

SUBJECTIVE QUALITY OF LIFE OF THE ELDERLY AFFECTED BY HIV/AIDS

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DECLARATION

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Dedication

**This thesis is dedicated to my dear friend, the late Sonia Alberta Cole, who has
always inspired me.**

(6 March 1960 – 15 November 2013)

Abstract

This research study investigated the effects of HIV/AIDS on the subjective quality of life of elderly caregivers. The purpose of the research was to develop an in-depth understanding of how HIV/AIDS affects the subjective quality of life of the elderly caregiver in multiple life domains.

A qualitative research design was used with a narrative approach to explore the lived experiences of elderly caregivers who are affected by HIV/AIDS. Semi-structured individual interviews were conducted to ascertain their experiences in providing care for family and community members affected by HIV/AIDS, and how their quality of life has been affected by their caregiving role. Data were analysed using thematic analysis and the adapted listening guide developed by Carol Gilligan. Through this process, the different voices of the participants were heard and used to establish the common themes.

The sample for this study was selected from Masiphumelele in the Western Cape, which has a high prevalence rate of HIV/AIDS. Purposive sampling was used to select 10 participants who care for relatives, friends, spouses and children with HIV/AIDS, as well as children orphaned due to HIV/AIDS. Fifty percent of the participants indicated in the course of the interviews that they were also infected with HIV.

It was found that the subjective quality of life within various areas within the participants' lives had been significantly affected by their roles as caregivers. The elderly caregivers found themselves having to take up multiple unexpected roles such as breadwinner, mother, father, grandmother and grandfather within their household. These new roles affected the elderly within multiple life domains, thus putting them at risk of experiencing a decreased quality of life. This compromised quality of life heavily affected the social, mental, physical and financial aspects of their lives.

Recommendations are presented to enhance the quality of life of the elderly who find their twilight years affected by having to cope with an extended caregiving role because of the effects and implications of HIV in their family and community.

Opsomming

Hierdie studie het ondersoek ingestel op die impak van HIV/VIGS op die subjektiewe lewenskwaliteit van bejaarde versorgers. Die doel van hierdie navorsing was om 'n dieper begrip te ontwikkel van hoe HIV/VIGS die subjektiewe lewenskwaliteit van bejaarde versorgers affekteer in verskillende aspekte van hul lewens.

'n Kwalitatiewe navorsingsontwerp is gebruik saam met 'n narratiewe benadering om die lewenservarings te ondersoek van bejaarde versorgers wie se lewens deur HIV/VIGS beïnvloed is. Semi-gestruktureerde onderhoude is met individue gevoer om hul ervaring te bepaal in die versorging van familie lede wie se lewens deur HIV/VIGS geaffekteer is, asook hoe hul versorgingsrol hul lewenskwaliteit geaffekteer het. Die data was geanaliseer deur gebruik te maak van tematiese analise en 'n aangepaste weergawe van die narratiewe metode voorgestel in Carol Gilligan se luister-gids. Deur hierdie proses is verskillende "stemme" van die deelnemers uitgeken, wat gebruik is om verskillende temas te bepaal.

Die steekproef vir hierdie studie was afkomstig van die Masiphumelele gemeenskap, geleë in die Wes-Kaap, waar daar 'n baie hoë HIV/VIGS voorkomssyfer is. Doelgerigte steekproefneming was gebruik om tien deelnemers te kies wat versorgers is van familie, vriende, eggenote en kinders wat HIV/VIGS positief is, sowel as weeskinders wat hulle ouers aan HIV/VIGS verloor het. Vyf van die deelnemers het ook in die loop van die onderhoudproses aangedui dat hulle HIV-positief is.

Daar is bevind dat die subjektiewe lewenskwaliteit van die deelnemers in verskeie lewensareas aansienlik geaffekteer is weens hul rol as versorgers. Bejaarde versorgers moet menigte addisionele rolle beklee soos die van broodwinner, ma, pa, ouma en oupa, binne hulle huishouding. Hierdie rol verandering het 'n nadelige uitwerking op die sosiale, psigiese, fisiese asook die finansiële aspekte van hul lewens. Die bejaardes wat as gevolg van HIV/VIGS menigte onverwagte rolle beklee, loop 'n hoë risiko om geaffekteer te word in verskeie lewensareas en om 'n verlaagde lewenskwaliteit te hê.

Aanbevelings word aangebied om die lewenskwaliteit van bejaardes wie se lewensgeaffekteer is deur die versorger rol as gevolg van HIV/VIGS in hul families en gemeenskappe, te verbeter.

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CHAPTER 1

INTRODUCTION

1.1. Introduction

Numerous studies have been conducted on the effects and impact of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS). HIV/AIDS has a devastating but largely unreported impact on older people (HelpAge International, 2014). This under-researched effect will invariably affect the quality of life of elderly caregivers as well. In 2010, an estimated 524 million people, constituting 8% of the total world population, were over the age of 65 years. This number is expected to increase, representing 16% of the world population by 2050, with less developed countries having the most rapidly expanding population of elderly individuals (World Health Organisation, 2011). The subjective quality of life (QOL) of elderly caregivers is likely to be affected by the AIDS pandemic in various domains of life. Research by Lekalakala-Mokgele (2011) indicated that HIV/AIDS has an impact on social, physical, economic and psychological domains in the life of the elderly. Analysis by Greener (2004) predicts rising levels of poverty for the elderly due to HIV/AIDS, with these elderly individuals having income levels in the lowest quartile of income distribution.

Fouad (2005) supports the above prediction, stating that the aged are a vulnerable group in most contemporary African societies; their quality of life is quite tenuous, often being dependent on many factors beyond their control. The concept *quality of life* is similar but not the same as life satisfaction. The latter refers to the subjective evaluation of the concept *quality of life* itself (Ventegodt, Merrick, & Anderson, 2003). This subjective view of the individual is very important in determining the quality of life. Every individual will have his or her own personal hierarchy of needs – as posited by Maslow in his model of human needs (Maslow, as cited in McLeod, 2007). These needs will differ from person to person depending on the individual's circumstances. These subjective needs can be understood as the relative needs of the individual and are influenced, enhanced or limited by objective needs. McLeod lists the needs of Maslow's

five level hierarchy as: biological/physiological, safety, love/belonging, esteem, and self-actualisation (Maslow, as cited in McLeod, 2007).

The elderly caregivers, who are not infected with HIV, may still be affected by HIV/AIDS in that they may have the burden of looking after people living with the disease. Such people could include their own children and/or grandchildren, as well as the orphans of the community. This role change has had a particularly negative influence on the elderly caregivers. That is, instead of the adult children taking care of the elderly as they enter their declining years (as per the norms of most communities and cultures), the elderly are now required to become caregivers and care for as well as provide various levels of support for their children, grandchildren and orphans infected with HIV/AIDS (Schatz, 2007).

Women are the most affected. This is because it is traditionally the woman's role to take care of the sick in the family (HelpAge International, 2002). This imposed caregiving role can be overwhelming for the elderly, putting strain on their own health and livelihoods and forcing them to contend with numerous demands such as coping with health care costs, and/or debts incurred as a result of HIV and AIDS-related illnesses of their dependants (HelpAge International, 2002). They are also burdened with the stress of taking care of the younger generation, which may cause emotional and physical problems resulting in poor health (Grobler, 2011), exacerbating or causing various age-related diseases (Schneiderman, Ironson, & Siegel, 2005).

Skovdal, Campbell, Madanhire, Nyamukapa and Gregson (2011) describe how grandparents across Sub-Saharan Africa play a significant role in the support and care of children affected with AIDS. In many South Africa communities, HIV/AIDS has been termed the "grandmother's disease" (Wilson & Adamchak, 2001), as the responsibility to care for orphans and infected family members has often fallen on the elderly grandmother. Makiwane and colleagues (cited in Lekalakala-Mokgele, 2011) propose that the epidemic has created an increased number of elderly female-headed households. Caring for children of sick adults puts huge pressures on older people. Bloom and Mahal (1997) noted that, historically, the cost of medical care for AIDS was higher than the cost of diagnosing other illnesses. However, in the last 18 years, great advances have been made in providing affordable universal access to treatment by

lowering costs considerably and making anti-retroviral medication (ARVs) freely accessible in public health facilities. Associated costs and opportunity costs such as transport to clinics or missing a day of work can still make HIV treatment expensive despite these advances (Avert, 2014). In becoming caregivers, the elderly must therefore sustain an income, nurse the sick, and care for the young, often at a high cost to their own livelihoods, health and well-being.

Philipson and Poser (cited in Bloom & Mahal, 1997) are of the view that because of the extent of the epidemic, the national income per capita has been significantly affected. This results in a negative impact on the national economic well-being (Bloom & Mahal, 1997). The elderly shoulder this added responsibility while concurrently contending with their own deteriorating health, low income, limited information and little support. The elderly caregivers struggle financially under these circumstances even more because their general disposable income is much lower due to being inactive in the working world (Schatz, 2007). Tshililo and Davhana-Maselesele (2009) argue that these elderly family members are therefore overwhelmed by their extended roles.

Most family caregivers often lack adequate education regarding the disease and its treatment (Tshililo & Davhana-Maselesele, 2009). Caregivers may not be informed on how to prevent contracting HIV/AIDS or how to provide care for infected family members who may be dealing with a range of debilitating symptoms. This is further exacerbated because of stigmatisation, which may lead to the loss of community support and isolation from their peers and their social network. However, workshops and other intervention methods can help alleviate these problems greatly by decreasing stigmatization as well as equipping these elderly caregivers with the skills needed to fulfil their roles (Boon et al., 2009). Caregivers often experience frustration as well as sadness because of the lack of support, both financially as well as socially (Tshililo & Davhana-Maselesele, 2009). As such, an examination of the elderly caregivers subjective QOL in these instances is essential to gauge the support, services and education they require in order to function as carers, supporters and teachers in the fight against HIV/AIDS, as well as in their caregiving capacities within their families and communities.

This research study focused on examining the impact of the burden on the elderly caregivers who are directly affected in their caring for HIV/AIDS affected family members and orphans in their communities. In this study, ages 50 years and older was used to designate this population group in alignment with the accepted definition of old age on the African continent (WHO, 2015). Age 50 is also associated with certain changes in biology and behavioural patterns (Chepngeno-Langat, Falkingham, Madise, & Evandrou, 2012). Despite the many studies focusing on HIV/AIDS, particularly in Sub-Saharan Africa, few have directed their focus at individuals aged 50 and older – that is, the elderly population (Dougan, Payne, Brown, Evans, & Gill, 2004).

1.2. Context of the study

The HIV/AIDS pandemic has attracted much funding and research interest but most of this has been devoted to those infected by the disease. The devastating effects of HIV/AIDS on the lives of the elderly providing care for loved ones living with the disease is generally not well-documented. Globally, it is estimated that more than 35 million people are now living with HIV/AIDS with 3.2 million being children, 2.1 million adolescents and 4.2 million over the age of 50 (United Nations Programme on HIV/AIDS, 2014). However, the elderly caregivers who are affected directly by HIV/AIDS are largely disregarded and the circumstances surrounding their plight as well as the attendant adjustments they have to contend with are under-reported. As the population with HIV/AIDS ages and larger amounts of the infected population grow older, research has shifted to studying the epidemiology of the elderly affected by HIV/AIDS, co-morbidity with age-related ailments as well as the interaction of ARV's with other chronic medicines (Nguyen & Holodniy, 2008). Most of these studies are medical by nature and few consider the emotional and psychological aspects of the problem for the elderly caregivers. Moreover, there is sparse research focusing on the impact on the elderly caregivers' quality of life while affected by HIV/AIDS. Given the indications that a staggering 24.7 million people living with HIV/AIDS are living in Sub-Saharan Africa and of these, 25% in South Africa (UNAIDS, 2014), the elderly caregivers are likely to shoulder the responsibility for the burden of care in their families.

1.3. Rationale of the study

It is clear that there are devastating effects of HIV/AIDS on families. However, little has been directed at how this impacts the elderly family members in particular. It is clear that a distinction needs to be made between the elderly caregivers infected with HIV/AIDS and the elderly caregivers affected by HIV/AIDS. The elderly infected with HIV/AIDS are individuals older than 50 years who have been diagnosed with HIV. This is supported by May (2003), who suggests that the age of 50 and older should be used to separate prime-aged adults from the elderly. For the purposes of this study the elderly caregivers are understood as being affected by HIV/AIDS when they carry the burden of caring for relatives, friends, spouses and children who are HIV or AIDS positive, as well as children orphaned due to HIV/AIDS. Masanjala (2007) argues that the AIDS epidemic is creating new poverty by increasing the risk of economic failure and adding greater financial pressure especially at times when state support systems are collapsing. Furthermore, the process of obtaining grants for orphaned grandchildren can be a cumbersome and lengthy process. It is therefore clear that the epidemic has a great impact on countries; affecting individuals, businesses thereby reducing economic growth and increasing poverty (Masanjala, 2007).

At the micro-level, HIV/AIDS has a negative psychological impact on the well-being of the infected and affected elderly (Lekalakala-Mokgele, 2011). The physical health of older people in both circumstances may deteriorate, which may accelerate the onset of chronic diseases. Psychological effects, without the appropriate social support structures in place, may result in an emotional burden and depression, thus leading to a deterioration of the elderly individual's mental health (Lekalakala-Mokgele, 2011). More research is needed to understand the psychological burden experienced by the elderly caregivers as they struggle to cope with these drastic adjustments to their QOL when affected or infected by HIV/AIDS.

The care and support of adult children and orphans, in most cases, falls on the elderly caregiver (Lekalakala-Mokgele, 2011). As such, it is imperative to include the elderly in their role as carers and teachers to assist in halting the spread of HIV/AIDS (HelpAge International, 2002). Therefore, research that explores subjective QOL is essential in order to understand the experiences of the elderly caregivers affected by

HIV/AIDS. Such a study can contribute to a broader understanding of the strain on the psychological coping skills of the elderly caregivers, the impact on various aspects of their QOL, and on professionals' knowledge of and capacity to improve the lives of the elderly caregivers, including various levels of support that they may need. Krause (2007) suggests that knowledge of the factors that influence life satisfaction and the quality of life will allow appropriate measures to be taken in order to assist the elderly caregivers to cope with traumatic and life changing experiences. The research will assist the elderly to deal more effectively with the additional social, physical, environmental and psychological impact of HIV on their lives and the lives of their loved ones, as they grow older. Due to this, the current study will examine the following research question: How does HIV/AIDS affect the subjective QOL of the elderly caregivers directly affected by the HIV/AIDS pandemic in their immediate family in multiple domains?

1.4. Aims of the study

The aim of this study was to examine the impact of HIV/AIDS on the subjective quality of life of elderly caregivers in multiple life domains.

1.5. The objectives of this study

The aim of this study was realised through the following objectives:

- To gain insight into the experiences of elderly caregivers affected by HIV/AIDS
- To identify how the quality of life of elderly caregivers who are affected by the HIV/AIDS pandemic is compromised.
- To identify how the elderly caregivers can be supported to improve the quality of life in their communities.
- To identify how community NGO's can better support the elderly caregivers to improve their quality of life

1.6. Research questions

The primary questions that directed the focus of this study are:

- What are the experiences of the elderly who are affected by HIV/AIDS?

- How is the quality of life of the elderly affected/compromised by the HIV/AIDS pandemic?
- In what ways, could communities support the improvement of the elderly's QOL?

1.7. Overview of the chapters

This thesis has been structured into five chapters with two additional appendices detailing information supplementary to the study. The thesis structure is as follows:

Chapter 1: This chapter presented the introduction and background of the study, the main aim and specific objectives, as well as the study's research questions.

Chapter 2: This chapter comprises the literature review pertinent to the study, which focuses on QOL, domains of life affected by HIV/AIDS, HIV in South Africa, caregiving and HIV, and caregiving costs. The theoretical perspectives of QOL, role strain theory, quality of life models and the Systems Theory approach to quality of life, follow this.

Chapter 3: In this chapter, the research design, sampling procedure, method of data collection, data analysis procedures (including the adapted Gilligan method (2003)) and ethical considerations are described.

Chapter 4: This chapter presents the findings of the research.

Chapter 5: This final chapter provides an integration of the findings and literature. The implications of the findings for research, theory and application are discussed. This chapter also includes concerns, recommendations and limitations of this study.

CHAPTER 2

LITERATURE REVIEW

2.1. Introduction

This chapter will explore the literature that underpins this study. The following elements will be covered: a history and definitions of Quality of Life, including subjective and objective quality of life measurements; the challenges of HIV/AIDS within the South African context, caregiving in the context of HIV/AIDS, as well as the experiences of the men and women providing care and support to those living with the disease. Also included will be the caregiving burden and its financial, as well as psychosocial impact including stigmatisation and discrimination.

The theoretical framework pertaining to this study will also be discussed. This includes the quality of life models as well as the various domains of life affected by HIV/AIDS - namely health, economic, gender, and education, social and psychological domains. Role strain theory will also be discussed as well as the Systems Theory approach to quality of life.

Although the literature presents these themes in a variety of contexts surrounding the topics of caregiving, HIV/AIDS and quality of life, this research paper will primarily focus on the subjective quality of life of the elderly caregivers affected by HIV/AIDS.

2.2. History of Quality of Life

As a population ages, there are anticipated tasks, activities and adjustments that characterise the last psychosocial developmental stage. In relation to the working life of ageing adults, this period is generally characterised by deceleration, where plans are made in preparation for the shift into retirement. In South Africa, the retirement age is around 65 in the formal work sector and this transition is regarded as one of the major life course transitions of late adulthood (Louw & Louw, 2011). The retiring person has “put in” her/his time and now prepares to relax and enjoy her/his twilight years. During this stage, a strong social network is important and people tend to limit their social interactions to people with whom they have built relationships. They fall back on the

social networks they have built and tend to spend less time with people they do not already have close ties with (Louw & Louw, 2011). Leisure time becomes more available during this life phase following retirement. Older adults generally prefer less physical leisure-time activities done in smaller groups than their younger counterparts do. Leisure time greatly contributes to the general well-being of elderly individuals and to their perceived levels of stress relief and life satisfaction (Louw & Louw, 2011).

However, in the wake of the HIV/AIDS pandemic, a major public health challenge that threatens quality of life of the remaining years of the elderly and their role in the family has silently emerged (Bowling, Hankins, Windle, Bilotta, & Grant, 2013). The term *quality of life* is used in daily semantics as well as in the context of research fields such as sociology, psychology, medicine and nursing, economics, philosophy, history and geography. The advances in technology in the 20th century have led to many medical developments, including kidney dialysis, organ transplantation, and the advent of anti-retroviral therapy (ART). The latter has increased the lifespan of HIV/AIDS sufferers (Farquhar, 1995a). However, quality of life has been a subject of contention. Watts (1970) contends that the advances in technology may be seen as a double-edged sword in that, while they have improved quality of life through increased life expectancy and more accessible economic resources, they can also be understood to have had a potential negative impact on quality of life. Technological advancements have extended the potential life span of the ageing adult, but the same advancements have seen society become increasingly plagued by the implications of over-population, social unrest, an upsurge in crime, illicit drug use, broken families and social alienation (Armstrong & Caldwell, 2004).

After the end of World War II, the term 'Quality Of Life' (QOL) was generally used in reference to material possessions such as cars, houses and money (Alexander & Willems, 1981). Political and social upheavals in the 1960s focused on personal freedom, leisure, emotion, enjoyment, simplicity and personal caring. As a result of this shift in value systems, the term evolved to imply that 'the good life' was predicated on more than simple material affluence (Campbell, 1981). American politicians who promised their constituents that they would improve their quality of life within their socioeconomic status (Schalock et al., 2002) also appropriated the term. Since the

1970's, quality of life was studied extensively in the field of medicine, resulting in a variety of measurement instruments and models (Coulter, 1997). Literature is rich with studies that examine relationships between a variety of impairments and their impact on a person's perceived place in the world (Bishop et al., 2002). Continuous advances in technology have led to longer life expectancy, and research regarding how quality of life can be improved as a result has also dramatically increased.

While this subject has been extensively researched, researchers have not come to an agreement on a definition of 'quality of life'. Arguments have been made that the construct is simply too subjective (Taylor & Bogdan, 1996), while others tend to focus more upon objective factors. The emphasis in current research is shifting towards a more balanced and multidimensional view of the construct, where both objective and subjective factors receive equal consideration. Mandzuk and Macmillian (2005) contend that subjective and objective measures are essential to conduct quality of life research. Subjective measures of assessment incorporate the subjective affect regarding key factors that affect perceptions of quality of life. Factors that include livelihood assets, strategies of livelihood, vulnerability within the context of transforming structures and processes are important in subjectivity (Masanjala, 2007). Objective measures of assessment emphasise factors that influence quality of life. Quality of life can be measured globally in terms of life satisfaction as a whole, or with reference to multiple domains of life. The basic assumption underlying domain measures is that the assessment of life domains such as personal, social and psychological domains, can contribute to global life satisfaction for the individual. Satisfaction within an increased number of domains commonly leads to an increase in the global quality of life (Campbell, Convers, & Rogers, 1976).

Adult ageing often involves common life-changes that are benign. However, for some, ageing is also associated with a loss of function, leading to increased susceptibility to disease, feebleness, and incapacity. Bowling et al. (2013) note that ageing, which may also bring chronic illness, can have an adverse impact on broader QOL. Natural ageing involves dynamic biological, physiological, and psychosocial processes and systems that result in wide variations in experience between individuals. Some elements of the ageing process are believed to decrease the quality of life

(Williams, 1977), but with the correct information and appropriate forms of support, the effects of ageing can be managed. When elderly caregivers need to care for the sick and orphaned, the pressure from such responsibility can have a detrimental effect on their health and well-being (Stock, Okun, & Haring, 1983). Quality of life has been assessed for various groups of people but historically only a small proportion of research focused on older people (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). Research that is more recent has shown that no reliable method for measuring quality of life among the elderly currently exists and that this gap in the research has not yet been thoroughly addressed (Birrin, 2014).

2.2.1. Definitions of QOL

Quality of life is a concept commonly referred to in everyday language. As mentioned, a wide spectrum of connotations has been attached to this concept, which has resulted in a variety of definitions and models to conceptualise it. According to Bowling et al. (2013), QOL is a subjective concept and, therefore, its measures must be socially relevant. Although it has its origins in health and politics, it is now used widely over a broad range of fields such as economics and environmental science, each providing specific meaning and focus to the concept. According to Schalock (2000), there are over one hundred definitions of quality of life, proving its subjective nature. Brown, Chen, Christianson, Lee and Stark (1994) define QOL as that dynamic interaction between external conditions of a person's life and the internal perception of those conditions. Farquhar (1995a) further adds that when considering the issue of QOL, both good and bad aspects need consideration. The World Health Organisation defines quality of life as:

...an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of the environment. (WHO,1995, p.1)

Farquhar (1995a) identifies three major types of QOL definitions. These are: (1) general or global definitions, (2) definitions that break the concept down into a series of component parts or dimensions, and (3) focused definitions where only one or two of the component parts identified in definition 2 are recognised and focused on. Global definitions are the most general in research. However, there are very broad definitions that may overlook certain possible components of QOL. QOL, in its most basic parts, consists of multiple dimensions or domains that should be considered to evaluate the overall concept. The context of QOL can be further divided into two separate categories. The non-research specific context categorises QOL into various objective and subjective domains. The second category is where research-specific component definitions are used. That is, the definition adopted reflects the researcher's considered, specific focus in the particular QOL research (Farquhar, 1995a). In this instance, potential dimensions of QOL may be overlooked or excluded from the definition because they are considered less pertinent to the research focus. The third approach to understanding QOL definitions relies on focused definitions, which are overtly or covertly expressed or perceived and could refer to one or many domains of QOL. Explicitly focused definitions originate mostly from research specific to the field of health where the focal point is on a select number of factors considered crucial to QOL. Contrary to this, implicitly focused definitions focus on one or two components of the concept without stating it explicitly (Farquhar, 1995a).

QOL research has produced a variety of definitions that encompass the following:

- Subjective factors that can be measured, including life satisfaction and happiness. These factors can be affected positively or negatively depending on the perceptions of an individual about their own life.
- Objective external factors can also be measured. These would include physical health, psychological state, level of independence, family, education, wealth, religious beliefs, a sense of optimism, access to local services and transport, employment, social relationships, housing and the environment.
- Further areas of study within quality of life can include cultural perspectives, values, personal expectations and goals as well as the interpretation of facts, events,

and choices; the level of acceptance of life condition, and our ability to manage thoughts and emotions about that condition are also key (Barcaccia, 2013).

Due to the above, a multidisciplinary approach is required to encapsulate a balanced perspective of the concept.

2.2.2. Subjective and objective measures of QOL

Subjective measures of quality of life focus on the perceived life satisfaction of the individual. It can be measured using both domain-specific as well as global life aspects (Sheppard-Jones, 2003). The critical element of the subjective approach is that it is concerned with the individual's unique understanding. Whereas a subjective approach focuses on individualised experiences, the objective component of quality of life can be measured using basic domains of life related to the human-environmental interaction such as safety, health, and shelter. This is also closely linked to socio-economic or demographic components, which includes some recognition of personal experience as well (Sheppard-Jones, 2003).

Researchers have come to a consensus concerning the importance of combining objective and subjective characteristics of QOL in order to enhance the strengths and alleviate the weaknesses of each method. Objective and subjective approaches should be regarded as equal, as both approaches are considered equally important within the measurement of QOL (Delhey, Bonhnke, Habich, & Zapf, 2002). Many models incorporate both objective and subjective domains of QOL (Cummins, 2000; Hagerty et al., 2001). Schalock (1996), however, contends that potential QOL indicators that can be assessed from a subjective or objective perspective should be chosen.

Within each field, there are various meanings and understandings attributed to QOL that need to be taken into consideration in order to create a comprehensive understanding of QOL. Detailed knowledge of how subjective factors are affected by objective conditions is required. Similarly, an in-depth understanding of how objective factors influence people's perception of their well-being is also necessary (Diener & Suh, 1997). However, the aim of this study correlates strongly with suggestions from researchers such as Krause (2000), who suggests that knowledge of subjective life

satisfaction and self-rated quality of life will allow appropriate measures to be formulated in order to assist the elderly. In the theory of subjective well-being, Cummins (2000) explains the relationship between subjective and objective factors in terms of a homeostatic relationship. He postulates that subjective and objective QOL are independent. Subjective QOL is required for survival. Human beings have developed a sense of positivity that allows them to maintain constant levels of satisfactory subjective QOL within a considerable range of objective conditions. Objectively, only when QOL reaches extremely low levels, such as long-term unemployment, is this homeostasis disrupted and subjective QOL decreased (Cummins, 2000). In this view, objective and subjective QOL are said to be mutually dependent, but this process is also influenced by cultural and individual values that should be systematically explored (Cummins, 2000).

Lekalakala-Mokgele (2011) discusses the social, physical, economic and psychological domains of the lives of the elderly, and these domains are spotlighted in the discussion of narratives. In this way, the narrative method foregrounds the understanding of QOL from the subjects' own revelations of their psychosocial lives.

In this study, QOL is understood as the general level of health, comfort, and happiness experienced by the caregivers affected by HIV/AIDS. This study specifically looks at quality of life through the subjective experiences of the participants. The domains pertaining to quality of life specifically looked at in this study are the social, spiritual, mental, physical and financial domains

2.2.3. Challenges of HIV/AIDS within the South African context

HIV/AIDS invariably impacts on the QOL of the person infected by the disease and on the QOL of family members affected by the disease. It is estimated that 12.2% of the population (6.4 million persons) in South Africa were HIV positive in 2012, with this figure having increased by 1.2 million (a 10.6% increase to 5.2 million) since 2008 (UNFPA, 2014). The age group 25-49 carries the highest HIV/AIDS prevalence at about 25% followed by those over 50 with a prevalence of 7.6%. A higher percentage of females are HIV positive, with the highest prevalence of 36% in the age group 30-34 years (UNFPA, 2014). There was also a slight increase in the recorded number of

orphans from 2008 to 2012, from 3,032,000 in 2008 to 3,132,041 in 2012. The Western Cape carries 5% of the total burden of HIV/AIDS in South Africa (UNFPA, 2014).

The HIV and AIDS epidemic has become one of the most important social and public health challenges in South Africa. The high infection rates place a heavy burden of care on the health care system and on society. Healthcare services are often unable to care for the increasing number of patients. Due to this, families become responsible for taking care of their sick and terminally ill relatives at home (Ndaba-Mbata & Seloilwe, 2000). Younger people infected with HIV often return home at the end stage of their illness to be nursed and to eventually die in the home of their older family members (Ssengonzi, 2007; 2009). For adults in South Africa, between the ages of 15-49, the prevalence of infection is approximately 16.8% (Statistics South Africa, 2014). Should HIV infected parents in this age group eventually become terminally ill and die, any children orphaned would be left to be cared for by the community and extended family members. Increasingly, older people are assuming responsibilities for raising orphans and bearing both the costs and demands of care (HelpAge International, 2004; Ssengonzi, 2007; World Health Organisation (WHO), 2002).

2.2.4. Caregiving in the context of HIV/AIDS

As aforementioned, the HIV and AIDS epidemic has led to an unexpected role reversal and a resultant deterioration in the well-being of older people (Seeley, Wolff, Kabunga, Tumwekwase, & Grosskurth, 2009). The burden of care has moved to a situation of increased responsibility coupled with a loss of security for the elderly caregivers. For the purposes of this study, the care-taking process experienced by the elderly caregivers consists of taking care of patients receiving HIV/AIDS treatment and orphaned children of parents lost to AIDS. An important element in the caregiving process is physical strength. (Viennese Ethnomedicine Newsletter (VEN), 2010). Elderly caregivers, however, may lack the necessary strength due to their age and this frailty can be further exacerbated by the caregiving process as well as physical illnesses associated with old age (Draper, Poulos, Poulos, & Ehrlich, 1996). In order to perform the physical chores required by their caregiving roles (such as nurturing and physical care of grandchildren -including picking up small children, and maintaining discipline),

physical strength is required. Working for the attainment of income also requires strength. Family relationships can become strained as younger adults can only assist the elderly caregivers within a limited capacity given their illness. Having to care for patients and grandchildren can cause added physical and emotional strain for the elderly caregivers. This is in addition to health deterioration as a result of the natural ageing process (VEN, 2010).

The future for the elderly caregivers becomes uncertain and fraught with anxiety due to sickly middle-aged adult relatives returning home for care, adding more financial and physical strain rather than relieving pressure with possible aid. The ageing process of older people, together with the impact of the loss of physical strength, is particularly exposed within the context of families overburdened by AIDS and these circumstances emphasise older caregivers' limited physical capacity to provide care (VEN, 2010). In such cases, care of sick relatives and family members predominantly takes place in the home (UNAIDS, 2013). This is often due to the lack of a public policy addressing care needs, inadequate health infrastructure, and preference by patients (VSO, 2006).

The costs of care are mostly borne by households and individuals and very often by the underprivileged, the non-governmental sector, volunteers in home-based care programmes, caregivers in the home, and the private sector. The non-financial cost of care is not clearly known and is not accounted for by governments in national policies that affect public health and the economy. Insufficient attention has been given to the physical, emotional and economic needs of the caregivers who assume these heavy responsibilities, and are often underprivileged and living with HIV (O'Mara, 2005).

Caregivers for people living with HIV in Africa are often women. Women comprise 70% of the world's underprivileged population and two-thirds of the world's illiterate. Older women and married women are significantly affected (UNAIDS, 2008a). The duty of care often falls on women and older married women. This is particularly true in cases where a large proportion of people living with HIV and AIDS move back to their homes to be cared for by their parents and relatives while simultaneously looking after their grandchildren (Saengtienchai & Knodel, 2001). In this context, care refers to the care for people living with HIV and AIDS as well as the care provided to those children, relatives and friends affected by HIV and AIDS. The carers often have to take on multiple roles

and require skills and strategies to deal with these roles (UNAIDS, 2008a). The caregivers who care for orphaned children will likely become the main providers of their emotional, material and financial support. Carers taking care of adults infected with HIV/AIDS provide emotional support, physical and nursing care, as well as economic support in some cases (Homan et al., 2005). The important needs addressed by various forms of caregiving, in the context of HIV, include physical care, financial assistance and emotional support. Physical care could include bathing, eating, and dressing, as well as fetching water and gardening, pain management, treating wounds, and supervising medication. Financial assistance includes the providing of transport and food and this financial family carers most often provide assistance (UNAIDS, 2008a). Primary caregivers must often contend with hospitals and administrative and governmental offices in order to carry out the necessary administrative paperwork to cover benefits. Caregivers are also often involved in arranging for burials, death certificates, and inheritance issues.

Oftentimes, older caregivers (both men and women) are at a stage in their lives when they expect to be cared for by their children. They seldom have the emotional, financial or physical resources to maintain their newly acquired roles and responsibilities (Homan et al., 2005). Physical infirmities affect many older caregivers, including strained muscles, diabetes, fatigue, arthritis, high blood pressure, hearing, vision and mobility problems (Knodel, 2001). These factors, in particular, play a major role in determining the perceived QOL.

According to Skovdal et al. (2011), since 2009 there has been a drastic increase in the availability of anti-retroviral therapy (ART) in Sub-Saharan Africa can potentially decrease the HIV-related burden of care as it enables people living with HIV to remain healthy and productive for longer and to provide for their own children (UNAIDS, 2008b). In 2010, most countries agreed that by 2015 they wish to provide 15 million people with ART. The general aim was to provide 80% of people in need with ART. By 2014 these joint nations reached 65% of people (Avert, 2014). Maher (2008) has suggested that historically, the impact of HIV treatment, including co-morbidities and side effects, could present long-term challenges for both informal carers and the health

sector. Despite this, since 1995 ART treatment has added 14 million life years, 9 million of which were in Sub Saharan Africa, to middle and low income countries (Avert, 2014).

Adherence to ART and its availability is thus of the utmost importance to people suffering from HIV/AIDS. Skovdal et al. (2011) indicated that the elderly, merely because of their living arrangements and their subsequent emotional attachment, have become the best treatment partners, especially for children infected with HIV.

2.2.4.1. Women providing care

The effects of care giving significantly impact married women. Research has shown that care usually takes place in the family and in the home and it is often that the carer tends to be the wife or the mother (Knodel, 2001). Men seem to be more discrete about their HIV status and do not readily seek external support, relying instead on the commitment and discretion of their wives for care (Corby, O'Farrell, Podmore, & Sepúlveda Zelaya, 2007). Tshililo and Davhana-Maselesele (2009) cite issues such as the threat of losing health, income, work and relationships as reasons for such discretion.

The consequences of caregiving go beyond the emotional issues. The physical labour of caring for sick family members and orphans can be detrimental to their health. Physical tasks such as lifting patients, washing patients, helping patients to the toilet, cooking, cleaning, doing the laundry, and farming often fall primarily on females (Corby et al., 2007). Thus, the elderly guardians might not be physically strong enough (Skovdal et al., 2011). The physical, psychological and social impacts of caring on a woman's well-being are seldom recognised and they often ignore their own health difficulties while caring for others (WHO, 2003). Tshililo and Davhana (2009) have highlighted how the responsibility of providing care can be overwhelming, and counselling, support, as well as training are needed for the family members who become the caregivers.

Inadequate information and education concerning HIV/AIDS increases the risk of exposure to contagious and opportunistic infections. Uneducated caregivers can suffer from distress due to the fear of HIV infection because of misinformation about the risks

of contracting HIV (Saengtienchai & Knodel, 2001). There are also caregivers who are living with HIV who have health concerns of their own (Pirragli, Bishop, & Stein, 2005).

Older women's plight is further exacerbated by age discrimination, low levels of literacy and education, all of which hinder their ability to earn an income (HelpAge International, 2007). These women are often left at the mercy of the state, living primarily on social grants and having to use this to support those in their caregiving role, thereby leaving them side-lined. This may also lead to reduced social activities and interactions because of the fear of negative community reactions (Leklakala-Mogkele, 2011).

2.2.4.2. Men providing care and supporting AIDS

The majority of the burden of caring for those living with HIV and AIDS is borne by women. A fewer number of men provide care in the home and volunteer in home-based care programmes. Research on the contributions of men in volunteer programmes, caring in the home and in supporting women who provide care, is limited (Ogden, Esim, & Grown, 2006). Traditional gender norms result in more women providing care and these norms can create barriers to men and boys becoming caregivers (VSO, 2006). In many cultures, it is traditionally regarded as unacceptable for men and boys to provide care, which may cause it to be underreported. This has a high prevalence in Sub-Saharan Africa (VSO, 2006). Strong cultural beliefs surrounding the division of labour force men to remain within the socially constructed gender division of labour. Within such traditional belief systems, men are seen as the primary breadwinners in the home and are therefore understood to be unable to devote their time to care for the sick and/or the orphans (Saengtienchai & Knodel, 2001). Women were more available for research purposes as they are traditionally seen to be the caregivers while men want to be identified with roles that are more masculine. Women also tend to be more intimate and self-disclosing and men more reserved (Louw & Louw, 2011).

Some research does evidence men as primary caregivers in the household as well as the financial provider. Women speak of men engaged in tasks such as providing transportation, lifting or carrying the frail and sickly. Men may play a lesser role in routine care, but their role is no less important when special tasks are required. There is

little data on the role of men in caring for children. This said a survey conducted by Ogden and colleagues (2006) found that older, more than younger men, take in orphaned or vulnerable children. This current research paper also attempts to explore the role of male and female caregivers, however, no male caregivers were found during the recruitment phase of the study.

2.2.5. The caregiving burden

The following section aims to develop a more complex understanding of the concept of the caregiving burden. The elements of financial burden, psychosocial impacts of caregiving, and the stigma and discrimination associated with caregiving are discussed.

2.2.5.1. Financial burden

There are increased financial costs related to caring for the sick, which further deplete the already limited resources in poverty-stricken households. These costs range from the cost of providing immediate care to financial expenditure on medicines such as prescribed and over-the-counter medicines, treatment by clinical therapists or traditional healers, transportation costs involved with attending clinics, and food costs. Anti-retroviral therapy is freely available but transport costs to clinics to collect medicines remains an obstacle, which may negatively affect adherence to the treatment (Ogden et al., 2006).

Women are often undervalued in the caregiving role, which forms part of the uncompensated work that they perform. In developing countries, women produce a large percentage of the food and are often involved in agricultural work. The burden of care is time-consuming, which can be seen as distracting them from the latter named productive tasks (UNAIDS, 2005). In caregiving households, caregivers will likely spend fewer hours working and more time in caregiving or alternatively, increase their work hours to pay for increasing expenses. In these families, women usually have to spend more time at home in a caregiving role because they earn a lower income and therefore have to sacrifice their careers in order to take on a caregiving role (Saengtienchai & Knodel, 2001). The caregiving tasks that they perform as well as the costs of caring are seldom factored into HIV and AIDS policies, planning and research (Ogden et al.,

2006). Many households in South Africa rely on social grants, as unemployment is very high (Homan et al., 2005). Access to social grants (such as foster-care grants) can be challenging when guardians cannot locate their dependants' remaining living parents in order to obtain the required signatures on the documents or they might lack their own necessary documentation required to register. Furthermore, economic pressures from the burden of care can lead to sexual risk-taking by carers of all ages thereby increasing their susceptibility to HIV infection. Such risk-taking activities include engaging in income-earning activities and survival strategies such as engaging in transactional sexual exchanges (UNAIDS, 2008a)

2.2.5.2. Psycho-social Impacts of caregiving

The emotional distress endured by carers can be substantial (VEN, 2010). Caring for several children of relatives and neighbours will likely intensify the level of poverty in the household, which may increase their level of worry and anxiety because of greater resource requirements. Many carers have to care for loved ones while also coping with their own declining health. This is a traumatic and stressful experience for the caregivers who may themselves be living with HIV/AIDS. In many cases, caregivers do not have the time to grieve for those they have lost as they have to support and care for dependants left behind (Knodel et al., 2002). Caring can be very demanding on their time and energy and carers may then not become involved in social activities. Older women and men looking after grandchildren cannot always easily return to the role of parenting as they may have expected to be cared for by their adult children (Homan et al., 2005).

2.2.5.3. Stigma and discrimination

The impact of stigma and discrimination towards those on anti-retroviral therapy is still widespread in many communities. Studies have found significant amounts of people who believe that people using ART are a threat to society and are spreading HIV/AIDS. There is also a strong link between the level of education and such forms of discrimination (Agnarson, Levira, Masanja, Ekström, & Thorson, 2013). Fearing discrimination, many people who are HIV positive do not want their status disclosed. As

a result, the caregiver and patient experience increased isolation. Caregivers are often wary of discrimination and stigma associated with caring for those with AIDS. Consequently, they tend to keep the status of those in their care a secret. Due to a lack of education and awareness programmes to address and prevent discrimination and stigmatisation, carers of people with HIV/AIDS are often assumed to be infected with HIV as well (Tshililo & Davhana, 2009).

The stigma surrounding HIV/AIDS is rife where there is inadequate knowledge of the cause and spread of HIV (Tshililo & Davhana, 2009). Perceived and actual stigma as well as a fear of the consequences thereof often results in carers choosing not to utilise the available support for the people they care for. This further discourages and prevents them from improving their knowledge of HIV and AIDS (Saengtienchai & Knodel, 2001). Many people living with HIV, including caregivers, fear their HIV status will be revealed by healthcare workers and that this would expose the caregivers to the possibility of discrimination. The consequences of these fears are that people will be discouraged from testing or seeking professional help, which could result in an increase in HIV and AIDS infection rates within the community (Saengtienchai & Knodel, 2001).

THEORETICAL FRAMEWORK

Various theories that inform the framework of this study are discussed below. These are the Quality of Life Models, Role Strain Theory, and Systems Theory approaches to quality of life.

2.3. Quality of Life Models

Zissi, Barry and Cochrane (1998) contend that, regardless of the growing importance of the QOL subject, the theoretical conceptualisation of this construct remains poorly developed. It is also important to note that the concept of QOL is ever evolving. The availability of social and economic indicators helps to give guidelines to the nature of QOL. QOL reflects micro-societal and socio-demographic influences but as it is subjective. It is also dependent on varying interpretations and perceptions (Gabriel & Bowling, 2004). Numerous researchers have identified various domains of life that have evolved into QOL models through which the construct is measured. These

researchers have drawn from a broad range of disciplines when examining the core QOL domains.

Schalock and associates (Schalock, 2000; Schalock et al., 2002) have proposed eight core dimensions in a theoretical model of QOL. Drawing from early research, they proposed a model based on the following domains: economic well-being (ownership, employment), physical health (health care, mobility), emotional well-being (safety, positive feedback), interpersonal relationships (friendships, interaction), social inclusion (support and participation) personal development (education), self-determination (choices, personal control) and rights (privacy, ownership). These domains are applicable to and are measurable for a wide range of people.

A model that emphasises subjective experiences, that influence the quality of life, has been proposed by Pearl (2011). Quality of life is measured by exploring the subjective experiences of the individual in the specific domains of life. Subjective QOL is measured across social, economic and physical domains. Lee (2008) concurs that QOL is subjective and should be measured by investigating perceived experiences of individuals within specific life domains. The World Health Organisation QOL Assessment comprises 6 domains. These include physical, environmental, social relationships', psychological, level of independence and spiritual domains (WHOQoL Group, 1993).

Hagerty et al. (2001) propose seven domains based on a review of 22 of the most frequently QOL indicators from around the world. They researched QOL in the field of economics and explored QOL as a social indicator. They extracted the following core domains: health, material well-being, feeling part of one's local community, work and productive activity, emotional well-being, relationships with family and friends, and personal safety.

Cummins (2000) also proposes seven similar core domains based on a review of 27 QOL definitions (researched in the field of disability). In his research he also produced these seven core domains: health, material well-being, community well-being, work/productive activity, emotional well-being, social/family connections and safety. It is clear that there are an infinite number of combinations of QOL core domains to be derived across a number of disciplines. However, there are core domains shared

amongst the disciplines. QOL, within research, should not be viewed as a construct that can be used to assess people in general. It is contended here that QOL is a specific term that should be adapted to suit a specific field. Due to this, in this study, QOL measures are established primarily through subjective data and personal revelations. Measures are then interpreted through an adapted method and placed alongside the domains highlighted in the literature review.

2.3.1. Domains of life affected by HIV/AIDS

The QOL of the elderly caregivers affected by HIV/AIDS affects multiple domains of life. The following domains of life are included in the theoretical discussion: health, economic status, social interaction (with particular focus on gender roles), level of education and social domains. Masanjala (2007) argues that the hard-hitting effects of HIV/AIDS have great potential to cause future collapse of livelihoods and thus have economic consequences. Bowling et al. (2013) also cite social capital and civic engagement as having a bearing on the different QOL domains in the elderly.

2.3.1.1. Health domain

Elderly caregivers are faced with their own declining health and ageing. As a result, the elderly may not be in a position to take care of adults, children and orphans in their care (HelpAge International, 2002). Elderly caregivers who take on the caregiving role are also likely to experience declining health due to the physical care of family members infected with HIV/AIDS (Ssengonzi, 2007). It has been reported that the elderly affected by HIV/AIDS are more at risk for declining health and decreased ability to perform in their daily lives than their HIV infected counterparts (Nyirenda et al., 2012). Not only is the physical health of the elderly at risk, their psychological health can also be affected. It has been reported that the elderly affected by HIV/AIDS suffer from pain, depression and weight loss (Ssengonzi, 2007). The elderly have been reported to suffer the physical impacts of looking after other adults due activities such as lifting and washing them. This has manifested in back pain, leg pain and even chest pain (Lekalakala-Mokgele, 2011). The state of health impacts directly on quality of life, that is, on the elderly's well-being and life satisfaction (Cavanaugh & Blanchard-Fields, 2011).

Research has shown that there is reduced functional ability in HIV positive elderly people, thus decreasing their functional independence and influencing their ability to age successfully (Levett, Wright, & Fisher, 2014). Food insecurity is also found to be prevalent in elderly caregivers' households and the caregiving responsibilities intensify the already compromised nutritional status of the elderly (Charlton & Rose, 2001; Nyanguru, 2003).

2.3.1.2. Economic domain

The associated costs related to HIV/AIDS can become very expensive (Avert, 2014). The HIV/AIDS pandemic has caused an increased financial burden on the elderly caregiver because they are compelled to take care of an increased amount of sick adults and affected dependants (Nel, 2004). Research by Lekalakala-Mokegele (2011) has shown that elderly caregivers, who are the least economically productive members of society, in many cases shoulder financial responsibility for sick relatives and orphaned grandchildren and yet do not have any secure financial support. The elderly caregiver must then cope with various costs associated with HIV-related illnesses as well as travelling, medical (Ssegonzi, 2007), and funeral costs; school fees, rising debt and even costs of visiting traditional healers (Nel, 2004). Often, extended families are not in a position to help caregivers (Lekalakala-Mokegele, 2011). It has been reported that greater wealth is strongly related to better quality of life (Nyirenda et al., 2012). This means that the elderly, who now carry the added financial responsibility as caregivers, are likely to have a poorer or diminished quality of life. In this regard, Kakwani and Subarao (2005) refer to the poor elderly who may receive pensions. Unfortunately though, their financial situation is still severely affected. It is likely that this unexpected role reversal will have broad ramifications on other aspects of QOL for elderly caregivers

2.3.1.3. Gender roles

According to Masanjala (2007), across Africa, gender roles will be affected by the prevalent socio-cultural norms and often these norms embed significant disparities in the power afforded to men and women. In many cases, elderly females seem to be the

main caregivers for HIV/AIDS affected and infected family members (Bock & Johnson, 2008). Nyirenda et al. (2012) found that women and men experience divergent health-related issues as they age and that older women are more susceptible to reduced functional ability and decreased health status. They also found that, due to women reporting poorer health than men, that there is a significant correlation between gender and quality of life among HIV affected and infected elderly people in South Africa. This brings with it financial and social responsibility and suggests that there is a greater physical and psychological burden being placed on the elderly female than the elderly male. Research by Hirve, Juvekar, Lele and Argarwal (2010) propose that reduced health status in women is associated with lower education, lower income and decreased career opportunities. Traditionally, a male's health declines more rapidly than a female as they age. However, in cases where women adopt a traditional caregiving role in society, their health is likely to decline at a quicker rate than their male counterparts (Nyirenda et al., 2012).

2.3.1.4. Education

A lack of skills, lack of education and limited access to resources play a significant role in how people cope with HIV/AIDS. The increasing elderly population is in critical need of HIV policy and programme interventions in South Africa (Nyirenda et al., 2012). Policies and institutions have the potential to contribute to transforming livelihoods through social and public services that the state provides (Masanjala, 2007). Research by Soong-Nang, Choi and Kim (cited in Cavanaugh & Blanchard-Fields, 2011) show a correlation between education levels and the ability to cope with age successfully. Cavanaugh and Blanchard-Fields (2011) propose that providing health education programmes for the elderly can successfully reduce emotional distress that the elderly may encounter. HIV/AIDS education for the elderly could buffer against physical illness and emotional distress among the elderly caregivers, thereby improving their quality of life.

2.3.1.5. Social domain

The elderly affected by and with HIV/AIDS tend to decrease their participation in social activities because they are fearful of possible stigmatisation (Alpaslan & Mabutho, 2005). The stigmatisation is perpetuated by negative stereotypes such as irrational fear of transmission through engagement with these caregivers, or even the notion that people with HIV/AIDS are sexually promiscuous. Even if the caregiver does not have HIV/AIDS, these stereotypes shame the elderly caregivers and their households who often respond by denying the situation (Ogunmefun, 2011). Research has found that the elderly find comfort, assurance and hope in social settings (Louw & Louw, 2011). Social support is a predictor of increased quality of life, which can be found in participation in social activities such as religion (George cited in Park, Roh, & Yeo, 2012). However, in other cases, the elderly may refrain from social interaction due to fear of stigmatisation, leaving them isolated and reducing their quality of life. It has been found that the elderly infected and affected by HIV/AIDS experience fear, trauma, isolation, hopelessness and stigmatisation (Lekalakala-Mokegele, 2011). The elderly also tend to withdraw from social activities and support systems due to their having to take care of the sick individuals and/or grandchildren. They may be required to travel to do so, resulting in their being absent from home for long periods of time, which could cause a collapse of social networks. Intra-family conflict may also arise as grandparents who are not the custodians of their grandchildren may judge other family members as being negligent in rearing their grandchildren (Lekalakala-Mokegele, 2011).

2.3.1.6. Psychological domain

Caregivers of those affected by HIV/AIDS usually face a number of psychological problems, experiencing a range of emotions from shame, anxiety, sadness and fear, to depression and loneliness. These emotions may have a number of causes, including the loss of a loved one, taking up a caregiving role later on in life, facing financial problems or bankruptcy, and isolation by society (Bezuidenhout et al., 2005).

There seems to be a high prevalence of depression among caregivers who experience a high care-giving burden, although mental illness is not limited to depression alone. They may also experience comorbid disorders such as PTSD,

anxiety disorders, loss and grief disorder, as well as drug and alcohol addiction simultaneously. This can gradually erode the ability of the caregivers to be effective in their caregiving roles (Pirraglia, Bishop, & Stein, 2005).

Financial support from NGOs and from government in terms of grants and pensions assists in alleviating emotions linked to economic constraints (Nyirenda et al., 2013). Those impacted by HIV/AIDS seem to question the relevance of psychological support in cases where poverty and daily struggles of life surpass the perceived need for mental healthcare (De la Rey & Ipser, 2004). Caregivers of adult children have been shown to suffer from greater psychological distress than those only taking care of their grandchildren (Lekalakala-Mokgele, 2011). It is possible the reason is that older parents often feel shame and guilt for their children's situation (Mall, 2005).

2.3.2. Role strain theory

The elderly caregivers whose lives are affected by HIV/AIDS are confronted with changing roles when caring for orphans and infected family and friends. Role reversal takes place for the elderly caregivers who, traditionally in their culture, were to be supported by adult children in their community (HelpAge International, 2002). The role strain is a consequence of incompatible responsibilities placed on the individual that produces negative effects, paired with an inability to fulfil their role expectations. The burden of care associated with their roles is accompanied by emotions such as stress and discomfort (Feldman, 2008). This may influence their subjective quality of life.

Role strain theory specifies that role strain is defined as the subjective challenges in the role of caregiving (Archbold et al., 1990). Role strain is conceptualised as having two levels. On the task-specific level, role strain is the subjective challenge of carrying out behaviours that comprise caregiving (Carey, Oberst, McCubbin, & Hughes, 1991). On a broader level, role strain is the perception that the overall caregiving situation is stressful (Archbold et al., 1990).

Archbold (cited in Niphawan, Saipin, Orapan, & Thavatchai, 2010) proposed a role strain theory as an explanation for the effects of added responsibilities on a caregiving capacity. The caregiver faces many challenges in the process of entering the caregiving role. The caregiving role can affect multiple domains within a person's life. These

domains of life could include daily tasks, general functionality, financial status, and social activities. These adjustments often produce an increase in perceived strain, which affects the caregiving ability of the carer. High levels of care correlate with an increase in role strain and a decrease in the health status of the carer. Caregiving responsibilities can also clash with social activities in which the caregiver was previously involved. It is important to note that the caregiving process can also have a positive effect on caregivers, which points to the subjectivity of the individual's experiences (Archbold et al., as cited in Niphawan et al., 2010).

The caregiving model of Archbold was expanded by Schumacher, Stewart, Archbold, Caparro, Mutale, and Agrawal (2008) to include three variables known as caregiving demand, which is the time spent in caregiving tasks; behaviours mutuality, which is the quality of the relationship between caregiver and patient; and preparedness, which is the caregivers perceived readiness to provide care. The model develops research conducted by Archbold, Stewart and Harvath (1990), who studied mutuality and preparedness as indicators of role strain among caregivers of incapacitated older adults who had been in hospital. In this model, increased levels of demand and decreased levels of mutuality and preparedness are correlated with negative consequences of care giving.

Caregiving demand has been defined in numerous ways, including the time spent in caregiving, the number of care tasks performed and the amount of assistance provided (Nijboer et al., 2001). Increased demand on a caregiver is associated with increased levels of threat and loss of self-assessments, disruption in daily schedules and decrease of physical strength, as well as role burden and role captivity (Nijboer, Tempelaar, van den Bos, & Sanderman, 2001). Mutuality is defined as the positive relationship between caregiver and care-receiver (Archbold et al., 1990). Research by Williamson and Schulz (1995) found that healthier relationships within the caregiving context were associated with lower levels of burden, hopelessness, and bitterness. "Preparedness", is defined as a perceived willingness to perform in multiple domains of the caregiving role (Archbold et al., 1990). Domains are broad areas in which caregiving can take place, such as providing physical care, providing emotional support, support services in the home environment, and dealing with the stress of caregiving. In a study

of family caregiving for older adults, preparedness was associated with lower levels of caregiver strain (Archbold et al., 1990).

Within this theoretical model, gender is understood to be an important indicator of caregiver well-being when caring for frail patients, with women experiencing greater anxiety, role captivity, emotional distress, depression, and impact on health (Given et al., 2004). Women experience greater emotional stress and caregiver burden, in general, than their male equivalents (Yee & Schulz, 2000).

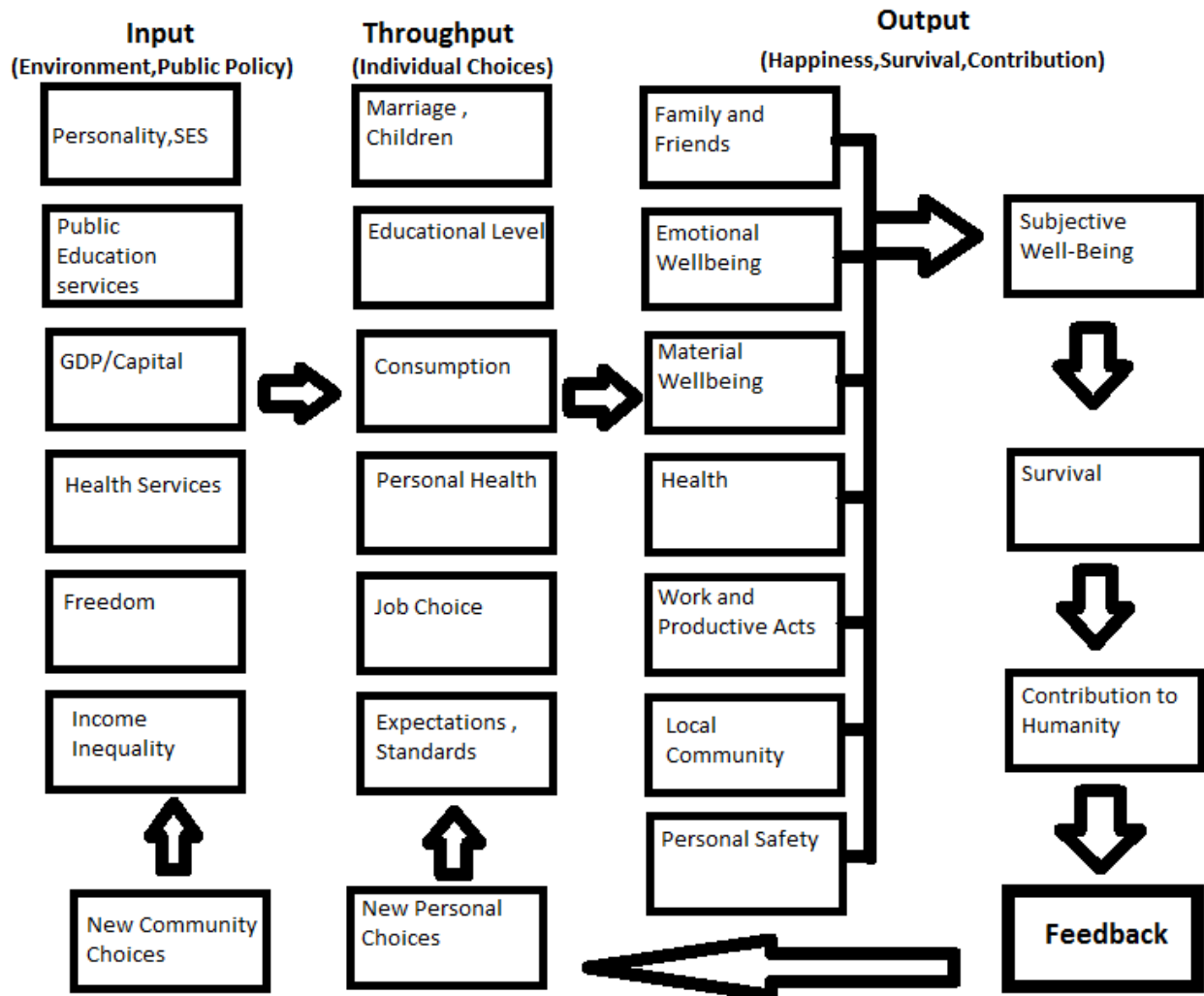
2.3.3. Systems Theory approach to Quality of life

Hagerty and colleagues (2001) proposed a Systems Theory approach to QOL (Figure 1) as a result of responses to indices and models that were not grounded in well-established theory. The systems approach to understanding quality of life is based on the domains of life (output), the individual (throughput) and external environment (input). The *output*, in terms of domains of life, includes health, material well-being, social support, emotional well-being and personal safety. The *throughput* includes people's response to the environment such as level of education, marriage status, the presence of children, and personal health. The *input* consists of government policy, health services, income inequality, and school policy. According to Systems Theory, the input will have an impact on the throughput and output which, in turn, will affect quality of life. Subjective and objective variables combine to contribute towards quality of life. Quality of life feeds back into the external environment (input) and personal choices (throughput).

According to this model, it is important to note that each variable has an influence on other variables in the system, as they do not occur in isolation. The relationship amongst the variables in the system is therefore interdependent and cyclical (Hagerty et al., 2001). The QOL of the elderly caregivers will not only influence their personal choices in caregiving but may affect the various government policies and health services. To illustrate the model, consider the following: the HIV/AIDS pandemic (input from the external environment) will influence their personal choices (throughput) such as taking on the caregiving responsibility and personal health, which influences the domains of life (output) and affects an individual's quality of life. The output then feeds

back into their personal choices (throughput) and external environment (input) in the form of decisions made both by individuals and the community (Hagerty et al., 2001). By incorporating the HIV/AIDS epidemic into the systems model of Hagerty et al. (2001) as an output, one can understand how this may impact caregiving choices (throughput) and, in turn, the domains of life of the elderly caregiver (output). Ultimately, the quality of life of the elderly caregiver is affected, which feeds back into personal choices regarding caregiving (throughput) and how the HIV/AIDS epidemic (input) is influenced by the various components within the system.

Figure 1: Quality of Life: Haggerty et al.'s Systems Model

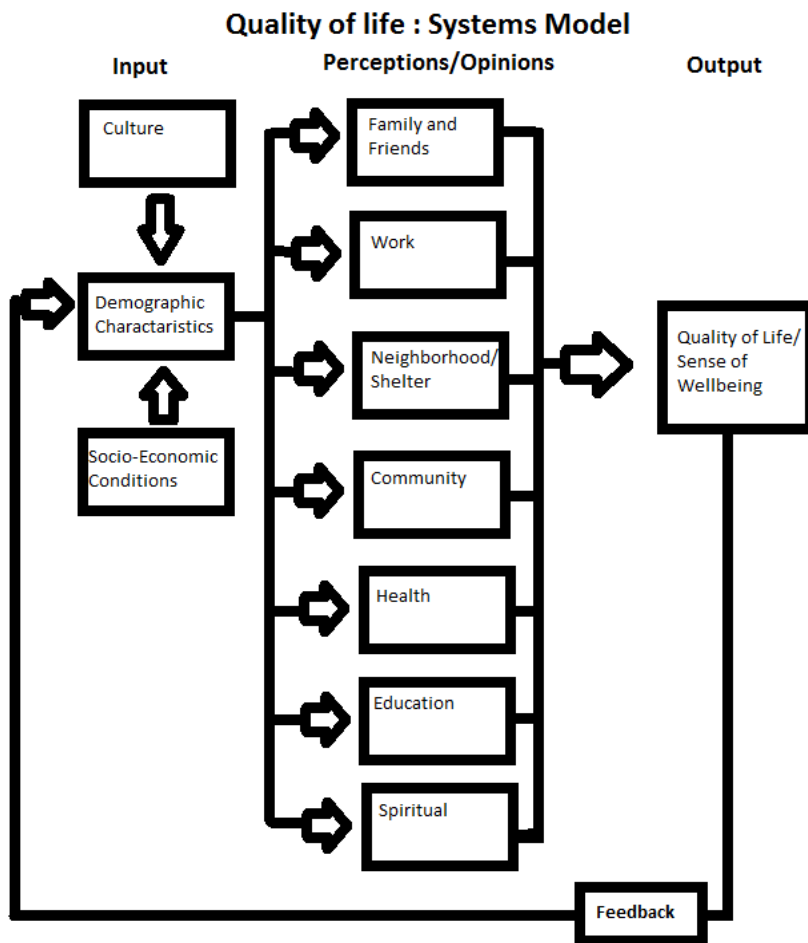


(Adapted from Haggerty et al., 2001)

The Quality of Life Systems Model was developed by the University Of Oklahoma School of Social Work (Figure 2). The information available on this model is very limited. However, this model developed its foundation on the assumption that there are different domains of life. The domains considered under this model include family and friends, work, neighbourhood/shelter, community, health, education, and spirituality. Inputs such as culture, demographic characteristics, and socio-economic conditions affect these domains of life. Perceptions, experiences and opinions of each of the various domains are also understood to add to a person's overall evaluation of quality of life that then

forms the output in this systems model. The evaluation of quality of life then provides feedback into the inputs (Global Development Research Centre, 2010). This model comprises fewer domains of life and inputs than the model proposed by Hagerty et al. (2001).

Figure 2: Quality of Life: University Of Oklahoma’s Systems Model



(Adapted from University of Oklahoma School Of Social Work, 2010)

2.3.4. Summary

In Chapter 2, a clear distinction was made between the elderly caregivers infected with HIV/AIDS and those affected by the virus. The focus of the current study is on elderly individuals in caregiving roles who are affected by HIV/AIDS. The models outlined above give an indication of the different domains associated with the subjective nature of QOL. These models also assist in distinguishing between the objective and subjective nature of QOL as well as showing the different inputs and outputs, which are influential in the perceived QOL. These domains were used to help identify the issues and experiences of the elderly caregivers in terms of how they are affected by HIV/AIDS, which would be essential to fully understanding their QOL, as well as the areas for intervention that could potentially improve their situation and ultimately better their quality of life.

CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction

This chapter discusses the methodology applied in executing this research study. Given the paucity of research with this age group, a qualitative research design was deemed more appropriate to gather the data pertinent to the aims of the study. A social constructivist paradigm was utilised in conjunction with a narrative approach to conceptualise, analyse and interpret the findings of the study. Salkind (2012) states that the qualitative approach studies phenomenon outcomes within the social and cultural context in which they occur. This enables the researcher to explore human behaviours and thoughts in response to different phenomena. Various techniques are associated with this approach, including interviews, case studies, surveys as well as other personal techniques. After positioning this study within a social constructivist framework, the research procedure is discussed and followed by a description of the research participants. What follows is a description of the method of data collection and a presentation of the ethical considerations that guided the research process.

As stated in Chapter 1, the focus of this study is the subjective quality of life (QOL) of elderly caregivers who are affected by HIV/AIDS. The adopted focus on the subjective nature of QOL was of great importance to the selection of the methodology for this research. Quinlan (2011) states that qualitative research aims to uncover those subjective meanings that participants place on the issues and phenomena that are being investigated. This is increasingly relevant in a post-colonial, developing country like South Africa, where context, as well as subjective perception of context, impact on how people access social services, perceive their access and ultimately, seek assistance to improve their lives. For this reason, given its alignment with the stated focus on subjective perceptions, a qualitative approach was adopted for the current study.

Qualitative research is holistic, requiring the researcher to gain an understanding of the process in its entirety (Denzin & Lincoln, 2000). It is becoming more important to illustrate local culture and changes in the average household, including tailoring social

services to the needs of patients and caregivers. This cannot be done via a top-down approach where directives for national and/or regional policy and health programmes emerge from discussions without appropriate contextual knowledge of the target-community. Aiming to improve healthcare and service-provision must be founded upon narratives (and a scientific method) that highlight the needs of the infected and affected individuals and families dealing with the HIV/AIDS epidemic and that specific to the places and conditions of their lived experience. This makes qualitative data collection vital to the epistemology of this study.

3.2. Research Design

Having considered the purpose of the research and the type of data that would best answer the research questions, a qualitative research design was chosen to explore the perceived quality of life of the elderly caregivers who have been affected by HIV/AIDS. A qualitative design seeks to focus on observing and understanding relationships and social settings pertinent to the study (Terre Blanche, Durrheim, & Painter, 2006). This qualitative design encouraged the researcher to examine the areas of interest contributing to the social context of Masiphumelele. By developing an understanding of the community, aligned to the qualitative design and focus, the researcher gained insight to what questions he would ask, what was culturally appropriate, when he could be direct and when he needed to be compassionate.

Qualitative research relates to a particular ontology, epistemology, methodology (Terre Blanche et al., 2006) and analysis (Denzin & Lincoln, 2000). That is, the researcher approaches the tasks with his own perceptions, a framework that consists of the theory (ontology), research questions (epistemology), a specific methodology and process of analysis. From the broad scope of qualitative research, the researcher selected the social constructionist paradigm and narrative approach to underpin the current research project. This was achieved by adopting the analytical and interpretive method put forth by Gilligan et al. (2003), which is discussed later in this chapter.

3.2.1. Social constructionism

Social constructionism has influenced post-modern thinking, which has led to a paradigm shift away from positivist notations of an objective reality. In postmodern thinking, the mind and object are not considered as existing independently of one another: subjective meaning is what is important to the researcher (Terre Blanche et al., 2006). No longer do we attempt to look purely objectively at a person's condition or behaviour, but rather at the context and norms inlaid in their perceptions. The ontology of social constructionism is that every person's reality is accepted as true without questioning whether that reality is accurate or rational (Corey, 2013). Social constructionism holds that the researcher must be aware of his/her own idealism so as to not enforce or impose his/her own reality on another person's worldview or experiences. The researcher must be aware that there are many subjective realities and that respect for another person's worldview is a key principle behind social constructionism (Terre Blanche et al., 2006).

Social constructivism refers to the individual's process of learning and creating knowledge through interaction in a group. It reflects the view that artefacts within someone's personal reality are created through shared understanding, practices and language (Norman, as cited in De Vos et al., 2013). Social constructivism and constructionism are said to have different emphasis. The former is more micro-focused while the latter is more macro-focused (Bevcar & Bevcar, 2009). In social constructivism (micro or individual level focus), we are dealing with the privileged agency of a person rather than the powerful relationship and social positioning in macro-constructionism that is concerned with the impact of social determination (Burr, 2003).

Denzin and Lincoln (2000) differentiate between weak and strong constructionism. According to their view, weak constructionism considers social factors as social constructions of external realities, thereby translating these into categories within society. In turn, strong constructionism opposes the presence of clinical facts thus viewing all reality as socially constructed.

The role of language has become a very important aspect of contemporary psychology. It allows individuals to know their world and construct it simultaneously.

Discourse is considered to be socially constructed; we learn to speak in acceptable ways and adopt shared values and ideologies of our language system. Deconstruction then takes place when we sceptically approach values, ideologies and assumptions that construct our realities (Bevcar & Bevcar, 2009). Discourse helps to construct reality, thus in social constructionism, rather than focussing on the technicalities of language, the broader patterns of social meaning encoded in language are the primary concern (Terre Blanche et al., 2006).

The choice of adopting the social constructionist paradigm was informed by the need to allow participants' subjective experiences and worldviews to emerge spontaneously in the interviews (De Vos et al., 2013). In other words, in the context of the study, subjectivity would be understood as fundamentally influenced and shaped by culture. Language too, is seen as a defining framework that can be deconstructed (Bevcar & Bevcar, 2009). The social constructionist perspective requires the researcher to look at culture as different while also interrelated to participants' lived experiences.

3.2.2. Narrative approach

The narrative approach is concerned with the structure, content and functioning of the stories people tell as well as when other people's stories are socially constructed so that they are interwoven (Camic, Rhodes, & Yardley, 2003).

Narratives can be drawn from text or discourse. Narratives often have one or more plots that shape the participant's past, present and future. In this approach, we are understood as living our lives according to the realities created by us; through sharing our stories with one another. The narrative approach seeks to understand subjective meanings of how the individual uses private and societal constructions to make sense of these experiences (Moen, 2006). This approach was deemed applicable to the study because narrative psychology provides an appropriate framework for listening to older people and their subjectively constructed systems of meaning, particularly as the elderly like to share their stories (Camic et al., 2003). It was, therefore, helpful for the researcher to be able to apply this to the participants.

Additionally, the narrative approach allows one not only to take into account the participants' stories, which have different voices, but also to assess meaning in context

by focusing on the content of interactions (Moen, 2006). This meant that along with considering the cultural aspects of the lives of the participants, the researcher could look deeper into their stories and see how they used their personal experiences to construct these stories. This allowed the researcher to develop a greater understanding of their meaning building as well as the contexts of the various participants. For example, this could relate to how they view their roles in terms of how it affects the manner in which they carry out their roles, as well as how this contributes to the increase or decrease in their perceived subjective quality of life.

3.3. Participants

The participants in this research were from the area of Noordhoek, specifically Masiphumelele, Western Cape. They were accessing services provided by the Living Hope Centre at the time of the study. The Centre provides a range of interventions. These include HIV/AIDS awareness courses, skills development programmes, a vegetable gardening project, support groups and a spiritual ministry. The Centre also provides services to the community such as home-based care, general counselling services and a wound-dressing clinic (Living Hope, n.d.). Participants were recruited from the residents of Masiphumelele who utilised services of the centre as outpatients and were known to the recruiters.

The inclusion criteria for participants for this study were:

- Individuals aged between 50-70 years; and
- Individuals providing care for relatives, friends, spouses and children with HIV/AIDS, as well as children orphaned due to HIV/AIDS.

Initially, 12 participants were approached and interviewed. However, after consultation, consideration and selection, it was decided to remove 2 of the transcribed interviews from the final data corpus. Only the interviews of 10 participants were then used in this study. The decision was taken due to the participants' reticence to provide additional content and elaboration. The researcher elected to remove these transcripts as the interviews were terminated prematurely. This eliminated the influence of these incomplete interviews from the final findings. However, it is still important to note that

participants' reluctance to share information is likely to be reflective of the way they experience the impact of HIV/AIDS in their lives. Fears of judgement, discrimination and stigma, as well as potential concerns regarding cultural sensitivity may have limited the participants' willingness to share their stories.

The age for the participants ranged from 50 to 61. The average age of the sample was 56 years, and education levels ranged from no formal schooling to a grade 12 qualification. Several of the participants were unemployed (N=4). Three participants are currently employed as domestic workers. Two participants were involved in the informal sector. One participant sells chickens from her house, while another earns an income babysitting children from the neighbourhood. Only one participant has a full-time job, working in administration for a NGO.

The majority of the participants (N=8) live in informal settlements – “shacks”, in the South African colloquial expression and two live in formal dwellings, including RDP housing and a container.

Despite concerted efforts to recruit both male and female participants, none of the participants recruited were male. Five participants voluntarily revealed in the course of the interviews that they are infected with HIV themselves. A brief description of the demographics of each of the 10 participants is provided in Table 1. This information is included to provide a deeper understanding of the participants' social contexts. For example, 'No. of children' refers to the number of children younger than 18 years that the participant has custodial responsibility for at the time of the interview, including their physical, social, and mental well-being.

Table 1: Demographics of the ten the participants

Participant A	
Age	: 59
Relationship status	: Separated
Employment	: Unemployed (former domestic worker)
Added Income	: Child grant
Residential status	: Informal dwelling
No. of children	: 3 children and 2 grandchildren

Participant B

Age : 50
Relationship status : Unmarried
Employment : Domestic worker
Added income : Child grant
Residential status : Informal dwelling
No. of children : 1 nephew

Participant C

Age : 57
Relationship status : Widow
Employment : Formal employment
Added income : Foster grant
Residential status : Container
No. of children : 1 granddaughter

Participant D

Age : 60
Relationship status : Married
Employment : Domestic worker
Added income : Child grant (and husband's pension)
Residential status : Informal dwelling
No. of children : 1 granddaughter

Participant E

Age : 50
Relationship status : Single
Employment : Unemployed
Added income : Foster grant
Residential status : Informal settlement

No. of children : 6 foster children

Participant H

Age : 57

Relationship status : Widow

Employment : Unemployed

Added income : Foster grant

Residential status : Informal settlement

No. of children : 1 daughter

Participant I

Age : 60

Relationship Status : Widow

Employment : Unemployed

Added income : Pension and child grant

Residential status : Informal settlement

No. of children : 3 children and 1 grandchild

Participant J

Age : 57

Relationship Status : Single

Employment : Own business

Added income : Foster and child grant

Residential status : Informal settlement

No. of children : 5 grandchildren

Participant K

Age : 50

Relationship Status : Single

Employment : Domestic worker

Added income : Foster grant

Residential status : Informal settlement

No. of children : 1 grandchild

Participant L

Age : 61

Relationship Status : Single

Employment : Part time child-minder

Added income : Foster grant and rents out a room

Residential status : Informal settlement

No. of children : 1 grandchild

3.4. Method of data collection

Given the subjective nature of quality of life and the sensitivity required in conducting HIV/AIDS research, the researcher deemed using face-to-face interviews with participants as the most appropriate qualitative method to observe behaviour and language in order to obtain the necessary data within the study's particular context. The researcher was aware that the participants would only be linked to this study by their role as elderly caregivers and how HIV/AIDS has affected their lives; they would come from various backgrounds and have different perceptions of their situation. Thus, the researcher felt face-to-face interviews would be the best approach to capture these experiences in an authentic manner. Silverman (2013) states that interviews are vital in that they aim to find out how certain groups perceive and express opinions around specific issues. This is particularly relevant given the subjective nature of QOL. The findings of qualitative interviews cannot be calculated empirically; the language used must, therefore, be clear and coherent to achieve credibility within qualitative research (Camic et al., 2003). This meant that the researcher needed meticulous transcripts of the interviews. These interviews needed to be semi-structured in order to capture the stories accurately from the participants while still keeping the information gained relevant.

Data was collected by means of semi-structured individual interviews, which are essentially focused on and facilitated by open-ended questions (Alpaslan, 2010). Semi-structured interviews were used in order to gain an in-depth understanding of the participants' perceptions and experiences regarding the effect of HIV/AIDS on their lives. HIV/AIDS is a highly personal and sensitive issue, hence the suitability of semi-structured interviews for this study (De Vos et al., 2013). The flexibility afforded by the semi-structured approach allowed the researcher to respond adaptively to the content supplied by the participants. Where necessary, the researcher made use of a series of prompts and asked further questions in response to participants' answers (Bryman, 2012). It should be noted that at no time were participants made to disclose information they did not wish to share.

Research was conducted in an empathetic manner. This helped to create a collaborative relationship between researcher and participants wherein participants were willing to share their stories. They narrated their stories and if they went off track or paused for a long time, the researcher would ask them open-ended questions to remain non-directive but to encourage them to allow their stories to unfold further. The researcher endeavoured to maintain sensitivity in his own responses and comments to allow the participants to reveal as much about their stories as they were willing to share. The researcher took care to transcribe, faithfully, the stories into written form (Camic et al., 2003).

During the process of data collection, the researcher had to overcome language and cultural barriers. Translators from the Living Hope Centre, who came from similar cultural backgrounds to the participants, were available to assist in overcoming some of these barriers. The researcher was able to establish a rapport with the participants by spending time with them prior to the interviews, thereby gaining some understanding of their personalities and empathising with their unique stories (Denzin & Lincoln, 2000).

The interviews were transcribed verbatim and reviewed. Later, follow-up interviews were conducted with participants to evaluate the dependability and credibility of the themes developed. This member-check allowed participants to assess the material and provide their personal input on the findings (Denzin & Lincoln, 2000). Where the need arose, themes and interpretations were adjusted after consulting with the participants

(Race et al. cited in Gibbs, 1997). The researcher remained mindful of the adapted listening guide (discussed in the next section) while interviewing the participants (Gilligan et al., as cited in Camic et al., 2003).

3.5. Procedure

Consent and approval for the study were obtained from the Stellenbosch University's Research Ethics Committee for Humaniora due to the sensitive nature of the subject. The researcher was aware that The Living Hope Centre, an NGO based in Noordhoek that supports communities affected by HIV/AIDS, serviced Masiphumelele community. He contacted the Centre, spoke to the director, and inquired if the research would be useful to them as well as whether Living Hope would be willing to assist. The director agreed to allow the researcher to utilise their premises for interviews and suggested that the Centre provide counsellors who were aware of the community context and lived in the community to further aid the researcher. The researcher initially used purposive sampling to identify participants who met the study criteria. Purposive sampling is a sampling technique in wherein the parameters and type of sample is chosen based completely on the judgement of the researcher. The researcher chooses a sample that is most representative of the study population as a whole and thus will optimally serve the purpose of the study (De Vos et al., 2013)

Thereafter, the snowballing technique was used to recruit more participants for the study. The snowballing technique consists of identifying an initial source or participant who can then identify other possible participants to the researcher (Babbie, 2005). This technique is used primarily to gain access to population groups that are normally concealed for social reasons such as criminal elements, social isolation or various forms of deviance (Lewis-Beck et al., 2003). In the current study, the researcher was aware that potential participants might not wish to disclose the nature of how HIV/AIDS affects them personally. Therefore, snowball sampling represented a useful way of gaining access to potential participants through references they would trust.

The researcher requested the assistance of the counsellors at the Living Hope Centre who are in daily contact with individuals affected by HIV/AIDS. The counsellors were briefed about the study and their input was solicited as to the best way to recruit

potential participants for the study. Counsellors were provided with request letters (Addendum A) with which to approach the participants. Once consent was obtained, the participants were requested to identify other individuals who shared similar experiences. Counsellors who initially recruited participants (referred to as peer-driven recruiters - PDR) can be classified as assistant researchers who received compensation for their time and transportation. The community was aware of these PDRs. The likelihood of selection bias was considered in using PDRs in the sampling process, as while they would be able to identify the most easily accessible participants; these individuals may not necessarily have been willing to or be interested in participating in research. With this project however, it was preferable to make use of PDRs as the elderly caregivers affected by HIV were not known to the researcher and were not identifiable by the community due to the sensitivity of the topic under discussion. The PDRs work on a daily basis with the participants and had previously established a good rapport with the community residents who were actively accessing services at the Centre. The venue at the Living Hope Centre was identified as a suitable, quiet and sufficiently private environment in which to conduct the interviews. The director of the Living Hope Centre suggested and provided the allocated space. Once the participants had consented to take part in the study, they were asked to sign the informed consent form (Addendum B).

The participants were assured that they were free to express themselves in English or in isiXhosa, as one of the counsellors who sat in on the interviews was fluent in isiXhosa and therefore were also able to serve as translator. The counsellors were also on hand to debrief participants should the need arise.

The researcher aimed to establish a collaborative and empathetic relationship with the participants. Prior to the first interview, the researcher met with each participant with the aim of building trust as well as to discuss the nature of the study, their rights as research participants and to reassure them of the commitment to confidentiality by the researcher. Participants were asked to sign consent forms to participate in the study and for the interview to be recorded.

The participants and researcher met at a neutral venue at the Living Hope Centre. Due to the sensitivity of the topic, the participants appeared to be more comfortable in

those surroundings and were reassured of confidentiality. When five of the participants revealed during the interviews that they were HIV positive, the researcher opted to include their data in the study because of the additional richness the data provided in understanding the impact for the elderly of being a caregiver and having to cope simultaneously with the bio-psychosocial impact of the disease. Despite the researcher's attempts to include both male and female participants, male participants were not available for the study despite the efforts of the counsellors to recruit potential male participants. .

3.6. Data analysis

As cited in Camic et al. (2003), the data was transcribed and analysed through a combination of thematic analysis and the adapted listening guide method proposed by Gilligan et al. Thematic analysis was conducted, thereby allowing the research findings to emerge from dominant themes in the data and through coding the data (Terre Blanche et al., 2006).

Gilligan's Listening Guide analysis focuses on the psychological intricacies of human nature by considering different "voices" in their narratives (Gilligan et al. as cited in Camic et al., 2003) with an emphasis on the importance of human relationships (Woodcock, 2005). According to Gilligan et al., "The Listening Guide method systematically attends to the many voices embedded in a person's expressed experience, allowing for multiple coding of the same text" (as cited in Camic et al., 2003, p.157). The listening guide consists of four steps that the researcher used to read and analyse the text multiple times:

Step one consists of attending to the main themes and contexts while considering the researcher's own responses (Gilligan et al. as cited in Camic et al., 2003). The objective is to identify the basic pattern and themes that develop in order to recognise the overall trends of the participant's narrative. The researcher sought to identify and understand the main themes of the participants, which, in Gilligan's approach, is called "*listening for plot*" (Gilligan et al. cited in Camic et al., 2003). The researcher's responses are included in the first reading of the interview transcripts, which is referred to as reflexive reading (Brown & Gilligan, 1992). As a result, the researcher was able to

observe his own reactions to and understandings of the participants that might affect interpretation of the data (Doucet & Mauthner, 2008).

The second step is the development of the '*I Poem*' (Debold, as cited in Gilligan et al., 2003), which included reading through the text and extracting the 'I-statements' of the participants. This assisted the researcher in the development of an understanding of how individuals view themselves through their subjective feelings (Gilligan et al., as cited in Camic et al., 2003). The focus of this step is to understand the participants' description of themselves within the context of their relationships with themselves, others and outside systems, such as the economic, social and political environment (Edwards & Weller, 2012). Gilligan et al. (as cited in Camic et al., 2003) suggest using the *I Poem*, to extract every first person "I" statement within the transcribed interview, including the verb that is attached to it, and to preserve the order of the sentences as it appears in the transcriptions. The sentences containing "I" are placed in separate lines in order to form a poem. The *I Poems* bring across the subjective experiences of the participants through the first-person voice (Debold, as cited in Gilligan et al., 2003) within the constructed narrative. Through this step, the researcher was given the opportunity to focus on the subjective understanding of the participants and how they viewed themselves and others (Edwards & Weller, 2012).

Step three involves "*listening for contrapuntal (multiple) voices*" to ascertain where two or more voices emerge from the participants (Gilligan et al. as cited in Camic et al., 2003) and which of these may be a dominant voice. The researcher was able to observe the participants in terms of their relations with other people, as well as the multiple voices that emerge because of these relationships (Douchet & Mauthner, 2008). Gilligan et al. (2003) further advise that the researcher should examine the transcribed interviews, identify themes and create *I Poems* to identify ambiguities and similarities that exist within themes (Brown & Gilligan, 1992).

In the final step, the information gathered from the previous steps is interwoven with the research question to give a preliminary understanding of the data (Gilligan et al., as cited in Camic et al., 2003). The researcher's attention was centred on macro-level procedures and structures which include the cultural, health care, social and economic contexts in which the participant lives. Douchet and Mauthner (2008) explain that these

societal structures mould the voices of the participants according to the dominant ideologies and power structures that prevail. The researcher sought to understand the link between the subjective voices of the participants and their macro-environments (Douchet & Mauthner, 2008).

Thematic analysis and step 1 of the listening guide are similar in that both seek to discover the main themes that emerge from the data (Edwards & Weller, 2012), which is the focus of data analysis in the present study. Thematic analysis provided an overview of key topics and patterns as they emerged within the data (Edwards & Weller, 2012). The listening guide facilitated the discovery of multiple voices and the personal meaning of participants as experienced within their social and cultural contexts. It is contended that this hybrid approach led to a more comprehensive form of data analysis, due to the multiple coding of the same text (Gilligan et al. cited in Camic et al., 2003). This encompassed identifying the pertinent topics and patterns, then segmenting and grouping specific parts of the text and linking related categories to construct themes (Gray, 2009). From the viewpoint of the narrative approach, thematic analysis enabled the researcher to access the underlying and recurring order of participants' stories (Chamberlayne, Bornat, & Wengraf, 2000).

3.7. Reflexivity

Reflexivity is an important component in every phase of the research process because the view of the researcher is vital in the creation and interpretation of information. Shaw (2010) explains that reflexivity involves continuous reflection on the researcher's subjectivity and the relationship between the researcher and respondent. Reflection on the self relates to the researcher's scrutinising his own assumptions and preconceptions as they affect the research process. Reflecting on the relationship between the researcher and respondent allows for the examination of the subjectivity of both. Malterud proposes that "a researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions" (2001, p.483-484).

The researcher should consider the relationship with the participants in terms of historical, cultural and social 'baggage', as well as elements related to race, gender, status and demographics (Marcus, 1998). Reflexivity guides the researcher into rendering an authentic account of the processes that were followed during the research (Denzin & Lincoln, 2000). Malterud (2001) suggests that the researcher's own preconceptions, beliefs, values and assumptions should be briefly documented in order to create awareness of the difference between the researcher and participants' respective interpretations. In qualitative studies, reflexivity is essential for the researcher to understand the subject under study and the research process (Watt, 2007). The researcher used realistic stories as primary information for his research to maintain objectivity in his conclusions on confessional stories (a function of reflexivity). This then served as a secondary reference to caution against contamination through personal bias. The researcher aimed to take as much precaution as possible to minimise his personal bias or moral judgement as he tried to build up his knowledge of the topic. Having come from another culture, an inductive form of analysis would be more appropriate (Smith, 2006).

As a white, Jewish, middle-class, English speaking male, the researcher had to familiarise and immerse himself with the literature on the chosen topic as well as the Centre's milieu, the community culture and the socio-economic difference between himself and the participants. He was conscious of the social differences between the participants and himself, which may affect both his own understanding of them and their appreciation of him. He was also mindful of the sociocultural differences between himself and the participants, particularly when parts of the interviews had to be conducted in isiXhosa through the translators. To close the knowledge gap, the researcher liaised with community organisations and workers and relied on a close working relationship with the counsellors.

The researcher's point of departure was his being cognisant of the differences between African and Western European cultures. One such difference includes the value of the collective in African culture as opposed to individualism in a Westernised/post-colonial society. The researcher also identified similarities between his own culture and that of the participants such as stereotyping and prejudices, family

and communal unity. The researcher found some familiar ground with the plight of the participants as he grew up with dyslexia. Dyslexia is rarely understood and people who struggle with it often find themselves the victims of stereotyping and marginalisation. The researcher realised that he had many advantages and resources dealing with his problems while growing up. This was not the case for the participants however, because they did not have access to the same resources to deal with their own situations. Coming from a different socio-economic background had made their suffering even harder as they have little voice or sense of agency around these issues. The researcher realised the participants did not have access to the same counsellors, services and resources he had had growing up, which would otherwise have made their lives easier to manage. The community also did not have access to the education opportunities that would have made the lives of the participants better due to their being understood and better able to deal with their challenges.

By comparing his own background with that of his participants, the researcher gained very useful knowledge for going forward with this study. It was understood that, despite similarities, there were many issues he would need to understand in the words and within the context of the participants because he did not have these issues in common with them. It allowed him to be more culturally sensitive, having been subjected to experiences in his life where he too had felt that he had no voice. The researcher was also aware that through this study, he was made privy to life experiences that were uniquely different to his own. Hence, in this study, the researcher felt challenged in giving an authentic voice to the participants, which was pertinent given the objectives of the study. It was very important to ensure good communication and understanding between the researcher and the participants to achieve this end.

The researcher had to examine his own background and demographics in relation to that of the respondents. This provided him with a deeper understanding of the personal views that may have led to assumptions and pre-conceptions in the research context. Reflexivity in the research process led the researcher to conduct another set of interviews in order to address accuracy of interpretation and identified gaps in communication. This provided a valuable learning experience and the opportunity to explore further perceptions and assumptions he developed.

3.8. Ethical considerations

Given the sensitive nature of the research and, particularly, the vulnerability of the participants identified as being directly affected by HIV/AIDS in their families; the researcher was mindful of the following ethical issues: informed consent, confidential management of information, autonomy, non-maleficence, beneficence and cultural context (Alpaslan, 2010).

Informed consent is described as being fully informed of and understanding all the possible risks involved in a research project as well as voluntarily participation therein. This also entails not exposing the participants to any harm or injury (Babbie, 2005). Initial contact with potential participants was made via the counsellors at Living Hope Centre. Over time, these counsellors have established a trusting relationship with the participants. Their support added to ensuring participants that trust and confidentiality would not be breached. The participants were given letters explaining the project and requesting their participation in the study.

In the initial meeting, the participants were informed of the aims and purposes of the study, and of their right to withdraw at any stage of the process. They also signed consent forms to confirm that they understood the focus of the study and that they had been invited to participate on a voluntary basis. The content and purpose of the consent forms were also explained to the participants by the counsellors. The counsellors explained the entire study to the participants in their language to ensure the participants understood the nature of the study and all expected.

Recalling their experiences carried a potential risk of individuals feeling some emotional discomfort during and after taking part in the study. The researcher gave close attention to the debriefing of the participants and arranged for counselling to be provided to the participants at the Living Hope Centre. Three counsellors trained at the Living Hope Centre were made available during and after the interviews for the counselling and debriefing to mitigate any feelings of discomfort that may have arisen during the interviews. The counsellors were known to the community and were fluent in isiXhosa, which served to diminish any cultural and language barriers. One participant (Participant B) required debriefing after the interview during which she showed signs depression. A debriefing session was therefore provided and no further follow up was

need by this participant. Although she was offered the opportunity to discontinue the interview, she stated that she wanted to continue. Several participants expressed positive sentiments at being able to share their stories.

The researcher also had to consider carefully how the interviews would be conducted. It was necessary to assure interviewees that he was always available for questions if anything seemed unclear. Stressing this was particularly important due to the language barrier. The researcher reminded the participants during the interviews if/when they were struggling to articulate themselves that they could communicate in their own language for comfort. The counsellor, who also acted as an interpreter, was known to the participants to ensure that they were comfortable with having the counsellor translate for them. The researcher also made them aware that he was not an authority figure, and endeavoured to be neutral in his listening skills while encouraging them to express their feelings.

In order to guarantee the confidentiality and privacy of the participants, the researcher used codes for all the participants to protect their identity. Esterberg (2002) points out that it is important to protect the participants' confidentiality while collecting and analysing data as well as when publishing it. Hence, names, telephone numbers, addresses and data were protected by means of password-protected files on a laptop to that only the researcher had access.

Follow-up interviews were conducted, whereby all the participants were given the opportunity to verify the information in their transcribed interviews. The follow-up interviews helped to validate the accuracy and trustworthiness of the data provided by the participants and the researcher's interpretations thereof.

3.9. Conclusion

Data were gathered utilising the structures and considerations set forth in chapter 3. There has been very limited research conducted on the subjective quality of life experienced by elderly caregivers affected by HIV/AIDS. A qualitative research design, underpinned by the social constructionist paradigm and narrative approach, was deemed suitable for effectively examining the elderly's life experiences coping as

caregivers, in terms of their experience with the disease as well as their personal constructions of quality of life.

The social constructionist paradigm allowed for consideration of the subjective realities of the participants. This was achieved by considering their situations and perceptions thereof within their own contexts rather than basing the research on perceived behaviours. The narrative approach further allowed the researcher to explore the subjective meanings created by the participants about their lives in order to take a deeper look at their stories, as well as the meaning these stories hold for the participants.

The participants were chosen from Masiphumelele, a community with one of the highest rates of HIV/AIDS infection in the Western Cape. Participants were recruited based on the inclusion criteria of being older than 50 years and being involved as a caregiver to a family member infected by HIV/AIDS. Participants were recruited utilising purposive and snowball sampling due to stigmatisation and privacy considerations.

Data collection was conducted using semi-structured individual interviews with the assistance of translators/counsellors from the Living Hope Centre. The interviews were transcribed and follow-up interviews were conducted with participants in order to further ensure the accuracy of the information.

The transcripts were processed and analysed using both thematic analysis as well as Gilligan's adapted listening guide method to assess the various levels of narrative present in the participants' stories. These methods allowed a deeper understanding of how the participants viewed their own lives. The findings of the study will be presented in chapter 4, and the interpretation of the findings and their implications will be discussed in chapter 5.

CHAPTER 4

DATA FINDINGS

4.1. Introduction

This study sought to gain insight into the experiences of the elderly caregivers affected by HIV/AIDS and thereby develop an in-depth understanding of how HIV/AIDS affects the subjective QOL of these individuals across multiple life domains. It sought to identify domains that could be better supported to improve the quality of life of elders and to identify how NGOs and communities can improve their strategies to better assist the elderly caregivers affected by HIV/AIDS both mentally and physically. The findings of the study are presented in this chapter. The implications and discussions based on the findings of the study will be presented in Chapter 5.

Data were collected via a semi-structured interview during which participants shared with the researcher their personal narratives. The researcher made use of a series of prompts to guide the narrative and asked additional questions in response to participants' further elaborated narratives as suggested by Bryman (2012). The researcher used an adapted version of Carol Gilligan's¹ listening guide (2003), supplemented with thematic analysis so that the dominant voices of the participants could be heard. The guide was used to identify *I Poems* and contrapuntal voices (as described in chapter 3) in the participants' narratives.

In this chapter, the narrative themes will be presented first. These primary themes emerged from the participants' responses within the interviews. Thereafter, the *I Poems* extracted from the participants' narratives will be presented. The *I Poems* are structured to follow the same order as the narrative themes but focus on the deeper underlying narratives of the participants by using the method found in Gilligan's listening guide. Lastly, a discussion of the contrapuntal voices will present the specific underlying contrasting voices found within all the narratives.

¹The lead author is Carol Gilligan, who with colleagues Spencer, Weinberg, and Bertsch, created the Listening Guide (2003) within postmodern qualitative research ontology.

4.2. Narrative themes

Various themes emerged from the participants sharing their experiences during the interviews.

The following table provides a summary of the narrative themes identified:

Table 2: Narrative themes derived from the interview data

Theme No.	Theme name
4.2.1.	Concerns with Mental and Physical Health
4.2.2	HIV/AIDS Education and Awareness
4.2.3.	Stigmatisation and fear
4.2.4.	Conceptions of caregiving: gender roles and fulfilment
4.2.4.1.	Role of the mother and wife
4.2.4.2.	Role of the father and husband
4.2.4.3.	Role reversal
4.2.5.	Financial constraints
4.2.6.	Spiritual support
4.2.7	Lack of friendship

4.2.1. Concerns with Mental and Physical Health

The elderly caregivers affected by HIV/AIDS reported a range of mental and physical symptoms. During the interviews, the participants highlighted their struggles as elderly caregivers within these two domains and how it has made their lives more difficult. This is illustrated in the excerpts selected from a number of interviews below:

Participant B: *I find .out 2007...*

Researcher: *That you were HIV positive?*

Participant B: *Yes.*

Researcher: *But how did you find out?*

Participant B: *I was sick with TB I was in the treatment for TB.*

Participant A: ... *I can't work anymore, I have worked all those year, and my legs cannot carry me anymore up to the stairs*

Participant A: *I got one son, I will tell you, he is also on HIV treatment; he is HIV positive. He is quite a long years on the treatment. He got asthma also when he gets ill.*

Participant J: *Sometimes I do feel tired because I have got diabetic, arthritis...*

Participant J: *My mother also had diabetic.*

Researcher: *You said your blood pressure is hereditary, so it comes from your parents. But when you were looking after your son, do you think it affected your health in anyway?*

Participant A: *I was so thin; you can ask that lady (gestures to the counsellor in the room). I didn't have any strength. I was so tired. I couldn't even sweep the house.*

Participant C: *I take my medication every day in the morning and in the afternoon and then I inject myself. This is the life; even your medication is your life.*

Participants were acutely aware of the various physical struggles they faced from being infected by HIV/AIDS. For Participant B, her positive status was discovered when she went for treatment for TB. The struggle of living with chronic comorbid illnesses is very apparent in the interplay between old age, hereditary illnesses, HIV/AIDS and the burden of being a caregiver. The caregiving role especially puts extra physical pressure on and requires greater exertion by the participants.

Researcher: *So you go for support or tell other people about it [illness]?*

Participant H: *I went to see the psychologist there; she keeps on talking to me and the child about it.*

Participant L: *I think this blood pressure from my daughter worrying too much because sometimes I'm feeling the cramps and everything and then my daughter says to me before she leaves she says, "Please mum I know you are working hard when you finish everything to me please go to the doctor to check yourself." Then I was done and when I went to the doctor, I saw I'm having blood pressure.*

Researcher: *Do you think you are stressed?*

Participant I: *Yes I am stressed; even now I have got shingles; even the doctor says I've got stress and I'm on T.B. treatment, I got these shingles now on my body.*

Researcher: *Do you think it's the mixture of this drinking ²and the other children you are looking after?*

Participant I: *Yes it's stressing me.*

Researcher: *How do you get help to help you relieve the stress?*

Participant I: *I always go to the clinic, and they give me tablets.*

Researcher: *Is that the ARVs or is it something else?*

Participant I: *It's ARVs and medication for stress*

Participant C: *I think it affects me because I am diabetic. I have got high blood pressure. If she [grandchild] didn't take the medication and she said to me she forgot to take the medication I ummm... things make me sad and sugar [diabetes] go up or down because of the worry.*

Participants also made it clear that physical illness is not the only consequence being affected by HIV/AIDS. They spoke of the mental strain, which also accompanies the physical illnesses they experience and occurs within the context of their caregiving roles. Seven of the ten participants utilised basic medical facilities and services to access treatment for both the mental and physical ailments afflicting them.

² "...this drinking" refers to the participant's earlier comment that she drank a lot in order to deal with her distress

Subjective quality of life is affected by how a person views their situation and, as Cavanaugh and Blanchard-Fields (2011) mention, the way in which people rate their health is a predictor of illness and health. For example, individuals who rate their health as poor, tend to believe their health is declining, and, by extension, their functioning. Self-rated health also reflects what internal and external resources people have at their disposal to support their health (Cavanaugh & Blanchard-Fields, 2011). Further research has shown that poor self-rated health is associated with psychological distress and depression, but is not dependent on real illness (Shadbolt as cited in Leibson et al., 1999). Thus, how people subjectively view and rate their own health can affect their quality of life.

4.2.2. HIV/AIDS Education and Awareness

Education and awareness appears strongly as a theme within the narratives illustrating how much the participants as well as the people in their lives know about HIV/AIDS. It also clarifies the degree of access that there is to proper education on the topic of HIV/AIDS as well as the potential consequences thereof (both positive and negative). The excerpts below highlight some of the statements made by participants, which reflected their degree of knowledge around HIV/AIDS:

Participant C: *I first know about HIV when my child was HIV [positive], my little one.*

Participant E: *I just tell my man that I love you, I want to stay with you; we must use protection.*

Participant D: *I don't worry about that because I am not sleeping with my husband.*

Researcher: *And if you were?*

Participant D: *No, no I am old now; I don't stay up for long time.*

Participant H: *Because it's a killer, so many people are just dying because they don't know about it.*

Education on the topic of HIV/AIDS is important in order to prevent the spread of the virus and to decrease the associated stigmatisation and discrimination. Older adults in this study had reached maturity during a time when HIV/AIDS and the need to use protection were virtually unknown. As a result, many lack education on this essential topic.

Participant E: *I think just to take older people of 50, 52, 55, 60 and 70 years together, and organise them just to explain about it (HIV/AIDS).*

Education surrounding HIV/AIDS and the use of protection has not typically been aimed at or inclusive of older people. It has been suggested that this is in part due to the misconception that older people do not engage in sexual activities (Berman, 2014).

Participant A: *We didn't use condoms that time; we was always honest to each other. I must say I caught from my husband because I was not a lady sleeping out with other boyfriends. I just get ill after my husband passed away. That's right; he was sometimes doing intercourse with other ladies you see. We didn't know that time about HIV.*

Participant A: *Many old people don't know about condoms. We never used condoms in our days and some of us are still stupid; they don't watch TV they don't know nothing*

Participant C: *The man, they don't want... they don't want to use the condoms, they don't want.*

Participant I: *I was married long ago and the husband would never use condom and it was not a suggestion that time.*

Not only did most of the older participants become aware of HIV/AIDS much later in life, but also it appears that social pressures prevented them from using protection. As can be seen above, male partner reluctance to use condoms and habits built from a lifetime of being unaware of the impact of HIV/AIDS combined to make it difficult for the elderly women to take steps to protect themselves.

Participant B: *Yah I was hear[ing] before that it is a disease is dangerous and if you do nothing it can be AIDS but if you get treatment it stays HIV ... I was hear[ing] from the radio that people is sick with HIV Yah I was using protection after I hear.*

Participant A: *I listen very much carefully to the radios, by people in counselling and so on...*

Radio seemed to be the most widely used form of media in educating elderly about HIV/AIDS. Six of the participants reported the radio as a valuable source of information.

Researcher: *If your husband says “no, I don’t want to use protection?”*

Participant D: *(laughs)*

Researcher: *If the man shouts at you and says I am the man, I want to have sex without a condom; what are you going to tell the man?*

Participant E: *I just tell my man that I love you I want to stay with you we must use protection.*

Researcher: *If he says, I am not interested in condom I have never had another girl, I am not HIV positive; [are] you going to still have sex with him or not?*

Participant E: *No, I am old enough to make my decisions.*

Participant K: *No I tell him it’s my life. This is my life not your life; if you don’t want protection you can leave.*

Researcher: *And now if a man comes to you and you love the man and you want to be with him, would you use protection even if that man says, no it's not my culture; what would you do?*

Participant L: *I will never have a man.*

As can be seen in the excerpts above, female participants, who were aware of the severe consequences of HIV/AIDS (despite their domineering male partners' hindering the use of condoms), appeared assertive about using precautions. Being educated about these dangers seems to have caused these women to adapt by strongly insisting on the use of condoms, going against the wishes of their male partners. Despite this however, some of the participants remain embedded in their traditional roles where they do not make the decisions and helplessly go along with what their male partners want. These women also seem to find it hard to trust that their partners would not sleep around. Some are even aware of it but feel there is nothing that can be done about the situation. This can be seen in statements such as "*...We didn't use condoms that time, we was always honest to each other. I must say I caught from my husband because I was not a lady sleeping out with other boyfriends. I just get ill after my husband passed away. That's right; he was sometimes doing intercourse with other ladies you see....*" made by participant A.

4.2.3. Stigmatisation and Fear

Misinformation or superstitions about HIV/AIDS as well as the lack of education, can lead to difficulties for people affected by the disease. This became apparent during this study with the social effects of the presence of stigmatisation. Additionally, ways to reduce its effects became known. The quotes below highlight cases where participants feared discrimination from people in their lives because of either having HIV/AIDS themselves or having an infected family member.

Participant B: *Maybe they can shout [at] me, criticise me ... they say but you shy, but you HIV positive.*

Participant K: *I'm not ready to tell people because the people are not right, other people is not right ... they are going to spread [rumours]; maybe shout at you.*

Researcher: *Do they know that your child is HIV positive? Those from church?*

Participant H: *No [I] did not tell them.*

Researcher: *Do your friends know?*

Participant H: *Some of them.*

Researcher: *Why some and not all?*

Participant H: *Because some of the friends cannot be trusted with your personal problems.*

Researcher: *So you just don't feel safe to tell your friends because you are not close to them?*

Participant H: *You can't tell each and every friend about your personal problems, because they might talk it the wrong way like I am a person who sleeps around with so many men (sic).*

Participant A: *That's the thing, people are very nasty ... I didn't have friends when my son was sick. I didn't even have a partner to go with me to the hospital. I don't like to think about it.*

Participant I: *I don't want to mix with a lot of people; I just stay at home.*

HIV/AIDS is a controversial sensitive topic and a lack of education can exacerbate insecurity and fear. Statements such as "... talk it the wrong way like I am a person who sleeps around with so many men", highlight how there is a negative association made between being infected with HIV and promiscuity; "sleeping around". In such cases, stigma or a perception of being stigmatised can cause fear, which may result in further isolation and alienation.

Researcher: *So you are not worried about anyone saying you have a grandchild who is HIV?*

Participant J: *I don't worry about HIV because it is better than any other diseases ... I talk about it at home with my children that whatever they are doing.*

Participant J: *Yes I know about HIV, and HIV does not kill anyone anymore if you follow the instruction and also take the treatment.*

Stigma and discrimination can be alleviated by providing information and education about the virus to the community (Tshililo & Davhana-Maselesele, 2009). A lack of this kind of education within the community and amongst carers who are affected by HIV/AIDS can lead to various problems. Participant H and Participant A expressed concern about how community members may react negatively towards people suffering from HIV/AIDS and the people close to them (such as the caregivers themselves), avoiding and shunning them. This can also lead to negative and false rumours being spread amongst the community members about those affected by HIV/AIDS. Caregivers and people living with HIV, who in turn do not fully understand HIV/AIDS, seem to feel this rejection particularly. They often isolate themselves and might not always know how to handle the impact of the illness on their lives. This can be seen in the statement, "I don't want to mix with a lot of people; I just stay at home."

This cycle seems to play less of a role for the participants that have received proper education on HIV/AIDS.

4.2.4. Conceptions of Caregiving: Gender Roles and Fulfilment

Gender roles can greatly affect what responsibilities fall on a caregiver (VSO, 2006). The data highlights the nature of the roles caregivers fulfilled within their households and how these roles affect their lives.

Researcher: *... if you had someone in your life, what would his role be in your life? How would he help you with your grandchildren?*

Participant C: *We will help the child together.*

Participant C: *I had a man, the brother of [name of a friend]; she died and she knew the child is HIV and then she did the right things like helping if I'm at work, she had to take the medication for the child and she helped me. Sometimes when she had to go to the shop she buy some clothes if its winter and she always want the grandchild to be warm at home.*

The gendered nature of caregiving became apparent. The elderly females were generally the only caregivers in their households. However, it is notable that four participants expressed interest in having the support of a male figure.

4.2.4.1. Role of the Mother and Wife

The role of the mother and wife emerged more clearly in the data, adding depth to understanding to this aspect of the participants. This included their responsibilities, traditional influence, as well as how such factors affect their quality of life.

Participant A: *Yes, it's my needs, but when we are partners, we can share to give children love. But most of all, the parent is the mother. You know when there is something wrong with your child.*

Participant C: *She is growing, sometimes she comes at home late and then I tell her the time she must be at home, she is supposed to put on the lights at home. Because she is a young lady now and she is growing, she must be at home early and she must do homework; not to do the homework in the morning, I don't like that We used to do that when I was young; my mother said to me I must come home very early ... and I would do supper.*

Despite needing the help of a male partner, the social convention that it is a woman's responsibility to take care of and raise children is very apparent. The tradition of caregiving is often passed from mother to daughter, grandmother to grandchild. In this way, girl-children learn and experience their 'female' role as synonymous with caregiving.

Participant A: *All my life it's too much, all of them. Now there is 2, it's like my own from... they grow up with me, I change them... ... they want their granny (smiles)...*

Lekalakala-Mokgele (2011) has highlighted how in African societies, grandmothers have always taken care of grandchildren. The selected excerpts below describe the experiences of grandparent-caregivers.

Researcher: *... you have to help him do things, you don't mind? You have got to take him to the clinic; it doesn't worry you?*

Participant B: *No.*

Researcher: *It's part of your routine?*

Participant B: *Yes.*

Researcher: *So they [adult children] don't provide any support for you?*

Participant C: *Yes.*

Researcher: *For this child?*

Participant C: *No... yes they... he gave me support sometimes when he was having money, but I am working. It's me who is looking after the child and give the support to the child.*

Researcher: *But why do you look after these children; is it for money or something?*

Participant E: *No, not for money I just want the children to feel safe and to get everything their need.*

Participant A: *... I must do the washing, and he was always calling me, give me this, give me that. I feel like I was doing a private nursing. I was always next to his bed; tablets I must give him.*

Participant C: *Ummm when the child, when my grandchild was young I was... I was feeling sad sometimes because I used to go to the clinic in the morning and then they take me to the hospital and then the hospital said I must go home. And then at 3 o'clock the child is very sick again and I have to take an ambulance to go back to hospital and then I stay at the hospital like a week...*

The female participants seem to be over-burdened by the level of accountability and the responsibilities they assume within their households. Chitayat (2009) notes how the unbalanced burden of caregiving on women and girls has an impact on their role fulfilment. This burden of time and effort is seen as the duty of the mother figure.

4.2.4.2. Role of the Father and Husband

Males also emerged as a theme within the care giving frames work. Namely the role of the male figures in caregiving, the nature and scope of their roles as fathers and husbands (in the participants' views) and also the impact of these roles on the participants. It should be noted that nine of the 10 participants did not have a husband or male partner at the time of the interview.

Participant A: *He must feed us, look after us.*

Participant D: *He must give me money and he must be like a grand dad and things like that in the house.*

Participant J: *If I was married, the husband is working and we are suppose[d] to plan on a payday to plan for the money before payday like this much we do this, and we do that.*

Researcher: *Now what do you want out of that partner? What must he give you to make you happy?*

Participant B: *Yah yah he gives me support. Money no, he loves him so much (gestures to the boy) and he takes him like the father.*

Researcher: *And you are very happy with that?*

Participant B: *Yes I am happy. He is there in the house. He takes him to the clinic. When he is going back [to work], the boy cries for him.*

Researcher: *If you had a man, what should his role be in your life?*

Participant H: *Supporting with everything money.*

Researcher: *But what is his main job?*

Participant H: *Financial.*

Several participants appear to hold the view that men have a role to fulfil in the household, which is mainly that of the provider or breadwinner, as seen in, “supporting with everything money”. However, despite these set views on the role of men in the household, there are indications from the participants for a need of further role fulfilment or extension of help beyond these traditional ideas.

The participants appear to have clearly differentiated roles in the division of their duties in the household, where women take on the majority of the household chores (Coltrane, 2000). There are many cases where it has been reported that men believe the caregiving role belongs primarily to women (Chitayat, 2009), and this was confirmed in the accounts of the participants. For example, when asking Participant A if she feels she needs to be the primary caregiver or if the role of parenting should be shared with the man in her life she stated, "Yes, it's my needs but when we are partners we can share to give children love. But the most of all, the parent is the mother."

"Social constructions regarding the division of labour place men in a position where it is difficult for them to move into a caregiving role, while women remain confined within their traditional roles (Saengtienchai & Knodel, 2001).

4.2.4.3. Role Reversal

Sometimes in life, individuals are expected to fulfill roles not normally ascribed to their gender or age. This phenomenon could be subtly seen within all the narratives presented, affecting the quality of life of the participants.

Participant D: *No, I want to work for myself; I don't want children's money, sorry. The children from today it's not like when we were growing up.*

Participant D: *I see myself as the mother, father, granny, grandfather everything else and all...*

Participant I: *Yes because I am not living my life now, I am living [for] my grandchildren's and kids' lives now because I am the only one taking care of them.*

Participant I: *...now I know I got a job to carry on my shoulder. I don't know when it's going to last because if I am carried to my grave my grandkids are going to suffer I won't be there; I am everything to them mom, dad...*

Participant L: *I was sitting; I was not working. I was looking after her; she was sitting in the house. I was doing everything for her, everything for her.*

Many of the participants reported experiencing dramatic shifts in the roles they play because of taking on the caregiving function. This involves both role reversal and the acquisition of new roles. As can be derived from the above excerpts, they report feeling overburdened with their newly acquired roles.

The impact of an individual in the household living with HIV/AIDS has resulted in the redistribution of household tasks (UNAIDS, 2008), where the bulk of the chores has been diverted to the grandmothers. The traditional roles that characterise African communities are reversed here, with the grandmothers taking care of ailing children and grandchildren. Traditionally, adult children would take care of their elderly parents. However, in this community, the elderly, who traditionally are to be revered for their knowledge and wisdom, have been forced, in many cases, to become breadwinners and the main source of caregiving assistance to their family and dependants (Nyasani, Sterberg, & Smith, 2009).

4.2.5. Financial Constraints

Money is a very significant factor that governs many people's lives. The researcher found that it has a significant influence on their lives. The following data indicates how financial needs directly affect their general quality of life.

Researcher: *Financially how does it affect you and why?*

Participant H: *A lot, a lot, I need lots of money for my bills.*

Participant L: *I think I need more help about the child maybe if someone can buy uniform and transport money or lunch box that's all I need.*

These statements reinforce the notion that the participants experience financial burdens due to their roles as caregivers and foster parents. Not only do they have to feed the orphans, but they also have to find money for school fees, clothing and transportation.

Participant K: *Eish damn, I suffer because it's my salary, but I try because my child is got R300 grant.*

Researcher: *As a foster parent, you get government grant, you have been to the social worker's where you get an order from the magistrate that you are a foster parent; so how much do you get paid?*

Participant E: *I get the foster grant.*

Researcher: *Which is how much?*

Participant E: *R4900 for 6 children*

Researcher: *Which is about R900 per child?*

Participant E: *Yes R820*

Researcher: *So it helps you to look after them; do you think it's enough money?*

Participant E: *No it's not enough money because it's plenty things children needs.*

Researcher: *Do you work?*

Participant H: *I am not working.*

Researcher: *Are you getting a grant for your 15 year old?*

Participant H: *Yes.*

Researcher: *Are you retired or working?*

Participant I: *I am not working at all.*

Researcher: *So do you get government grant?*

Participant I: *I get disability grant.*

Most of the caregivers obtained government grants; these either included child grants, valued at approximately R300, or foster grants, which were approximately R800 in value. Caregivers often rely heavily on subsidies such as government grants for income (Homan et al., 2005).

Researcher: *So how do you cope financially?*

Participant K: *Working*

Participant A: *No, I have come to that lady when she asks me, can you do me a bit of washing I will give you R100 or R50. I do small jobs only to keep us alive.*

Participant J: *I slaughter chickens in the farm, and they buy 10, and I give people on credit for 1 week and I get R800 for the grandchild.*

Participant L: *I have one extra room which gives me R350; this is a shack.*

The excerpts above highlight how some participants used their own initiatives to uplift their economic status through entrepreneurial activities.

Researcher: *You come from Eastern Cape? How long have you been in Masiphumelele?*

Participant B: *Long time now hey*

Researcher: *And why did you come here?*

Participant B: *I come to look the job*

Researcher: *For a better life?*

Participant B: *Yes*

Researcher: *And you think you found it?*

Participant B: *Yes I think so.*

Some of the participants migrated from rural Eastern Cape to Masiphumelele in the hope of gaining better jobs, services and government infrastructure. They viewed moving to Masiphumelele as an improvement to their lives. Despite this view however, Masiphumelele lacks certain resources and services which, in turn, negatively affects their quality of life.

4.2.6. Spiritual Support

Religion provides people with hope and has been found to be a coping mechanism for older adults who are faced with daily changes, as they grow older. Many elderly caregivers have associated their coping strategies with religion (Cavanaugh & Blanchard-Fields, 2011). According to research by Park et al. (2012), it has been proposed that religion is positively associated with mental health and well-being in later life.

Many of the participants mentioned that they have used religion to cope with the multitude of problems they endure. Prayer, chanting and meditation, which are part of religious and spiritual ceremonies, play a role and have been shown to help relieve stress and bring down blood pressure (Louw & Louw, 2011). This section explores the role of religion in participants' coping strategies.

Participant B: *When I am praying or when I feel sad like when I am praying... I see*

something, something touch me, I pray, pray, pray, I cry, cry, cry and then I wake up feeling alright.

Participant C: Umm I need the church, they support my grandchild because they know everything about my grandchild.

Participant A: I worry a lot. When I pray I ask God to send someone to help; to show me a way.

This spiritual support provided by religion provides the participants with comfort and assurance. These coping strategies include placing their trust in God, praying and receiving strength from God. It has been found that many of the elderly caregivers, who face crises such as death of a loved one and terminal illnesses, cope by using religion (Cavanaugh & Blanchard-Fields, 2011).

Participant C: They help me because my grandchild is also in the church; she is leading the small children. Sometime we have the workshops at church about HIV and AIDS and healthy foods; and since she is a leader at the church they invite her when we have these meetings to be there.

There are many advantages of religion and spirituality, such as higher life satisfaction and psychological well-being. In religious and spiritual communities, there tends to be increased social support, positive relationships and a wider social circle. Social support has also been positively associated with life satisfaction in older adults, and this is often found in religious communities. Social support is a predictor of increased quality of life, which is a positive outcome of religion in the lives of older adults (George, as cited in Park et al., 2012). This is highlighted in the excerpt below:

Participant A: Yes and the church didn't abandon me from the first step when my son got ill. They come visit me, and my daughter is also in church; she asked the church people to come and pray. After that, I feel I have got a family.

Recent studies have shown that higher levels of religious activities predict greater life satisfaction among older adults (Moberg, cited in Park et al., 2012). This is succinctly captured by the following quote made by participant J:

Participant J: *I can still enjoy life because in everything, I trust God.*

4.2.7 Lack of Friendship

As highlighted previously, social support is very important for a good quality of life. This becomes apparent when looking at the role of friendships and subsequent consequences of social isolation within the lives of the participants.

Participant B: *I have friends just around me I am not going from house to house.*

Participant I: *I just stay at home with my kids and our problems, I don't have friends now when I get out of my marriage I drank a lot. When I found out I was HIV positive I drank too much so I fell sick and then I stopped drinking so I am alone now...*

Participant L: *Sometimes I'm not having lot of friends. I'm having only 2 but the people always were coming to my house. Sometimes a lot of people comes to my house just to talk.*

As can be seen from the quotes above, some participants have experienced a loss of friendship that has had a negative effect on their wellbeing and quality of life. There is social isolation reflected in the participants' narratives. For some, this appears to be self-imposed because of their own preference and privacy concerns. For others, it appears to be a result of the stigmatisation associated with the disease, whether by infection or by association.

Participant B: *No, I do not have lots of friends, maybe my friends, one or two that's HIV also. I talk about the HIV and I am open to tell them*

It is also significant that having at least one very close friend or confidant in old age, such as in the reflections of Participant B above, helps to buffer against the loss of roles and status that accompany this time of life, as well as with the stigma of the disease. It has been reported that women seem to deal better with stress in life as they have more intimate friendships (Berndt, 1992) Friends, who make high demands however, especially during adulthood, can be seen as a liability rather than as a positive factor (Cavanaugh-Blanchard Fields, 2011). The participants' loss of friendship can increase the risk of stress suffered in life and exacerbate social isolation.

4.3. I Poems

This study used *I Poems* as a representation of the subjective views of the participants to augment the findings in the study. Each *I Poem* forms a single strand of narrative that allows the reader to see both overt and subliminal themes from the full narrative given by the participant. The *I Poem* also filters out /technical words, and summarises the participant's stories as a whole, to better associate it with the research questions and aims (Gilligan et al., 2003).

An *I Poem* is constructed for hearing how the person speaks about himself or herself. To do this, all first person "I"s are identified in sentences along with verbs and accompanying adjectives (where appropriate). Then all I-verb phrases are placed on their own individual lines in the order of the original sequence (Gilligan et al., 2003).

The *I Poems* make the voices within the narratives easily accessible. In the full narrative, information can become clouded or disrupted by emotions (like laughter), excess words, pauses, word-search sounds like 'ummm' and 'ahhh'. *I Poems* circumvent this by extrapolating the root meanings of what is being expressed by the participant. The researcher then tested these voices against the thematic analysis of literature and data collection.

I Poems emphasise the subjective views of the participants, their sense of place in the community, their hopes and needs and their understanding of their situation.

According to Gilligan et al. (2003), in the analysis of the respondents' narratives, the researcher must read into the voices multiple times to ascertain the overarching themes that commonly occur.

Different narrative voices are evident in each participant's story. These voices express the embodiment of coping with a condition of diverse symptoms and effects:

Participant D:

I have high blood pressure

But I don't feel old and things like that

Participant I:

Yes I am stressed

I have got shingles

Even the doctor says I got stress

I'm on TB treatment

I got the shingles now on my body

Participant C:

I think it affects me

I am diabetic

I have got high blood pressure

... Things make me sad

Participant A:

I was so thin

I didn't have any strength

I was so tired I couldn't even sweep the house

The participants interviewed, reported a number of ailments showing how their mental and physical health is affected by HIV/AIDS.

Participant L:

Yes I am having [high] blood-pressure

I think the blood-pressure is caused by my daughter [dying]

Worrying too much

Sometimes I am feeling the cramps and everything...

And then my [grand]daughter says to me

Please mum I know you are working hard

Please go to the doctor to check yourself

Participant C:

I always tell her:

I was young... I talk a lot [to her]

I say to her

You see me; I take my medication everyday – I inject myself [diabetic]

This is the life: even your medication is your life

The participants, at a personal level, acutely feel the awareness of HIV/AIDS and its outcomes. A better knowledge and understanding of HIV/AIDS also increases participants' ability to cope with associated difficulties.

Participant D:

(Researcher: Did you know much about HIV?)

No, nothing...

I hear about it, yes,

But I don't know much about it

Participant I:

I wasn't worried

I was not aware of it

I learnt about it when I knew I had it [HIV]

Participant B:

I hear before, that it is a disease [that] is dangerous

I was losing weight

I hear from the radio that people is sick with HIV

I was using protection after I hear

It appears that the affected elderly caregivers were not concerned about HIV/AIDS until they themselves or their family members were affected. It is clear that the problems associated with HIV/AIDS were not as prevalent or widely acknowledged during their youth. The participants' responses indicated that their fears and concerns around HIV/AIDS become more pressing or immediate once they themselves or a family member became infected

Participant J:

I hear about HIV on TV

I did not like to hear about HIV on TV

I was scared

Participant D:

Because people can talk so much

I would rather keep to myself...

Participant B:

I have [not many] friends that's HIV

I talk about HIV and I am open to tell them

I don't want to tell [strangers]; it's only my family, only they know

The people sometimes, they can insult you (laughs)

Participant I:

I don't feel like [socialising]

I just stay at home with my kids and our problems
I don't have friends
I get out of my marriage
I drank a lot
When I found out I was HIV positive I drank too much
I fell sick
Then I stopped drinking
I'm alone now

An additional element which emerged in the narratives was that fear of stigmatisation can lead to a breakdown in social connections and self-imposed isolation. It is further suggested that education on HIV/AIDS can play a role in reducing stigmatisation.

Participant A:

I am not shy...
It's not to hide, it's not [a] secret to hide...
We are living in one community
[A local] is shy from me, he don't want I must know his status
We are all together in the clinic; I can't hide myself away
I am so glad to speak nicely
I want people to help me when I get hurt
They will know [that I am] HIV positive

Participant I:

I don't care what they say
I'm on my way to my grave
I am tired of everything
I don't care if everyone knows

Participant L:

I'm not scared
I'm telling the people
Even if someone is having a sickness
I tell [them] how to manage:
I was not working
I was looking after [my daughter]
I was doing everything for her

However, other participants tried to be as open as possible and accept their situation instead of isolating themselves. This is another type of coping mechanism employed.

Participant L:
The lady came...
I was sitting [in] my house
She came and told me [about the study]
I was so happy
Although I didn't know you – I didn't know I was [getting] parcels – but
I feel happy to come to talk to someone I don't know

As difficult as their lives are, physical and emotional support mean a lot to them. This can be seen in the value attributed to these connections in the participants' reflections.

Participant C:
I cope with it
They gave me the container to stay with my child
When I forget, she always say to me
Mommy I am taking the medication
When we wake up very late
She take the tablet

She says to me when its 1st break, I am going to have something to eat and then drink my medication

Participant D:

Researcher: Do you think that older people should be educated on HIV?

I don't know (laughs)

I don't know if they know

They need to know

[The clinic] told me I must know it

We can do meetings [where] everyone can learn

Participants rely on their family as well as outside support from community-based organisations and counsellors. This can be seen in the positive engagements recorded between family members' looking after one another both physically and psychologically.

Participant J:

I am happy to look after my grandchild

I can live for her

Participant B:

Researcher: So your life is better, and do you think your life is better or worse because you have this boy that you must look after?

I have got someone now

I was thinking I have no children

Now I have got; I am happy

As can be derived, there seems to be a symbiotic supportive relationship between the child and the caregiver.

Participant K:

I need to go to clinic

*If the clinic give us a place to go to support
I mean, to support others [who] don't know [of] HIV*

Positively, government clinics and NGO's are seen as community resources that provide support to those infected with or affected by HIV/AIDS. This is encouraging in terms of participants' actively accessing available resources and services.

Participant D:

I see myself as the mother, father, granny, grandfather, everything else and all

As highlighted above, the caregiver can be stressed in his or her occupation of several different roles.

Participant A:

I didn't grow with African culture

I grow up with Coloured culture

I feel that I always think that one of my sons would take me in and stay with them

And treat me like a mother like I did grow them up

Participant C:

I am working...

I was married long ago

My husband is still alive – [he is] very sick in the Eastern Cape –

I have 3 daughters and 1 son

Participants often seemed to prefer being cared for rather than to be the carer. This could point to the toll that the caregiving role necessitates.

Researcher: So you don't think that looking after him has affected your money?

Participant B:

Yes, but nothing I can do (laughs)

I am still look[ing] to go to the social worker to give me help...

The social worker; they do everything

Participant J:

I feel that I am poor

I grow up in a poor family

I was poor even here in Cape Town

I am still poor

The *I Poems* of participants B and J show the impact of a sense of resignation and helplessness, which reflects on their quality of life. This is emphasised in phrases such as “still looking” and “still poor”.

Participant C:

Researcher: Did you think at 56, you would still be working?

(Laughs) No I didn't know that

I look at my life at age 20;

I was thinking I will stay at home in my house, my children will support me

I was thinking of that but now I am still working

Participant D:

I want to work for myself

I don't want my children's money

The children from today are not like when we were growing up

It's different

Participant L:

I'm looking after the kids

In my house...

I need more help [for] the child

Uniforms and transport money or lunchbox...

That's all I need

The role of the elderly caregivers has changed from that of being dependent to needing to become financially self-sufficient because of various circumstances. The needs are also not self-centred but relate to those for whom they are caring.

Participant E:

I feel pain

I don't have enough money

I worry

I get stress

I want my [children] to get warm things

I do not get the things

Here the physical and emotional toll of the caregiving role is clearly manifested in E's narrative.

Participant B:

I am fine

I am taking ARVs everyday

I am thinking about him in the future

I can even get rent

I am the one who is looking after this boy

Participant C:

I am looking after my grandchild

I take care of the child [for] the mum...

I am staying with the boy –

I must go to the social worker

I am the foster mother

While financial constraints exert pressure on the caregivers and their quality of life, there are psychological and social QOL dispositional benefits accruing from providing care, especially to children.

Participant K:

Eish! Damn, I suffer

It's my salary, but I try because my child [has] a grant...

It's only R300

The excerpt above highlights that most of the caregivers are aware of government grants that help to alleviate their plight.

Participant A:

I didn't have friends

I didn't even have a partner

The church didn't abandon me

The church people [came to] pray, after that I feel I have family

Participant C:

I do my washing

I go to church... I need the church

I am scared to talk about [HIV]

I am scared to talk to other people

They are going to talk about my child

The church functions as an important means for social support in the absence of other emotional bonds, notwithstanding fears around stigmatisation. The statements above highlight how the church environment provides a trusted source of stability in difficult times.

Participant B:

When I am praying or when I feel sad when I am praying

I see something; something touch me

I pray, pray, pray

I cry, cry, cry

I wake up and feeling alright

Participant K:

I pray, I pray

I cry, I cry

When I'm finished [crying] I sing

I was so sad

I was so angry;

When I go to church I talk with the other women

But it's only God who can help you

Participant E:

When I am in church I get something in my heart

I go there with stress

Once I am there my stress is gone

Participant L:

I was feeling very bad and [it was] very hard

I was praying to God

Please God, let me be colder, let me give love to my daughter

Give love to my grandchild...

Only God was helping me

Sometimes the nurses are coming; they help me to clean my daughter

To clean my house

Then I was enjoying – not in my heart – I was sad...

It's better

I must enjoy

Several participants identified spirituality as a powerful resource in helping them cope on an individual level with the challenges of HIV/AIDS. This was especially true in their attempts to handle their negative emotions.

Participant I:

They know: I told them when I found out my daughter and me are HIV

I nearly killed myself

I drank a lot

Participant C:

(Respondent speaks of her sister)

I called the mother to come to test

The mother refuse, she said:

I am HIV

My child is HIV

My child is going to die, I am going to die

As seen in the case of Participants I and C, the effects of isolation and lack of proper support may drive people affected by HIV/AIDS to substance abuse and into despair.

Participant D:

I have friends just around me

I am not going from house to house

My family stays there and down there

I'm not going there

Participant A:

Researcher: What can be done right now to help you? Is there anything that can be done, by the community that is not being done?

I don't know

I can't say

I have never been helped before

I don't know how I can start to be helped

I would like to receive counselling

Participants D and A provide examples of how overburdened caregivers find themselves isolated due to the fact that they have no time to visit their friends and family. Despite isolation being self-inflicted among some of the participants, there is still a need for outside support.

4.4. Contrapuntal voices

Gilligan et al. (2003) refer to contrapuntal voices as voices having two or more meanings: they may be notions of contradiction or simply layered emotions present in the same statement. The themes below illustrate some of these nuances.

Table 3: Contrapuntal voices emerging in the interview data

Contrapuntal Voice:
4.4.1. Multiple Voices of Emotions
4.4.2. Voices of Caring Vs. Burden of Care
4.4.3. Voices of Contentment vs fear
4.4.4. Voices of Depression
4.4.5. Voices of Disclosure Vs. Silence
4.4.6. Voices of the Past, Present and Future
4.4.7. Voices Of Trust Vs Mistrust

4.4.1. Multiple Voices of Emotions

The participants experience a multitude of emotions through the caregiving process. They report experiencing, sometimes in extremes, contentment and depression or a mixture of both as they contend with their daily struggles. This reflects the multifaceted, ambivalences and ambiguities associated with their experiences.

4.4.2. Voices of Caring vs. Burden of Care

Participant L: *It's better because I'm not alone. Sometimes if I'm sitting she is talking to me. Sometimes if she see me like now I'm little bit crying, she is coming to hold me; she's asking me why I'm crying, and she is saying to me, "Please my granny don't cry you must believe that the Lord is here for us"...*

Participant A: *...they can't sleep by other people. The whole family can take them home, they must hire a car in the middle of the night. They want their granny (smiles) that's why they have got a problem. We can't let them go to people, but only for the day. They will say we go to visit but at night, they want their grandmother...*

Participant A: *It's like my own ... They grow up with me.*

Participant B: *I have got someone now. The time I was thinking so much; I was thinking I have no children but now I have got I am happy.*

Participants described having gained a sense of purpose, pride and achievement from their caring role. This feeling was not only from raising their own children (who may have become infected with HIV/AIDS), but also from becoming the single-most important person in the lives of orphaned and abandoned children. The participants experienced a sense of fulfilment and perceived themselves to be playing an integral role in the lives of those cast aside by their family members in the community.

Participant I: *[I am] Always busy with the children so I don't have the time.*

Participant A: *I must do the washing and he was always calling me, 'give me this, give me that.' I feel like I was doing a private nursing. I was always next to his bed, tablets I must give him...*

Participant C: *I was feeling sad sometimes because I used to go to the clinic in the morning and then they take me to the hospital, and then the hospital said I must go home, and then at 3 o'clock the child is very sick again and I have to take an ambulance to go back to hospital and then I stay at the hospital like a week. Then I come back at home, the child started to get sick...*

Participant C: *It's me who is looking after the child and give support to the child.*

However, as can be seen in these latter examples, this burden of care can become demanding and overwhelming.

4.4.3. Voices of Contentment vs. Voices of Fear

Participant A: *Yes they brought love to my house. I would be very, very sad if their mother will come one day and say she's taking them.*

Participant J: *I am happy to look after my grandchild because she is my child's child.*

Participant J: *Yes until she dies I can live for her.*

Participant L: *Yes I'm happy to have my granddaughter. Although my heart sometimes I'm feeling bad because if myself I'm getting sick or else I died, there is no one that can take her because the family of her father [will] not support her. And then I don't know where is the family now because the father just left the mother before she died; then even my family are not helping me they is no one in my family helping me.*

Participant L: *It's better because I'm not alone; sometimes if I'm sitting, she is talking to me. Sometimes if she see me like now I'm little bit crying, she is coming to hold me, she's asking me why I'm crying, and she is saying to me, "Please my granny don't cry, you must believe that the Lord is here for us.*

The participants reported that their experiences as caregivers bring them contentment. They also expressed a sense of satisfaction in caring for dependents. They reflected emotions such as love and happiness as well as a finding a reason to live.

However, another voice becomes apparent in the narratives wherever this contentment is present. There is a definite voice of fear. This fear pertains to losing the person in their care, which, in turn, would also mean a loss of this contentment. Additionally, some participants fear the consequences for their charges if something were to happen to them. With old age, passing on is a very real reality and there is a fear as to what will happen to those in their care if they are not there anymore.

4.4.4. Voices of Depression

Participant I: *First it's my marriage falling apart, then my kids. I found out about HIV, so I have to live with that. I got TB and gout now; I have got these shingles; it's too much to take.*

Participant I: *I don't care what they say now because I am on my way to my grave. I am tired of everything, my kids don't take it. I don't care if everybody knows.*

Participant K: *Ya before last year I was so I was so sad. I was angry, angry and I was, but when you go to the church I talk with eh... other woman to give you support. She said, "No, you must pray because there is no one can help you; so it's only God who can help you; you must be strong, you must be strong."*

Participant L: *I was feeling very bad and very hard when the years was coming. I was praying to God "Please God let me to be colder [sic]; let me give you love to my daughter, give me love to my grandchild," because the only God was helping me. Sometimes the nurses are coming that time maybe they coming with food parcels and maybe they help me with to clean my daughter to clean the house.*

Participant L: *I was crying a lot even sometimes now.*

Some of the participants exhibited depressive symptoms and showed indications of being overwhelmed by their circumstances. Casale, Wild, Cluver and Kuo's (2014) research points to high risk of clinical depression among caregivers who are HIV positive and/or are chronically ill. There is concern that heightened depression may make the elderly caregivers vulnerable to suicidal ideation. The church, as social support, helped alleviate this sense of depression for many of the participants.

4.4.5. Voices of Disclosure vs. Silence

Participant A: *People are very nasty; they can be very nasty. I didn't have friends when my son was sick. I didn't even have a partner to go with me to the hospital. I don't like to think about it.*

Participant A: *I am scared. Some people are very scared of this. They don't want to say but they don't like us.*

Participant C: *I am scared to talk about it to other people; I am scared to talk to other people.*

Participant D: *No... because people can talk so much, so I would rather keep to myself.*

Participant E: *Yes I'm scared they might not come and support me because I have a child with HIV.*

Participant H: *You can't tell each and every friend about your personal problems, because they might take it the wrong way like I am a person who sleeps around with so many men.*

Participant H: *I've never told anyone; I don't know who is HIV... I don't know who is not.*

Participant H: *No, I can't tell in the church; I can't tell everyone in the church.*

Participant K: *Ya, I am not ready to tell people because the people are not right, other people is not right.*

Participant A gave a difficult account of her experience of being stigmatised by the community. She felt rejected by her community and treated as an outcast, as can be seen in the statement, "Some people are very scared of this. They don't want to say but they don't like us." The participants' barriers to disclosing HIV diagnosis have persisted. These include fears of stigmatisation, rejection and abandonment, as well as

discriminating treatment such as eviction or termination of employment, retribution, violence, and other forms of abuse. This illustrates the stigma associated with having HIV/AIDS (Lekalakala-Mokgele, 2011). Reverting to silence, thoughts of, “I can’t tell everyone” (participant H) is a safer option for many of the participants.

The participants want to protect their children and grandchildren from hostility by their extended families and community, where they might be rejected, denied access to schooling and health care, and left to fend for themselves (Avert, 2011). The participants’ experiences reveal the multi-layered nature of stigma. External stigma is rooted in fear and judgment of what is different, leading to blame, distancing, and discrimination. Internal stigma, also described as self-stigma, is caused by the internalisation of shame, blame, hopelessness, guilt, and fear of discrimination associated with being HIV-positive. This can affect caregivers and family members who may internalise feelings of shame, guilt, or fear (Brouard & Willis, 2006).

Conversely, some of the participants find that they were able to overcome the fears of stigmatisation and were able to disclose their status within their communities:

Participant A: I can disclose myself, but I haven’t got that problem. The people come for help from me because I disclose myself.

Certain advantages of disclosing your HIV status are a sense of closeness, sharing, living authentically, loss of fear and increased confidence.

4.4.6. Voices of the Past, Present and Future

Participant A: I always think that one of my sons would take me in and stay with them and treat me like a mother.

Participant C: I was thinking of that when I become 56: I will stay at home in my house with grandchildren and my children will support me.

Participant I: I was hoping for a happy life, marriage, not working and to see my kids living a happy life... not this.

The participants' voices span a lifetime and therefore shift between the past, present and the future. The voices of the past represent the expected futures of the participants. By definition, the quality of life of individuals is dependent on their expectations of the future. The participants provided accounts of past voices and how they envisioned their futures:

Participant A: *I did always thought he will take me in when I don't work anymore. Marra [but] at the moment, he hasn't got a place on his own.*

Participant C: *I was thinking of that but now I am still working; I am 56 years now.*

The participants anticipated a future entirely different to what they are currently enduring. The participants expected to be provided for by their children and grandchildren. Their children and grandchildren are, however, still in need of care. The voice of the present represents by the current situations of the participants.

The voices of the participants encapsulate their current struggle. The participants have had to endure physically demanding occupations for most of their lives and are anticipating retirement. There is a clear discrepancy between what they expected in their twilight years and the circumstances to which they have had to adjust.

Participant I: *I don't care what they say now because I am on my way to my grave. I am tired of everything. My kids don't take it; I don't care if everybody knows.*

Participant I poignantly expressed how pessimistically she sees her future. She had a very bleak future vision of her future, which she expected to be filled with fatigue, despair and hopelessness, eventually leading to death. Her *I Poem* represents a requiem to her lived experience, which reflects an expected poor quality of life.

In African cultures, time is viewed very differently to Western cultures and this permeated the participants' responses. African cultures do not follow the linear

convention of time found amongst western European and northern American cultures. Instead, they are intimately attuned to a long past filled with their traditions and heritage, the present and a very limited view of the future (Meyer et al., 2011).

4.4.7. Voices of Trust vs. Mistrust

Participant E: *No I don't like man, I don't like man; I stay with my children.*

Participant J: *It's like when you are being supported by a wall and then that wall falls then you fall also. So that's why I choose to be a single mother; maybe one of my children can help me support me also.*

The voices of mistrust and trust run concurrently throughout the accounts of the participants. HIV/AIDS infection has, in some cases, brought to light the indiscretions of partners that for many years went unnoticed. Partners who have been exposed to HIV were faced with both life-changing illness as well as the reality of their partner's infidelities. These accounts describe the loss of trust within relationships.

Participant J used the metaphor of a wall to explain the level of trust that she experienced when she was in a relationship with the partner. Trust provides confidence and security in the context of the relationship. However, when their trust was broken by infidelity, she lost both the confidence and sense of security she once had in their relationship.

Participant D: *No I want to work for myself; I don't want children's money, sorry. The children of today, it's not like when we were growing up.*

The participants had expected their children and grandchildren to provide them with support as this has been the cultural expectation for many years. However, due to their declining physical health, the adult children can no longer provide for their elders as they once would have. Participant D has lost confidence in her children and grandchildren's ability to care and provide for her. This is seen in the statement, "it's not

like when we were growing up” above. With a limited amount of working years remaining, she and those in her care will likely be at the mercy of government grants.

Participant A: People we are living in one community. When he see me he rather not take his tablets. He is shy from me, he don't want (that) I must know his status. We are all together in the clinic.

Participant A: You see if somebody knows you have got HIV, they never ask water at your home and HIV is not something that just go to a person.

There seems to be a level of mistrust on the part of the community due to stigma. This is driven by fear and ignorance. They tend to become isolated, existing in a world of their own, apart from the rest of the community. Cut off from the community, they can no longer rely on the system in which they lived and were part of for many years. They can no longer connect with their communities for fear of stigma and discrimination. This mistrust is encountered in the most basic relationships within the family and has made its way into the broader community.

4.5. Conclusion

The quality of life of a particular person depends on the subjective interpretation the individual derives from the circumstances and events that are seen as a priority in their lives. Quality of life is increasingly acknowledged as being strongly dependent on the individual's subjective experience. Older women affected by HIV/AIDS are exposed to greater risk factors and face a potentially drastic reduction in quality of life due to overwhelming circumstances. However, mitigating factors such as financial resources, coping skills and personality traits, do predispose certain people to handle life challenges more effectively than others.

In this chapter, the social, spiritual, mental, physical and financial domains of the participants emerged through various themes. The researcher found that the participants' mental and physical health was severely affected by HIV/AIDS. Stigmatisation also adversely affected the mental state of the participants because of fear and a lack of education about HIV/AIDS amongst both the participants and their

community. Effective education and awareness seems to be a strong mitigating factor against stigmatisation and gives a sense of empowerment.

Role strain, which was seen in cases where grandparents were raising their grandchildren, also had implications on a number of other factors, which, in turn, affected their quality of life. Most of these caregivers occupy several roles at once due to the absent parent figure/s. This means they are often the primary breadwinners. However, physically these elderly caregivers are too old to still be working for a living as well as raising children without it severely affecting their health. The caregivers thus face heavy financial constraints caused by having to sustain and support their families while lacking the ability and strength to generate a large enough income to meet their needs.

Support from the community, especially spiritually, aids the participants greatly. Many had lost friends due to stigma but a good support network that they can trust, whether from their church or friends and family, has a very positive effect on the participants.

The *I poems* delved deeper into the themes mentioned previously. An understanding was developed of the ambivalent feelings sometimes accompanying the caretaking role as well as of the nature of the relationship between the caregiver and their charges as they helped support each other in various ways. Additionally, the way in which different participants coped with the pressures of their daily situations and the role that community support plays in the lives of the participants was explored as an emerging theme.

Finally, the contrapuntal voices gave expression to another level of meaning making in the unspoken elements of the participants' narratives. There was an acute degree of strain expressed, with participants being torn between the urge to care for their charges, versus the need to care for themselves. This pressure placed a heavy strain on the physical and mental health and wellbeing of the participants, thereby compromising their subjective quality of life. These findings will be fully analysed and discussed in the following chapter.

CHAPTER 5

DISCUSSION OF FINDINGS

5.1. Introduction

The current study sought to deepen the understanding of how HIV/AIDS affects the subjective QOL of the elderly caregivers. In this chapter, an in-depth interpretation of the findings discussed in chapter 4 will be presented, including how these findings relate to the theoretical frameworks of the study and the current literature. Thematic analysis, in conjunction with an adapted version of the listening guide method proposed by Gilligan et al. (2003), and the narrative method were used to identify the dominant themes in the data. These approaches guided the extraction of the *I Poems* and contrapuntal voices from within the participants' narratives.

This chapter also highlights problem areas where more support could help increase the QOL of the elderly caregivers and makes recommendations to Government and NGOs as to where they could potentially improve their strategies. It is suggested that implementation of these recommendations, in conjunction with improved service delivery, may have a greater positive impact in the community of Masiphumelele.

The chapter concludes with a technical review of the trustworthiness of the research method, and the limitations, advantages and implications of this study for theory development, application and future research.

5.2. Integration of themes

It is clear that the elderly caregiving participants of this study have been affected by HIV/AIDS. This applies in whether they have lost a partner, an adult child or are looking after children left orphaned as a result of the pandemic (VEN, 2010). It emerged in the stories of the participants, that HIV/AIDS has a range of different impacts on the quality of life of the elderly caregivers; there were both positive shifts and negative shifts observed across multiple life domains during this study. The data, as presented in chapter 4, will now be discussed and interpreted in conjunction with links made to the

literature and overall findings. The discussion of themes reveals these positive and negative shifts in QOL, contextualising them within Role Strain theory. This examination is premised upon the understanding of the participant as an individual in their life and employment, and in the struggles of performing the duties associated with their caregiver roles.

5.2.1. The Impact of Mental and Physical Health on Quality Of Life

The *I poems* presented in Chapter 4 painted a picture of a powerful struggle to cope with the pressures of deteriorating mental and physical health linked to the effects of HIV/AIDS. Participants taking care of individuals, some carers living with HIV/AIDS themselves or just caring for someone that has the disease, struggled with the effects of it in their lives. This occurred in terms of the physical impact, as well as the psychosocial sequelae and adjustments required to cope. These complexities are further influenced by the ageing process, affecting the participants' health and abilities.

Amongst all the participants, the most significant effect of HIV/AIDS identified was the major impact on their physical health due to the intense physical and emotional strain they encountered in their caregiver role. A range of physical and psychological symptoms was identified, including high blood pressure, shingles, diabetes, anxiety, and depression. Participants described various adaptive and maladaptive means to cope with this strain, ranging from substance abuse to relying on prayer and religion, and turning to specific friendships and social groups as means of support. It became evident that, for the participants, having to care for immediate family members (as patients) can cause physical and emotional strain, and their health can deteriorate as a result (VEN, 2010). The physical, psychological and social impacts of caring on a woman's well-being in particular, are seldom recognised (WHO, 2003). Given that the sample was comprised of women only, the impact of the strain described above, in terms of gender roles, is recognised within this study and is specifically discussed later in this chapter.

The literature identifies the consequences of caregiving as far exceeding an emotional impact alone. The physical labour of caring for sick family members and orphans can be detrimental to the health of elderly caregivers. Physical tasks such as lifting and washing patients, helping patients to the toilet, cooking, cleaning, doing

laundry, and farming, often fall primarily on females (Corby et al., 2007). Furthermore, physical strength is needed to care for children as well; a prerequisite for activities such as picking them up, cooking food and cleaning (VEN, 2010). Due to the natural ageing process, as caregivers become older, it becomes harder and more demanding for them to maintain the level of activity required in their caregiving roles (VEN, 2010). Physical impairments affect many older caregivers, including strained muscles, diabetes, fatigue, arthritis, high blood pressure, and hearing, vision and mobility problems (Knodel, 2001). Responses from participants alluded to a specific concern for their health as a direct result of the stresses and anxiety related to their caregiving responsibilities.

Interestingly, the researcher noted an increase in distress and decrease in happiness as the participants got older. This is consistent with the literature that states the ageing process places increasing physical and emotional strain on those in caregiving roles (Knodel, 2001). For some, their illness seemed a hopeless battle they could not win. For others, treatment and alleviation of their physical symptoms gave them hope. This, along with better services such as access to social grants, added to their general quality of life. Some participants indicated that they expected to die soon “anyway”, and were therefore resigned to coping with their ailments.

Several studies have noted that the emotional distress endured by caregivers can be substantial (Grobler, 2011; Lekalakala-Mokgele, 2011; VEN, 2010). Caring for several children from extended families and neighbours is often associated with increased worry and anxiety. For example, with more mouths to feed, the financial pressure experienced by the household is increased. Many elderly caregivers find themselves having to care for loved ones while also attempting to cope with their own declining health. A number of participants expressed insecurity about the protection and custody of the children in their care should they die. This is a traumatic and stressful consideration for the caregivers. This situation is even more complex for caregivers who themselves have been diagnosed as HIV positive, as they are likely to be coping with a new understanding of their lifespan. In addition, caregivers indicated that they did not have time to grieve for those they had lost because they have to support and care for dependents left behind (Saengtienchai & Knodel, 2001).

Feelings of sadness, worry, and, in one participant's case, thoughts of suicide, were part of the range of emotions displayed by caregivers. The contrapuntal voices, which emerged in the participants' responses, point to a weighty voice of depression. As mentioned, one participant admitted to wanting to "drink herself to death", while others showed signs of immense emotional distress such as crying. Depression, anxiety and other psychological disorders such as post-traumatic stress disorder were noted among participants. This can gradually erode the ability of the caregiver to be effective in their caregiving role (Pirraglia et al., 2004).

These negative emotional states manifested as a very powerful sense of despair and frustration amongst the participants. According to Nevid et al. (2005), common features of depression include mood changes, such as being persistently sad, excessive crying, loss of motivation, and loss of function in daily tasks and thoughts of suicide or death. All of these markers were present in the various narratives of the participants, despite their not being able to name what they were feeling as depression. It is very clear within the participants' reflections that they are experiencing depression. Two *I Poems* derived from participants' narratives illustrate this:

Participant I:

I don't feel like [socialising]

I just stay at home with my kids and our problems

I don't have friends

I'm alone now

Participant I:

I don't care what they say

I'm on my way to my grave

I am tired of everything

I don't care if everyone knows

Despair is a common human emotion that is occasionally experienced during life but usually dissipates overtime. It can be understood as a feeling of deep

discouragement and loss of faith about one's ability to find meaning, fulfillment and happiness, and a satisfactory future for oneself (Diamond, 2011). If despair becomes chronic, diminishing quality of life, impairing daily functionality, and keeping the individual from moving toward his/her goals; dreams and desires it can be regarded as clinical (Diamond, 2011). Clinical despair can be conceptualised as intense hopelessness, helplessness, powerlessness and pessimism about life and the future.

The women who expressed this voice of depression most powerfully had several features in common. They did not have the coping mechanisms and skills necessary to deal with their situations properly and they lacked the resources (emotional, financial, or both) needed to take care of their charges. They were also generally much older, suffering more acutely from the aforementioned hardships, which place strain on their declining health. It is suggested that, given the lack of options available to these participants to cope with or improve their situations, many of the depressive feelings reported by participants are likely caused by hopelessness and frustration,

Some of the participants had better financial and social coping mechanisms in place than others. These adaptive factors were associated with a lesser degree of distress. Participants who showed maladaptive coping mechanisms were likely to express a greater degree of psychological distress. This was seen in participants' substance abuse and the perception of their situation as hopeless.

As highlighted earlier, according to Cavanaugh and Blanchard-Fields (2011), the state of health of a person directly affects their quality of life. The participants in this study who had been diagnosed with HIV/AIDS struggled with a combination of mental and physical symptoms caused by the virus. Their mental and physical health, as well as the reciprocal relationship between the two elements, can be seen to affect the general wellbeing of the participants. The ability to provide proper mental and physical self-care (even if assisted) could increase a participant's quality of life.

5.2.2. The Impact of HIV/AIDS Education and Awareness on Quality Of Life

In a 2009 research study by Tshililo and Davhana-Maselesele, it was found that most family caregivers lacked adequate education regarding HIV/AIDS and its treatment. In this study, the researcher found that, although there was a prior level of

HIV/AIDS awareness amongst participants, it was largely ignored or not salient for them. It was only after the participants were infected HIV/AIDS, that the need for awareness and more knowledge became important to them. The *I Poems* that emerged illustrate this by showing that the elderly caregiving participants had learned a lot about HIV/AIDS, but unfortunately very late, or after it had already affected their lives. HIV/AIDS awareness initiatives were available at local clinics as well through NGOs like Living Hope. Certain media sources also provided significant HIV/AIDS information.

Participants spoke of first learning about HIV/AIDS from popular media forms in South Africa, such as radio and television. The information contained in these media forms was based on what the HIV/AIDS virus is, how it spreads, how to properly care for someone that has HIV/AIDS and methods of prevention (such as the use of condoms). They also passed this knowledge on to their family and the younger generations in order to help equip them to cope with and protect themselves against HIV/AIDS infection and its consequences.

It appeared that some of the participants affected by HIV/AIDS were assertive enough to insist on the use of protection, despite pressure from their male partners. The ability of the female caregivers in this study to take a proactive stance on the need to use protection highlights a positive shift among women who represent a particularly affected category in society. Additionally, this shift emphasises the degree to which information and awareness can make an impact in the fight against ignorance of HIV/AIDS and unsafe sexual practices. An additional example of the need for appropriate HIV/AIDS awareness can be seen in how one participant confirmed that the clinic nurses had taught her how to handle bleeding in a safe manner to prevent HIV infection. However, a trend emerged in the *I Poems* highlighting the fear of education on such topics as it makes HIV/AIDS more of a reality for them.

Participant J:

I hear about HIV on TV

I did not like to hear about HIV on TV

I was scared

Differing levels of awareness of HIV/AIDS were apparent within the participants' / *Poems*. The feelings and sense of hopelessness evident in the words of many participants also substantiate the contention that a lack of awareness prevents some participants from familiarising themselves with the consequences of HIV/AIDS. This lack of awareness and associated fear can actually lead to individuals' avoiding finding out information on HIV/AIDS. This also led them to develop a skewed view of their own situations and many of them then hid their status out of fear of stigmatisation and potential ostracism.

While caregivers of people with HIV/AIDS are often assumed to be infected with HIV, this is not always the case.

Participant H: You can't tell each and every friend about your personal problems, because they might take it the wrong way like I am a person who sleeps around with so many men.

Five of the participants in this study were comfortable enough to disclose that they were HIV positive. One participant's response reflected her knowledge of the subject:

Participant J: Yes I know about HIV, and HIV does not kill anyone anymore if you follow the instruction and also take the treatment.

It has been repeatedly shown in the literature that inadequate information and education on HIV/AIDS increases the risk of exposure to contagious opportunistic infections (Saengtienchai & Knodel, 2001). Moreover, Tshililo and Davhana (2009) contend that a lack of education and appropriate treatment of the disease can lead to discrimination and stigmatization. Caregivers with less access to formal education can suffer from distress due to the fear of HIV infection and/or because of misinformation about the ways in which one can contract HIV (Saengtienchai & Knodel, 2001). Perceived and actual stigma often result in carers choosing not to utilise the available support for the people for whom they care and not to improve their knowledge of

HIV/AIDS. The stigma surrounding HIV/AIDS is rife where there is inadequate knowledge of the cause and spread of HIV (Saengtienchai & Knodel, 2001).

In examining the content of the contrapuntal voices, there is a voice of disclosure present among some of the women where the need to tell their whole story is strong. They wished to lighten the burdens they carry by speaking about their experience in a safe space. However, they expressed concern that the community may label them and some indicated initially being fearful, despite their agreeing to speak to the researcher. A majority of the participants made it clear they would be comfortable to share their stories with people who are in situations similar to their own.

Contending with this voice of disclosure is a voice of silence. This voice appears where the participants express mistrust or fear in having their wider community know what is happening in their personal, private lives. This voice of silence is strongly linked to fear of stigmatisation. This is apparent in the latter example of Participant H explaining that, "You can't tell each and every friend about your personal problems because they might take it the wrong way like I am a person who sleeps around with so many men".

Many people living with HIV, as well as their caregivers, fear healthcare workers might reveal their HIV status and that this could leave the caregivers exposed to the possibility of further discrimination. The consequences of these fears are that people will likely be discouraged from being tested or seeking proper help and treatment, which could further influence the health of the caregivers as well as the people for whom they are caring. Some of these women spoke of isolating themselves in order to not deal with social situations that would reveal their HIV/AIDS status and the resulting struggles they face. The literature confirms that the elderly affected by HIV/AIDS tend to decrease their participation in social activities in this way because they are fearful of possible stigmatisation (Alpaslan & Mabutho, 2005). Most of the participants indicated that they were scared to divulge that they had been affected by HIV/AIDS as they felt that they would be labeled and, in certain cases, face reprisals from the community.

Participant K: I'm not ready to tell people because the people are not right, other people is not right ... they are going to spread [rumours]; maybe shout at you.

This said, certain participants felt that it was acceptable to disclose the effects of HIV/AIDS. It seemed the reason for this was that they did not really care what others thought, as they were too tired to care:

Participant 1: *I don't care what they say now because I am on my way to my grave, I am tired of everything. My kids don't take it, I don't care if everybody knows.*

The women that were more educated about HIV/AIDS seemed to disclose much more readily as they understood their situation better. The suggestion made by Cavanaugh and Blanchard-Fields (2011) that health education programmes for the elderly can reduce emotional distress is substantiated by the above findings. The results suggest that high-quality health education programmes could both reduce and prevent some of the difficulties associated with life with HIV/AIDS, which could empower and enhance the quality of life of the elderly caregivers.

5.2.3. The Impact of Gender roles On Quality of Life

Wilson and Adamchak (2001) state that "HIV/AIDS has often been referred to as the grandmother's disease". This is due to the high burden of care associated with HIV/AIDS, which falls primarily on older women. From the participants' own accounts, it could not be clarified whether in fact all children were biologically related to the elderly caregivers who were acting as their grandparent and/or custodian. Of the ten participants, five identified themselves as grandmothers. However, in the majority of participants' cultural belief models, foster-children become part of the family and, as such; the elderly woman caregiver becomes the de-facto grandmother/adoptive mother. Several participants indicated their foster care grant applications were being processed, which suggests that they were also possibly taking care of children who were not biologically related to them.

Older caregivers are at a stage in their lives in which they traditionally expect to be cared for by their children. They seldom have the emotional, financial and physical

resources to provide fully for the new caregiving roles and responsibilities that they find suddenly thrust upon them (Homan et al., 2005). In the context of HIV/AIDS, the burden of responsibilities on caregivers can increase exponentially over time. This has been shown to lead to a loss of security for the elderly who have to now suddenly take care of orphaned children, patients, or both (VEN, 2010).

Some of the participants embraced their new role as caregivers, enjoying the social benefits of caring for children, despite the associated difficulties. Others struggled to cope with this change in life roles, grudgingly accepting their situation with an attitude of resignation and despair. Despite the challenges, and out of a sense of duty, none of the participants reneged or appeared to neglect their responsibilities as a caregiver, although some expressed anger at the role reversal.

When the narratives are considered as a whole, there is very apparent strain experienced by participants. This emerges from the fact that while many voiced an enthusiastic and willing voice of care for their family members, this was accompanied by a second voice of burden. This voice reflected the extreme strain this caregiving role place on their lives. Some of the participants spoke of how looking after their grandchildren gives them hope and purpose. There is a sense of empowerment, upliftment of self and spirit evident in their narratives. This was generally the case when the older caregivers were taking care of younger children with HIV/AIDS or those orphaned by HIV/AIDS. Notwithstanding this strong sense of positive purpose, as highlighted above, there is also a counter-voice of responsibility and burden within these narratives. Compare the voices of Participants J and L below:

Participant J:

I am happy to look after my grandchild

I can live for her

Participant L:

Yes I'm happy to have my granddaughter. Although my heart sometimes I'm feeling bad because if myself I'm getting sick or else I died, there is no one that can take her because the family of her father [will] not support her.

Both of these participants expressed personal content taking care of the child they look after. In part, their willingness to care seems to come from a sense of duty. The caregivers also expressed their willingness to take care of their grandchildren even though they are aware of the physical and mental strain that this role places on them. Moreover, the elderly caregiving participants who are caring for their sick and dying adult children feel the burden of care very strongly. The sense of despair seems much greater here and the participants who faced this situation seemed to lack the more joyful tone apparent in the narrative of the caregivers looking after young children.

Participants who were taking care of their dying adult children seemed to feel that the caring role was more of an obligation brought on by circumstance than something they want to do. Based on their traditions and past, the participants expected that they would have been taken care of by their children during this advanced stage in their lives. Now, however, they focus on the present, trying to make ends meet as best they can with the limited resources they have. Future planning does not factor greatly into these plans as most feel the future is bleak and that there is not much time left for them. This made these caregivers even more susceptible to feelings of being burdened by their role and thus experienced a decreased quality of life.

Participant I:

*They know: I told them when I found out my daughter and me are HIV
I nearly killed myself
I drank a lot*

The duty of care often falls on women, especially older married women. This is particularly relevant as a large proportion of people living with HIV/AIDS move back to their childhood homes to be cared for by their parents and relatives (Saengtienchai & Knodel, 2001). UNAIDS (2008a) statistics confirm that caregivers for people living with HIV in Africa consist mostly of women. Women comprise of 70% of the world's underprivileged, and two-thirds of the worldly illiterate, occupying a dire socio-culturally disadvantaged position, making them having to take on the burden of care even harder.

Older women and married women are significantly impacted, as older female caregivers are often the only surviving partner and therefore the acting head of the household. The participants in this study had to take on the responsibility of care as well as the financial implications of caregiving (medicine and transport costs, and access to healthcare providers). Some participants took to their role as caregiver and breadwinner very successfully. Many of these individuals established their own entrepreneurial enterprises such as by selling chickens to the local community or looking after children in order to alleviate the problems caused by the lack of finances. This gave them control over some aspects of their lives and increased their general quality of life.

Other participants however, struggled immensely with the multiple new roles with which they were now faced. They felt they now had to do everything in their household. The voice of burden takes many forms here and is seen in the participants' complaints about struggling to find the time, energy and money to attend to their duties and charges. The effects of role strain were very apparent as all participants struggled not only to maintain financial stability, but also to manage all the requisite physical tasks of care on their own. New tasks were also added. This includes lifting and carrying young children as well as sustaining their regular, more traditional roles through tasks such as cooking. Finding equilibrium, whilst managing the concerns and commitments associated with their multiple roles, presented a significant challenge for many of the participants.

These findings correlate with the literature (HelpAge International, 2002; Makiwane et al., 2004; Wilson & Adamchak, 2001), which suggests that the majority of the burden of caring for those living with HIV and AIDS is carried by women. The lack of male participants in this study further strengthens this argument as no men fitting the criteria of caregiver could be found to be recruited in the community to participate in this research. This is consistent with the narratives shared by the participants about the men in their lives as well as what the literature highlights about male roles. Despite this, it must be noted that the sample size for this study was small and limited to one community only and may not be reflective of situations in all communities.

Research on the contributions of men in volunteer programmes, caring in the home and in supporting women who provide care is limited (Ogden et al., 2006). Traditional

gender norms result in more women providing care, which also create barriers to men and boys becoming caregivers (VSO, 2006). The participants either claimed Xhosa or Coloured cultural identities and within South Africa, these are shown to follow the conventional gender roles mentioned above. Strong, socio-culturally constructed beliefs around the division of labour guide men's perceptions around the responsibility for caregiving. Men are often seen as the primary breadwinners in the home and therefore, cannot devote their time to caring for the sick and orphans (Saengtienchai & Knodel, 2001). The female participants confirmed that even if there was a male figure around, that his caregiving duties were usually limited.

The female participants expressed that they would like to share some of their caregiving responsibilities with a male member of the household. The contrapuntal voices of trust and mistrust also emerged strongly when engaging participants about their partners. Many stated that they would like a man in their lives. In other words, it seems participants felt a need to trust and let someone help. However, this is contrasted against the narrative of those who assert that they no longer trust men at all (likely to avoid being vulnerable again).

Despite this, in certain cases, the male provided a limited amount of financial support if he was working or from his pension. Only two of the participants had experienced some or limited emotional and physical support by a male figure. Despite the dominant finding of males being less active in the caregiving role, evidence suggests that men can have an important role to play in providing care in the home context, even as primary caregivers and not solely in terms of providing financial support. Men can effectively apply themselves to tasks such as providing transportation as well as in lifting or carrying the sick, which requires greater physical strength (Ogden et al., 2006).

Skovdal et al. (2011) suggested that the elderly caregivers have become the best carers, especially for children infected with HIV/AIDS, because of their living arrangements; spending lots of time at home and their subsequent emotional attachment. However, there are dangerous role strain impacts that can negate these positive benefits. Despite their emotional attachments, women caregivers often cannot handle these burdens on their own. The amount and scope of responsibility can simply

become too much unless the female caregivers are assisted by their male counterparts. The findings of the study support the possibility that gendered cultural norms could be impeding male caregivers from sharing in the responsibilities of care and, consequently, forcing the female caregivers to shoulder and cope with the entire burden of care. Further research is required into the sociocultural barriers that impede men's involvement as caregivers as well as encouraging equality and a more fair distribution of the workload between the two genders despite these traditions could help alleviate the problem.

5.2.4. The Impact of Role Reversal on Quality Of Life

The HIV/AIDS epidemic has caused an increase in role shifts and reversals in caregiving relationships and deterioration in the well-being of older people as a result (Seeley et al., 2009). Older women and the few men looking after grandchildren are not always able to return to the role of parenting easily. This may be because they have planned their life, having expected to be cared for by their adult children (Homan et al., 2005). The participants did not have nuclear families and it became clear to the researcher that the degree of role strain was proportionate to the levels of support the participants experienced.

The researcher found that the younger the caregiver was, the more positive their account of their wellbeing was. It seemed their perceived quality of life was higher when they felt they had a reason to live. These included seeing to their children and grandchildren's needs. However, as the caregiver ages, the physical strain of their caregiving tasks affected their motivation for providing care as well as their quality of life. Looking after their adult children who were sickly or terminally ill meant that their role strain increased, adversely affecting their quality of life

5.2.5. The Impact of Financial Constraints on Quality of Life

The fact that the participants referred repeatedly and in detail to issues around their limitations in their access to economic resources and support systems; highlights the influence finances have on general quality of life. The additional financial strain placed upon the elderly caregivers interviewed was apparent in the multiple expenses they

cited. These included transportation costs to and from health facilities, school fees and school uniforms, daily nourishment and medicine, taking care of their sick and dying children, and funeral costs. Most notably, the burden of HIV/AIDS, in conjunction with ageing, ensures more types of prescription medications is needed.

The available literature supports these findings, with Ogden et al. (2006) noting that there are increased financial costs relating to caring for the sick, the cost of medicine, clinical therapists and even traditional healers. Ogden et al. (2006) also highlight hidden costs for the elderly caregivers. For example, despite ARV treatment being free, transport to and from clinics for treatment is expensive.

Food insecurity was found to be prevalent in the elderly caregiver households in this study. The burden of caregiving responsibilities often exacerbates the already compromised nutritional status of the elderly (Charlton & Rose, 2001; Nyanguru, 2003). Research by Lekalakala-Mokegele (2011) shows that elderly caregivers, who are the least economically productive members of society, often are saddled with financial responsibility for sick relatives and orphaned grandchildren, yet they do not have secure financial support.

In the case of elderly women, age discrimination, as well as low levels of literacy and education, all of which hinder their ability to earn an income (HelpAge International, 2007), exacerbate their plight. Homan et al. (2005) found that households in South Africa rely heavily on social grants for income, as unemployment is high. This is the case in many communities, including Masiphumelele, and specifically the participants in this study as well. These women are usually left at the mercy of the State, living primarily upon social grants and having to use this to support those in their care. They are left short-changed for their own living expenses. The researcher found that, despite the availability of the government pension and social grants to alleviate the financial plight of caregivers, the enrolment process is cumbersome and not all the caregivers were aware of the procedures required in order to obtain such grants. Some were not even aware that this financial assistance exists.

In caregiving households, caregivers are often forced to spend fewer hours working to allow for more time in caregiving or alternatively, increase their work hours to pay for increasing expenses. Within the family unit, women usually take on spending more time

at home in their caregiving role because, in general, they earn a lower income and therefore are more likely to sacrifice their careers in order to take on the caregiving role (Saengtienchai & Knodel, 2001). The application of Role Strain theory reveals the impact and influence of conflicting interests and duties. Because of the participants having taken on a caregiving role and increasing their responsibilities as a result, their perceived role strain increases.

Research shows that greater wealth is strongly correlated with a perceived better quality of life (Nyrenda et al., 2012). Conversely, this implies that elderly caregivers who face the extra costs associated with their caregiving roles are more likely to suffer from a diminished quality of life if they have little or no access to income or government support. It is clear that government grants and self-initiated entrepreneurial activities play an essential role in improving access to financial resources, and thereby influence their quality of life.

5.2.6. The Impact of Social Support on Quality of Life

Social support is a predictor of increased quality of life; it can be found in participation in social activities such as religion (George, cited in Park, Roh, & Yeo, 2012). Krause (2011) found that in times of high stress, people who practice some form of spirituality or religion cope better with their circumstances than those who do not. He also points out that people who engage in very little religious activity report lower levels of self-esteem. It is suggested that this may be because they do not have the social support associated with such communities where they would be encouraged and uplifted. People who are part of religious communities and participate on a regular basis have been shown to have a higher level of cognitive functioning (Cavanaugh & Blanchard-Fields, 2011). The *I Poems* also highlight how support networks are seen as very important in providing reminders of essential duties; sometimes this crucial responsibility even falls to the children. As highlighted previously in this chapter, the caregivers are a valuable source of support and information for the younger generations affected by HIV/AIDS. These relationships of the participants highlighted a very important two-way support network. The caregivers help and support the children and

the children's presence provide the caregivers hope and purpose, which helps them cope better.

Participant C:

I cope with it

They gave me the container to stay with my child

When I forget, she always say to me

Mommy I am taking the medication

When we wake up very late

She take the tablet

She says to me when its 1st break, I am going to have something to eat and then drink my medication

The contrapuntal voices of trust and mistrust illustrate the importance of this kind of support structure. Mistrust stretches, in some of the participants' cases, to their adult children. In this study, participants seemed to have lost confidence in their adult children's ability to take care of them in their old age, as would be custom in their culture. Although there is a need to have people that can be trusted around them, where this is not possible, mistrust appears to be the defence mechanism that comes into play. This leads to secrecy and social isolation in order not to have to deal with stigmatisation from their community. This problem can be avoided with proper support structures in place.

The researcher found that most of the participants participated in some form of religious practice or spirituality. Many of the participants cited a relationship with God as a significant form of support in their lives. The participants found that this spiritual connection provided a means of coping as well as a way of socialising. As most of the participants were very occupied by their role as caregiver, and because of the sensitivity of HIV/AIDS (and fear of stigma/discrimination if they identified as being affected by HIV), they either decided to isolate themselves or socialise with friends who were in a similar position. However, several found solace in going to church and being supported emotionally by their church and congregation. Membership and participation in such

communities contributed significantly to building coping mechanisms that give them hope. The participants that were a part of some form of spiritual practice had a much better perceived quality of life.

The church provides a support system for the elderly caregiving participants who feel strained due to looking after themselves and their charges. The church community bolsters the role played by family and friends in hard times, or can be the emotional support network where stigma and isolation have cut off the caregiver from their family. The context of the church provides a space for personal and spiritual connection, reflection, understanding and advice. This was reported to provide hope and meaning in coping with life's hardships.

Amongst the participants, there was a surprising, yet strong voice of contentment. The fulfillment of duty, taking care of children and running the household instilled a strong sense of pride and contentment within some participants. It seems that completing these tasks satisfied self-set goals. It can also be inferred that completing these tasks, by rising above their burdens, gives them a sense of control and accomplishment. It is, however, apparent that without various forms of support, the participants would find it very difficult to accomplish these tasks or adequately cope with their situations.

The women that primarily expressed this feeling were the ones that were supported and appeared empowered by their situations. They were also managing better financially. This was supported by activities such as renting rooms, running a crèche or selling chickens. These women also seemed to cope better with their situations. They displayed a much more positive view of taking care of orphaned and sick children and seemed genuinely content with their situations. The participants who had a stronger voice of contentment underlying their stories appeared to be less affected by the outcomes of role strain. Thus, it appears that proper support from their community, the church and the government can greatly help these women increase their quality of life.

5.3 Conclusion of Themes

From the analysis of the themes presented, certain deductions can be made using Quality of Life, Role Strain and Systems theories as frames of reference. Quality of life

is a complex notion for the participants. HIV/AIDS affects their lives in a myriad of ways, which in turn can directly affect various aspects that contribute to overall QOL for the participants. The pressures placed on them physically – by HIV/AIDS and co-morbid illnesses – as well as the psychological toll from caring for the members of their family, can have a major impact on their general health, thereby reducing their capacity to maintain or improve their quality of life.

Snyder (2002) indicates that higher levels of hope are associated with greater social competence, the experience of greater social support, less loneliness, higher sense of satisfaction in life, greater self-esteem, better coping with physical discomfort such as pain, and improved learning achievements. Snyder further suggests that the positive or negative quality of their thought structures and coping mechanisms strongly raises or lowers their conception of their own wellbeing and their actual quality of life. The level, strength and stability of their support networks have a similar proportional effect on QOL.

The impact of financial security on perceived QOL is also considered. It appears that the better the individual's financial position, the more improved were the opportunities associated with income generation and employment. Access to financial and employment resources greatly contribute to their perceived quality of life (Snyder, 2002).

Most of the participants were past the age of retirement and had to engage with unanticipated role shifts. All were thrust into the role of becoming breadwinners again in order to shoulder the new financial burden of providing once more as caregivers in their homes. They also had to cope with occupying several roles simultaneously, which lead to role strain. Given their fears around HIV stigma, many of the participants opted to withdraw socially, thereby restricting access to social networks that could offer the necessary support systems. The strain this causes was very apparent amongst the participants, undermining their ability to cope and their subjective perception of their QOL.

From a Systems Theory approach (Hagerty et al., 2001), the participants' quality of life is seriously eroded when they are not able (by choice or social barriers) to access important resources and support systems in their microsystems, even more so in low-

income communities. In order to improve quality of life for elderly individuals in similar circumstances, it would be important to influence the various domains of life shown to affect participants. The focus of such endeavours should be on improving inputs and resources at meso and macro-system levels, namely, government policies, services and structures. It is suggested that improving upon the current legislation as well as health and social services policies geared towards the specific needs of the elderly caregivers will have a direct impact on the daily lives of these elderly caregivers. Implementation of policies aimed at improving social support, simplifying processes and access routes and easing financial and physical burdens would greatly improve the QOL of these elderly caregivers. Furthermore, implementation of programmes and policies aimed at ramping up physical and mental health support services as well as awareness initiatives around HIV/AIDS stigma in the affected communities would improve the daily lives of the caregivers and lead to their improving and sustaining enhanced QOL (Hagerty et al., 2001).

In the next section, the validation process of the study is presented followed by the limitations of the study, before implications of the findings are discussed.

5.4 Review of the validation process

5.4.1. Critical Review

This study adopted a qualitative approach as the researcher wished to obtain a rich, in-depth understanding of the narratives of the participants. This was achieved through semi-structured individual interviews. The open-endedness of the questions used for this study allowed the researcher to adapt the interviews according to the information that was shared in the interview session in order to gather the most authentic narrative from the participants. The researcher was also conscious to give the participants the necessary freedom and space to relate their stories. This was achieved by not interrupting or helping them when they struggled to express their ideas. The researcher used direct questions and prompts to guide the interview when necessary. This was done in order to create a sense of structure as well as to narrow the focus of the conversation in a way that was pertinent to the points of the interview schedule and the study as a whole.

The researcher was also aware of his views and attitudes that were shaped by South African history and endeavoured to maintain awareness of how such views may have influenced his worldview of the participants. Considering this, the researcher spent time with the participants beforehand in order to get to know the participants better as well as to help them relax and become more comfortable with him.

The interviews were recorded and then transcribed into written documents. Twelve interviews were initially transcribed. However, as has been stated in Chapter 3, after consideration two were removed from the final data corpus. This was done due to those two participants' being reluctant to share enough information for their input to be viable for this study. The remaining transcripts were then read repeatedly to allow various thoughts and conceptual connections to coalesce. Colour coding was used to highlight emerging themes in the transcripts.

The researcher also wanted to immerse himself and familiarise with the subject matter so he could better understand the cultures and context of the participants. He visited the Centre on several occasions; the researcher did not visit the community alone as there was a concern that going into the community itself could compromise the privacy of those taking part in the study. This helped develop a sense of the physical and social context in which the participants live and interact, and allowed the researcher to set up the recruitment process. As the narrative approach takes an in-depth look at the structure, expressive function and emotional content within the stories and narratives told by the participants (Camic et al., 2003), it was ideal for revealing the subjective realities of the elderly caregivers in this study. Further validation factors considered are also discussed in the next section.

5.4.2 Limitations and constraints of the study

Conducting research on HIV/AIDS is necessarily complex given the ethical considerations that need to be applied to maintain participant privacy and confidentiality. The main limitation of this study was in obtaining an appropriate sample of 10 participants at the Living Hope Centre, with due diligence exercised, to protect the privacy and confidentiality of potential participants. Obtaining a sample at the Centre required delicate handling as HIV/AIDS still attracts considerable stigma, and therefore

elderly caregivers affected by HIV/AIDS could not be readily identified and approached directly. Due to this, the researcher approached counsellors at the Centre to assist with recruiting potential participants who met the inclusion criteria. With the researcher's limitation of only being conversant in English, the counsellors were also asked to serve as interpreters to ensure that the participants understood the research project's purpose, consent form and their rights as participants in their own language. Permission was also obtained to have the counsellors present in the room for the interview in the event that the participant opted to switch to the language of her preference. While on the surface, the presence of the known counsellor in the interview appeared to facilitate the process, it may be that the counsellor's presence may have restricted the level of disclosure of the participant.

Another limitation is that the obtained sample consisted of individuals aged 50 to 61 years old. Although the initial intention was to include both male and female elderly caregiving participants, older and male participants were difficult to obtain. Research done by Betron et al. (2012) found men reluctant to participate in research of this kind for cultural and social reasons. Individuals over 65 are also frail and could not always travel to the designated venue for the interviews, which meant a further limitation restricting the upper age of the sample pool.

Another significant limitation that is critical to consider was language as a barrier to communication. Language is the medium by which we construct our reality and convey our personal narratives and, as such, was a pertinent concern in the study. English was not the primary language for many of the participants and it is likely that they may have been limited in expressing themselves. It is possible that the participants could also have misunderstood the researcher's questions or even that the researcher misinterpreted the participants' responses. The presence of the HIV counsellor as interpreter may also have inhibited the participants from disclosing more personal information and opinions.

With the analysis and presentation of the data, it also became apparent that the language barrier would make it impossible to follow Gilligan's guidelines exactly as set in her listening guide method. The participants would use adapted English grammar, words, and expressions to convey ideas and thoughts. For the data presented in

chapter 4, grammatical corrections were made to ensure that the ideas were conveyed clearly to the reader without compromising the authentic telling by participants. This resulted in forming *I Poems* that were slightly more extended than usual. It also involved adding concepts in brackets to clarify ambiguous expressions from translation or to complete thoughts that participants did not finish.

The researcher took into account the translators' interpretations, knowing they would not be exact word-for-word translations. The translators did their best to convey exactly what the participant was trying to say. Whilst this adapted translation was required, to date, there are no other reported studies known to the author where the Gilligan approach has been applied in the African context with similar language barriers.

The researcher was aware of the cultural barriers between himself and the participants as another limitation of this study. This was because he is a white middle class male from a different culture and despite his efforts to make the participants comfortable before the interviews; he was at best an intruder into their lives and context. Given participants' concerns around exposure and resulting discrimination, it would also have likely had various social implications for the participants had he entered the community itself in order to gather data in their own environment. As such, the Living Hope Centre that serves the community was used as an entry point into the community.

Purposive sampling, as opposed to random sampling, was used with the assistance of the snowballing technique (De Vos et al., 2012). Purposive sampling, by its nature, carries an inevitable risk of sampling bias. However, given the study's explorative objective and the ethical considerations, generalisation of the findings was not intended but rather, the study aimed to gain a deeper understanding of the experiences of the participants. The participants were familiar with the venue and the social implications were anticipated to mitigate harm for the participants. The participants knew the counsellors that recruited them and could trust that the research was being done for the good of the affected elderly caregiving community.

5.4.3 Dependability

Reliability, which is used in quantitative research to determine whether a psychological measure constantly/repeatedly measures what it is supposed to measure,

has been supplanted by the term dependability in qualitative research (Lincoln & Guba, 1985). Dependability refers to the degree to which the reader can be convinced that the findings do indeed occur as the researcher says they do and that such a process can be replicated in a similar future study. This is done by taking into consideration the ever-changing contexts in which qualitative research is carried out (Lincoln & Guba, 1985).

The dependability of this study was ensured by doing multiple interviews with participants, each of whom had been independently selected by different recruiters. Two interviews were conducted with each participant to clarify the data provided in the first interview and to ensure that participants were satisfied with the content recorded from their interviews. This helped to ensure that translated transcripts were accurately interpreted. Using an adapted version of Gilligan's method, the researcher looked at all the contributing voices and endeavoured to understand them in relation to one another in describing the community, the state of services and the unique, subjective opinions of participants. The overall picture created was consistent across participants and with literature on the topic.

5.4.4. Confirmability

Qualitative research assumes that every researcher brings a unique perspective to his or her research findings. These findings need to be confirmed by others. This could be achieved through having another researcher corroborate the findings and by the researcher meticulously documenting every step of the research process (Lincoln & Guba, 1985). By undertaking this process, the research results can be correlated with both the process of data collection and the content of the transcripts, thereby proving confirmability (Lincoln & Guba, 1985). The researcher used a second interview with each participant to confirm his interpretation of the data analysis. Further discussion with the counsellors and the researcher's supervisor assisted in clarifying and confirming the interpretations made of the themes.

Stipulating the research process systematically in chapter 3 and then connecting findings with the literature further ensures confirmability in this study. Transcripts were used consistently throughout the research process in order to both state the data found

as well as to guide the interpretations thereof. These elements together, endeavour to enhance confirmation of the research findings.

5.4.5. Transferability

This section discusses the degree to which a qualitative study describes and interprets the data that emerged and can be transferred to other contexts. This study gathered rich, in-depth data on the narratives of the participants, which were compiled, into transcripts. By transcribing the interviews exactly as they happened, the researcher ensured that the narratives collected were accurate, making them valuable for interpretation into valid data. This study has documented narratives on HIV/AIDS in the Masiphumelele area, in the Western Cape of South Africa. Given the ethical considerations implicit in HIV/AIDS research and the potential affect the participants within this community, the study did not seek to attain a randomised sample. Hopefully, the findings obtained from this small purposive sample of elderly women caregivers can contribute to informing further research on this neglected population. This sample revealed that a number of elderly women affected by HIV/AIDS were not only caring for their own adult children infected by the HIV, but were also caregivers to their grandchildren and, in some cases, foster children also.

The study revealed the following:

- The networks, status of health, financial position and social vulnerability of these women;
- The data provided rich details of the mental and physical illnesses and symptoms experienced by the participants; and
- The participants' own admissions revealed their efforts to seek employment, including migration, reliance on government grants and their efforts to obtain money through entrepreneurship.

While the findings cannot be generalised to all other elderly people affected by HIV/AIDS, the relevance and implications of the findings of the study for this sample of elderly women from Masiphumelele are extended in the section, which follows along

with the transferability of data conclusions and the recommendations made by this researcher.

5.5. Implications of the research findings

5.5.1. Theory and practice

The research study aimed to understand the existing body of knowledge around the subjective quality of life of the elderly caregivers affected by or infected with HIV/AIDS. This section discusses the implications of the findings pertinent to theory and practice. The narrative theory interpretations, developed with the use of Gilligan's Listening Guide, proved contextually appropriate and produced rich descriptions of the participants' experiences. However, the use of Gilligan's guide may have been restricted. The participants were not first-language English speakers and sometimes switched between different languages. This meant that I-verb sentences were not easily extracted from the narratives in the way Gilligan et al. (2003) suggest. The researcher did not want to recreate sentences for grammatical correctness, but preferred to reproduce the participant's voices as authentically as possible. This adapted method was very successful and it is contended here that this method could be utilised in other similar scenarios where research is being conducted using Gilligan's Listening Guide with a population where there are similar language barriers present. The implications and potential restrictions of using this approach were explored earlier in the discussion of limitations and constraints. The adapted method allowed for the voices of the participants to be heard. The content expressed by these voices was consistent with the themes that emerged through use of the narrative method. This suggests that the adapted method is feasible and the results maintain content validity (Cohen et al., 2013).

Role strain played a large part in the increased negative pressure experienced by participants, which in turn, lowers quality of life. Understanding this phenomenon more thoroughly through further research could present solutions for helping caregivers affected by HIV/AIDS. Role strain seems to place both mental and physical strain on the participants. This strain could be lessened through education programmes, which aim to

improve general understanding and attitudes within families and communities about HIV/AIDS, as well as the implications of caregiving. Improved understanding and attitudes can decrease isolation and increase support from various sources such as individuals in the community, churches, NGO's and other organisations. This can further help lessen the negative effects caused by role strain and thus increase quality of life. Additionally, access to government grants can help relieve the pressure of occupying multiple roles at once (such as breadwinner and caregiver) by providing financial support. In this way, the participants would likely be able to cope better with role strains and have a better quality of life.

Gender roles seem to be closely linked to role strain, especially the absence of male figures helping caregivers with their tasks. Culturally acceptable ways to increase the role played by males within these communities in relation to caregiving should be explored and could potentially lead to solutions to improve quality of life for female caregivers.

A Systems Theory approach was used to understand the patterns of behaviour and agency of the participants in relation to their community and government. With further research, the interventions of the state and organisations can likely better empathise and support the families affected by HIV/AIDS. The research confirms that a positive input into a system can have a positive effect on the quality of life of a community, particularly looking at caregivers affected by HIV/AIDS. This research paper validates the effectiveness of Systems Theory in helping to identify what these positive inputs are. The major inputs in this study aim to increase the quality of life through financial and emotional support for caregivers.

From the research, significant findings were identified as to how HIV/AIDS affects quality of life of elderly caregivers affected by the virus. The findings have implications for the understanding of the HIV/AIDS-related burden experienced by elderly women of Masiphumelele, as well as the kinds of interventions stakeholders in the community ought to consider. There is a definite need for aid amongst these women and a more direct way of addressing their problems in order to improve their quality of life is clearly necessary. The recommendations that have emerged from this research can be found in the next section of this chapter. These recommendations are, in the researcher's

view, suitable ways to meet the needs of the participants based on the findings within the research.

5.6. Recommendations of the study

5.6.1. More grants, subsidies or providing goods for the household

Financial support from government, in terms of grants and pensions, assists in alleviating stress linked to economic constraints (Nyirenda et al., 2012). Money is necessary to purchase food, household products and to pay for transport. It is recommended that these take the form of a special grant for elderly caregivers that can be applied for in order to meet these needs. Access to applying for this grant could be controlled by a home visit from a social worker. The fulfilment of this financial need helps increase the quality of life experienced by the elderly caregivers by reducing financial worry. It also gives the affected person the feeling that they have broader support structures and can trust their local organisations and municipality.

However, it was found in participants that access to government grants was hindered by the complicated bureaucratic system that is in place. Many participants do not even know of the various grants. Those with some knowledge are often confused about whether they are eligible or not and then how they should go about gaining access. Interviewees spoke of their struggle with the complicated system, which wastes valuable time in order to get the correct paperwork to the proper office and which is often situated far away from their community. This further incurs additional transportation costs on the participants' already strained budget.

5.6.2. Legislation

This study recommends that legislation governing the afore-mentioned grants be re-evaluated in order to streamline the process for easier access. Policies and guidelines governing social workers can be changed so that they inform the elderly caregivers affected by HIV/AIDS during home visits of available grants. Furthermore, social workers can build a registry for the affected elderly caregivers during home visits. This kind of registry would allow the government to send community workers directly to the houses of the affected to inform them of the grants that are available and to help them

fill out the paper work as well. These community workers could also make use of a mobile clinic that deals in information and application for grants. This would allow access to these services to many who desperately need it within the community.

The government, as well as NGO's, should roll out education programmes in the community, to educate the people about the relevant government grants. This can be conducted through media such as newspapers, radio, television, and through community centres on the ground. This will allow more elderly caregivers in need of these services to become both aware of them but also to understand how to access them more efficiently. However, it is a concern of community workers and government that people, in general, may become complacent about the need to be active in pursuit of material income and spiritual/psychological stability.

These women are undervalued in the caregiving role that forms part of the uncompensated work that they perform. The caregiving tasks that they perform as well as the costs of caring are not factored into HIV/AIDS policy, planning and research (Ogden et al., 2006). The plight of these older women is further exacerbated by age discrimination, low levels of literacy and education, hindering their ability to earn an income (HelpAge International, 2007). These women are dependent on the state and living primarily upon social pension and financing care and children's needs; this sidelines them (Lekalakala-Mogkele, 2011). Being dependent on the government for essential material needs means they cannot fully develop their sense of personal agency; they are surviving on government subsidies and do not have the family wealth or personal savings to directly improve their living conditions. Their capacity to be truly independent is limited and this affects their control over their own lives and the lives of their dependents.

By further researching these policies, by focusing on access, the amount given and eligibility, versus the financial and resource-needs of caregivers, a better understanding can be gained in targeting and alleviating problems. As has been shown in this research paper, many of the participants have problems getting access to enough money to make ends meet because they are growing older and cannot keep up with the pace of work. By looking at their individual situations, assessments can be made to give them access to more significant grants to help alleviate this problem. More financial support

could mean the elderly caregivers can work less, taking a lot of pressure off them while taking care of orphaned children or adults affected by HIV/AIDS.

5.6.3. Health Education

Cavanaugh and Blanchard-Fields (2011) propose that providing health education Programmes for the elderly can successfully reduce emotional distress that the elderly caregivers may encounter. This study concurs and adds that an increase for educational programmes on a wider range of topics is needed over and above standard HIV/AIDS information and education. Points of interest for agents of social development, NGO's, the state, and public healthcare can see many of these topics detailed within the discussions above – diseases and ailments, medical risks of children and adults. HIV/AIDS education and outreach to the elderly caregivers would reduce emotional stress and risk for infection among the elderly caregivers affected by HIV/AIDS and thereby improve their quality of life. A big part of the struggle of living with HIV/AIDS is the stigma surrounding it. This leads to being misunderstood and a lack of discussion of topics, which then also means low availability of high quality information.

Using the media to educate in this way can be a powerful tool. For example television programmes for children have been used to encourage them from a young age to avoid strangers and be safe when crossing the road; or a mascot used to educate them on power saving. A similar approach could be employed to give a fact or tip of the day on HIV/AIDS through media such as television, radio and newspapers. This method could cover a very wide array of subjects useful to people affected by HIV/AIDS. Spreading this kind of awareness could help lessen the fear from other community members and increase social support. Ideas such as how infections spread and how to prevent this would help elderly caregivers care for their charges and help them not to contract HIV/AIDS themselves. By understanding how HIV/AIDS works, the caregivers would gain great peace of mind instead of living in fear of the unknown. Below are recommendations of targeted programmes that communities can implement to assist the elderly caregivers of people living with HIV/AIDS.

5.6.4. Community-based targeted Support Programmes for the elderly caregivers

This study recommends that communities support the elderly caregivers of HIV/AIDS sufferers adopt the following programmes:

5.6.4.1. HIV/AIDS and STI educational programmes as well as sensitivity workshops to combat stigmatization can be held at schools, churches, community clinics/centres and neutral public venues such as NGO's like Living Hope. The aim should be to facilitate better understanding of the position of people suffering from HIV/AIDS, and to lessen the amount of fear and resistance to the topic.

5.6.4.2. Education programmes aimed specifically at caregivers on money management and entrepreneurship should be planned and implemented. Supplementing these programmes; information to help the elderly caregivers cope better and manage their role as caregivers

5.6.4.3. Programmes that educate the caregivers to grow their own food should be encouraged. Educating the community on small-scale subsistence gardening and farming can allow the caregivers to grow their own fruits and vegetables in their backyards. However, it should be noted that this may be too much for the already overburdened caregiver but the children in their care can be encouraged to participate as well. The advantage of including children in such programmes is that it can provide the existing families with food and educate them on basic farming skills, providing them with a personal sense of hard work and investment

5.6.4.4. Grief and stress management programmes specifically aimed at elderly women, which empower them with skills regarding caring for person(s) that have HIV/AIDS.

5.6.4.5. Programmes should be implemented in educating the males in the community about HIV/AIDS, their role in caregiving and how they can assist female caregivers.

5.7. Recommendations for further research

Below are this study's recommendations for research that can be undertaken within the same research topic.

5.7.1. Tshililo and Davhana (2009) state that the role of caregiving can be overwhelming. They further state that counselling, support, and training for caregivers could help alleviate this. The research showed that the church plays a powerful role in the above domains as well as the everyday lives of the elderly. Therefore, further research should be carried out to consider how the church and pastoral counselling can play an even more vital role in the lives of the elderly caregivers affected by HIV/AIDS.

5.7.2. Many elderly caregivers struggle with income and so government grants are of vital importance to them. The major problem, however, is education about government grants and accessibility of these grants. Further research should be done on the scope and scale of the monetary needs of elderly caregivers, as well as how the process to access these funds can be streamlined to make the grants more accessible to those in need.

5.7.3. Research should be undertaken in order to look into the feasibility of government funding for support programmes aimed at the elderly caregivers dealing with HIV/AIDS. Subsidising counselling services, incentivising people to organise and attend support groups, special training in conjunction with the abovementioned education programmes for caregivers will help vulnerable people cope better with their life's challenges.

5.7.4. Research should be implemented on the role of males in caregiving. More specifically, how positive changes can be implemented in order for men to play a more significant role as caregivers and have them share the burden of caregiving with their female counterparts, despite traditional cultural gender roles.

5.7.5. Finally, social action research should also be done within the elderly caregiver communities affected by HIV/AIDS to ascertain their specific needs. This would empower the elderly caregiver community to uplift their quality of life with the collaboration of NGO's, governmental organisations and other community workers by addressing their specific needs.

5.8. Conclusion

This study sought to examine the quality of life of the elderly caregivers who are directly affected by HIV/AIDS in their family contexts; the concerns of the elderly caregivers have been relatively neglected in HIV research. The main findings of this study indicate that these elderly caregivers have very specific needs that can be addressed. However these needs had not been properly defined until now. It is also clear that the caregiving role associated with HIV/AIDS undermines the elderly's ability to maintain their quality of life.

The findings of this study indicate that elderly women affected by HIV/AIDS are encountering major adjustments in their lives as they try to accommodate new responsibilities linked to their caregiving roles in their families. This can have a detrimental impact on their quality of life. Erikson (2008) believes that as people age and mature, their goal should be to move successfully from one developmental stage to the next. Elderly caregivers struggling with the constant obligations associated with caregiving find it increasingly difficult to have resolved their final developmental stages satisfactorily (Meyer et al., 2008).

More community-based care facilities, services, and government support are needed if the elderly caregiving population is to age with dignity and security. This can greatly increase the quality of the remaining years in their lives.

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APPENDIX A

Cover letter

Dear participant

You are hereby invited to participate in a study of Ivan Cohen who is a master's student at the University of Stellenbosch. If you choose to participate, this study will be about your experiences and stories of how HIV/AIDS has impacted and affected your quality of life. While much has been researched about HIV/AIDS, there has been little focus on how the elderly is affected in various aspects of their lives. Your experiences will be helpful to better understand how the elderly's quality of life is impacted by the disease and what can be done to provide the necessary support.

Your participation will entail interviews with you at a time and place that would suits you. The first interview should be about 40 minutes; we can terminate the interview at any time should you feel tired or upset by any of the questions. In the follow-up interview, the information gathered in the first interview will be discussed with you in order to verify the accuracy of the information gathered. You can stop the interviews at any time.

Here are some of the questions I will keen to discuss with you.

1. Tell me how you are experiencing your retirement and the quality of life you have had since retiring?
2. Could you tell me about social activities that you are involved in?
3. How have you learned about HIV/AIDS?
4. I am interesting in your culture's beliefs regarding HIV/AIDS. Can you please tell me about how HIV/AIDs
5. How has your quality of life been affected by HIV/AIDS?

At the end of the interview, I will check with you to see if you are feeling okay because sometimes, recalling experiences may leave individuals feeling some discomfort. If it becomes necessary, I have arranged with the Living Hope Centre for counselling to

discuss any feelings that you may have. The Living Hope centre can be contacted at livinghope.co.za or (021) 784 2800.

To consent to take part in the study, you will need to sign the attached form. Please take your copy of the consent form as it has all of the relevant contact details regarding this research (in case you should have any questions).

Please turn over to continue....

CONSENT TO PARTICIPATE IN RESEARCH

Subjective quality of life of the elderly affected by HIV/AIDS

You are asked to participate in a research study conducted by Ivan Cohen (Masters' student) from the Psychology Department at Stellenbosch University in partial fulfilment of a research thesis as the requirement for the completion of the Psychology Research Masters Programme. You are eligible to be a possible participant in this study because you are between 50-85 years old and affected by HIV/AIDS because you are caring for relatives, friends, spouses, and children with HIV/AIDS and/or caring for children orphaned due to HIV/AIDS.

1. PURPOSE OF THE STUDY

The present research represents a qualitative exploration of the in-depth understanding of how HIV/AIDS affects the subjective quality of life in multiple life domains. Quality of life can be described as your perceptions of how you view your life in the context of your culture, values, personal goals, and expectations.

PROCEDURES

If you volunteer to participate in this study, we will ask you to do the following things: Firstly, you will be given a consent form to sign before the interviewing process begins and all the details of the research will be explained to you in both English and isiXhosa. You will be encouraged to ask questions to make you feel comfortable. The interview will take place in the privacy of your own home or a private venue at the Living Hope

centre for approximately 30-40 minutes about your experiences regarding HIV/AIDS and how it has affected your quality of life. Follow-up interviews will be arranged with you, to discuss information that was gathered in the interviews.

2. POTENTIAL RISKS AND DISCOMFORTS

Recalling experiences may leave individuals feeling some discomfort and there is a potential risk of emotional discomfort while taking part in the study. If it becomes necessary, I have arranged with the Living Hope Centre for counselling to discuss any feelings that you may have. A counsellor trained at the Living Hope Centre will be available during and after the interviews for the counselling and debriefing. The counsellor is known to the community and is fluent in Xhosa should any language barriers arise. The Living Hope Centre can be contacted at livinghope.co.za or (021) 784 2800.

3. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

There are no direct benefits to be gained by participants, and there will be no form of remuneration. However, participants may gain personal insight into how their quality of life has been affected by HIV/AIDS and how they can be supported in various domains of their lives.

PAYMENT FOR PARTICIPATION

There will be no payment available to participants.

CONFIDENTIALITY

Any information that is obtained in connection with this study and can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of assigning pseudonyms to participants. The data will only be accessed by the researcher and will be stored electronically until the Master's thesis is complete. Information may only be released to the Masters Research supervisor (Professor Naidoo) at the Psychology Department, and the participants themselves if they wish to obtain feedback.

4. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may still withdraw at any time without consequences of any kind.

5. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research or would like to receive feedback, please feel free to contact the researcher Ivan Cohen at 18448283@sun.ac.za or 082 900 5544 and the Masters Research supervisor Professor Naidoo at avnaidoo@sun.ac.za or (021) 808 3441.

6. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Maléne Fouché at mfouche@sun.ac.za or (021) 808 4622.

SIGNATURE OF RESEARCH SUBJECT

The information above was described to me by Ivan Cohen in English and I am in command of this language or it was satisfactorily translated to me in isiXhosa. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Signature of Subject/Participant

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ and/or his/her representative _____. He/she was encouraged and given ample time to ask me any questions. This conversation was conducted in English and an isiXhosa facilitator was used.

Signature of Investigator

APPENDIX B

Semi-structured interview guide

The following biographical questions were posed to participants to compile a demographic profile of the participants:

1. How old are you?
2. What is your main language?
3. What is your marital status? If yes, how long have you been married?
4. Do you have any children? If yes, how many? How many children and grandchildren are living with you?
5. Where do you live?

The following questions were used to guide the semi-structured interview:

1. Tell me how you are experiencing your retirement and the quality of life you have had since retiring.
2. Could you tell me about social activities that you are involved in?
3. How have you learned about HIV/AIDS?
4. I am interested in your culture's beliefs regarding HIV/AIDS, can you please tell me about how HIV/AIDS is perceived in your culture?
5. What are your own beliefs about HIV/AIDS and the use of condoms?
6. In your opinion, what is the role of females in caring for the sick and orphans?
7. In your opinion, what is the role of males when caring for the sick and orphans?
8. How has your quality of life been affected by HIV/AIDS?
9. Do you have extra financial responsibilities because of HIV/AIDS?
10. How has your health been affected by caring for a family member with HIV/AIDS?
11. Have you faced any discrimination (been treated differently) by people in your community because you look after someone with HIV/AIDS.
12. Tell me about the type of support you received from your family and friends.

13. In your opinion, what has the government done to educate elderly people about HIV/AIDS?
14. What do you think NGO's have done to educate and support the elderly affected by HIV/AIDS?
15. What do you think can be done to educate the elderly more about HIV/AIDS?
16. In what ways can you and other elderly people be supported to cope with the impact of HIV/AIDS in your life?