sick continuously, doing dangerous work and having high levels of anxiety and stress (Heslop, 1999). This situation can be worsened by the fact that they are retired and not economically active. Being a caregiver can increase the risk of vulnerability to poor health since they do not have time to look after themselves anymore (Fouad, 2004). The increase in daily chores is more likely to compromise the well-being of older people. This situation is exacerbated by a lack of access to public programmes.

In order to achieve a certain level of well-being that is acceptable and to minimize health hazards, there are requirements that must be met. Some of the preconditions can be: having enough time to sleep and rest, having some spare time and seeking medical attention when necessary. However,

caregiving can restrain the mobility of the caregiver as he/she is expected to monitor the care-recipient. The intensity of caregiving can result in isolation. The fact of being isolated can be harmful to the well-being of the caregiver. On the other hand, caregivers, especially the elderly, seem to hold the belief that the well-being of care-recipients is more important than their own because they may feel that they have nothing to lose at their age. All in all, the well-being of elderly caregivers is at risk of being compromised. However, not much is known about the implications of caregiving on the health and well-being of the elderly.

1.5. Main objectives

Since the outbreak of the AIDS epidemic, some parts of the world have been particularly hard hit, especially sub-Saharan Africa which constitutes only 10% of the world's population (Agyarko *et al.*, 2000). The contribution of older people to the well-being of people living with AIDS as well as AIDS orphans has been substantial but not enough is known about the implication of caregiving on their health and challenges inherent in the caregiving activities of the elderly. Exploring this feature is very essential. The present project aims to contribute towards filling this gap by attempting to get older people to provide more insights into the way the increased household chores and their "family obligations" shape their daily living. The following questions will be addressed in the course of this study:

What are the implications of caregiving for the health of older people?

What are some of the challenges older people face in providing care to AIDS patients and orphaned children?

What are some of the difficulties older people face as substitute parents?

1.6. Specific objectives

HIV/AIDS has become a serious issue of concern, since it has deprived several communities of their active young population; the contribution of the elderly to the well-being of these patients has increased in importance but the fragile health of these caregivers require attention. The present study will look at factors affecting and constraining caregiving on a daily basis. The objective of this study is:

To investigate the challenges and obstacles faced by the elderly as caregivers of AIDS patients,

To assess the health challenges experienced by the elderly as substitute parents,

To get the elderly to describe their health situation and highlight hindrances to accessing health care,

To provide an overview of the tasks involved in the caregiving activities of AIDS patients and AIDS-orphaned children.

1.7. Research question

HIV/AIDS has become a serious issue of concern since it has deprived several communities of their active young population. The contribution of the elderly to the well-being of AIDS patients has increased in importance but the fragile health of caregivers requires attention. The elderly have become primary caregivers to an increasing number of AIDS-orphaned children. However, the well-being of the elderly is more likely to be compromised by the burden of their caregiving activities. In order to address the research questions, this study will look at factors affecting and constraining caregiving. The objective of this study is to examine the experiences of the elderly in terms of their challenges and to shed light on their perception of health and well-being.

1.8. Principal theories of the research project

Stressors are associated with lifestyle events and the multiplicity of these events might be conducive to an increase in ill-health. It is submitted that stressors are rarely isolated phenomena since some stressful events experienced in one area of life influence others, which result in an accumulation of several stressors in other spheres of life. This process has been termed stress proliferation (Aneshensel *et al.*, 1995; Pearlin *et al.*, 1997). Pearlin (1999) reveals that there is stress proliferation when an initial stressor or a given number of stressors related to one sphere of life create (secondary) stressors in other areas of life. Examples of stress proliferation are common in everyday life. Eckenrode and Gore (1989) provide more insights into this issue in stating that problems at work may exacerbate tensions in a couple. Shapiro (1996) reveals that there is a relationship between divorce and financial strain and juggling between childcare and work may result in increased stress of working mothers. Given that stressors in one sphere of life may negatively impact on activities or relationships in other areas of life with which they are directly or indirectly related, new stressors can be created.

Regardless of the period of time that multiple stressors take place, they have the ability to put an end to a various set of activities in spheres of life related to those in which the primary stressor was experienced (Pearlin *et al.*, 1997). These disruptions may separately exert a negative impact on the people's health and well-being. Each stressful event has its own level of influence (Aneshensel, 1992). Looking after AIDS patients is stressful since it is associated with discrimination, stigma, loss of social networks and secrecy. The death of these patients in the prime of their life is part of the factors that exacerbate the situation of caregivers since they are not only deprived of their loved ones but also of "old age assets". Further, AIDS orphans may constitute another stressful event for the elderly since they are expected to take on a parenting role in spite of their old age and failing health. The "pile-up" of expectations placed upon caregivers may lead to the proliferation of stress over time.

1.9. Organisation of dissertation

Chapter one explores the “collateral damage” of HIV/AIDS at the household level and its impact on the restructuring of the household. The role played by the elderly in the era of HIV/AIDS as caregivers, substitute parents and breadwinners is also highlighted. This section also draws on the abilities of the elderly to cope with caregiving activities and also outlines the aims and objectives of the study. The second chapter will provide insights into the existing literature, covering causes leading to the formation of skipped-generation households in the AIDS era and over time. The issue of gender and caregiving will be also highlighted. More light will be provided on coping strategies and challenges that the elderly encounter. Finally, some concerns over the health or well-being of the elderly will be highlighted. In chapter three, the study methodology will be thoroughly explained. The sampling and the study setting will be presented in depth as well as an overview of the non-governmental organisation (NGO) that assisted in recruiting the sample for the interviews. Furthermore, ethical considerations and limitations of this study will be discussed in the same section. Chapter four will focus on the results and discussion of the fieldwork of this study. This section will provide insights into challenges faced by elderly caregivers. The last section will draw on obstacles to successful caregiving of AIDS-orphaned children. From the study findings, recommendations will be made for future investigations as a way forward towards the involvement of communities in support of elderly caregivers and surrogate parents.

Chapter two

LITERATURE REVIEW

AIDS is one of the major challenges facing the 21st century. The extent of devastation caused by this epidemic has led to profound changes in the composition of households. As a matter of fact, most infections occur among the age group 15-49 years which constitutes the reproductive age. It is the age at which young adults start working and also begin their families. The death due to AIDS of these young adults deprives families of breadwinners and the elderly of “old age assets”. Studies suggest that poverty stricken grandparents allocate their meagre resources to care for their dying loved ones until their passing away and also take on the parenting role of their AIDS-orphaned grandchildren (Munthree and Maharaj, 2010). The death as a result of AIDS is instrumental in the formation of grandparent-headed households. There is a growing amount of literature on the causes affecting household composition in academic writing. The first part of this section will highlight the causes leading grandparents to take on the parenting role of their grandchildren around the world before and during the HIV/AIDS era. The second part will deal with general causes leading to surrogate parenting in the global context with much emphasis on the implications of HIV/AIDS in Africa and South Africa in particular.

2.1. Causes impacting on household composition

Far from being a new phenomenon, the issue of grandparents raising their grandchildren is in the spotlight because of a significant rise in the number of skipped-generation households. Backhouse (2006) reveals that the attention of sociologists has been focused on the issue of grandparents raising their grandchildren around the world. For example, it was indicated that there were approximately 22 500 grandparent-headed families in Australia in 2004 (Australian Bureau of Statistics, 2004). Although it was acknowledged that multigenerational households are not new in the United States, Ruiz (2000) has revealed that it is on the rise particularly among African Americans (grandmothers taking on a parenting role of their grandchildren). This

increase in proportion of grandparent-headed families is fuelled by the risk-taking habits, carelessness and illness of young adults. It goes without saying that the behaviour of parents plays an important role in the formation of skipped-generation households throughout the world.

2.1.1. Parents' death and illness

The change in family structure and composition is caused by several factors, especially, illness. For instance, parents in poor health often are not in a position to assume their family responsibilities. HIV/AIDS is one of the factors that lead grandparents to take on the parenting role of their grandchildren (HelpAge International, 2003). UNAIDS (2000) reveals that one in two people contract HIV before their 25th birthday, become AIDS patients at age 35 and then leave behind children to be cared for by their grandparents or to live in child-headed households. Though treatment can be available, effective and have resulted in reduced mortality, there is going to be an increase in the proportion of AIDS-orphaned children over the next decades (Joslin, 2000). This holds true since AIDS death is unlikely to be cancelled out and reach zero mortality rate.

The outbreak of HIV/AIDS has resulted in serious challenges for most affected countries. For example, it was predicted that by 2000, 125 000 male and female adolescents in the United States could lose their mothers due to AIDS. A significant proportion of them come from a disadvantaged background (Joslin and Harrison, 1998). Most AIDS orphan children whose parents have died of and are living with AIDS have as sole or primary caregivers their grandmothers (ibid).

The devastating effect of HIV/AIDS on the household is more visible in Africa and in some Asian countries as outlined by Knodel (2005). This author argues that these two continents are experiencing the effects of HIV/AIDS; one of the main focuses in debates is the death of prime-age adults and the issue of orphans left by them. The parents of AIDS patients, in particular, older people, are affected by the epidemic as they suffer the consequences of losing their

children and they are also among key actors that care for the terminally ill and look after AIDS orphans. Adult children infected by HIV living elsewhere, very often return to their parents' home in order to be cared for at advanced stages of illness when they are no longer able to care for themselves or, it sometimes happens that parents move to join them in the later stages of sickness to provide them with assistance. An adult child living near or with parents from the onset of illness is ever more likely to expect their care at the terminal stage after leaving his or her spouse (ibid). It transpires from these writings that surrogate parenting is a worldwide challenge, however, it is emphasized by a wide range of issues preventing biological parents from rearing their offspring. Although this kind of parenting existed before the outbreak of the AIDS epidemic, the sudden rise in the number of children placed in the care of the elderly is a recent trend. The increasing number of AIDS orphans is more likely to strain the ability of the extended family to care for vulnerable children.

Sub-Saharan Africa is home to the largest AIDS epidemic in the world with 70% of the total number of infected people living on its soil (UNAIDS, 2010). The sub-Saharan region also experiences the worst AIDS orphan crisis with approximately 18 million affected children (UNAIDS, 2004). It is reported that six African countries - Kenya, Nigeria, South Africa, Uganda, United Republic of Tanzania and Zimbabwe - are themselves home to more than 9 million AIDS-orphaned children. Despite the gradual increase in the provision of ARVs, the number of AIDS orphans has witnessed a rise over the last five years (UNAIDS, 2010). In Ghana, a study carried out by Ansah-Koi (2006) reveals that there are 132 000 AIDS-orphaned children and a peak of 291 000 will be reached in 2015. Most of these children will be looked after by their grandmothers. A quantitative study conducted in rural South Africa by Hosegood *et al.* (2004) highlighted that during 2000 and 2003, the probability of household dissolution increased with an adult death. The death as a result of AIDS was very high and played a significant role in the household dissolution. An estimated 50% of deaths during this period was due to AIDS. Furthermore, in a quantitative study conducted in KwaZulu-Natal (KZN) on the impact of AIDS mortality on the mobility of children, it was substantiated that AIDS accounted for 50% and 67% of the death of fathers and mothers respectively. On the other hand, AIDS-

orphaned children were less likely to migrate than other orphans (Ford and Hosegood, 2005). This can be explained by the fact that the caregivers of their parents become their guardians and substitute parents and there is no need for children to move, or it can give rise to the formation of child headed households.

The contribution of grandparents to the rearing of AIDS-orphaned children is also substantial in most hard-hit countries outside of Africa. UNAIDS estimates that 300 000 children have lost one or both parents to AIDS in Thailand (UNAIDS, 2002). Taking on a parenting role is not a new phenomenon since there are communities around the world that view this type of caregiving as part of their family duties.

2.1.2. Traditional role

Traditionally grandparents were not directly involved in the rearing of their grandchildren. In Africa, Rosenmayr (1993) expounds that there was not a direct relationship between the upbringing of children and grandparents. Their relations were referred to as 'joking ones'. For instance, grandmothers often praised the physical appearances of their grandsons and promised to dump the older males for the young ones. These findings are supported by the studies conducted by Wearing and Wearing (1996) among American grandparents and by Neugarten and Weinstein (1964) in Australia. However, grandparents would move in when parents failed to bear their responsibility. This fact was observed in Australia by Hammill (2001) who argues that grandparents, especially grannies, spend much time providing care and are demoralized both by their lack of voice and for being denied their traditional responsibility as well as their 'natural ageing processes'. Even if further investigations are not undertaken about reasons leading grandparents to take on a parenting role, it transpires that extended families set up mechanisms for dealing with the grandparenting issues. In Africa, placing children in foster care has been acceptable in many traditional societies as well as countries. According to some studies conducted in Cote d'Ivoire (Ainsworth, 1996) and Burkina Faso (Akresh, 2004), this practice is viewed as beneficial to children and their family. It makes sense to argue that both sending and

receiving families seek the best interest of these children since fostering does not apply to orphans only. There are various arrangements across the continent. In South Africa for instance, it is common that children live in grandparent-headed households while their non-resident parent(s) provide them with financial support (Hill *et al.*, 2008). Foster care is also widespread and inherent in Benin. According to Meier (1993) females are prepared to play the role of mothers, wives, aunts, sisters and grandparents. For grandmothers, fostering is a gift or a way of offsetting the loss of the daughters given away in marriage.

In other words, being part of the safety net of the extended family, grandparents are also 'eligible' to take on the parenting role. Hence, having a background of caregiving can be viewed as one of the factors conducive to the formation of grandparent-headed households in the community or family.

2.2. Gender, age and caregiving

The "division of labour" or the "social division of labour" between men and women seems to have something to do with the designation of caregivers. In a study conducted in Canada, by Armstrong and Kits (2004), it was found that most caregivers were females: daughters, mothers, and partners. They constituted the overwhelming majority of unpaid primary caregivers and were likely to spend more time than males in providing personal care and offering emotional support while males were more interested in managing care, maintaining households, transporting or shopping. These findings are also supported by a study carried out in the United States that revealed that there were more females taking care of AIDS-orphaned children than males. A large number of these caregivers were made up of grandmothers, great-grandmothers and great-aunts who were 60 years and above (Mellins *et al.*, 1996). This trend was also observed in India (Mehta and Gupta, 2011). In South Africa it was also found that the burden of AIDS caregiving is felt more by elderly females, especially maternal grandparents. The maternal (grandparents) caregivers look after most people in the final stage of illness, who return home accompanied by their own children (Whiteside, 2008). Caregivers are recruited among parents, friends, relatives,

siblings, partners or spouses as well as others who have some ties with the affected people (Sosnowitz and Kovacs, 1992). These findings are also consistent with a study conducted in Botswana, Zimbabwe and South Africa (Richter *et al.*, 2004). In rural Tanzania it was found that both male and female elderly were caring for terminally ill AIDS patients in their households, however the time spent by the female caregiver was twice as much as that of their male counterpart (Dayton and Ainsworth, 2002). In an attempt to understand the reasons for the low representation of males in HIV/AIDS caregiving activities in Lesotho, a qualitative study was undertaken in health facilities across three districts in rural and urban sites. It transpires that caregiving is overlooked because of its unpaid status and is traditionally reserved for females since they are viewed as nurturers (Newman *et al.*, 2011). With regard to gender, given that the tasks of females are more personally demanding than the caregiving activities of their male counterparts, the former are more likely to feel greater tension than the latter.

According to Baines *et al.* (1991) the gendered division of labour which entails that females are caregivers and males breadwinners, forces older women to take on caregiving roles instead of being care-recipients. Looking after AIDS patients as well as caring for AIDS orphans results in several difficulties. This assertion holds true for both male and female caregivers regardless of their age and social ranks.

2.3. Caregiving and challenges

Raising grandchildren is associated with several challenges, for instance, financial and legal difficulties, health problems, social isolation as well as other parenting issues (Backhouse, 2006). This argument is supported by other studies conducted in Australia and other countries which emphasizes that raising grandchildren can have negative repercussions on personal, interpersonal and economic interactions (Cox, 2000; Solomon and Marx, 2000). A study by Armstrong and Kits (2004) provides more insights into the nature of relationship existing between care-recipients and caregivers. At first, some of the caregivers describe this task as frustrating, particularly because of its repetitiveness. Next, some tasks are exhausting given that patients are

no longer able to care for themselves; in particular bathing is viewed as hazardous and physically labour intensive. As a final point then, some intimate tasks could create additional stress to the relationship and also caregivers feel guilty for being in good health. In a mixed methods study conducted in South Africa, it was found that older women were taking care of AIDS patients and foster AIDS-orphaned children. Although other older women care for kin in almost all households, their tasks are viewed as a burden (Newman et al., 2011). It transpires that providing care entails several difficulties and this literature will highlight some of the most common challenges to caregivers.

2.3.1. Burden

Caring for AIDS patients or AIDS orphans is very crucial for their well-being but it can also result in much pressure on the shoulders of caregivers. According to Lemelle and Harrington (1998), AIDS caregiving is very demanding and the workload rises with the increase in the number of AIDS-orphaned children. The intensity of caregiving required for AIDS patients depends on the phase of illness; this is to say that the more imminent the terminal stage, the more intense the workload. Besides changing dressings and administering medication, caregivers are expected to perform tasks such as feeding and bathing (Gordon-Garofalo and Lynch, 2000). Land (1992) also mentions that the amount of care needed by the AIDS patients in the terminal phase can be so huge that their caregivers might not be up to it. For bed-ridden AIDS patients, caregivers are needed 24 hours a day (Mehta and Gupta, 2011). In a study conducted in rural and urban areas of some provinces of South Africa, it was found that urban and rural females caring for AIDS patients with full blown AIDS should use up to 24 buckets of water in order to clean up diarrhoea and vomit, bathe as well as do other households chores such as cooking and mopping the floor (Peacock, 2003). This illustration shows how demanding the burden of caregiving is which could be worsened in the case of lack of access to running water. The expectations placed on caregivers are unbearable and detrimental to their health; for communities lacking current water - collecting water from remote streams at such a pace is untruly realistic and can even result in injuries or strains for caregivers.

According to Kennedy *et al.* (1988) caring for the sick is associated with chronic distress that leads to occasional negative psychological and immunological changes in caregivers. Sosnowits and Kovacs (1992) emphasize that the extent of depression in caregivers is subject to the duration of the period of caregiving; the more this period lengthens, the more frequently depressed they become. Given the high prevalence rate in most hard-hit countries, it is possible that caregiving lasts longer than expected because of the high number of AIDS patients per caregiver. The repetitiveness of this task entails a long period of caregiving which might be accompanied by much depression, therefore the well-being of caregivers can be deeply challenged.

Although they confront several challenges, the contribution of elderly caregivers to the well-being of AIDS patients is substantial. Beegle (1998) relates that the age group of 50-65 are breadwinners to more than 25% of households with people living with HIV in Northern Tanzania and Thailand. The contribution of the elderly to the medical expenses accounts for 60% of the total needs (Knodel *et al.*, 2000). In a study carried out in Cambodia, it is outlined that adult children who die due to AIDS have parents that survive until an older age. Firstly, nearly 80% of the elderly with an adult child infected with HIV plays the role of caregiver and the length of care may last seven months. More than 60% of these caregivers live with AIDS patients at the terminal stage. Secondly, regardless of their place of residence as well as of their marital status, parents were providing care to dying siblings. Finally, a significant proportion of AIDS patients have children who end up receiving support from their grandparents (Knodel *et al.*, 2006). These findings are supported by a study conducted in Thailand (Knodel *et al.*, 2001). This shows the valuable contribution of older people. Caregivers are committed to caring for their loved ones and do their best to ensure that AIDS orphans are not going to join those who are already on the street. Nevertheless, looking after AIDS patients and spending on their health care results in a drastic increase of the expenditure of caregivers – inclusive of health care spending – which might compromise their well-being.

The impending death of AIDS patients is more likely to compromise the well-being of caregivers. It is reported that the experience of a sudden event may have a negative effect on the health of the elderly, for instance the death of a spouse or loved one might alter their physical or mental well-being (Kaye, 1992). Given that AIDS patients die in the prime of their life, it is more likely to affect the well-being of the elderly to whom they are related. The impact can be deeply felt if the deceased was supporting the elderly. The absence or lack of social support “provided by the deceased children” can do more harm to the elderly since the infection of their children sometimes turns older people into caregivers. Consequently, the loss of adult children deprives parents of the much-needed old age support.

Prior to the death of adult children, the most stressful period for the elderly is the terminal stage of illness since it results in a huge burden. During this time there is also a decrease in the body mass index of the elderly (Dayton and Ainsworth, 2002). In a multi-method study conducted in Thailand, it was found that some impact can be prolonged over a long period of time, particularly when the elderly care for AIDS orphans. Other negative impacts could be substantially delayed and become more noticeable when the parents become frail, economically needy and want to rely on their children’s support and care (Knodel, 2005). Parents losing their adult children as a result of AIDS could suffer “through physical strains associated with caregiving, extra work taken on to pay expenses, or potential exposure to TB or other opportunistic disease that persons with AIDS suffer” (ibid, 17).

Furthermore, the burden imposed on the caregivers of AIDS patients is equated with that of chronically ill people. According to Lemelle and Harrington (1998) chronically ill people rely on caregivers for their day-to-day activities. This observation holds true for chronically ill AIDS patients since it challenges the well-being of caregivers and drains the meagre resources of households.

2.3.2. Poverty

A scarcity of resources is a serious issue for caregivers. A significant number of studies related to the financial aspect of grandparent-as-parents have highlighted that they live below the poverty line (Smith *et al.*, 2000; Fuller-Thomson and Minkler, 2000). Besides their scarce resources, grandparent caregivers do not have enough social support (Kelley and Whitley, 2003). According to Backhouse (2006) lacking enough resources to provide for the needs of the household may generate another health problem such as anxiety and stress. As a result the household head is more likely to worry in excess and feel guilty for not being able to meet the minimum needs of all 'dependents'.

The precarious standard of living of caregivers negatively impacts on their well-being. According to van Dyk (2008), there is a given amount of stress that is necessary for every human being to function. Too much stress might negatively impact on the ability to work or to lead a normal life. The high amount of stress placed upon caregivers can be explained by three factors. Firstly, expectations placed upon them are higher than available resources. Secondly, there is a lack of social and occupational support that can help to meet their needs. Finally, they experience a significant level of negative emotions that reduces their well-being (Cox *et al.*, 1993). This research highlights an important fact and provides more insights into the day-to-day challenge of caregivers. In addition, given that most people affected as well as afflicted by this epidemic are poor, it makes sense to argue that the amount of stress placed upon caregivers is more likely to negatively impact on their health.

According to Nalugoda *et al.* (1997), most caregivers are females who barely provide for the needs of AIDS-orphaned children. These females are ill-equipped to take on parenting roles since they lack clothing, food and adequate income to pay school fees and afford medical expenses (Agyarko *et al.*, 2000). Furthermore, Dayton and Ainsworth (2002) have highlighted that there is a relationship between income and the well-being of the elderly. In another study using mixed methods carried out in Western Kenya, related to changes in household composition

and food safety, it was revealed that an increase in the number of younger care-recipients in the households resulted in food shortage. The elderly were unable to provide enough food and adequate resources for all their dependents. The majority of households were headed by the female elderly who could hardly cope with an increase in demand in the household (Muga and Onyango-Ouma, 2009). Another factor that was affecting the ability to provide food for the dependents was ill-health on the part of the head of the household. This situation was worsened by the death of young adults which deprived the community of their much-needed support.

The comparison of body mass index of the elderly living in well-off households and those in socially disadvantaged ones shows an association between income and this index (Dayton and Ainsworth, 2002). This shows that the elderly can be easily afflicted even when they are not primary caregivers. If in general the passing away of an adult child is more likely to have a negative outcome on their well-being, the impact can be more severe for those who are primary caregivers. Besides financial difficulties, caregivers experience other serious challenges such as stigma and discrimination.

2.3.3. Stigma and isolation

The outbreak of the AIDS epidemic has generated another “epidemic” that can affect the social network of caregivers. This second “epidemic” can be viewed as a social reaction to AIDS and is worse than the first, or fuels it. In order to avoid this isolation, caregivers manage to keep secret the HIV diagnosis of their care-recipients. According to Kreibick (1995), a caregiver is very often well informed of the HIV/AIDS stigma and may experience vulnerability as soon as it is clear that HIV is present within the household. Prior to the onset of HIV within the family, caregivers may have relied on their social networks in order to cope with major difficulties in life. But with the diagnosis, there is concern about public reaction and retaliation should this infection become known. The fear of being rejected by close friends and acquaintances may lead caregivers to become mentally disturbed. It is also possible that they may not be comfortable

with disclosing to family and friends the diagnosis of AIDS for fear of being stigmatized and isolated. Such isolation can cause depression and amplify the effect of grief and loss.

Though caring for an AIDS patient results in grief, a common attitude to chronic illnesses, there are other reactions that seem to be more specific to this epidemic. It is worth mentioning that caregiving may lead to intense anger, directed at individuals and institutions, as a direct outcome of stigma. One of the most prominent aspects of AIDS is social isolation. This isolation is not only the fear of reaction to their illness but it is also sometimes self-imposed (Sosnowitz and Kovacs, 1992). According to Knodel (2005, 17), “stigma may lead parents to withdraw from normal community life or cause others to sever contact with them”.

Moreover, family members caring for AIDS patients can be affected by stigma and discrimination. This can lead to the isolation of caregivers and also result in anxiety and misunderstanding within the household (Mullan, 1998; Songwatana, 2001; Stein, 1997; Palloni and Lee, 1992; Goffman, 1963). These findings are consistent with Backhouse (2006) that reveals that the impact of HIV can be extended beyond infected people. In other words, the entire family of AIDS patients living in developing countries can be affected by HIV/AIDS.

Stigma is fuelled by fear of infection and ignorance of transmission routes, opportunistic infections, treatment and the illness phases (Gordon-Garofalo and Lynch, 2000). A qualitative study carried out in rural Mpumalanga found that older female caregivers were victims of secondary stigma. They were isolated, gossiped about, finger-pointed by family and the community. A better way of anticipating this situation was to live in denial or refuse to disclose the positive status of infected family members (Ogunmefun *et al.*, 2011). Despite the awareness of the methods of transmission, this attitude is still explained by the belief that HIV can be contracted through casual contact like eating together and interacting with the patients (McDonald and Schatz, 2006). Stigma and discrimination can be viewed as one of the ways of hiding ignorance or unwillingness to investigate the unknown. In other words, HIV/AIDS is associated with people that are on the fringes of the society, the stereotypes depend on culture.

AIDS patients are equated with promiscuous, sinful or people of ill-repute. Therefore disclosing the onset of an HIV diagnosis or/and illness could entail jeopardizing the emotional well-being of the household. This situation leads some caregivers to care in secret. In view of the stigma and discrimination associated with HIV, caregivers may feel ashamed or embarrassed, therefore, they might end up being isolated or withdrawn. Such attitudes on the part of the caregivers can result in depression and emphasizing the emotional effect of grief and bereavement (ibid). These reactions towards AIDS patients and their loved ones are fuelled by lack of knowledge. This ignorance is also in one way or another shared by caregivers.

2.3.4. Training

The lack of adequate training is part of the challenges that caregivers face on a daily basis. Mehta and Gupta (2011) reveal that the larger proportion of caregivers live in dire poverty and do not receive any support to care for their children. Furthermore, Gordon-Garofalo and Lynch (2000) argue that there is on the part of the caregivers the fear of infection since many of them do not know much about it. These authors argue that, although some caregivers are well-informed of the methods of transmission, they may still be emotionally affected. Even the caregivers that are well-informed about HIV infection are emotionally worried. It is argued that the fear of infection is an important feature among AIDS caregivers (Hoffman, 1996). This reaction may be in part justified by the impending death of people living with AIDS.

In order to address this lack of knowledge, some support structures are organised. There are support groups that provide training and counselling on the way of handling some tasks. For example, caregivers are taught how to lift up a sick person in order to avoid back strain (Wiener, 2003). But, due to stigma and isolation surrounding this epidemic, joining such groups might cause more harm than relief.

2.3.5. Caregivers versus non-caregivers

Providing care to AIDS patients and AIDS-orphaned children has been a major breakthrough in the fight against the AIDS epidemic. In fact, the devastation caused by AIDS has led to a rise in the number of unpaid caregivers filled with goodwill and ready to do their best to pick up the pieces and move on. However, taking on this role is very challenging and impacts on their well-being or quality of life. Although caregiving is voluntarily undertaken, it negatively affects the emotional and physical health of caregivers (Zarit *et al.*, 1980), and the extent of negative effects depends on the length of caregiving (Backhouse, 2009). Moreover, caregiving activities demand much physical effort that might result in muscle aches, disrupted sleep, irregular eating and chronic fatigue (Toseland and Smith, 2004). A survey carried out in the United Kingdom reveals that one in two caregivers had sustained a physical injury – a strained back – from the time they started caring. Nearly 50% had undergone treatment for illness associated with stress since they began to provide care. These findings are supported by a study conducted in South Africa which found that caregiving tasks are so demanding and stressful that caregivers end up neglecting their own health (Mehta and Gupta, 2011).

The poor health of elderly caregivers can be worsened by the stresses of taking on a parenting role, previous burdens and inadequate income. These stresses can be viewed as a corollary of HIV diagnosis, its progression and the stigmatization of all family members: “social withdrawal and isolation; the eventual death of children, parents, siblings, other family members; and disenfranchised grief” [grief related to a death whose circumstances should not be unveiled] (Joslin and Harrison, 1998: 65). Therefore, the parenting role of AIDS-orphaned children occurs in the difficult context of regretting the death of their parents. The increase in daily chores has compromised the well-being of older people since some reveal that caregiving tasks have affected their general health status (*ibid*).

Recent studies have identified these caregivers as a high-risk population, especially if they are from poor communities or live in marginal economic circumstances (Joslin and Harrison, 1998).

Nearly half of all grandmothers raising AIDS-orphaned children have reported poor or fair health. These findings sharply contrast with the majority of studies which suggest that older people in the United States rate their health as good, better or excellent (Waldrop and Weber, 2005). In fact, on one hand, most elderly have experienced years of hardships, instead of being looked after as it was more likely to happen in the past. They have to provide support for their grandchildren who have lost their parents. This situation worsens their fragile health since they may not be able to look after themselves (Fouad, 2004). On the other hand, raising children is demanding and may prevent them from caring for their own health (Joslin and Brouard, 1995). The burden of caregiving can be one of the main reasons leading elderly caregivers to miss medical appointments and have exacerbated chronic conditions.

According to Hunter *et al.* (2000), some elderly caregivers were expressing concern about “restarting families late in their lives”, since it results in the deprivation of their own freedom. These worries are also fuelled by the fact that they assume a parenting role while having limited resources which makes it difficult to meet the basic needs of the households. This reaction shows how demanding the task that awaits caregivers is, especially if they are too old to cope with the demands of children. Having a low income makes it hard on elderly caregivers to provide better care for the households. Furthermore, failing to meet these needs makes caregivers feel more stressed, powerless and uncomfortable. Looking after orphaned children does not only deprive elderly caregivers of time to care about themselves but also depletes their meagre resources. It is therefore more likely to make them feel uncomfortable and powerless.

On the other hand, the expectations placed upon caregivers seem unbearable. It is reported that the amount of work that they have to fulfil varies, ranging from coordinating medical appointments and medication regimens to dealing with symptoms and treatment side effects (Armstrong and Kits, 2004). The elderly taking on the caregiving role of their infected loved ones, have to cope with the pain, grief and anger of AIDS patients traumatized by having to lead a shortened life (Joslin and Harrison, 1998). The plans of caregivers are subjected to caregiving activities; they cannot do anything as long as there are outstanding tasks. This is to say that the

isolation of caregivers is both imposed and self-imposed; imposed by stigma surrounding the illness, and self-imposed by the workload. Sometimes, it is not possible to leave AIDS patients unattended, especially in the terminal stage, because some caregiving cannot be scheduled. For example, the need to use the toilet is less likely to be predicted.

In addition, the onset of HIV/AIDS has led to changes in the role of caregivers; from caring for health and dietary problems, performing daily tasks, dealing with financial concerns and providing recreational and social activities of counselling, advising, deciding, nursing, and becoming a sounding-board to AIDS patients (Lubkin and Larsen, 2006). Caregiving is too demanding for caregivers and might result in negative emotional and physical outcomes.

Though caregivers have some health problems, their own needs were the least cared for and met (Broun, 1996). In a study conducted among elderly females in Warwick Junction in Durban, it was found that two in three females have provided care for AIDS patients who were either family members or neighbours. However, these elderly caregivers suffered from several chronic illnesses such as diabetes, arthritis and hypertension (Chazan, 2006). Similarly, it was found that African American grandparents raising their grandchildren were dealing with “a number of health problems such as depression, insomnia, hypertension, back and stomach pain, and other problems associated with emotional and physical demand of childcare” (Minkler and Roe, 1996). According to Kaye (1992), chronic illness such as arthritis necessitates home-based care. Instead of being cared for, these elderly are expected to care for others; their role is surely overturned.

Cooper *et al.* (2007) reveal that while comparing Australian caregivers and non-caregivers, it was found that the former were characterized by poorer health and higher anxiety than the latter. Moreover, these caregivers report having disrupted sleep which is documented as symptomatic of mental illnesses, in particular, of post-traumatic stress (Mellman and Hipolito, 2006). In line with these findings, Armstrong and Kits (2004) argue that caregivers living with or close to care-recipients report experiencing changes in their sleep patterns, poor health, depression and less involvement in social activities. On the other hand, lacking resources to provide care for family

members may result in grief or illness for the elderly (ibid). These findings are supported by a study conducted in New Zealand by Worrall (1999) that reveals that female caregivers experienced tiredness, exhaustion and reduced immunity.

With approximately 50% of caregivers affected, it transpires that depression is one of the main health concerns for caregivers (Butler, 1992; Schulz *et al.*, 1995). Caregivers are more likely to be affected than non-caregivers; they reported experiencing health issues such as depression and anxiety and they were more psychologically distressed than non-caregivers (Toseland *et al.*, 2001). A survey carried out in the United States on caregiving and depression found an association between caregiving and poor health (Minkler *et al.*, 2000). Another study conducted in the United States highlighted that grandparents rearing their grandchildren were more likely to develop stress, serious enough to require a visit to the psychiatrist (Kelley and Whitley, 2003). It was also found in Australia that the role of grandparent-as-parents was associated with high levels of stress, anxiety and depression compared with their non-caregiver counterparts (Dunne and Kettler, 2008).

Bearing the responsibility of caregiving entails being more responsive. A study conducted in Tanzania by Ainsworth and Dayton (2000) reveals that the well-being of older people is negatively affected during caregiving and improves shortly after the death of their infected adult sons. These findings are consistent with the survey of Knodel (2005) conducted in Thailand. This author notes that caregivers are the most affected after their children become seriously ill. Some effects are immediate and short-term, that is, they take place when parents are still involved in caregiving or just a while after the death. The death of a care-recipient has a negative impact on any elderly person, it can be worse for the elderly who are primary caregivers.

2.3.6. Control issues

As symptoms are emerging in the beginning stages of illness, both caregivers and care-recipients must accommodate themselves with their new role, but these changes are not noticeable. As time goes on, caregivers deal with uncertainty, fear, concerns over future plans and worries about what is to come. The load of caregiving gets increased; caregivers and care-recipients do not have enough control over their choices, time management and other daily issues (over the way some issues should be handled). The issue of social network resurfaces at this stage. The more caregivers are involved in nursing AIDS patients, the more isolated and withdrawn they become (Gordon-Garofalo and Lynch, 2000).

According to Gordon-Garofalo and Lynch (2000) the caregivers of AIDS patients are more likely to feel out of control; they look angry, hopeless, helpless and frustrated. Writing about it, Pollin and Kanaan (1995) reveal that they are very often in search of social work treatment since they run into difficulties related to the managing of their multiple roles and responsibilities as well as of the care-recipients. They feel so overwhelmed that they do not know what can be controllable. For example, Gordon-Garofalo and Lynch (2000) outline that at the terminal phase of illness, they are overpowered by the day-to-day practical tasks and expressing their emotions before the death of their loved ones. It is hard to be in the seat of caregivers, and Sosnowitz and Kovacs (1992) argue that the situation of caregivers is unbearable on a daily basis since they are squeezed between caregiving activities and their own needs. They are in need of psychological support and play the part of service providers who are seeking out ways to cope with “endless care” on a daily basis, moreover, they are overwhelmed by the demands they are confronting.

The feeling of hopelessness and lack of control of AIDS caregivers is clear in the writing of Sosnowits and Kovacs (1992). According to these authors, there is a tendency on the part of the caregivers to already “bury the sick before death”. This attitude seems to be justified by the impending death of AIDS patients; as a result their caregivers are so affected that they act like the sick are to die soon. It was also found that some caregivers as well as their family members

were more afflicted than their patients. The amount of grief in some caregivers was so high that it could represent a threat to the well-being of the sick. This attitude led some AIDS patients to believe that they were buried before their death. This feeling was common to the caregivers of patients suffering from multiple opportunistic infections (ibid).

2.4. Consolation

Orphaned children should not be viewed only as care-recipients, but they can also provide emotional and practical care which is very helpful to their grandparents as caregivers (Barnett and Whiteside, 2002). It seems obvious to argue that the extent of care that AIDS orphans can provide for the elderly is subject to their age and ability. Unlike AIDS patients not on ARVs, healthy AIDS-orphaned children need more attention and physical care when they are still young, and over time they can provide caregivers with some crucial assistance. But sometimes the ability of the elderly to offer emotional support is lowered by the number of AIDS orphans looked after.

According to Armstrong and Kits (2004), caregiving is not only associated with stress and remorse but pleasure of helping and rewards. Caregivers have a positive experience and feel rewarded. The pleasure of caregiving comes from interaction with patients and the feeling of providing assistance to those who desperately need it. For instance, the grandparents assuming a parenting role who took part in a study conducted in Australia revealed that their caregiving activities were life-enriching experiences. They reported that they were patient and tolerant in dealing with orphaned children that confront psychological problems (Backhouse, 2006). In a study conducted in the United States, 11% of respondents asserted that raising their grandchildren had contributed to their health, making them healthier and more active (Waldrop and Weber, 2005). In another study related to the health of grandmothers of the African American community, one in four females argued that caregiving had improved their health. This claim was based on the fact that caring for grandchildren had resulted in weight loss and they gave up smoking since they were concerned with their grandchildren's health. Although

over 50% of grandmother caregivers claimed to be in good health, there is on their part an intention of overlooking their own health problems. This attitude can be explained by the fear of having these grandchildren reared by foster families (Minkler *et al.*, 2000).

2.5. Treatment and caregiving

The scaling up of ARVs has shifted AIDS from a “death sentence” to a chronic illness. Sub-Saharan Africa has witnessed an ambivalent AIDS-statistic; that is a decrease in the rate of new infections and a rise in the number of people living with HIV (UNAIDS, 2010). The provision of ARVs has contributed to reduced AIDS deaths (WHO, 2009). It is reported that an estimated 5,2 million people living in the least developed and emergent countries were on ARVs by December 2009. These statistics indicate that an additional 30% of AIDS patients have access to ARV therapy worldwide (*ibid*).

In sub-Saharan Africa, the increase in the proportion of AIDS patients on ARVs accounted for 33%. In 2009, there were 19 least developed and emergent countries out of 25 that have scaled up the provision of ARVs: Rwanda 88%, Botswana 83% and Namibia 76%, while eleven other countries: Cameroon, Cote d’Ivoire, Ghana, India, Indonesia, Mozambique, South Africa, Ukraine, United Republic of Tanzania, Vietnam and Zimbabwe, had delivered to less than 40% of eligible adults (UNAIDS, 2010).

The scaling up of ARVs has allowed AIDS patients to live longer, however, living with HIV is associated with stigma and social isolation which can affect “the rest of their life”. In view of the high levels of discrimination against AIDS patients (*ibid*), it is possible that this attitude affects or increases the reliance of the sick on caregivers, although they can be physically fit to lead a normal life. Furthermore, given that the ARV regimen is “for life”, caregivers can find themselves in the seat of “mentors” that help the sick to cope with the ongoing intake of ARVs.

2.6. Risk and exposure

Several studies have outlined a significant number of risks that elderly caregivers may be exposed to. According to the study of Knodel *et al.* (2001) conducted in Thailand, there are some pathways through which the disease in adult children can affect their parents. The vulnerability of caregivers is emphasized by their poverty, and this means that they are not able to afford the equipment required to perform their tasks. For example, because of competing priorities, buying medication may prevail over the purchase of handgloves and increase the risk of contracting HIV. It is also possible that in the 'name of love' or 'compassion', wearing protection can be interpreted as a form of discrimination against AIDS patients.

Despite the onset of ARVs which increases the life expectancy of AIDS patients, the pattern of HIV/AIDS is unpredictable and can result in somatic, physical and psychological symptoms as well as emotional exhaustion for caregivers (Pearlin *et al.*, 1997; Ashton, 1988). The burden of caregiving is unbearable since it involves physical, emotional challenges and financial dilemmas. The most difficult stage (for caregivers) seems to be social isolation imposed by communities towards families with AIDS patients or which is self-imposed. This stage is more likely to deprive caregivers of possible emotional support.

In a study using mixed methods conducted in rural and urban sites in the province of KZN dealing with impact of HIV/AIDS on older people, it was found that few elderly caregivers found themselves at risk of HIV infection because of their knowledge and involvement in caring for people living with AIDS. Some feel vulnerable to the infection because of their inability to control the situation. On the other hand, these older people live in dire poverty that could not allow them to afford minimal protective measures that are more likely to decrease the risk of infection (Munthree and Maharaj, 2010).

Furthermore, the elderly are not only at risk because of caregiving but their old age also constitutes a risk factor. Nevertheless, given that they have to take on the parenting role of

AIDS-orphaned children, they tend to ignore their health problems and prioritize the care-recipients. They are to some extent 'hidden patients' (Joslin and Harrison, 1998). A shift from infection to illness makes AIDS the focal point of the attention of family members and its needs overshadow all others (ibid). It goes without saying that family members may experience shame, stigma and social isolation. Moreover, all other desires can be downplayed since providing care for AIDS patients has become the household priority (ibid). Older people are among the high risk population; the fact of being confronted with stigma and isolation may worsen, to some extent, their fragile well-being.

2.7. Summary

Taking on the parenting role of orphaned children and looking after the sick are not new problems, but a recent increase in the proportion of affected people seems to be unprecedented. Despite their several health problems, the contribution of the elderly to fight the epidemic and support of AIDS patients and AIDS-orphaned children constitute a major breakthrough. Elderly caregivers have succeeded to give a human face to the suffering of these care-recipients. The involvement of all community members could help to curb stigma and discrimination associated with HIV and ease the burden of caregiving. This literature has provided a broad overview of the issue at hand, but it does not provide more insights into the way the well-being of elderly caregivers is compromised. This research will try to fill the gap in this respect.

Chapter three

METHODOLOGY

The outbreak of the AIDS pandemic more than three decades ago has led to an increase in the proportion of current caregivers. These “new caregivers” are often elderly. In order to provide more insights into the way the burden of caregiving impacts on the health of the elderly, qualitative research methods were used. The first part of this section will start by describing the context in which the study took place. The second part will deal with the non-governmental organisation that works with elderly caregivers and was instrumental in recruiting males and females for the study. The next section will look at the research methods of the study. Finally, the last section will focus on limitations of the study and ethical considerations.

3.1. Overview of the province of KZN and study setting

The study was conducted in KZN, the province covering a total area of 92 100 square kilometres, approximately 7,7% of the land area of South Africa. It is the third smallest province in the country. It has as its capital Pietermaritzburg, and Durban the major city. The present territory of KZN was made up of a merger between the province of Natal and the homeland of KwaZulu. It is also one of the major holiday attractions because of its beaches and warm weather.

KZN also accounts for 21,4% (10,8 million people) of the entire South African population. Approximately 3,66 million (23%) of the total population under the age of 15 live in KZN (Stats SA, 2011). This high proportion of under 15 paralleled with teenage pregnancy might be one of the reasons that explain the high HIV prevalence in the province. According to a study carried out in 1998, 41% of females attending antenatal clinic were HIV positive (Wilkinson *et al.*, 1999). These findings still held true more than five years later and were supported by a study conducted by Welz *et al.* (2007) which revealed that the most affected province was KZN with a HIV prevalence of 51% among 25-29 year old female residents and 44% for male residents aged 30-34 years. Further, most AIDS patients are aged between 15 and 49 years (Knodel and Van

Landingham, 2002). Despite the level of investment in fighting the AIDS pandemic, millions are likely to die as a result of this illness for years to come.

The interviews in this study were conducted in Lindelani, an informal settlement located in the northern suburbs of the city of Durban, is adjacent to KwaMashu (a formal township). Durban is the largest coastal city of the province of KZN. The word Lindelani means ‘wait a while’ in isiZulu. The community of Lindelani, which emerged in the early seventies as a ‘squatter camp’, was named after the promise of infrastructure delivery made by the KwaZulu province to the first people who settled in the then vacant land (Xaba, 1994).

The first members of this new community came from northern Zululand (Braathen and Khandlhela, 2005). This informal settlement was part of those previously involved in political violence between the supporters of the ANC and the IFP in the early 1980s. Despite years of political unrest, Lindelani witnessed a significant basic infrastructural development in the eighties which was far better than some of the formal townships, notably KwaMashu (Xaba, 1994). This community could not be compared to other ‘squatter camps’ as it had schools, crèches, a football field, main tarred roads, small shops as well as other basic facilities (ibid). Besides this infrastructure, the community of Lindelani has running water, a clinic and easy access to the main road that can save caregivers as well as residents from some burden or tasks such as travelling for miles to fetch water, and in the case of medical evacuation much time could be gained. This relatively good infrastructure contrasts with the high prevalence of HIV in the province (Welz *et al.*, 2007). In order to attend to the needs of AIDS patients and orphaned children; communities and extended families are expected to provide caregiving. Additionally, even if the tide of AIDS is overturned, it will be necessary to care for AIDS patients and AIDS-orphaned children. The involvement of the elderly caregivers in the day-to-day care of these care-recipients is no longer a secret, however the extent to which caregiving impacts on the well-being of the elderly is not known. In line with this quest for further investigations into the way caregivers cope with their tasks, the contribution of some organisations was very crucial.

3.2. Presentation of the NGO Sinani

Sinani, also referred to as the KZN programme for survivors of social violence, was launched by some social workers, health workers and psychologists. The founders cared for the victims of political unrest and ex-detainees during the apartheid era. In the early 1990s when the political violence peaked between the African National Congress (ANC) and the Inkhata Freedom Party (IFP), the victims of this violence were also counselled and cared for by Sinani originators. These founders soon reached the conclusion that the western model of counselling that targets individuals and groups was less appropriate and instead they favoured the community-centred approach. At present, Sinani works in partnership with over eight communities in the province of KZN and its mission evolves around three programmes: peace building, poverty alleviation and HIV/AIDS.

With regard to caregiving, Sinani intervention is threefold. Firstly, this organisation has appointed some members of staff to help out elderly caregivers by providing some assistance to AIDS-orphaned children. Given that some of the substitute parents are old and might have sight problems or are not educated enough to deal with school work, Sinani assists orphans to do their homework or other school work on a daily basis. During school holidays, these children gather in the yard of the old clinic of Lindelani under the supervision of a member of staff for nearly the whole day in order to share their experiences. Their activities revolve around storytelling, a memory box (a box given to children in which anything worth remembering can be kept), a dream board (a board bearing pictures that represent different professions that children dream of), psychosocial support to vulnerable children, HIV and TB prevention, child abuse, right and responsibility, netball, soccer, Zulu dance, as well as other risk-free games. This organisation aims at protecting vulnerable children by promoting quality health care and preventing any type of violence against them. Secondly, substitute parents are empowered through access to employment and improvement of caregiver-care-recipient relationships. Finally, once a month caregivers are taught how to use protective gloves, to do a bed-bath and to prevent HIV infection

while caring for AIDS patients. Acquiring relevant information and conducting reliable studies requires a certain amount of data collection.

3.3. Research methodology and methods

This study required a method that helped explore the different situation experienced by the sampled population and shed light on it. Thus, the qualitative research method was the most appropriate in this respect. Arguing about this method, Morse and Richards (2002, 43) state that "qualitative research assumes that there are multiple realities and that the world is not an objective thing out there but a function of personal interaction and perception". The approach adopted for data collection was based on purposive sampling and using individual in-depth interviews. This approach was found very useful since it helped unveil some relevant issues or topics which could not be highlighted if a structured questionnaire was used, therefore the qualitative approach was relevant to provide more insights into the way caregiving activities shape the daily living of older people.

The data in this study was collected in the province of KZN from two different sources. Before data collection, an in-depth library search was carried out as there is an important database that has been gathered since the outbreak of the epidemic. The second phase of the study, the fieldwork, required the assistance of a NGO working with older people, namely Sinani. The crucial stage of this project dealt with a given number of individual interviews.

3.4. Interviews

3.4.1. Overview on in-depth interviews

An in-depth interview, also referred to as a face-to-face interview, is a type of qualitative research that consists of asking questions to participants on an individual basis. It tends to be slightly long and takes place in an environment conducive to self-disclosure (Johnson, 2002).

This type of investigation is associated with advantages as well as disadvantages. The conduct of in-depth interviews is very interesting as it allows other observations to be made at the same

time. During face-to-face interviews, the interviewer can take note of some important information sent out by the respondent such as body language, and intonation that might give more insights into the issue under investigation. However, the interviewee does not have much time to think and gives spontaneous answers, and the interviewer must listen to the answers and prepare his/her next questions. This type of research requires much attention on the part of the interviewer. Further, there is too much pressure on the interviewer as he or she is expected to take notes and record the interview on the tape if the informant is happy with this. Depending on the quality of recordings, transcribing can be time consuming and the conduct of interviews costly if the sample is large and scattered in an immense area (Opdenakker, 2006). It is also essential to notice that face-to-face interviews allow the interviewer to probe for more insights into any important issue being investigated. Some unanticipated issues can be unveiled through the interaction between interviewers and interviewees (McCullough, 2011).

3.4.2. Conduct of interviews

A total of 14 individual in-depth interviews were conducted in Lindelani. The interviewees were recruited among elderly caregivers who are currently looking after AIDS patients or who did it previously and/or are taking on the parenting role of AIDS-orphaned children; other criteria were not taken into consideration. These interviewees were aged 60 and above and, although, some in the late fifties were willing to take part in the study and succeeded in being interviewed. Their information was not included in the data analysis or any section of the project but could be used to compare the trend of their caregiving experience with the age group 60 and above, outside this project. Further, in the quest to include a significant number of both sexes, some more days were given to the interviewer to gather information on the whereabouts of male caregivers. Unfortunately, only two males met the requirements and took part in the study. The table below sheds more light on the characteristics of the respondents and it also provides insight into the extent of responsibilities placed upon them.

Table 1: Distribution of respondents according to their gender, age and type and number of care-recipients.

Name	Gender	Year of birth	Number of children		Pensions	Matrimonial status	Have cared for AIDS patient	Child grant
			Male	Female				
1	Female	1944	2	7	Yes	Widow	Yes	Yes
2	Female	1931	5	2	Yes	Single	Yes	Yes
3	Female	1939	6	1	Yes	Single	Yes	Yes
4	Female	1942	1	2	Yes	Single	Yes	Yes
5	Female	1943	3	3	Yes	Single	Yes	No
6	Female	1946	0	5	Yes	Widow	No	Yes
7	Female	1947	1	1	Yes	Single	Yes	Yes
8	Female	1949	0	0	Yes	Widow	Yes	No
9	Female	1951	1	3	Yes	Single	No	Yes
10	Female	1950	0	3	Yes	Widow	No	Yes
11	Female	1940	4	0	Yes	Single	No	Yes
12	Male	1952	0	0	No	Married	Yes	No
13	Male	1941	8	15	Yes	Widow	Yes	Yes
14	Female	1952	3	5	Yes	Married	No	Yes

Sinani appointed two members of staff working and living in the community of Lindelani to assist in selecting interviewees. Their assistance was very important since they live either in Lindelani or in neighbouring KwaMashu and know the situations of most caregivers living in the community, and which ones qualified to take part in the study. It is worth mentioning that this contribution was very crucial as it has assisted in quickening the pace of collecting data and was helpful since the prospective interviewees did not have to deal with strangers but also with “trusted community members”. Therefore, the introduction was short and straightforward.

On the other hand, some practical precautionary measures were taken to ensure that the data collection stage was carried out in the way it should be. Firstly, given that the researcher was unable to speak isiZulu, the interview guide and the informed consent form were translated in this language in order to minimise any misunderstanding. The translation seemed to pay off as it reduced interview length. Secondly, because of the sensitivity of the topic, individual in-depth interviews were favoured to semi-structured ones in order to ensure that interviewers stuck strictly to the interview guide and avoided addressing other sensitive issues.

All interviews were recorded with a digital recorder and none of the interviewees objected to the use of this device. The interviewer took notes in some interviews, but because of time constraints, especially the interviewer's time frame or other unforeseen circumstances surrounding the fieldwork, using the recorder was viewed as the right way of quickening the pace of gathering data within a reasonable period of time. This flexibility in terms of the use of "storage units" has also impacted on the length of interviews; some were slightly above 20 minutes while others could reach up to 45 minutes. Every individual interview was associated with a particular environment that provides insights into the way caregivers dealt with care-recipients on a daily basis and which could attract the attention of anybody concerned with their well-being.

3.5. Some observations

Most interviews were conducted on a face-to-face basis at the homes of caregivers. This setting presented two-fold advantages. Firstly, the interviewees did not have to stop their normal caregiving to meet with the researcher. Home visits seemed to make the respondents comfortable since it allowed them to keep an eye on care-recipients and they could take a break from the interviews at any time in order to attend to the sick or AIDS-orphaned children. Secondly, it allowed the researcher to make more observations of the "world" of caregivers. The most important observation was the constant attention paid to the sick by caregivers looking after AIDS patients. They seemed to be ready to provide assistance at any time while those taking on the parenting role of AIDS-orphaned children were under less pressure. It transpired that the former were so concerned with the well-being of care-recipients that they closely monitored them. This observation held true for caregivers who were assisting the sick when interviews were conducted, as they were all found in the same room. However, the other group of caregivers were more relaxed and some seemed lonely, especially those parenting children of school going age or older children. It should be noted that not a single caregiving task was witnessed, this observation was totally fuelled by the body language of caregivers during the interview.

Almost all caregivers seemed to be very affected by the loss of their loved ones, asking them questions on this issue was reminding them of sad events which very often led the interviewer to take a break and wait for the respondents to be in the mood to answer again. This is to say that the loss of their loved ones was still fresh in their memory and it makes sense to argue that those who experienced death in the past few months prior to the interview were more emotional than others.

Despite the noticeable emotions visible on most of the faces of elderly caregivers, they looked eager to share their experiences, their “untold story”, which in turn gave the impression they were comfortable with the interview. It is possible to believe that their attitude was fuelled by the fact of having someone to speak to, share their worries, challenges and hardships. This fieldwork seemed to have given them a “platform” to voice their frustration, to feel relieved from their burden and also to take notice that there are other people out there who are interested in their hardships.

It made sense to argue that from the body language of respondents, the interviews could be broken down in three parts. The first part on the question of identification of the respondents was straightforward. The second part led to emotions since it highlighted the burden and challenges of caregiving activities. In the last part, caregivers were expecting some material assistance from the researcher as they were asked some questions related to their financial difficulties. With regard to these expectations, the researcher avoided making any promises and highlighted that his mission was to shed light on the burden of caregiving on the health of older people.

The skipped generation households headed by the elderly were common among interviewees. Almost all elderly caregivers were living in skipped generation households and had no more than two bedrooms. It was also sad to realise that none of the caregivers were caring for or looked after AIDS patients on ARVs.

3.6. Limitations

This study has a number of limitations inherent to sampling and choice of organisation. Firstly, the NGO Sinani is one among many others dealing with fighting HIV/AIDS in South Africa; it is operating from the province of KZN. Although this province has the highest HIV prevalence in the Republic of South Africa, the results of this project cannot be generalizable to the entire caregiver population of this country, let alone the African continent. However exploring this particular feature of the epidemic can provide interesting information about the way in which caregivers can be supported and helped out. Furthermore, there is a substantial proportion of NGOs specialising in fighting HIV/AIDS spread across South Africa which deserve to be sampled as well, but given the time and funding constraints of this study, such an attempt cannot be realistic. It would then make sense to argue that some factors might have been explored more than others.

Secondly, Sinani was launched before HIV/AIDS became a serious threat and had to deal with child abuse and gender-based violence. The outbreak and increase in the number of AIDS patients in South Africa has motivated this NGO to include HIV/AIDS in its interventions. The HIV/AIDS programme of Sinani is more centred on prevention. The involvement of the elderly or grandparents in the day-to-day support of the sick and AIDS-orphaned children is part of the new development or facets of the epidemic. The organisation is not expected to provide any data or key information on this project. In other words, it is out of the sphere or aim of this project to assess the implementation and impact of the programme of Sinani on communities.

Thirdly, although the sample is drawn from a population living in a disadvantaged settlement and exposed to various challenges on a daily basis, it makes sense to argue that some factors might be more explored than others. However, in order to counterbalance this effect on the quality of data, several questions covering various issues were asked and interviewees were also given the opportunity of alluding to any other issues which might not be covered in the interview guide. In addition, the information gathered does not have any statistical significance. This project is

solely aimed at unveiling difficulties and challenges that caregivers might face, and is therefore less concerned with statistical evidence.

Finally, despite being aware of difficulties encountered by caregivers on a daily basis and the sensitivity of the subject, it was very essential that the researcher avoided displaying any kind of emotion while being receptive and understanding of the nature of hardships experienced by them. A personal daily journal was kept, describing step-by-step the details of interviews and observations. Every effort was made to keep track and situate conversations within the framework of the study and get rid of irrelevant details.

3.7. Ethical considerations

The ethical clearance to undertake this study was obtained from the High Degrees Committee of the University of KZN. The NGO Sinani freely agreed to allocate some of its members of staff to assist the researcher in the selection of respondents in the community of Lindelani that met the requirements of the research. The informed consent form - translated into isiZulu - was read to individual interviewees before interviews to let them know what their rights were and the interviewees were asked to sign this form. Every effort was made to ensure that participants understood what was expected from them. They could ask questions at any time during interviews. Further questions were asked to make sure that their rights were not infringed upon or that they were not frustrated or embarrassed before proceeding with the interview. A paper containing the contact details of the researcher and supervisor was handed out to interviewees and they were urged to feel free to contact them in case of any problem related to the research, especially should they decide they did not want their information to be included in data analysis. In order to ensure the confidentiality of every caregiver that participated in this project, a pseudonym was assigned to each during data analysis to protect their identity. Besides some of the personal questions that were in the interview guide, none of the participants was asked to disclose their HIV status. Even if such information was willingly provided, it was not included in any chapter of the study. The data collected for this project cannot be used for other purposes without the participants' consent.

Moreover, in order to respect the confidentiality of the respondents while transcribing, every interview was recorded without the introductory part, notably names and addresses, which were handwritten on the interview guide. Additionally, all transcripts were done by a graduate who knows the confidentiality policy and were kept on the researcher's password protected student email address and drive. All hard copies of the interview guide used during the fieldwork stage were kept separately in a safe environment and were not transcribed since full recording of interviews were available. Any personal life experiences shared during interviews which did not have anything to do with the project were not included in the dissertation.

On the other hand, every effort was made to comply with Sinani's requirements in terms of handling every demand of financial assistance or other concerns of interviewees. In fact, it was initially agreed not to promise anything to the participants of this project. The fieldwork revealed that some were desperate, "sported an assistance seeking attitude" or expressly asked for the researcher's promise of assistance. Every request to this respect was dealt with as agreed upon.

This study did not get funding from any organisation. Besides expressing its willingness to have the findings shared, Sinani did not pose conditions or get its own agenda adopted in order to grant participation in the study. The results and data of this research project were not manipulated in order to achieve any goal, but reflects the experiences of every respondent. All in all, this current research remains the genuine property of the author.

3.8. Summary

This section has highlighted the research methods used to assess the experience of the elderly looking after AIDS patients and AIDS-orphaned children in the province of KZN. An overview of Sinani, the organisation that works with some communities affected by the AIDS epidemic was provided as well as the study setting, the province of KZN and the informal settlement of Lindelani. The qualitative research methods employed and personal observations used in this writing, the advantages and disadvantages, were also clearly explained. In addition, limitations

and ethical considerations were explained. The fieldwork was conducted with much discipline and strict respect for the research protocol.

Chapter four

RESULTS AND DISCUSSION

The impact of HIV/AIDS is felt more at the family level since it results in the formation of the skipped generation and elderly-headed households. The elderly are at the forefront of the epidemic as their family duties oblige them to care for AIDS patients and take on the parenting role for orphaned children. This chapter will draw on the day-to-day life of elderly caregivers, or those who provided care in the past, by highlighting their challenges, difficulties, dilemmas and expectations.

4.1. Caregiving

4.1.1. Grandparents as mentors and parents

The number of orphaned children cared for by the elderly is variable and can exceed five in some households. Prior to the illness and passing away of their biological parents, some children were already under the care of their grandparents. However, the death of parents has made it necessary. The following respondents talk about their experiences:

I have the responsibility of looking after six grandchildren, three of which have lost their mother. (IDI #5)

There is not much difference because I have always played the mother role even when their biological mother was alive. I was the one that gave them love, I would defend them when their mother hit them, I would tell her that hitting a child does not build them. Also they called me mother and called their biological mother by her first name, as you may know. (IDI # 7)

The elderly take on parenting roles for the children, they do not see themselves as substitute parents or caregivers but as biological parents to the children. The issue of ill-discipline remains one of the serious challenges, as given that the elderly deal with vulnerable children, it is not easy to punish them. They report that the children are manipulative and describe any action taken against them as a form of discrimination. The following respondents share their experiences of caregiving:

It so happens sometimes that the child does something that you may not like as a parent and so you end up policing them to ensure that they do not get into trouble. I watch out for things such as smoking because I want the young ones to know right from wrong and the older ones have to set a good example. (IDI ≠ 4)

It's just that a lot of times....in actual fact the children I live with are my daughter's and the community has always known them as mine, they call me mother. So luckily they do not have a reason to see themselves as orphans, so much so that I do not want them to even think that they are orphans because I am still alive and I give them more than what they need. (IDI ≠ 7)

The elderly do not only provide care to orphans but also play the role of mentors in order to make sure that their grandchildren do not lose faith and stay positive. By instilling these positive attitudes, the caregivers are trying to boost the morale of their grandchildren by keeping the dream of a bright future alive. It is so interesting to realise that the extent of hardships does not affect the positive thinking of the elderly. The following respondent speaks about her experience:

I talk to them, give them hope when they are feeling hopeless, I encourage them to pray and instil that belief that God will pull them through. I used to talk to her, give her courage to face her challenges. She really needs help. (IDI ≠ 9)

Caregivers encourage the children to get over their worries and memories and try to adjust to their “new life” without their biological parents. The elderly attempt to make the children feel

comfortable with their new family environment and also make them realise there is no difference between orphans and non-orphans in terms of care and treatment. This stance is picked up through the following response:

Sometimes actions of the children do sort of reflect that they might be thinking how it would be had their parents still have been alive. But I do take them aside one by one to tell them that they should let the past go otherwise they will go crazy. (IDI ≠ 13)

One of them really loved their mother and he always has his mother's picture in his room. Even when I take it away, he takes it back. But generally they are happy children because I make sure that they get everything they need. (IDI ≠ 4)

They constantly acknowledge that they do not have a mother and I do not like that mentality. Orphans are sensitive because of their situation so you have to be very gentle with them and you always have to avoid situations in which they may feel abused. It's basically treatment, you have to be extra careful with how you treat them because they have no one else. (IDI ≠ 1)

Caregivers are role models, they must lead by example and manage to instil positive thinking. This can also be made possible by avoiding being emotional, affected or disturbed by any situation and they communicate this attitude to all household members. The following respondent talks about her ability to encourage the household members:

When you are a caregiver you have to be happy, and be able to make them feel that they are part of the family. Nobody should feel like an outsider and none of my grandchildren feel like an outsider. (IDI ≠ 10)

Prior to the death of their children, elderly caregivers were already parenting some of their grandchildren while others were added on following the death of their parents. As parent-caregivers, the elderly have the duty of making sure that all grandchildren that are emotionally

affected by the loss feel loved and welcome. Grandparents-as-parents seem to have more responsibility than normal parents since they have to deal with children that are adjusting to the loss of their parents. Caring for the grandchildren could also entail performing parenting tasks. Besides their grandchildren, the elderly are also taking caregiving responsibility for other vulnerable children. These children either live in the same households as the caregivers or in child headed households.

On the other hand, the skipped generation households have lots of arrangements among residents. Some AIDS orphans are cared for by their grandparents while others live in the households without having family ties with the heads. The passing away of the current caregiver might result in several outcomes for non-family members. Depending on the type of relationships between the latter and the prospective heads of the households, some orphans will continue to be part of the household.

4.1.2. Tasks involved in caregiving

The elderly substitute parents take complete responsibility for the well-being of AIDS-orphaned children. They make sure that the children have everything that is required for school. The following respondents highlight their experience:

When they have to go to school, I wake up early to prepare them and make sure that they are ok. (IDI # 5)

The presence of older children in the household can be of great help to elderly caregivers since they are able to perform some domestic tasks and ease the burden of caregiving. The elderly inculcate the sense of responsibility among AIDS orphans as they are able to take some initiatives and avoid relying on others. The following respondents highlight their experience:

I taught these children to be independent and know how to do things themselves. I just monitor them to ensure that they are on the right track. They wash their own clothes, iron them etc. (IDI ≠ 3)

They are old enough to do it themselves apart from my two-year-old grandson. But for the main meals I cook for them. Honestly speaking I have yet to experience such because I do not do too much for them and they are well trained when it comes to doing things on their own. (IDI ≠ 10)

The older children provide valuable assistance that eases the burden on the elderly. Some of the elderly suffer from a number of health ailments and are not physically strong. Besides doing household chores, the older children can also nurse the caregivers or assist them in performing other tasks. This is to say that looking after older grandchildren can also be useful to the elderly when they are physically unfit or unable to perform some tasks. The following respondents give an illustration of how helpful these children can be:

It's a sore point because you are caring for someone that has nobody else. I am an elderly sickly female and sometimes I have body pains which are unbearable and I soak myself in hot water. Luckily two of the orphans are older so they help me by rubbing me and getting pills for me. (IDI ≠ 11)

My main problem is that I cannot walk properly, so I cannot walk for long distances alone. One of the girls helps me. The problem is that I am alone with these children and due to my sickness I send them to get my medication for me. (IDI ≠ 4)

With regard to physical burden, AIDS orphans are not always passive care-recipients but also active household members since they can provide crucial assistance to the elderly in case of illness or other situations that arise. Caregivers are expected to perform every task for younger children but once they grow older, the elderly become less involved in their daily care.

4.1.3. Caring for AIDS patients

Caring for the sick requires the use of some protective measures that caregivers must always put on when dealing with the sick. Instead of providing confidence, taking these precautions does not seem enough for caregivers; they are frustrated and fearful of being infected. The following respondent explains:

I use gloves and other special aids that will prevent me from being infected by the disease. Even after their deaths in 2005, I went to hospital for a check to make sure. (IDI ≠ 6).

Some elderly do not only look after their infected relatives but also volunteer to assist other community members living with HIV/AIDS. This attitude seems triggered by compassion towards the affected:

The first was when I had just started out volunteering. He was a male. At times I think about their problems that they have told me about, I feel sorry for them but I do give them love. (IDI ≠ 7)

Some families are hard-hit by the epidemic: the elderly often care for more than one AIDS patient. This situation can happen in the extended family where more than one member was infected. This is a vivid account of the extent of bereavement that families, particularly, the elderly, went through over the last few years and which has resulted in an increasing number of children to look after.

In view of stigma and discrimination related to HIV/AIDS, having volunteer caregivers sends out a strong message that it is possible to overturn the tide and change the perceptions of the epidemic. A rise in the proportion of AIDS patients leads the elderly to care for more than one person. As a result, there are more AIDS-orphaned children to look after and there is also an increase in the number of frustrating experiences and repetitive tasks.

4.1.3.1. Terminally ill care

Very sick people need special treatment since they are not able to care for themselves, and sometimes they cannot express their feelings or needs, and must be monitored constantly in order to provide for their tacit needs. The elderly are expected to carry out a range of activities including bathing, changing and feeding the sick person. This is physically exhausting for the elderly and they have to sacrifice a great deal of their time to meet the needs of the chronically ill. The following respondents highlight some of the tasks caregivers are expected to perform:

It is not easy at all. Because I had to do everything and also there are too many safety measures one has to follow when looking after a critically sick person. This includes having to supervise them all the time and wearing gloves when touching them. If they are weak and cannot do things themselves, you need to take them to the clinic or hospital. She was home all day and only went out to go to the clinic, but then she didn't live for long. (IDI ≠ 11)

Taking care of a sick person means you have to keep them clean, bath them, feeding and washing for them to make them to look presentable even though they are sick and taking them to a doctor. (IDI ≠ 10)

It's not easy. We used to spend all day everyday with the two, nursing them even at night. They were constantly in pain and that hurt me as well. We were continually on standby to make sure that they had help whenever they needed it. At the point where they were critically ill, we had to change and wash their clothes. If a person is critically ill you have no choice but to do everything for them. I was constantly next to them and ensuring that they got everything they wanted whether it was food or water. At times they had to be fed. Basically my life revolved around them. (IDI ≠ 13)

I let go of my plans and focused on the sick person. It is important to clean the home because we can easily catch diseases in a dirty place. I have to ensure that the sick one

has her bath and clean clothes, she can't do it by herself. I have to be close to check what she may need, whether it's water or something else. Getting an internal toilet would help a lot because I struggle to get her outside since she cannot walk on her own. (IDI ≠ 12)

Caring for others is difficult because of the intensity of caregiving or other related challenges, but the interaction between caregivers and care-recipients can also present other difficulties. It is also possible that care-recipients verbally abuse caregivers, or that their type of illness leads them to live in denial. The following respondents expand on this issue:

It was difficult: I had to ensure that he got what he liked. They needed to be cared for and there was nobody else. It was difficult because the person would refuse when I would help them change positions in bed. He screamed at me whenever I did. (IDI ≠ 1)

They were constantly in denial about having the disease which made it difficult to take care of them. Obviously I could not force them to admit what they were suffering from. (IDI ≠ 2)

Besides the care-recipients' abusive attitude, there are other challenges inherent in the nature of illness. In other words caregivers feel powerless because there is nothing that can be done to save the sick from impending death. They are disappointed and experience feelings of helplessness. To some extent, the elderly feel guilty of being in good health while their loved ones are suffering from deteriorating health. The following respondent shares her worries:

The fact that you are busy nursing this person yet there is no hope for them to live, it is like you are abusing them. It affects my emotional state negatively because HIV positive people tend to hide that they have the disease and by doing so you can't really help them even when they need it. (IDI ≠ 1)

Caring for the sick entails monitoring them constantly in order to ensure their well-being. It is not easy for caregivers to make plans since they are required to be available for the sick person whenever a need arises:

As an elderly person, looking after a sick person can drain you because you constantly worry about not having physical strength when she has to be taken to the toilet, given a bath and be taken to the clinic. My old frail body cannot carry the weight. I feel anxiety deep in my heart which is a burden. (IDI ≠ 7)

Depending on the type of relationship between the elderly and AIDS patients, having other adult family members in the household can be helpful to the sick. A male family member is less likely to provide all the care the opposite sex needs. It transpires that the caregiving activities of female caregivers are more inclusive than males.

As a result of their caregiving activities, the elderly are prevented from having a social life since they have to be around all the time and be ready to provide assistance. This situation does not only affect them physically and financially but also emotionally. On the other hand, they are helpless since the risk of losing a loved one to the epidemic looms large.

4.1.4. Sleep deprivation and fragmentation

Spending the whole night without sleeping or having fragmented sleep has never been a good experience. Unfortunately, it is part of the challenges that awaits caregivers. The caregivers' time is shared between providing care to others and looking after themselves, hence their resting time depends on the intensity of caregiving. This respondent depicts a worrisome example:

How can I sleep when I have a sick person? Sleep does not come. I am disturbed because I constantly have to keep an eye on the sick person, they may need something like water to drink so you have to be like a nurse to them to ensure that they get everything they may need. (IDI ≠ 4)

Orphaned children are monitored closely to ensure that they do not have any worries. The elderly are expected to attend to all situations that these orphans experience in order to provide

assistance if possible. Some experience disturbed sleep because they have to take care of their younger grandchildren's needs at night. Some grandparents are awakened by their grandchildren and they find it difficult to return to sleep.

I have to because they are young so I have to wake up to make sure that they don't need anything. When they cry I have to be there and figure out what is wrong if they cannot tell me. He once had fits in the middle of the night and I had to walk all the way to the clinic because there were no ambulances to take him to the clinic. (IDI ≠ 6)

Yes I sleep well but it happens that some other nights where she gets really sick I get disturbed. (IDI ≠ 12)

Not anymore, when my grandchild was about four to five months he would need care at night but as he is growing, the need to wake up every now and again at night decreases. Now he manages to sleep through the night and if he needs to go to the toilet, he tells me so I wake up then. (IDI ≠ 10)

Not unless they are sick. It's usually them wanting water or when they are hungry because they didn't have enough food. (IDI ≠ 1)

Unlike the elderly looking after AIDS-orphans who have to wake up at any time at night to check on the children, the caregivers of AIDS patients must be alert at all times in order to attend to the sick. The following respondents talk about what they experienced:

If there are sick persons of course your sleep is interrupted because you have to keep an eye on them. It is important that you attend to them when you hear a sound from them. When they moan you have to be there to make sure that they are ok. (IDI ≠ 13)

I helped him take his pills and made sure that he was sleeping comfortably. (IDI ≠ 1)

Another factor that impacts on the ability to sleep is the state of mind, in other words, having a peaceful sleep depends on the type of difficulties that the caregivers encounter. This situation highlights the stressful life of caregivers that struggle to cope with their responsibilities. The following respondents are part of those that experience such a situation:

Sometimes I struggle to sleep when I have a lot on my mind. (IDI ≠ 9)

But sometimes I don't sleep due to thinking a lot. It's usually about my life struggles such as debts that I have. I don't know how I'll manage to pay them and still remain with enough to sustain my family. (IDI ≠ 6)

With regard to taking a nap, it is not very common but can be possible sometimes. It makes sense to argue that the elderly taking on the parenting role of AIDS-orphaned children are more likely to rest during the day since they deal with healthy care-recipients that do not need to be monitored closely and are of school going age. Hence, caregivers can ensure that they get some rest during the day when children are on the playground or away from home.

Sleeping does not only depend on the willingness to rest but also on the state of mind. Given the high level of stress, taking a nap when care-recipients are not around is not always possible. It seems more reasonable to argue that their resting time is also uncomfortably affected by challenging events. With regard to waking time, the elderly looking after orphans are more likely to wake up early in the morning in order to prepare children for school or to attend to other tasks.

4.1.5. Competition between caregiving and other programmes

In the case of competing demands, providing care takes priority for the elderly. When caregiving or parenting-related issues clash with other programmes, substitute parents prioritize the former. They often delay, postpone or make alternative plans. The following respondents make it clear:

My plans have to wait and I put the children first. It would make me unhappy but that's how I prioritise. If it happens that on pension day there is a school meeting, I go to the school meeting and postpone collecting my pension. We would rather go to bed hungry but it is ok because their education comes first. (IDI ≠ 11)

It doesn't work too well and I sometimes feel crippled. The person that used to help me when such a scenario happened now has a job so I get stuck at home and let go of my plans. I usually go to a traditional church, but I cannot do that because I have many responsibilities at home. I don't really know how to explain it. (IDI ≠ 6)

I forget about my plans and focus on the sick person because they need you to do almost everything for them, like warming water for them to bath and feeding them. (IDI ≠ 11)

When there is a clash in their responsibilities, the elderly are more likely to attend to the person who is in a more critical condition. If both care-recipients are sicker, the younger ones are favoured because they are more vulnerable than the adults. This choice seems to be justified by the children's impatience and tendency to seek attention.

It transpires through these responses that caregivers are explicitly favouring caring over anything else. The stance is clear: "caregiving comes first" and nothing else can stand in the way of providing assistance to family members in need. Hence, other plans are either postponed or dealt with in another way. The health of the elderly is also not a priority.

4.2. Health concerns

Despite their increasing involvement in caring for family members suffering from HIV/AIDS and taking on the parenting role of AIDS-orphaned children, the elderly caregivers have their own health concerns and some are even chronically ill. However their determination to assist others is visible. The following respondents provide more insights into this issue:

I'm not ok, just this morning I needed a massage because my back hurts. I have diabetes and high blood pressure. I worked before, a long time ago but I had to stop because I had too much to handle. (IDI ≠ 14)

Life is difficult, I am also sickly. I have arthritis, and a stroke I had made it worse. Ever since I had the stroke, which was two years ago, another thing is that I have a big lump on my leg. The doctor told me to think about an operation to remove it but I refused. It does hurt on some days. (IDI ≠ 4)

I have a kidney problem. I first heard about it when I went to a doctor last year. He said my kidneys are dirty, so I drink a lot of water and sometimes they stop functioning and sometimes they work ok. (IDI ≠ 4)

Life is not too bad. The bad thing is that I am old so my back, knees and eyes give me trouble due to old age. I can barely see as we speak. (IDI ≠ 2)

The elderly suffer from a range of health ailments. Depending on the type of illness, the time spent on medication is variable and ranges from a few weeks to years. The elderly should be care-recipients rather than caregivers since they suffer from a number of chronic illnesses. This provides an insight into the universe of caregivers who have to sacrifice their own health in order to care for others. Some of the illnesses are minor but are very frustrating.

The elderly's normal caregiving is not only disturbed by continuous poor health but also by the frequency of visits to medical facilities. This is to say that the increase in the number of visits is likely to hinder their ability to take care of themselves and look after care-recipients. Further, their well-being can be seriously challenged if they deal with young children or terminally ill AIDS patients who rely heavily on them for all needs since providing assistance to this kind of care-recipients requires much physical effort. These respondents have serious health challenges:

I go to the clinic more often but this time they have suggested that I go to the hospital because my back is in constant pain. I do see a doctor on the side in between my appointments. I go more often now because of all the sicknesses I have which are ulcers, high blood pressure, diabetes, a painful back and my sore legs. They are all occurring at once. (IDI ≠ 9)

When I run out of medication I go to the clinic. Once or twice a month, I only go to the hospital when I am really sick, I go to the clinic more frequently. I have suffered from high blood pressure since 2006. (IDI ≠ 13)

I don't go to the hospital rather I get money to see a doctor. I go more often now because the pain in my legs is unbearable and I'm always carrying painkillers in my pocket. I broke one of my legs and had a cast on for four months. (IDI ≠ 11)

As they become older many report increasing ill-health. It can be argued that the extent of annoyance caused by illness varies from one caregiver to another. It was also interesting to come across some elderly that claim to be in good health or claim to have “minor illnesses” as these respondents state:

I don't take any treatment... I don't have any because I am not sick. I do not, Oh yes I am fine, very fine. (IDI ≠ 5)

I am fine. It's just my eyes that are giving me trouble. I have had this problem for a long time. Also there is something new I suffer from, one of my breasts has recently started to be painful. (IDI ≠ 10)

The extent of expectations placed upon the elderly and their concerns over children's well-being is believed to lead to poor health. The elderly were asked to stay away from children as much as possible for the sake of their well-being. They recall that interfering too much with the children's problems was one of the causes of high blood pressure in caregivers. In addition, old age is often

associated with more health problems; their commitment to care for others is more likely to worsen their fragile and precarious standard of living.

4.3. Barriers to elderly health care access

With regard to reasons preventing the elderly from seeking medical care, it is noted that the quality of assistance is to be blamed for poor attendance, and hindrances are also inherent in the attitude of service providers towards older people. It is also claimed that barriers are created by medical staff through their attitude towards the elderly. Further, the elderly are barely assisted and they end up regretting going to the hospital. The following respondents share their experiences:

We are old, our hearts easily become strained, sometimes you go to the hospital and the help that you get is unsatisfactory. You end up asking yourself why you bothered to go there because it doesn't make any difference. (IDI ≠ 7)

Nurses neglect us in hospitals and clinics and I am talking from personal experience. I had high blood pressure yet they ignored me. So I do not bother going there. (IDI ≠ 2)

When you go there, they just give you two or three pills for the pain you're in at that moment and that will be it. Sometimes the distance is too much, other times when you get there you are not attended to. Elderly people are abused and not attended to. (IDI ≠ 12)

The extent of illness forces some caregivers to go to the hospital while they may not themselves be in the mood to go or because there is no hope of getting adequate assistance. Nurses are to blame for their attitude towards the elderly. In reaction to this, the elderly rank the need for medical care lower than other plans on their priority list. Some medical institutions run out of key medication and the elderly therefore feel it is necessary to find alternatives. In addition, other factors can also be mentioned as preventing older people from seeking medical assistance such

as lack of means to fund the trip, lack of physical strength to travel to the facility as well as the issue of long distance between hospital and home.

4.4. Household income

The main source of income of most elderly caregivers comes from a social grant which is sometimes coupled with the Child Support Grant for those who are living with eligible children. The elderly are not economically active; they rely solely on social grants to support their households. Many elderly caregivers feel this is not sufficient since they barely meet their needs. In addition, accessing this grant is a time consuming process with uncertain outcomes. Some respondents have shared their experience and concerns:

I do receive pension but it's far from being enough because everything is expensive these days. (IDI ≠ 4)

No, apart from the foster care grant for the children after their mother died there isn't any. It's that and my pension. I do not get any other help, I support them with my pension. One of the children has completed matric but can't study further because of financial issues while two are still at school and I pay for their fees with my pension. (IDI ≠ 5)

I had problems when I tried to get foster care for these children, up to today I have not found it. (IDI ≠ 7)

The Republic of South Africa alleviates poverty and empowers older people in providing them with a source of income. The child support grants and social grants are used to support households and meet the needs of skipped generation households. The loss of loved ones results in an increase in the proportion of dependents and it puts much strain on the main caregivers.

4.4.1. Financial burden and frustration

The terminally ill rely on caregivers for all their needs. The financial burden can be more serious for the caregivers of AIDS patients since they sometimes have to spend almost all their money to assist the sick. Following the death of their loved ones, elderly caregivers are expected to spend more of their funds on their funeral. Thereafter, the elderly also have to deal with the burden of the debt and the emotion of losing their loved ones. The following respondent shares his experience:

Nursing a sick person till they die gives rise to other problems such as debts. (IDI ≠ 13)

One of the serious burdens that the elderly taking on the parenting role of AIDS-orphaned children encounter is financial. AIDS orphans have several needs that the elderly find difficult to meet, especially, when there is a large number to look after. The age of these orphans ranges from early childhood to late adolescence. Their needs revolve around food, clothing, school fees and also emotional support. The household does not have sufficient finances to meet all the needs of the children, some are too important to be ignored. This situation leads the household heads to make other arrangements, such as borrowing money, in order to support the orphans. Failing to meet the needs of the households affects the emotional well-being of the caregivers, especially, when there is no hope of assistance. The account of these respondents is explicit:

It exhausts me so much that I end up sleeping the whole day. I think about how we will survive with so little money and how I can make my situation better. I keep everything bottled up because I have no one to confide in about my hardships. I end up feeling like I am going crazy trying to figure out what to do for us to survive. (IDI ≠ 4)

I do get hurt emotionally when they want something I can't afford. Their grants and my pension do not cover much. There is just enough for food, clothes and a few other essentials. (IDI ≠ 4)

Further, the extent of needs among caregivers is alarming since some do not have the basic necessities for their caregiving activities. The lack of gloves entails handling all diapers of the sick with bare hands or finding alternatives that might not be hygienic. The likelihood of contracting HIV cannot be overlooked. Despite the fact that caregivers might be aware of the methods of transmission, in case of emergency there is nothing to do. A solution must be found in order to relieve the sick. The following respondent gives an account of what is required:

When taking care of a sick person, they need to be given necessities such as diapers, gloves, porridge as well as other things that are useful but we don't get them and so there must be means that make it possible for us to get them. (IDI # 7)

Living with orphans is a dilemma for caregivers since they are willing to provide better care and make them happy while they can barely cope with the child-rearing demands. The elderly end up being worried and having mixed feelings over playing a parenting role. The extent of frustration is so high that they feel powerless. It results in resentment and compromised well-being. Further, caregivers are more interested in protecting and sheltering AIDS-orphaned children. They do not pay much attention to the possible impact of an increase in the number of dependents on their standard of living. Similarly, the elderly are more concerned with the needs of AIDS orphans than their own well-being. Every effort is made to please the orphans. Failing to provide for these needs might leave the caregivers powerless and remorseful. In their endeavour to avoid bearing the blame for compromising the future of AIDS orphans, the elderly are committed to doing whatever is possible to successfully meet all their needs. They voice their frustration and concede that caring for orphans is really a difficult undertaking, a burden, and they also describe their life as difficult.

4.4.2. Assistance

Despite several challenges that the elderly encounter, placing AIDS-orphaned children into foster care is not an option. They prefer to take care of these orphans and provide them with financial and material support. With regard to the organisations that provide assistance to caregivers or

ease the burden of looking after people living with HIV/AIDS, the sick and AIDS-orphaned children, elderly caregivers do not have adequate knowledge of any that are functional. They reveal that there is not a visible organisation that takes care of caregivers or the elderly on the ground, however, some make sporadic appearances and provide spontaneous assistance before disappearing. It transpires that the assistance required is not always material but also advice in the way of handling some tasks or caring for AIDS patients or orphans. Nevertheless, friends and neighbours assist some of the caregivers. For those who do not have friends, they have to keep to themselves and try to manage their finances in order to survive hardships.

4.5. Emotional health

The elderly have lost several family members and are affected by their deaths. Every caregiver interviewed has at least one AIDS-orphaned child in their household. Though some relatives died of other causes, AIDS remains the main cause of death. Regardless of the cause of death, its occurrence seems unbearable and their life remains haunted by it. The death of children in the prime of life is one of the saddest events in their life. Many elderly caregivers have made an attempt to try to get over it and accept that it has happened. Hence, looking after their grandchildren is viewed as a family duty to honour those who passed away by striving to ensure that the orphans are cared for in a proper manner. However, the elderly caregivers that look after AIDS-orphaned children are very emotional. The emotion seems to be equated with the extent of expectations placed upon them following the untimely deaths of their loved ones. This feeling can be picked up through this response:

It has affected me badly because after the death of their mother I had to carry the responsibility of taking care of the children and so my expenses increased. (IDI # 5)

In order to avoid adding to the problems of orphaned children, elderly caregivers manage to overcome their emotions. The loss of adult children has profoundly affected the life of the elderly by assigning them a “compulsory role” of assuming the parenting role of AIDS-orphaned children. They are helpless and broken-hearted. The assumption of responsibility for caregiving

and the loss of their loved ones have rendered them vulnerable and as a result, they feel very emotionally distressed. Their worries are triggered by both the extent of loss experienced and the “new role” they have to play as caregivers and heads of the households. Further, what seems to worsen this situation is the succession of untimely deaths that do not allow them to get over the first loss before the occurrence of the second one. There is therefore the feeling of being left helpless and empty handed, especially, for those who were relying on their loved ones for support.

4.6. Perception of infection

There is a belief among caregivers that AIDS orphans cannot be infected as long as they are under their care. To some extent, this is to say that they cannot be infected because they are still young; it can only happen to those who are older or other reasons are put forward as possible causes of infection. It transpires that the caregivers do not know much about the means of transmission of HIV infection. As argued by the following respondent:

Sometimes I think about that because from what I've heard you can contract it in many ways especially when you live with many people. (IDI ≠ 9)

Similarly, some caregivers do not see themselves at risk of infection because they are not in contact with AIDS patients or are not sexually active, while others think that they can get infected since they have casual contact with an AIDS patient. The following caregivers speak about this issue:

No I am too old to be worried about that. I haven't had sex since 1982. (IDI ≠ 4)

I do think that I could be in danger because in this place there are a lot of people with the disease. I come across different people on a daily basis. The one thing that frustrates me is that neighbours just direct everyone and anyone to my house even if they just need a room to stay, just because I am helpful. (IDI ≠ 9)

Caregivers live in denial and disagree that they cannot lose the grandchildren due to AIDS as their parents. This can be viewed as an overprotective attitude in their willingness to be surrounded by their grandchildren and keep the memories of those who passed on alive. On the other hand, this attitude can be considered as a reason to worry about because they do not know much about the methods of transmission and can therefore deal with AIDS patients in the wrong way and be infected as well.

4.7. Stigma and discrimination

The issue of stigma is serious and can result in suicide for some victims. In order to ensure orphaned children are not discriminated against because of the death of their parents as a result of AIDS, elderly caregivers do their best to protect the rights of the orphans. Though they do not have family ties with some of the orphans, caregivers place them under their responsibility. The following respondents share their experience:

Orphans are often discriminated against all the time, people treat them badly and say whatever they like to them because they know that orphans do not have parents that will fight back for them. (IDI ≠ 9)

There is one that suffered because of that stigma, he even tried to hang himself because some people would ask questions he had no answers for. I even involved the police because that's how bad things were. (IDI ≠ 6)

There are several events that take place and cause lots of changes. Orphans are victims of discrimination because they are misunderstood. AIDS orphans are an easy target and may be seen as responsible for their misfortune. It is not always easy for caregivers to maintain their social networks. They end up being isolated and withdrawn as a result of the intensity of caregiving. In addition, both caregiver and care-recipient are victims of stigma on the part of the community and family members. The following respondents share their experience:

I think it's because they were not taught about life in general, that people are different and go through different situations. (IDI ≠ 13)

I don't have family around here. It so happens that her family is around but they don't bother caring for her and they don't do anything for her. Her mother is still alive yet she doesn't. The neighbours come once in a long while. People are scared to come into contact with a sick person. I did mention that before. I can't go anywhere and I have run out of food and that's the main problem. (IDI ≠ 12)

In an attempt to avoid hurting caregivers there is a tendency to keep secret the status of patients. This practice could do more harm to the elderly than expected since it is riskier that they care for patients without knowing that they are HIV positive. The following respondent talks about what she encountered:

They never told me that they have it but I saw their status on the medical card. They were probably scared to tell me because it was my child. (IDI ≠ 11)

Stigma and discrimination is a serious issue among community and family members. The elderly are isolated as a result of secondary stigma and also because of the intensity of caregiving activities. It is sad to mention that some elderly are at risk of contracting HIV since they are expected to care for AIDS patients without knowing their status. This attitude shows that much is not known about the methods of transmission.

4.8. Discussion

The outbreak of the AIDS epidemic has resulted in several challenges that affected the well-being of a particular type of individuals, notably the elderly. They are increasingly playing the role of caregivers to AIDS orphans and AIDS patients. This involvement in the daily care of loved ones constitutes a major breakthrough but it is not without consequences. This project has

highlighted some factors surrounding the caregiving activities that have an impact on the physical, emotional and social well-being of the elderly.

This project found that elderly caregivers took on the parenting role of AIDS-orphaned children whose ages ranged from early childhood to late adolescence. The number of AIDS orphans per household was variable. These findings also held true for a study carried out in Uganda that highlighted that the high fertility in rural areas resulted in an increasing number of AIDS orphans per caregiver (Ssengonzi, 2009). It was found that caregivers were old and frail and could hardly perform all the tasks of the household such as cooking, washing, cleaning and bathing children. Likewise, they were expected to wake up early in the morning in order to assist the children to prepare for school, especially the young children. The intensity of caregiving was dependent on the age of orphaned children. The elderly were more involved in caring for young children while the older ones were able to assist their caregivers in doing some domestic chores, and they only needed some guidance. Besides reducing the amount of pressure placed upon caregivers in terms of domestic tasks, older children were also able to provide much-needed assistance to the frail elderly. For instance, orphaned children nursed those who were sick or physically unfit. Moreover, the elderly crippled by illness and unable to walk were assisted by these older children so they could attend some important gatherings.

Prior to the passing away of their loved ones, some elderly were living with their grandchildren, hence, the major shift in their responsibility was the loss of support or remittances. This situation entailed caregivers having to assume all the responsibilities of bringing up their grandchildren. It was revealed that orphanhood played an important role in the composition of households in South Africa but it was not the only cause of the formation of the skipped generation households, since a significant proportion of children were living apart from their parents. Some of the reasons leading to these living arrangements were the financial and physical incapacities of breadwinners to care for children and the need for these children to assist a sick family member (Klot and Nguyen, 2009).

Following the death of their loved ones, the elderly became the primary caregivers of AIDS-orphaned children. Their caregiving activities went beyond normal parenting since both caregivers and AIDS orphans were affected by the death of their loved ones, however, the elderly had to get over their worries in order to comfort the orphans. As guardians, the elderly did their best to be emotionally strong in order to help the children to forget about the death of their parents and focus on the future as the only way through which their misfortune could be reversed.

Besides being emotionally affected by the loss, elderly caregivers were expressing concern over meeting the needs of an increasing number of dependents. In fact, social grants were the only major source of income for all the respondents. The Old Age Pension was introduced in South Africa in 1924 but was a Whites-only privilege because of the racial discriminatory policy that was practiced at that time. Nevertheless, there was over time an increase in the proportion of South Africans receiving social grants. The share allocated to Whites was still larger than any other racial groups and in 1944 these pensions were extended to all South Africans (Triegaardt, 2005). Furthermore, in an attempt to address inequalities inherited from the apartheid system, a new social policy targeting poverty alleviation among children and families was designed in 1996. The committee set for shaping the policy came up with a means-tested Child Support Grant (*ibid*), which had four objectives. Firstly, allowing poor children to have access to integrated and sustainable income. Secondly, providing a grant to any needy child without taking into consideration his origins, racial group or family composition. Thirdly, keeping children away from foster care placement that was not necessary. Finally, providing children with an incentive to stay off the streets and away from minors' detention centres (Lloyd, 2000).

Though they are recipients of social grants, caregivers felt it was not sufficient to meet their needs. The social grants were spent on food, clothing, medication, education and other household basic necessities. They were financially burdened and could not cope with the household demands. An increase in the proportion of dependents put much strain on the main caregivers. A study by Klot and Nguyen (2009) revealed that many people were indirectly affected by AIDS

since sick parents or breadwinners relied on someone else along with their dependents. The extent of dependence increases with the death of breadwinners. It was found that the financial strain was part of the serious threat to the well-being of the caregivers of AIDS patients as they spent all their earnings on the sick and ended up dealing with the burden of the debt after the funeral. These findings are consistent with a number of studies (Steinberg *et al.*, 2002; Munthree and Maharaj, 2010). The quality of life was lowered because the elderly could not live up to the expectations placed upon them, further, it has become difficult to meet the needs of all the dependents since social grants were intended only for pensioners (Triegaardt, 2005). Every increase in the number of dependents was supposed to be followed by a rise in income in order to meet the demands; unfortunately it did not happen this way. These findings are consistent with a study conducted among elderly female farmers in western Kenya who were unable to produce enough food for the whole family following an increase in the number of household members (Muga and Onyango-Ouma, 2009). Furthermore, caregivers were more interested in protecting and sheltering AIDS-orphaned children. Some of the children under their responsibility did not belong to their family. Similarly, other vulnerable children were either assisted with food parcels or cared for during home visits.

Following the death of their loved ones, it was difficult for caregivers to receive remittances to supplement their income. Some elderly were worried about their well-being and made it clear that caring for orphans was a burden. It was found that they became resentful and were spending sleepless nights if the needs of AIDS orphans were not met. This reaction was triggered by orphans that viewed their unmet needs as a form of discrimination against them. In order to illustrate the extent of frustration, some older caregivers suffering from hypertension, and reported that they were advised against interfering excessively with orphaned children. Although, the relationship between stress and high blood pressure is not scientifically proven, this situation highlighted the difficulties of their task.

Moreover, caring for the terminally ill was frustrating, the life of elderly caregivers was revolving around the sick day and night which resulted in either sleep deprivation or sleep

fragmentation. The intensity and repetitiveness of caregiving along with sleep deprivation and fragmentation was compromising the quality of life of the elderly. According to Naitoh *et al.* (1990) sleep deprivation results in a reduction of the quality of life, sleepiness, sluggishness and tiredness. It also restricts the ability to work efficiently, stay focused and causes some physiological changes in humans. It was found that the caregiving activities of the terminally ill were very demanding in terms of physical efforts since the elderly had to monitor them closely. Caregivers had to perform all the tasks required or expected by the sick while some older people reported poor health such as a strained back and knees, high blood pressure, impaired eyesight and others suffered from chronic illnesses such as arthritis, diabetes and health problems. These findings are supported by a study conducted among elderly hawkers in Durban (Chazan, 2006). Old age is associated with an increase in health problems, and Kramarow *et al.* (1999) argued that approximately 80% of people aged 65 years and above had at least one chronic illness. Despite their health problems, caregivers performed risk-loaded tasks such as bathing, dressing, feeding, and lifting up the sick; these findings are consistent with Munthre and Maharaj (2010). Some of the tasks involved in caregiving were too demanding in terms of physical effort and exposed caregivers to back injuries as well as other crippling illnesses since they were not trained on how to handle them. In addition, caring for the sick requires the use of protective equipment. It was however sad to realise that caregivers were at risk of infection because of a lack of protective measures.

The extent of poverty and the existence of competing priorities prevented them from affording the necessary equipment. Munthre and Maharaj (2010) found that they were performing tasks such as cleaning wounds and changing diapers. It is proven that the risk of contracting HIV during caregiving is minimal (Task Force on Paediatric AIDS, 1988), however lacking adequate protection is more likely to increase the risk. Further, the elderly were expected to care for AIDS patients without being informed of their status or the type of illness. These findings are supported by a study conducted in Uganda (Ssengonzi, 2009). This situation exposed caregivers to the risk of infection since they could not afford protective measures. The high prevalence of HIV has led some older people to care for more than one AIDS patient, and some of the patients cared for

were not family members or loved ones. The elderly were caring on a voluntarily basis, they were compassionate and felt obliged to assist the patients as well as to help out the affected families. Besides the frustration inherent in the type of illness, caregivers were struggling with their emotions, given that there was no hope of saving lives. In other words, taking into consideration the fact that death was the only way out, it would be better for these caregivers to passively witness its occurrence instead of hopelessly providing meaningless care. Caregiving was viewed as a torture since it just delayed the occurrence of death, however, giving up was not morally acceptable. This feeling was termed by Sosnowits and Kovacs (1992) as a tendency to “bury the sick before they were dead”.

Moreover, caregivers were confronting several challenges that could compromise their well-being. For instance, one of the requirements in the management of hypoglycaemia in diabetes patients is to maintain a regular diet by avoiding skipping or delaying meals and snacks for more than half hour (Macheca, 1993). Without taking into consideration their chronic condition, caregivers starved and even deprived themselves of some material needs in order to please their care-recipients. The experience of the following respondent described this situation: *I give them all the love I have. Even when I am eating somewhere I always think of them and instead of eating the food I bring it home for them. (IDI # 6)*

The extent of risk taken by the elderly was more considerable, in the case of a clash between caregiving and other plans, they were comfortable with meeting the needs of AIDS patients and/or AIDS orphans. Caregiving ranked higher on the priority scale of the elderly while their own needs were the least met; all their plans were dependent on the care-recipients. Though they acknowledged that caring was a burden, other programmes were either postponed or not attended at all. This is to say that nothing could be done as long as there were outstanding caregiving activities and even the health of caregivers was less paramount. As a result, they ended up missing medical appointments (Joslin and Brouard, 1995). Furthermore, given that the relief of some chronically ill elderly (such as diabetes and arthritis patients) relies on continuous medication, this situation could compromise their well-being. It was found that caregivers

suffering from arthritis could hardly walk, therefore playing the role of caregiver was more likely to worsen their condition. Although there is no cure for arthritis, Buckley (1950) revealed that it was possible to improve the well-being of patients. This improvement can be achieved by resting the joints, avoiding a long distance walk and carrying weight. Unfortunately, sometimes the intensity of caregiving prevented the elderly from caring for themselves.

Caregivers were emotionally affected and have reached a point where they suffered from high levels of stress. Older caregivers were stressed over losing their children in the prime of life and were entangled in a huge number of stressors since they had to care for their dying loved ones and then take on the parenting role of orphaned children. The level of frustration and irritation was very high. They had to deal with lots of stressful situations such as bereavement and grief, and pretend to maintain a semblance of control over an ever growing number of dependents. Therefore, the elderly had to deal with the loss of their loved ones and confront the frustrating issues of parenting orphans. Further, the quality of life was compromised as they had to take on a parenting role at retirement age and strive to adjust to it. The elderly had to ignore their own problems and focus on their care-recipients.

Given that there is an increase in health problems in old age, (Kramarow *et al.*, 1999), elderly caregivers reported an increase in the frequency of visits to the hospital and clinic. Depending on the type of illness, their visits were on appointment or in case of emergency. In spite of their poor health, this study found that they were reluctant to seek medical care. They blamed the attitude of service providers towards them. Research highlights that communicating with older patients is very important in nursing them (Armstrong-Esther *et al.*, 2006). Similarly, Caris-Verhallen *et al.* (1999) found that irrespective of the age of patients, there was no difference in the way that nurses communicated with them. On the other hand, the elderly found it hard to go to the hospital or clinic because there was no hope of getting adequate assistance. Taking into consideration that the quality of care might depend on the attitude of service providers towards patients, nurses were less likely to take the requests of older people seriously when they stereotype them as bad-tempered, argumentative, uncooperative and unable to adjust to changes

(Courtney *et al.*, 2000). Instead of being nursed, some elderly reported being told to go home since they were not sick, that their health problems were not due to illnesses but to their old age. The poor knowledge of service providers might be one of the reasons for this attitude. It was found that over time there is an increase in the proportion of elderly patients, while the number of nurses qualified in gerontology does not follow this trend (Mitty, 1995; Johnson and Connely, 1990). Other studies found that elderly patients were discharged without being informed of their illness, precautions, recovery and medication (Mistiaen *et al.*, 1997; Henderson *et al.*, 1996). Given that having access to health care is a necessity, some elderly patients ended up using traditional medicine as an alternative to formal health care. Besides the attitude of service providers as a deterrent to the elderly's medical care, obstacles such as lack of transport fare, poor health, existence of other competing priorities and distance between home and hospital were put forward as other causes.

Besides reporting poor health as well as other health problems, there were however some elderly who reported good health. It is possible that some intended to keep their health status a secret. Writing about this issue, Norland (1994) found that older people in Canada rated their health as "good, very good, or excellent" while there was a significant number of disabled and chronically ill. Similarly, in a study conducted in the United States, the elderly claimed to be in good health because the intensity of caregiving had resulted in weight loss (Minkler *et al.*, 2000).

Providing care was the first priority of caregivers and as a result they ended up being isolated and withdrawn. The intensity of caregiving played a significant role in the loss of social life. The isolation was exacerbated by stigma on the part of the community as well as family members. This observation was also made in a study carried out in rural South Africa (Ogunmefun *et al.*, 2011). By the same token, sometimes the interaction between AIDS patients and caregivers was difficult and the former were accused of verbally abusing the latter. AIDS patients attempted to deny their HIV status which highlighted their desperate attempt to hide their illness while they indeed needed assistance. This reaction was also found in AIDS patients in Uganda (Ssengonzi, 2009). Such attitudes might have something to do with stigma and discrimination, a sort of "self-stigma".

On the other hand, it is proven that the risk of infection is very minimal during caregiving (Task Force on Paediatric AIDS, 1988), however, some elderly reported being at risk of contracting HIV because they had casual contact with AIDS patients. Likewise, the risk of infection was overlooked by others who revealed that they were sexually inactive or too old to be infected. The elderly disagreed that their grandchildren (AIDS-orphaned children) were at risk of infection. These responses illustrated the lack of knowledge of the methods of transmission, on one hand, and their eager desire to be surrounded by their grandchildren on the other hand. Furthermore, assuming the parenting role of AIDS orphans resulted in two other challenging issues, namely misconduct and emotional manipulation. The elderly assuming the parenting role revealed that misconduct was one of the challenges in raising AIDS orphans and every effort was made to deal with it. However, they confronted the emotional manipulation on the part of the orphans and tried to avoid being punished. The elderly reported that when actions were taken against them, after wrongdoings, the orphans complained that they were being punished because of their vulnerability.

The death of elderly caregivers could result in increasing vulnerability of AIDS-orphaned children under their care as it was difficult in most cases to predict the prospective caregivers should the current ones pass on. The case of non-family member orphans could be more serious since some could hardly find new families (households). It was also highlighted that although the division of labour is gendered and undeniable at the family level, males were also involved in caregiving activities. Their involvement was going beyond the roles traditionally assigned to them.

Unlike financial support that was solely provided by the government, some caregivers were emotionally and spiritually assisted by church and community members. While those who did not have friends had to keep to themselves and tried to find inner resources to deal with hardships. With regard to special structures, such as home-based care, that were supposed to ease the burden of caregiving and provide some much-needed support to the elderly, none was reported to be functional in the area (Lindelani informal settlement). However, some

organisations made sporadic appearances, handed out food parcels and promised to take care of caregivers before disappearing. It also transpired that the type of assistance required from support structures was not always financial or material; there was a need for practical advice on the way some issues or tasks should be handled or dealt with.

4.9. Summary

This chapter has highlighted the major findings of the fieldwork conducted in Lindelani, an informal settlement in the province of KZN. With regard to in-depth interviews and personal observation, which were used at this stage as a tool of data collection, it has emerged that there were lots of factors that impacted on the well-being of elderly caregivers and affected their health.

It was found that the well-being of elderly caregivers was severely affected by several caregiving activities. Firstly, they had their own health concerns and were chronically sick for years. Secondly, there were too many caregiving activities which made it difficult for them to cope. Sometimes, they were expected to monitor AIDS patients closely. Thirdly, the elderly were financially burdened and could hardly cope with the demands of an increasing number of dependents. They often refrained from meeting their own needs in order to please other household members. Finally, they were confronting lots of challenges inherent in the upbringing of AIDS-orphaned children and caregiving.

Chapter five

CONCLUSION

According to Mann (1987), AIDS has given rise to three interrelated epidemics instead of one. The first one is related to the hidden stage of infection which began in the 1970s. The second one is AIDS that was discovered for the first time in the United States in 1981. The last one is the reaction of the global community to HIV/AIDS. Over time, the AIDS pandemic has resulted in several challenges. At the global level, it was the first health issue to be addressed by the United Nations (UN) Security Council as a threat to world stability and peace, particularly in many African countries (Birmingham, 2000). More specifically, the threat of HIV/AIDS was perceived as serious enough to reverse the gains made in terms of the Human Development Index (Botswana Human Development Report [HDR] 2000, 2005; Malawi HDR 2005, 2005). This threat was not only felt by high ranking officials but also by the people on the ground. The profound impact of HIV/AIDS on the communities around the world led some to give it the pseudonym of the “modern plague” (Marks, 2002). This perception led to stigma and discrimination of AIDS patients as well as every person involved in casual contact with them. At the family level, AIDS has resulted in shortening the life of young adults and in imposing the role of caregivers on their parents or older relatives, as well as the parenting role of AIDS-orphaned children.

The involvement of the elderly in caregiving is gaining momentum as a direct outcome of an increase in the proportion of people living with HIV/AIDS throughout the world and Africa in particular. The caregiving activities of the elderly constitute a breakthrough towards better care of AIDS patients as well AIDS-orphaned children. This intervention highlights the extent of damage caused by the epidemic and its implications on the structure and composition of the households. The death of young adults due to AIDS has forced the elderly to come out of retirement to take on the parenting role of their grandchildren and of vulnerable children at large. Following the death of their loved ones and an increase in the number of dependents under their

responsibility, the elderly are expected to provide to the needs of the households. This situation compromises their physical, emotional and financial well-being since they have their own health concerns and are not economically active. The change in the household structure is deeply felt in Africa because of the high HIV prevalence.

The Republic of South Africa is home to the largest epidemic in the world and HIV/AIDS is one of the main health challenges, since over 10% of the total population is infected (Department of Health, 2010). Recently, a drop in the proportion of new infection was recorded, which is a start towards overturning the tide of the epidemic. The proportion of AIDS patients on ARVs is on the rise which results in greater longevity of AIDS patients, a reduction in mortality and an increase in HIV prevalence. The government investment in the fight against HIV/AIDS is yielding fruit but the elderly will be in the spotlight for several years to come as the death due to AIDS is waning in magnitude. However, AIDS-orphaned children could be under the responsibility of their “grandparents” for a decade or more. In addition, the change in the AIDS pattern, from a death sentence to a chronic illness for the patients on treatment, is more likely to give rise to the new type of relationship between caregivers and care-recipients. This implies that the assistance of the elderly will be needed for several years.

5.1. Summary of results

Elderly caregivers experienced lots of challenging events that affected their standard of living. This project has highlighted physical, emotional and financial factors related to family structure and composition that had an impact on the health and well-being of caregivers.

Firstly, the caregiving activities were too demanding since the elderly were expected to perform all the household tasks. It was found that older people were frail and struggled to live up to expectations in terms of physical demands placed upon them. Further, they had to wake up early in the morning to prepare for school-going children, especially young children. The caregiving activities were intense for the elderly living with the terminally ill as they were expected to monitor the sick. The physical burden was one of the serious concerns among caregivers; the

intensity and repetitiveness of tasks along with sleep deprivation and fragmentation impacted on the quality of life. This situation was exacerbated by the recurrent health problems; some caregivers were chronically sick and needed special care. Further, caring for the terminally AIDS patients required the use of protective equipment, which the elderly were unfortunately unable to afford. This was more likely to increase the risk of contracting HIV and compromised the well-being of these caregivers. The issue of secrecy surrounding the AIDS epidemic represented another threat to the well-being since some older people were expected to care for the sick without knowing their status.

Secondly, the elderly were not emotionally prepared to assume the responsibility of caregivers. They were desperately in need of support and experienced high levels of stress. They were entangled in a series of stressors that affected their well-being. The caregivers' worries were related to their emotional, financial and physical abilities to cope with their responsibilities. They had too many serious issues to handle, namely, dealing with the parenting issues of AIDS-orphaned children, attempting to get over the loss of their loved ones and confronting their own health problems. The extent of frustration and irritation was very high. Becoming the primary caregivers to an increasing number of dependents, the elderly pretended to exert a semblance of control over lots of stressful situations. Therefore, the quality of life was compromised as they took on a parenting role at retirement age and managed to adjust to it. One of the vivid examples of compromised well-being, when caregivers failed to meet the needs of their dependents, was their inability to sleep at night as there was no hope of getting assistance.

Finally, the elderly were financially burdened and could not cope with the household demands. It was found that the only source of income was the old grants pension that could be combined with a child support grant. The financial burden was one of the serious threats to their well-being since it was difficult to meet all the needs of care-recipients. The expectations placed upon caregivers were so high that they could hardly live up to it; they had to spend all their earnings in order to assist the sick and deal with the burden of the debt after the funeral. The burden of caregiving was also huge for those who were caring for AIDS-orphaned children; it was found

that they became resentful if the orphans' needs were not met. In addition, following an increase in the number of dependents, the elderly were unable to meet all the needs of the households. These needs were physical, financial and emotional.

The elderly reported experiencing several challenges inherent in caregiving on a daily basis. Given that providing caregiving was the first priority and it had an unpredictable pattern, it then became difficult to make plans and they ended up being withdrawn. An increase in the frequency of caregiving along with stigma and discrimination played a prominent role in the social isolation of caregivers. The elderly were not only isolated by the community but also by their family members. The role of the elderly as parents went beyond normal parenting since caregivers and AIDS orphans were affected by the loss of their loved ones and the former had to get over their emotions and focus on caring for the latter. Further, the extent of AIDS resulted in an increase in the number of patients or care-recipients per caregiver, with some elderly caring for more than one patient. However, the burden of caregiving was sometimes shared among elderly as some volunteered. The interaction between AIDS patients and caregivers was sometimes difficult as the former were accused of verbally abusing the latter. This antagonistic relationship took place when AIDS patients tried to hide their HIV status in a desperate attempt to prevent any assistance. Similarly, the elderly felt like they were involved in the physical abuse of the sick because their care could not save lives.

Despite their health problems, the elderly were reluctant to go to the hospital to seek assistance, and they complained about the quality of care and the attitude of service providers towards them. They described their life as difficult since they had to spend a lot of money on care-recipients without any hope of support. Caregivers also had to confront the issue of the misconduct of AIDS orphans, and they reported being harsh in dealing with wrongdoings. On the other hand, orphans were 'fighting back' by using their orphanhood status to blackmail or emotionally abuse the caregivers in order to escape punishment.

5.2. Recommendations and suggestions

This project showed that the well-being of the elderly was challenged by caregiving. Their involvement in the caregiving activities of AIDS-orphaned children and AIDS patients exacerbated their condition. It did not, however, investigate the well-being of elderly non-caregivers in order to assess their experiences. Although old age is associated with recurrent health problems (Kramarow *et al.*, 1999), comparing both groups would provide more clues towards the understanding of this issue. Much more research is needed, both qualitative and quantitative, in order to provide more insights into this issue.

Over time there has been an increase in the number of AIDS patients on ARVs across South Africa. This treatment has shifted AIDS from a death sentence to a chronic illness, and it is hoped that the scaling up of ARVs is more likely to result in a new type of relationships between caregivers and AIDS patients. This project failed to gather information on the elderly looking after people living with HIV on ARVs, and some research on this issue is needed in order to assess the role that caregivers play and how it might impact on their health and well-being, as well as to provide insights into the expectations placed on them.

Besides financial challenges, caregivers lack training and are at risk of injuries. They do not have enough knowledge on how to handle some tasks that require physical effort. Further, they are in need of emotional and psychological support. The home-based care programme should be strengthened in order to reach them.

There is reason for concern since the elderly seem to have poor knowledge of the methods of transmission of HIV. Some participants of this project did not see themselves at risk of HIV because they were not sexually active while others believed that the casual contact with AIDS patients put them at risk. Investigations need to be made in order to shed more light on this issue.

Finally, the issue of the elderly taking on the parenting role of AIDS-orphaned children and the caregiving activities of AIDS patients lead to lots of financial challenges while they were economically inactive. Given that most caregivers rely on social grants to make ends meet, the increasing number of dependents under their responsibility makes their lives more difficult. More financial assistance in the form of grants could allow them to take better care of their dependents and provide much relief.

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Appendix: INTERVIEW GUIDE

1. Background Questions

Today's date _____

Age _____

Date of birth _____

Sex: Male _____ Female _____

Marital status: Married _____ Living Together _____ Never Married _____ Divorced
_____ Widow _____

How many grandchildren (children) are living you? Male _____ Female _____

2. Specific Questions

How would you describe your health?

Probe: Sick or healthy? Do you have any health problems? How long have you been experiencing these health problems?

Are you currently on any medication?

Probe: How long have you been on medication?

How often do you go to the clinic/hospital?

Probe: are you going to health facility more or less than before? Why is this? How far is this health facility?

How does providing care for the terminally ill affect ones daily life: what tasks are involved in caregiving?

Probe: How has it affected your physical health? Emotional health? Have you experienced any other problems? What about sleep interruptions?

How does providing care for orphans affect ones daily life: what tasks are involved in caregiving?

Probe: How has it affected your physical health? Emotional health? Have you experienced any other problems? What about sleep interruptions?

What are some of the issues involves in caring for orphans of AIDS

Probe: clothing/ health/ education/ food/ other

Probe: emotional distress due to loss of parents to AIDS

Probe: children face stigma, and discrimination

Can you describe your ordinary day?

Probe: what time do you wake up? When do you go to bed? Do you have a nap?

What do you do when caregiving clashes with parenting tasks?

Probe: what task do you prioritize and why?

In the case of older people caring for orphans what are the concerns of older people for the children they are caring for

Probe: that these children may someday become infected?

Who will care for these children should the older adult die

What do you believe to be some of the strategies that can be put in place to help meet the needs of children?

Probe: how can we help older people care for orphans?

Who do we harness to help care for orphans?

Do we provide money, goods, free services?

If you were to fall ill would you be able to get to health facility?

Probe: What are some the difficulties or barriers older people like you may face in accessing health services?

Are there any services or strategies in place that help to ease the burden of caregiving.

Probe: home based care programs

Activities done through community churches/ organizations

Government support

Are there any informal ways in which older people gain help in caring giving.

Probe: home based care programs

Activities done through community churches/ organizations

Community/ family/ friend support

What in your opinion can be done to ease the burden of the caregiver!

Probe: financial support from government, community/ family member

Social support from community/ church

Emotional support from community/ friends/ family

Spiritual support from religious organization

Physical caring from community groups/ church/ friends/ family

Other