

**AN INVESTIGATION INTO OLDER CAREGIVERS' LIVED EXPERIENCES OF ADULT AIDS-ILL  
CHILDREN IN UMLAZI TOWNSHIP, KWAZULU-NATAL**

by

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I declare that **AN INVESTIGATION INTO OLDER CAREGIVERS' LIVED EXPERIENCES OF ADULT AIDS-ILL CHILDREN IN UMLAZI TOWNSHIP, KWAZULU-NATAL** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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## **ABSTRACT**

The purpose of this study was to explore the lived experiences of older caregivers of adult AIDS ill children in Umlazi Township in the province of Kwa- Zulu Natal. A qualitative research design which was exploratory was executed with a sample of purposively selected participants who are the members of the organization that provides support to the older caregivers.

Data saturation occurred after focus group and in depth individual interview with ten participants.

The findings revealed that older caregivers experience lot of challenges which ranges from emotional, physical, financial, psychological, social and time constraints when caring for their adult AIDS ill children .The study further revealed that older caregivers developed a wide range of coping strategies to face their challenging caregiving task and most of the older caregivers utilized positive coping strategies. Recommendations that are described focus on the inclusion and consultation of older caregivers in all decisions and programmes about them.

### **Key terms :**

Older caregivers, adult AIDS – ill children, lived experiences, Umlazi Township, coping strategies, caregiver identity theory, isolation, stigmatization and discrimination, acceptance, maintaining hope, negative coping mechanism.

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## **CHAPTER 1**

### **INTRODUCTION AND BACKGROUND TO THE STUDY**

#### **1.1 INTRODUCTION**

This chapter discusses the background of the research problem, the statement of the research problem, the significance of the study, the research setting and the key research questions addressed. It also presents a layout of the chapters in the dissertation and closes with the conceptual definitions of the key terms used.

#### **1.2 BACKGROUND TO THE STUDY**

The present study focuses on the lived experiences of older caregivers for their adult AIDS-III children in Umlazi in the province of KwaZulu–Natal. Globally, 34, 0 million people were living with Human Immuno–Deficiency Virus (HIV) in 2012, and 0. 8 % of those living with HIV were adults aged 15-49 (UNAIDS 2012:8). Although the burden of the epidemic continues to vary considerably among countries and regions, sub-Saharan Africa remains the most affected, with nearly 1 in every 20 adults (4, 9%) living with HIV (UNAIDS 2012: 8). This region accounts for 69% of the people living with HIV worldwide. Even though prevalence remains high, among those dying from AIDS-related causes there has been a noticeable decline of 32% from 2005 to 2011 (UNAIDS 2012:12). According to Shebi (2006:10), HIV continues to spread across the world, strengthening its grip on adults. National HIV prevalence in the general population has shown a general downward trend among children and teenagers, while there is a slight upward trend among adults (SANAC 2011: 21). With this in mind, the researcher aims to conduct the study on older caregivers of adult children who are AIDS-III.

The HIV and AIDS pandemic is the most significant humanitarian challenge ever to confront the world. The scale and intensity of the pandemic has posed a great challenge to those who care for the infected and affected. Never before have caregivers faced a situation like this. The global AIDS epidemic is not only devastating for individuals who become infected but it can also adversely affect their families (United Nations Population Division 2011: 3).

With the increase of life expectancy owing to the progressive improvement in management and treatment of the HIV infection, the number of infected adults living longer with HIV is increasing (Pulido 2012: 4). In countries with widespread access to Anti-Retroviral Therapy (ARVs) like South Africa, the HIV population is aging.

This success has ironically brought about the challenge of multi-morbidity, whereby multiple chronic illnesses result in disability; increasing caregiving needs (Brennan-Ing & Karpiak 2012: 3).

Caregivers who support the affected and infected often face unique challenges and demands as a result of dealing with several infected members of the family. According to Anjum, Chaudhry and Irfan (2010: 2), caregivers play an important role in the management of all chronic illnesses. Older parents are increasingly playing the principal role of caring for younger adults who are AIDS-III. Most adults who die of AIDS related illness have parents who survive them (Zimmer & Dayton 2006: 18). Research conducted in Thailand, Zimbabwe, Cambodia and Uganda found that over two-thirds of elderly parents were the main caregivers for their Adult AIDS-III children (Knodel 2001:12).

Because the pandemic has affected mainly young adults, caregiving engenders role reversal, which represents a major upheaval for elderly parents. South Africa is no exception to the caregiving process. We have a growing number of informal caregivers who are taking care of AIDS-III family members (UNAIDS 2012:12).

As mentioned above, older parents are increasingly taking on the greater part of the caregiving responsibility, so it is necessary to understand their needs, strains and coping skills. Despite their important role in caregiving, there has been little research conducted in order to better understand their unique caregiving challenges and coping strategies. In response to this gap, the researcher will conduct an exploratory study on the lived experiences of older caregivers for their AIDS-III Adult children in the Umlazi Township, in the province of KwaZulu-Natal.

### **1.3 RATIONALE FOR THE STUDY**

The rationale for the study is discussed under the following headings:

Scientific reasons

Personal reasons.

#### **1.3.1 Scientific reasons**

The existing literature on the HIV and AIDS epidemic tends to focus on the impact of the disease as it relates to older caregivers looking after orphans. This is despite the emerging scholarly work pointing to the impact of HIV and AIDS on the older caregivers for their Adult AIDS-III children, a phenomenon that remains largely under-reported and under-researched (Fouad 2004:12). Shebi (2006:13) concurs with Fouad (2004:12) in that limited research has been conducted on the experiences of primary caregivers for People Living with AIDS (PLWAs).

Shebi further argues that most past research has been primarily on the role and experiences of formal caregivers like doctors or nurses, and that little attention has been given to the experiences of primary caregivers.

Although some studies deal with the effects of HIV and AIDS on older people in sub-Saharan Africa, there is still a great need for more knowledge and understanding about the lived experiences of older caregivers in South Africa, a country suffering one of the world's largest HIV epidemics (UNAIDS 2012:4). In the South African context, most research is conducted into caregiving, its burdens and coping strategies, with the focus on volunteers and home-based care workers (Melnick 2002:14; van Wyk 2002:18). This leaves room for research into older caregivers. All these studies have identified challenges associated with caregiving in HIV/AIDS, but to date the effect of caregiving on older caregivers for adult AIDS-III children has not been looked at with specific reference to South Africa. This study intends to bridge this gap in the literature and add to the body of knowledge as far as AIDS is concerned.

### **1.3.2 Personal Reason**

To give the reader an explanation for what prompted the current study, the discussion will now turn to the researcher's experience of being raised in a multigenerational household. This personal experience has acted as a catalyst for the current study in that the researcher's mother faced the numerous challenges of being the sole care provider for her two siblings (brother and sister) and sister-in-law, who were living with AIDS. The researcher's mother had to leave the workforce so as to provide extended care, not only for her adult children but also for their children. The latter are now orphans, for whom she is still caring. Her caregiving experience highlights the researcher's sensitivity when it comes to older parents. The researcher's personal experiences may shape her perspective in that she witnessed firsthand the struggles and challenges faced by parents as informal caregivers of adult AIDS-III children. The study will therefore reveal the lived experiences, challenges and coping strategies of parents who are caregivers for their adult AIDS-III children.

### **1.4. PROBLEM STATEMENT**

As demonstrated in the literature, HIV and AIDS place heavy demands on the informal and formal coping mechanisms of the societies affected (Lindgren 1993:12). Indeed, caring for a terminally-ill person is a stressful activity (Akintola 2006:23; Maslanka 1996: 198; Pearlin, Aneshensel & Leblanc 1997: 230). Researchers have associated this stress with negative psychological and emotional determination (Pearlin et al 1997: 231).

An increasing number of older parents are struggling to absorb the multiple impacts (social, financial, emotional and physical) of HIV and AIDS on their families, households and communities. However, previous studies that explored the lived experiences associated with caregivers of people living with HIV have focused only on the caregivers for young orphaned children, and little is known in South Africa about how older caregivers for Adult AIDS-III children are affected by their role.

The most extensive study on older caregivers was carried out in Thailand by Knodel et al in 2001. None of the studies on older caregivers and their caregiving role with adult children was conducted in South Africa.

This study aims to respond to this gap in knowledge by exploring older caregivers' lived experiences and coping strategies with their adult AIDS-III children in the township of Umlazi in KZN.

### **1.5. PURPOSE STATEMENT**

The purpose of this study is to seek an understanding of the lived experiences of elderly parents who are caregivers for their Adult AIDS-III children. This study will also explore the coping strategies used by the older caregivers when dealing with the challenges of caregiving.

It is essential that older caregivers' own experience and coping strategies are understood so that the carers can be given appropriate support.

Psychosocially, HIV and AIDS is a chronic illness with a long-term, incapacitating, terminal and stigmatizing character. Like other chronic illnesses, HIV and AIDS unleash a devastating effect on the affected families, leading to changes in family roles and relationships. Frequently observed outcomes (D'Cruz 2002:416-419) are the drain on the family economy, the exacerbation of deprivation and emotional distress and an increased burden on the caregiver. The caregiving experience associated with HIV and AIDS is therefore complex, and is singularly different from that associated with other chronic conditions owing to the stigma attached to this disease. It is for the above reasons that the researcher set out to conduct a study on older parents and to document their lived experience and coping strategies.

### **1.6 AIM OF THE STUDY**

The aim of the study is to explore the lived experiences and coping strategies of older caregivers who are caring for their Adult AIDS-III children.

### **1.7 OBJECTIVES OF THE STUDY**

The objectives are:

- To determine the lived experiences of the older caregivers for their Adult AIDS-III children.

- To establish how the older caregivers cope with their caregiving tasks.
- To explore caregivers' support service needs.

## **1.8 RESEARCH QUESTIONS**

The research questions will be organized, as Cresswell (2003:41) recommends, into one central, overarching question with sub questions. In order to understand the lived experience of older caregivers, the central question will be formulated as follows:

- What are the lived experiences of the older caregivers for Adult AIDS-III children?

The sub questions will be:

- How are the older caregivers coping with their caregiving tasks?
- What are the caregivers' support service needs?

## **1.9 SIGNIFICANCE OF THE STUDY**

A search for similar studies conducted in the province of KwaZulu-Natal yielded nothing. The South African studies (Melnick 2002:23; van Wyk 2002:34) focused mainly on burnout, stress and coping mechanisms among trained caregivers. The researcher discovered that, to date, the effect on older parents of caring for an AIDS-III adult child has not been looked at in South Africa. Shebi (2006:16) argues that most of the research is quantitative in nature. This study is qualitative and is aimed at addressing a gap in the field by exploring the lived experiences of older caregivers for their adult AIDS-III children. The study also addresses the coping strategies employed by these individuals in the context of AIDS caregiving.

It can therefore be concluded that this area is one that needs attention. As far as the researcher knows, this study will be the first of its kind in the KwaZulu-Natal province. The study will bring to light issues facing elderly parents who are caregivers for Adult AIDS-III children.

This will be considered significant in that literature does not indicate the existence of any similar study in the country, more precisely, in the KwaZulu-Natal province. The findings of this study are expected not only to inform interventions but also to impact on training programs and policy formulation. The study will benefit HIV/AIDS personnel by providing a framework for meaningful intervention with older caregivers. It will also benefit these older caregivers by making their plight known and removing their invisibility, allowing for recognition and support.

### **1.10 RESEARCH SETTING**

Setting refers to the physical location and conditions in which data collection takes place in a study (Burns & Grove 2005: 12; Polit & Beck 2008:11). The setting in which this study will be conducted is Umlazi. Umlazi is a township on the east coast of KwaZulu-Natal, South Africa, the second largest township in South Africa, the largest being Soweto in the Gauteng province. Umlazi Township has a population of approximately 1, 2 million with 29% of the population below 15 years of age (Riess, Reijer & Mukuvisi 2012:1).

Epstein (2008: 21) posits that HIV infection in South Africa's townships is among the highest in the world. Umlazi Township is no exception; it is overcrowded and impoverished, thus impacting emotionally, socially and economically on the caring process. It is one of the reasons why the researcher has chosen to conduct the study in this township. As is observed in many South African townships, hundreds of adult children who are AIDS-III are taken care of by their elderly parents.

A study conducted in Umlazi Clinic by Riess and Reijer (the Directors of Global Project Management) from the AIDS Health Foundation and Mukuvisi from Ithembalabantu Clinic reported that the clinic currently has more than 3,750 pre ART patients and over 6,500 patients on ART. A poster presented at the 2012 International AIDS Treatment and HIV Prevention workshop titled "Test & Treat Programming experiences in Umlazi, South Africa" highlighted the challenges this township faces when it comes to issues of HIV prevention and treatment (Riess et al 2012: 1).

They further reported that, by March 2012, among those testing HIV positive, 1,5% were 0-14 years old, 93,4% were 15-49 years of age and 4,2% were 50 years and older. This is further evidence of the burden of HIV and AIDS among the adult population, hence the need to focus on older caregivers facing the challenge of AIDS-III adult children.

It could be argued that morbidity is expected to decrease with the universal provision of ART. However, experience on the ground contradicts this assumption. For example, Ries et al found that there is lower enrolment into care and treatment among HIV positive clients who are tested through mobile outreach (Ries et al 2012:1). Consequently, those who present themselves for treatment often come when they are at an advanced stage of AIDS and are really ill. Another major challenge cited by Ries et al (2012:2) is that more than 90% of HIV positive clients do not want to be followed up at a physical address, and over 30% of mobile phone numbers provided by clients are not reachable or were wrong numbers. All the above cited challenges impact heavily on linkage into care and treatment, and lead to high levels of morbidity, placing a burden on caregivers to provide support and caregiving.

### 1.11 OPERATIONAL DEFINITIONS

- **Adult AIDS-III Child:** In this study this term refers to a person between 19 and 45 years old who is sick with AIDS and dependent on an elderly parent for care and support.
- **Caregivers:** Reinhardt, Given, Petlick and Bemis (2004:41) define a caregiver as an “unpaid family member, friend or neighbour who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks”.
- **Caregiving:** This term refers to the provision of unpaid assistance for the physical and emotional needs of another person, ranging from partial assistance to 24-hour care, depending on the care recipient’s condition (Goodhead & MacDonald 2007:13). There are often no formal agreements or services specifications in such caregiving, which is often characterized by relationships and social expectations.

- **Lived Experience:** According to Rooney (2001: 843), lived means to remain alive or to continue living and further defines “experience as the sum total of an individual’s thoughts and feeling and the things that have happened to an individual (Rooney 2001: 341). Lived experience in this study refers to older parents’ expression of their experiences, feelings, emotions and perceptions while coping with caregiving for their adult AIDS-III children.
- **Older Caregiver:** refers to both male and female parents who are aged 55 and above, who are providing care for their Adult AIDS-III children, and those who cared for their adult AIDS-III children who have died of AIDS.

## **1.12 OUTLINE OF THE STUDY**

### **Chapter 1 - Introduction**

This chapter presents the background, rationale, aims and significance of the study, as well as the clarification of the key terms to be used in the study.

### **Chapter 2 -Theoretical Framework and Literature Review**

Chapter Two examines the theoretical framework, the role of caregivers and the relevant literature on the experiences by caregivers.

### **Chapter 3 – Research Design and Methodology**

Chapter Three describes the research design and methodology, the research instrument, the sample design and sampling technique, as well as the data collection and data analysis procedures.

### **Chapter 4 – Results**

Chapter Four presents and discusses the main results or findings of the study.

## **Chapter 5- Conclusion and Recommendations**

Chapter 5 concludes and makes recommendations based on the findings of the study. This chapter also summarises the salient points in the results.

### **1.13 SUMMARY**

This chapter discussed the prevalence of HIV and AIDS globally and more specifically in sub-Saharan Africa. It further gave the rationale for and background to the study. Arguments that have been formulated by previous researchers were highlighted. The aims of the study are detailed, together with the potential significance of the study. The researcher also gives clarity on operational definitions used within the study. The chapter ends by noting the information to be discussed in the following chapters.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1. Introduction

This chapter will discuss the theory underpinning this study, which is the caregiver identity theory. This will be followed by the section on the review of literature on HIV and AIDS prevalence globally, nationally, provincially and specifically in Umlazi, the township where the study will be conducted. This review will further explore the impact of caregiving in relation to what other researchers and scholars have observed. The nature and extent of informal caregiving will also be considered. Literature on gender and caregiving will be reviewed. Literature on the impact of HIV and AIDS on older caregivers will be reviewed, analysed and grouped into the following themes: the health and psychosocial impact of caregiving, social impact, economic impact and the positive impact of caregiving as cited by the caregivers.

#### 2.2. THE THEORETICAL FRAMEWORK: CAREGIVER IDENTITY THEORY

The theoretical framework adopted in this study is caregiver identity theory, which was developed by Montgomery, Rowe and Koloski (2007:1). The caregiver identity theory is an extension of the caregiver marker framework, which is a useful tool for guiding the design and delivery of support services (Montgomery et al 2007:23). The underlying premise of this model is that caregiving is a dynamic change process which includes changes in care activities, in the relationship between the caregiver and the care recipient and changes in the caregiver's identity (Montgomery et al 2007:43).

This theory refers to the idea that taking care of a loved one involves a gradual, change in identity from the original family role as a mother, spouse or other to that of caregiver. These changes in identity eventually influence the type and level of stress or burden (Montgomery et al 2007:2). This theory is aimed at helping caregivers cope with their caregiving role.

The approach views the caregiving career as a series of transitions resulting from changes in the caregiving context. Montgomery et al (2007:5) argue that, like many other social behaviours, caregiving is governed by norms or social values.

In addition, a person's ethnic and cultural background influences her expectations, because each culture has its own norms relating to the caregiving responsibility.

### **2.2.1 Aspects of the Caregiver Identity Theory**

Montgomery and Kwak (2008:12) highlight three important aspects of the caregiver theory. Firstly, caregiver stress has been shown to be the most direct measure of the caregiving experience. Caregiver stress is multidimensional and is influenced by a wide range of factors, such as a change in the relationship between the caregiver and the care recipient, or a change in the caregiver's physical health (Montgomery et al 2007:2).

Secondly, Montgomery and Kwak (2008:12) argue that the caregiver identity theory takes into account the great diversity among caregivers. This diversity involves the type and number of tasks undertaken by the individual caregiver, the costs incurred and the benefits they perceive in their caregiving role. Montgomery et al (2007: 32) and Gaugler (2005:178) agree that this theory recognizes that the experience of caregiving is determined not only by the care recipient's disease process and level of disability but also by factors grounded in the family roles and culture.

The third aspect that the authors highlight is that the caregiver identity theory provides insights into the great variation in the services that they think they do not need. The perception of need is influenced by the characteristics of the caregiver, the care recipient and the provider.

Research conducted using the caregiver identity theory indicates that caregivers will not use the services that they do not perceive to be necessary or useful (Montgomery et al 2007: 24). Montgomery et al (2007:45) further argue that, for most caregivers of persons with chronic conditions, the change in identity is a slow, insidious process that occurs in stops and starts.

It is expected that older caregivers for adult AIDS-III children may initially have minimal or small care needs and that the corresponding care tasks may represent only a minimal extension of their familial role relationships.

However, as the disease progresses, it is expected that the needs of the adult AIDS-III child and the resultant demands placed on the older caregiver will increase.

Consequently, the older parent then begins to assume a “caregiver identity”. Thus, over time, the caregiving activities transform the initial mother-child relationship into a caregiving relationship.

### **2.2.2. Five phases of the Caregiver Identity Theory**

Montgomery et al (2007:43) have identified five phases of the caregiving career that are linked to changes in the care recipient’s needs for assistance.

**Phase 1:** This phase of the career is the period of role onset. This period begins at the point when a caregiver assists the care recipient in a way that is not usually part of the caregiver familial role. During this phase of the care process, the caregivers are rarely aware of their caregiving identity.

This phase is very common among the older caregivers, whereby they find themselves providing care for their family members without noticing that their identity is gradually changing to that of a caregiver.

**Phase 2:** This stage begins when the caregiver acknowledges that his or her care activities are beyond the normal scope of the initial familial role. Montgomery et al (2007:45) termed this phase as the point of self-identification as a caregiver.

During this phase, the caregiver is maintaining his or her primary familial identity in relation to the care recipient, while acknowledging the presence of the caregiver role (Montgomery et al 2007:45). During this phase, the caregiver gradual notices some changes in his /her role, which means that the role is now slightly different from what it used to be. The care recipient will make more demands for care than in the initial stage. Older caregivers for their adult AIDS-III children are no exception to this stage.

**Phase 3:** This phase manifests itself when the care needs of the care recipient increase in quantity and intensity to a level that requires assistance that is substantially beyond the normal boundaries of the initial familial relationship (Montgomery et al 2007:46).

During this phase, the caregiver is often torn between his or her initial identity as a relative and assuming the role of caregiver as a primary identity in relation to the care recipient. This is very common among the caregivers for AIDS-III people, because the intensity of care usually increases over time to such an extent that the caregiver role comes to dominate the dyadic relationship.

**Phase 4:** The caregiver then moves into this more intense phase. This phase requires more time from the caregiver since the care recipient requires constant and very intensive care (Montgomery et al 2007:46). This is the stage when most AIDS-III patients are bed-ridden and demand a lot of attention from their elderly parents.

During this phase most caregiving tasks are very strenuous for the older caregivers, like changing bed linen, feeding, administering medication, bathing, making hospital visits or taking care of the care recipient's children.

**Phase 5:** This is the final phase of the caregiving career, and involves moving the care recipient into a setting that relieves the caregiver of the primary responsibility of care (Montgomery et al 2007:47). Most often, this phase entails placement in a nursing home, hospice or care center or else movement to the home of another family member. In this proposed study it is expected that this phase might be a more challenging one for the older caregivers.

In the African culture, however, hospices and other facilities are seen as abandoning or giving up on the loved one. The researcher has observed that, instead of going to places of care, many adult children choose to be taken back to their parents' home. Alternatively, parents move into their adult children's home to be their caregivers. This is the beginning of role reversal, whereby elderly parents find themselves having to be full-time caregivers for their adult AIDS-III children. In this process of changes, there are adjustment periods during which there is a difference between what a caregiver is doing and what the caregiver thinks he or she should be doing, given his or her personal identity. The core tenet of the caregiver identity is that the caregiver will experience distress during those periods when they are engaged in activities that are inconsistent with their views of self (Montgomery et al 2007:49). Subsequently, this distress will prompt caregivers to be open and seek help. These points of distress may be viewed as periods in the caregiving process when a caregiver is overburdened.

This is common among older caregivers who find they are performing activities that are now discrepant with their previous role identity. Furthermore, older caregivers are experiencing additional activities such as taking care also of the children of the AIDS-III child. All this demands their time and limits their role performances.

In conclusion, Montgomery et al (2007:50) emphasized that “tremendous variation exists in the trajectory of caregiving careers and that movement between phases is not a universal experience for caregivers or a steady smooth process”. The authors further highlight that many caregivers exit from the caregiving role during Phases 2 and 3 and move directly to Phase 5, where they remove their care recipient from their care to other institutions of care. Most older parents prefer to look after their own adult children and experience significant distress at various points of transition during their caregiving phase. Their plight needs to be highlighted so that they can be successfully supported in their caregiving role.

### **2.3. HIV AND AIDS Prevalence: The global and regional picture**

In Chapter One, the researcher provided a short synopsis of the HIV prevalence picture. In this section, the researcher will review the latest figures, with special attention to the state of the epidemic in this country. With increasing access to anti-retroviral therapy, it is expected that people living with HIV will live longer, which means that in the interim we will see an increase in HIV prevalence in the context of a mature epidemic. In total, South Africa has 5.6 million people living with HIV (UNAIDS 2012: 7). HIV prevalence amongst the middle-aged is increasing significantly and therefore poses a great threat to older parents who eventually assume the role of care giving.

Sub-Saharan Africa has recorded a 25% reduction in new infections, but is still leading globally. Out of 34 million, 23.5 million (72%) are cases from sub-Saharan Africa (UNAIDS 2012:4). Sub-Saharan Africa also leads in adult HIV prevalence (15-49 years) and with new infections. It is estimated that, of the 2.5 million new infections reported, 1.8 million of these were in this region. Furthermore, of the 2.5 million newly-infected cases reported globally, 2.2 million were adults and fewer than 330 000 were children younger than 15 years of age. The good news is that there were 700 000 fewer new infections globally in 2011 compared with 2001.

South Africa, the country with the greatest number of HIV infections, managed to reduce new infections by 41% between 2001 and 2011. Although HIV prevalence among pregnant women remains high (29.5%), there was a slight drop of 0.7% in prevalence among pregnant women attending state clinics in 2011 (DOH 2011:16).

The numbers of people living on treatment for HIV has increased. AIDS-related mortality remains a challenge, with 1.7 million AIDS deaths reported in 2011 (UNAIDS 2012:1-3). However, Africa has managed to cut AIDS-related deaths by one third in the past six years (UNAIDS 2012: 2). Interestingly, fewer than 100 000 deaths occurred, owing to ARV access in South Africa (UNAIDS 2012: 3). When it comes to treatment, 14.8 million people are eligible for HIV treatment in South Africa, but only 8 million are on it (UNAIDS 2012:6). The 6 million people who are not on treatment pose a great challenge to caregivers, especially when they advance to the AIDS stage.

The ART prolongs an infected person's life, but also poses further challenges to caregivers, who must provide emotional and practical support to the relatives and friends living with the disease (O'Neill & McKinney 2003:1). O'Neill and McKinney (2003:1) are of the opinion that the prolongation of the disease causes uncertainty about the overall prognosis and a "roller coaster" pattern of repeated exacerbations and remissions in the later stages of the disease, intensifying the emotional and physical demands on caregivers.

### **2.3.1 HIV and AIDS Prevalence in Kwa Zulu Natal**

Among the nine provinces in South Africa, KwaZulu-Natal still has the highest HIV prevalence among the 15-49 year olds (DOH 2011: 29). Nevertheless, a decrease of 2% between 2010 and 2011 has been observed. This figure has declined from 39,5% to 37,4% (DOH 2011: 29). UNAIDS (2012:12) describes the epidemic in KwaZulu-Natal as hyper endemic, generalized and mature. This province has an HIV prevalence among the general population estimated at 24,7% UNAIDS (2012:12) compared to 2010 which was 24,59% (DOH 2011:30).

According to Beaubien (2012:1), parts of KwaZulu-Natal have HIV rates of more than twice the national average. Yogan Pillay, a senior Health Department official, confirmed that KwaZulu-Natal remains the province with the highest prevalence rate, stated in the briefing of parliament's health portfolio committee in October 2011. He pointed out that the five districts that recorded the highest rates in the country during the survey were all in the province of KwaZulu-Natal. These were UMgungundlovu 42,3%; ILembe 42,3%; UMkhanyakude 41,9%; UGu 41,1%; and EThekweni with 41,15 % (DOH 2011: 31). It is in this province that the researcher will conduct her study in the district of eThekweni, specifically in the township of Umlazi, described in Chapter One in 1.10 under research setting.

## **2.4. Impacts of Caregiving**

Caregiving almost always impacts on the life of the caregiver. Those who are involved in caregiving, like the older caregivers for adult AIDS-III children, experience profound and wide-ranging changes in their lives. HIV/AIDS presents great challenges, not only to the person living with AIDS, but also to their family caregivers who undertake the role of caring for them (Palattiyil 2006:11). Palattiyil (2006:13) further argues that the family caregivers are the cornerstone in the support of the people living with AIDS and refers to them as the invisible heroes. Grant (2003: 97) suggests that, over the centuries, families have been the bedrock of care, providing support for their ailing and disabled family members and that this has been a symbol of their natural love and altruism.

Despite the importance of the family caregivers, especially older caregivers, their contribution is virtually invisible.

### **2.4.1. The nature and extent of caregiving**

Caregiving is routine and an ongoing process. According to Goodhead & MacDonald (2007: 14), caregiving arises out of a relationship with the care recipient in response to the need for support. This is greater than normally expected owing to impairment in functioning. Goodhead & MacDonald (2007:4) further argue that caregiving is relatively invisible since it often emerges outside any formal agreement. It is also true, as shown in this study, that it is the older caregivers who automatically become the caregivers for their adult AIDS-III children.

Most of the studies reviewed reveal that the caregiving task is undertaken mainly by women and girls, so caregiving often becomes a gender issue.

#### **2.4.2. Gender and Caregiving**

Women are the major providers of long-term care and play a major role in the provision of a backbone of support. Women provide the majority of informal care to spouses, parents, friends, adult children, orphans and neighbours (Arno 2002:18). According to UNAIDS (2008:3), evidence now abounds on the unequal AIDS-related care work responsibilities which are assumed disproportionately by girls and women of all ages as compared to boys and men. There are men and boys who are involved in the caregiving role though they are a lesser but not insignificant number due to traditional gender norms which result in more women and girls providing care (Gomo 2008:11). Gomo (2008: 12) further argues that men and boys who provide care may be invisible and underreported because it is socially unacceptable for them to be caregivers.

The study conducted by Good head & MacDonald in Australia , the United Kingdom and Canada highlighted that about one household in twenty has a primary caregiver who are predominantly women (Good head & MacDonald 2007:4). This is further confirmed by a study conducted by Steinberg et al 2002 as cited by UNAIDS (2008:3), saying that, in Southern Africa, numerous studies reveal that two thirds of primary caregivers in the households surveyed are female and one quarter of these are over 60 years of age.

It is with this in mind that the researcher seeks to understand these older caregivers' experiences, to provide a deeper understanding of the challenges they face and the efforts they make to cope with these challenges. UNAIDS (2008: 3) further highlights that, in South Africa, a national evaluation of home-based care found that 91% of caregivers were women and a survey of 62 organisations deploying a total of 2,635 volunteers in three Ugandan districts found that 68% of volunteers were female.

This is also evident in Thailand, where two thirds of people living with HIV/AIDS are nursed at home by their parents, usually their mothers (Knodel 2001:1314). Older women and married women are significantly affected by caregiving for their adult children with AIDS.

Care responsibilities fall to older women because a substantial proportion of people living with AIDS move back to their communities of origin at some stage of the illness to be cared for by their parents (Knodel 2001:1318).

#### **2.4.3. Research on the impact of HIV and AIDS on older caregivers**

A literature search on the impact of HIV and AIDS on older caregivers was carried out by means of a multiple electronic database search by using the combined key words of older-caregiver, older-parent, HIV and AIDS, socio-economic impact, emotional impact and caregiver lived experience.

An additional manual search was conducted to obtain the published works identified through the electronic search. The researcher focused more on the studies conducted in sub-Saharan Africa, academic literature that refers to the elderly and HIV and AIDS in sub-Saharan Africa, and reports written by various organizations that support the cause of the elderly.

Studies on older caregivers conducted internationally and locally have focused on their caregiving role of orphaned children, and no local qualitative study on older caregivers' experience of giving care to an adult AIDS-III child was found in South Africa.

The study conducted by Lekalakala-Mokgele in 2011 showed that the AIDS pandemic has direct and indirect effects that have manifested in a set of interrelated social, economic and psychosocial dimensions. These could ultimately impact on the health and wellbeing of the elderly (Lekalakala-Mokgele 2011:1). Knodel and Saengtienchai (2002: 23) identified seven pathways by which older people experience the impact of the AIDS pandemic at the family or household level: caregiving, co-residence with an adult child, loss of the child, providing financial or material support during the time the adult child is ill, funeral costs, fostering grandchildren and negative community reaction.

The literature reviewed also revealed that caregiving can have a positive impact on some caregivers. Literature on the impact of HIV and AIDS on older caregivers was reviewed, analysed and grouped according to the following themes: the impact of HIV and AIDS on the psychosocial condition and health of the older caregiver; the social impact; the economic impact; and the positive impact of caregiving. Each theme will be discussed further below.

#### **2.4.3.1 The health and psychosocial impact of caregiving**

According to Robinson, Fortinsky, Klappinger, Shugrue and Porter (2009:1), caregivers demonstrate high levels of psychological distress and depression; increased rates of physiological illness and suppressed immune responses; lower rates of engaging in preventive health behaviours; disruptions in paid employment; and personal, financial and social problems. Arno (2002:16) concurs with Robinson et al above that the physical impact of care can lead to long-term care needs for the caregiver. For instance, they could suffer from coronary heart disease and other health effects like elevated blood pressure, uncontrollable hypertension, poor immune functioning and an increased risk of mortality.

Studies on the impact of HIV and AIDS on the caregiver indicate that elderly people have singled out this epidemic as one of the illnesses that have affected their health. It has cost them both socially and economically (Baden & Wach 1998:14; Bamett & Whiteside 2002:33). The strain of caring for people with AIDS in the final stage of the illness can also be harrowing and tiring and takes its toll on older people's own health (HAI 2012:16).

This strain is more evident when there is no support. In a study conducted in Kanye district in Botswana, it is reported that 85% of caregivers indicated disappointments as far as visiting counseling and supervision by health care personnel, counselors and doctors were concerned (Kangethe 2009:116). This had a negative bearing on caregiving productivity and coping in general for caregivers.

Other risk factors include being infected with HIV in the course of providing care. In Uganda, some elderly people reported that they had been infected by HIV owing to caregiving (Nankwanga, Phillips & Neema 2009:21).

The risk of infection among the elderly is in the context in which they are often not educated about the virus or how to protect themselves while they provide care for adult children living with HIV and AIDS. According to Help Age (2005:2) research have shown that elderly people have been excluded from most of the ongoing HIV and AIDS campaigns and that this increases the chances of vulnerability and contracting the disease because of ignorance.

African people's belief in being bewitched also has an impact on the health of the elderly caregiver and the sick adult, since many may initially deny that they are infected with HIV and thus the caregiver may not be aware of the infection.

Secondly, these beliefs have a negative impact on health-seeking behaviour, so many seek treatment very late. HAI (2004:23) reports that the health of older caregivers has deteriorated as a result of the physical and emotional stress of assisting their children.

According to Sengonzi, Konde-Lule, Wankambo and Wawe (1996:2-4), the frequent changing, lifting and bathing of adult patients results in severe backache, and chest and leg pains among the older caregivers. Women have been found to be less likely than men to engage in preventive health behaviours like time for rest and exercise (Montgomery & Kwak 2008:7).

The lack of time to devote to self-care and preventive health behaviours on account of caregiving demands may contribute to long-term negative health outcomes for caregivers, in addition to the direct effects of objective burdens and depression (Vitaliano, Young & Zhang 2004:16).

Impacts on mental health have been described as caregiver distress, burden, strain, depression and poor psychological well-being (Chappell & Reid 2002:19). Caregiver stress or strain has been linked to both the functional level of the elderly and the activities of the caregiver.

In general, the demands of assisting with personal care and dealing with the problem behaviours and demands of the care recipient, as well as the need for constant supervision are stressful and lead to psychological distress, changes in social activities and negative feelings about caregiving (Levesque, Cossete & Laurin 1995:22; Montgomery 1989:16).

According to Navaie-Waliser, Feldman, Gould, Levine, Kuerbis and Donelan (2002:410), a four-year study conducted in the USA revealed that middle aged and older women who provide care for an ill or disabled person were almost six times as likely to suffer depressive or anxiety symptoms than those who had no caregiving responsibilities.

Knodel and Saengtienchai (2001: 14-16) cite a variety of mental health problems among older caregivers, ranging from fatigue and insomnia to anxiety. Many older caregivers experienced strained muscles, headaches or stomach aches. Physical health can also be impacted negatively; this was shown in a Zimbabwean study (WHO 2002:18-19), in which older caregivers cited the physical illnesses afflicting them, such as swollen limbs, high blood pressure and severe headaches.

The increase in older caregivers' daily chores compromises their physical and emotional well-being (WHO 2002: 18) and has a negative effect on their general health status. In Malawi, the increase in older caregivers' daily chores is a significant challenge, as the majority of older people are dependent on hand-hoeing (use of traditional way of planting by using hand hoes instead of tractors ) in their subsistence agriculture (Sefasi 2010:102). Food production requires people who are physically strong. Similarly, caregiving also demands a lot of energy and affects older people in the pursuit of their subsistence agricultural existence.

Caregivers have been reported to spend much of their time performing caregiving activities, which often infringes on the time available for other life activities (Montgomery, Rowe & Koloski 2007:6). Most caregivers have reported restrictions on their personal time and socialization as a result of caregiving.

This restriction of caregivers' activities has, in turn, been identified as a critical cause of depression among caregivers (Yee & Schulz 2000:148).

A Cambodia study conducted by Knodel & Saengtienchai (2002:2) concluded that older caregivers of their adult AIDS-III children experienced their caregiving tasks as being very strenuous and found the disabling stage of the illness emotionally and physically draining. Some parents revealed that emotionally the experience is wrenching and the grief is long-lasting.

The pain and loss of dignity inflicted on the caregivers is significant, and in some isolated cases the abuse was so acute that the older person reportedly developed a serious medical condition (WHO 2002:21).

#### **2.4.3.2. The social impact of HIV and AIDS on older caregivers**

Most studies conducted on the social impact of HIV and AIDS have revealed that being a parent of an adult child who has AIDS, especially if they have taken the role of caregiver, leads to stress in interpersonal relationships within both the local community and the family (Leary & Schreindorfer 1998: 11; Lekalakala-Mokgele 2011:6; UNAIDS 2001:52). Caregivers often feel like outcasts from other community members and experience a loss of social contact with others. Many experience severely negative reactions like stigma and discrimination. In the study conducted in Taiwan, older caregivers who were caring for their adult AIDS-III children cited their caregiving experience as one in which they suffered from shame, the change in their daily lives and interaction with others (Ming-Chu 2008:14).

Other sources of social stress highlighted by caregivers include exacerbation of preexisting conflicts within the family or community; the lack of cooperation in sharing caregiving or related expenses; attribution of blame for the infection to the son/daughter's spouse; and disagreements over the responsibility for fostering the surviving children (Leary & Schreindorfer 1998:16; UNAIDS 2012: 57).

A study conducted in Thailand revealed that the most common negative reactions included gossiping, avoiding contact, looking repelled by the appearance of the person with AIDS and boycotting food products sold by the family of the infected person (UNAIDS 2001:53). Caregiving often leads to increased social responsibility of the elderly and there is noticeable increase in social isolation because the elderly cannot afford the time or money to take part in social activities (Lekalakala- Mokgele 2011:4).

According to HelpAge International (HAI) (2005:6), older caregivers do not disclose their family members' HIV status because they fear people's reactions.

This eventually leads to isolation and stress, as older people miss out on potential sources of help and support, including services specifically designed to help them. Kangethe (2009:116) reported that in Botswana there was a noticeably weak community support system, whereby caregivers were inadequately assisted by relatives, friends and neighbours.

Some caregivers have reported abuse and rejection by the community relating to caregiving. About two thirds of the respondents (64, 7%) in the Zimbabwean study confirmed this (WHO 2002:20).

#### **2.4.3.3. The economic impact of HIV and AIDS on older caregivers**

Elderly people are also affected financially by caring for their adult AIDS-III children. Parental caregivers for adult children with high and complex needs or those who need palliative care are commonly under financial pressure (Goodhead & MacDonald 2007:50). Financial pressure adds to stress, and places constraints on the manner in which they can care for their sick child. It also severely limits the family's participation in normal activities. Many have less or no time to engage in income-generating activities (Ntozi 2001:14). Many older caregivers have lost economic hope as a result of losing their adult children to HIV and AIDS (Nankwanga et al 2009:21).

HIV and AIDS have indirectly changed the role of the elderly from one of being provided for to that of being the provider (Kakooza 2004:6).

Most of the older caregivers are less likely to have any regular income. Most parents, like those in Cambodia, play an important role in paying for their adult AIDS-III child's medical treatment and parents often have to stop or reduce their economic activities because of their caregiving role.

In Uganda and Zimbabwe, researchers reported that older parents often lose a great deal of money owing to ignorance about the disease. Many go from one traditional healer to another to find a cure (HAI 2012:15; Ntozi 2001:14; WHO, 2002:15). Most of them have sold their possessions and have stripped themselves economically naked (Nhongo 2004:18; WHO, 2002:15) in their efforts to reverse what was perceived as a curse.

Financial loss stemming from dwindling remittances was the single most debilitating factor in the study on the impact of AIDS on older people in Zimbabwe (WHO 2002:15), where the older persons without financial resources found it extremely difficult to provide adequate and sustainable care for both the dying adult child and the orphaned children (WHO 2002:15).

This was exacerbated by the loss of remittance (due to the incapacitation of the adult child afflicted with AIDS) and dispossession associated with the looting of inheritance resources which often follows the death of the breadwinner (WHO 2002:16). This often leads to food insecurity.

Another major economic challenge is transport problems (the affordability), especially problems in ferrying the person living with AIDS to and from clinics. This eventually leads to failure to collect medication for both the sick adult child and the older caregiver herself. A number of other expenses are commonly incurred, which include incontinence products, medical expenses, medication, house adaptations, extra bed linen or mobility aids and special dietary requirements (Goodhead & MacDonald 2007:51).

The level of desperation and lack of resources is witnessed in the sad case study of a 53 year-old woman from Highfield in Harare whose circumstances appeared so desperate that she reports that she was “forced” to sell illegal drugs to raise money to feed the orphans. “I am no longer afraid of going to jail” (WHO 2002:18). HIV and AIDS impact negatively on the economic life of the older caregivers and can cause levels of poverty which potentially prevent the whole family from achieving acceptable standards of living.

#### **2.4.3.4. Positive impact of caregiving**

Although widespread agreement exists that caregiving has negative consequences for many caregivers, positive outcomes have also been observed.

These include a sense of mastery, positive effects and an improvement in the quality of the dyadic relationship between the caregiver and the care recipient (Yee & Schulz 2000:1). Many caregivers find caregiving to be a source of deep satisfaction and meaning that strengthens their relationship with the recipients of their care (Goodhead & MacDonald 2007:13).

Some caregivers feel that they have grown as a result of their experiences. Some parents view caregiving as part of their responsibility as parents and want to do their best to help their sick children (UNAIDS 2002:73).

In Taiwan, too, parents cited much positivity regarding their caregiving experience. They commented as follows:

*We didn't expect our children's controversial illness, so we pretend to ignore the taboo.*

*We provide advice frequently to protect our children from pain, and try our best to take care of them in order to bring them better fortune.*

*We feel helpless in the face of predestined causality, and wish we could bear the burden of sin for our children (Feng 2008:25-26).*

Unconditional love and endless responsibility were the essential experiences of the Taiwanese parents.

The study conducted by Vellone, Fida Cocchien, Sili, Piras & Alvaro (2011:238) in Thailand points out that giving care to adult persons can be perceived as a positive experience, with satisfaction, gain, personal growth, reward and a feeling of usefulness, all of which give meaning to the experience and reduce depression and stress. Caregivers who experience the positive impact of caregiving are those who perceive it positively and attach worth to caregiving.

They maintain good relationships with care recipients and also experience the feeling of being appreciated (Vellone et al 2011:238).

## **2.5. Summary of the chapter**

This chapter presented the current global trends for HIV and AIDS and its prevalence. The chapter also discussed the caregiver identity theory, which highlights the gradual change in role identity of family caregivers. The chapter further attempted to describe the impact of HIV and AIDS on older caregivers of adult AIDS-III children.

The methodology that was used for the study is described in the next chapter.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1. INTRODUCTION

This chapter discusses how the study was conducted and also describes all the processes involved in data collection. The chapter further outlines the population that was studied; the sampling procedure followed; the research setting; data collection; the analytical procedure; and the issues of ethical consideration.

#### 3.2. The Research Method

Rajasekar, Philominathon and Chinnathambi (2006:1) define research methods as various procedures, schemes and algorithms used in the research that are scientific, essentially planned, and valued neutral. This is a general framework that guides a research process.

This study was of a qualitative exploratory nature aimed at providing an in-depth understanding of the lived experiences of the older caregivers of their Adult AIDS-III children. This understanding was gained by exploring and interpreting the experiences of caregivers as articulated by the caregivers.

Qualitative research is a form of enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live in (Holloway & Wheeler 2003:74). Qualitative research takes place in the participants' natural setting in order to involve their actual experience. This makes the study humanistic in nature (Cresswell 2003:24). Strauss and Corbin (1990:21) concur with Cresswell (2003:24) in that qualitative designs are naturalistic, allowing the researcher to engage in naturalistic enquiry. This makes it possible to gain both depth and detailed information concerning the phenomenon of interest without manipulating the research setting (Strauss & Corbin 1990:23).

Cresswell (1994:45) states that qualitative research has the following characteristics:

- Qualitative research is concerned with the process rather than outcomes of products. This is relevant to the proposed study since the focus here is to explore the participants' lived experiences of caring for their adult AIDS-III children.
- Qualitative research is interested in meaning (i.e. how people make sense of their lives, experience and structures of the world). In this proposed study, the focal point is on the meaning that the participants assign to their experiences.

This research was interpretive and also viewed social phenomena holistically (Cresswell 2003:11). The researcher helped older caregivers to interpret and make sense of their experiences and the world in which they live (Holloway & Wheeler 2003:74). A qualitative design enabled the researcher to reveal, through stories, the lived experience of the older caregivers for their adult AIDS-III children.

This lived experience assisted the researcher in identifying needs. In constructing the broad guidelines it can be shown how, in the South African context, older caregivers could be supported.

Qualitative research lends itself to describing phenomena in all their richness (Lo Biondo-Wood & Haber 1990:25). Qualitative research also brings to the fore the innate complexities and idiosyncrasies that form clients' experience of illness (Streubert & Carpenter 1995:64). The researcher has found this research design ideal for a research study that focuses on human phenomena i.e. the lived experience of older caregivers. Polit and Hungler (1994:58) argue that qualitative research is based on the premise that knowledge about humans is impossible without describing human experience as it is lived and defined by the actors themselves.

Furthermore, qualitative research is well-suited to the exploratory investigation of problems about which little is known (Sinuff, Cook & Giacomini 2007:11). This was relevant to the study undertaken, since little is known about the impact of caregiving, coping strategies and the needs of older caregivers for Adult AIDS-III children.

### **3.3. Research Design**

Thyer (in De Vos & Fouché 1998a: 77) defines a research design as a blue print or detailed plan of how a research study is conducted. Burns and Grove (1997:225) further explain the research design as the end result of a series of decisions made by the researcher concerning how the study will be conducted. The research design includes how data is to be collected, what instrument will be employed and how it will be used and further explains how data will be analysed.

In this study the researcher employed a qualitative research design using the phenomenological research strategy. The phenomenological strategy aims to understand and interpret the meaning that subjects give to their everyday lives. The phenomenological strategy described the meaning that the experience of a phenomenon or concept has for various individuals. The researcher should enter the subject and place herself in the “shoes” of the subject (Leedy & Ormrod 2005 :153), and Fouche 2002: 273). The researcher interviewed ten respondents in the focus group discussion and three in the individual in –depth interviews, who were identified and have experienced the particular phenomenon to collect data and were willing to share their experiences.

The older caregivers participated in the interviews to share their experience, strength and hope. The interaction of the participants in answering the questions within the semi-structured interview generated an interpretation of the phenomenon. The meanings behind their actions and responses helped to identify the older caregiver’s perceptions concerning their lived experiences as caregivers of their AIDS ill adult children. The use of the interviews for data collection allowed the researcher to pose follow –up questions to gain better understanding of shared experiences and meanings associated with the older caregiver’s experiences.

### **3.4 Area of study**

The area of study refers to the place where data will be collected, which is also called the research setting. In this study, data was collected at Umlazi Township, in the province of KwaZulu-Natal.

For the focus group, the researcher used the nonprofit organization venue, since the interviewees are familiar with it; they were relaxed and free from distraction.

For the individual interviews the researcher met with older caregivers at a venue suitable for them and at a time convenient to the older caregivers. Three older caregivers and their care recipients felt comfortable with home-based individual interviews which was an added advantage for the researcher. The researcher had an opportunity to observe the caregiver and get the true reflection of caregiving experience.

### **3.5 Target population**

Research has identified that older caregivers make about 78% of caregivers of both orphans and adult children with HIV and AIDS (Help Age, 2012: 16). That is the reason why the researcher targeted this population so as to understand their plight better and their service needs. Study participants were drawn from the Non-Profit Organisation for older and younger caregivers in the township of Umlazi in the province of Kwa Zulu Natal. The target population in this study constituted the older parents of adult children who are AIDS-III and who are the members of the selected support group. The participants selected to participate in the study will be those who have cared for and who are still caring for their adult AIDS-III children.

Burns and Grove (1997:236) define the target population as the entire aggregation of respondents who meet the designated set of criteria, and can also be defined as the eligible population for the research work. They further illustrate that the population is the aggregate or totality of those that conform to a set of specifications. Likewise, Cox (2013:1) describes the target population as the entire set of units for which the survey data are used to make inferences. It also defines those units for which the findings of the study are meant to generalise.

### **3.6. Sampling**

A sample is a subset of the population selected to participate in the study (Polit & Beck 2010:131; Uys & Basson 1991:87). Sampling refers to the process of selecting a portion of the population that conforms to a designated set of specifications to be studied, whereas a population is divided into smaller subsets for sampling purposes.

In splitting up the population in this way, each section has an increased likelihood of being selected for the sample, thus making the results more conclusive.

The participants of the research were obtained by purposive sampling. The site for obtaining participants was the Qondokuhle Gogo's Organisation whose mission is to empower younger and older caregivers to become successful and productive caregivers. Purposive samples consist of people who are typical of a targeted group or those who present diverse perspectives on a single issue. The researcher selected purposive sample for participation based on those characteristics (Leedy & Ormrod 2005:160). To obtain the participants for the research study a recruitment flyer was posted on the notice board at the organisations Centre, requesting participants. The potential participants were asked to provide their name and contact number. Identification of the potential participants originated from the responses to the recruitment flyer and their willingness to participate in the interviews. The recruitment flyer listed the requirements for participation in the research, i.e. inclusion and exclusion criteria as follows:

- An older parent who has lost her adult child to AIDS and those who are currently giving care to adult AIDS-III children.
- An older parent must have been giving care to the adult child for more than six months.
- Age restriction of participants to be 55 years or above and for the adult child to be 25 years or above.
- Older parents who are able to articulate and willing to share their caregiving experience with the researcher.
- Older parent who indicated their willingness and that of their care recipients to be visited at home for observation and in depth interviews.

The researcher ended up with a large number of thirty one participants that were willing to participate in the research and further sampling was required and the researcher embarked on systematic sampling as follows.

Systematic sampling:

Further, the researcher used systematic sampling technique to further reduce the research participants to a manageable number.

Systematic sampling is a method of choosing a random sample from among a larger population. This was done by first selecting a fixed starting point in the larger population and then obtaining subsequent observations by using a constant interval between the samples taken (Holloway 2005 :208). In this study, the researcher listed all the potential participants in an alphabetical order and then selected every third person on the list of caregivers. This procedure enabled each research participant to have an equal probability of selection. Fortunately only three respondents cited their willingness to participate in the individual in-depth interviews and no further sampling was required.

### **3.7. Data collection instrument**

This is an instrument or device that the researcher uses for collecting data. Sometimes it is referred to as a research tool or a way of gathering data. In this study, the researcher conducted one focus group discussions and three individual in-depth interviews. Interviews refer to dialogue between the researcher and the research participants with the purpose of eliciting the participants' perspectives or ideas on the phenomenon of interest (Holloway 2005:293). The term focus group refers to the group of people who often have similar experiences or common traits and are interviewed as a group, This is done in order to obtain their thoughts and perceptions on a particular topic or an exploration of the way in which they talk about the issues within a particular context (Holloway 2005: 297). The interview guide was first prepared in English and then translated into IsiZulu, in order to accommodate participants who were not able to express themselves in English. Isizulu is the language that is largely spoken in Kwa Zulu –Natal. The researcher had an assistant who assisted in note taking so as to enable the researcher to have full grasp of all the conversations without any disruptions. The tape recorder was used as a tool for collecting data and this enabled the researcher to translate the interviews into English. The researcher discussed with the participants the use of audio recording before commencing with it. The participants were taken step by step of the informed consent and it was also mentioned that they are participating freely and they can withdraw at any time. They were also informed that notes will be taken during the interviews and the permission to audio tape record the discussion and interviews was granted by the participants. They were also informed that the tapes will be kept in a locked file cabinet and only the researcher will have access to the tapes.

The researcher further explained that the reason for audiotape recording was to compensate for incomplete notes and to ensure accuracy of direct quotes.

This combination of focus group discussion and individual in-depth interviews benefited the researcher, gave an opportunity to contrast the data collected in groups and that collected in individual interviews. In –depth interviews involve one-on –one, face to face interaction between an interviewer and interviewee. They seek to build the kind of intimacy that is necessary for mutual disclosure (Johnson 2002: 91).

The decision to use both focus group and individual in-depth interviews is also motivated by the assumption that people are most “honest” in groups or speak differently and reveal different aspects of their experiences on their own, away from the group. This is the main reason why the researcher opted to conduct in-depth interviews with the same participants of the focus group because the group provided an opportunity to identify participants who will be good candidates for follow-up interviews. The in-depth interviews gave them an opportunity to reveal all their experiences they couldn’t share in the group. The researcher succeeded to explore the contextual boundaries of the older caregiver’s experiences that revealed what was unknown to the ordinary observer. The decision to follow-up the participants was based on them having a unique story and ability to provide rich data for the study. In-depth interviews allowed a more reflective understanding about the nature of the older caregiver’s experiences.

The individual interviews enabled the researcher to get the in-depth and real aspects of older caregiver’s experiences. The researcher used the same semi-structured questions to guide the individual in-depth and focus group interviews .

Semi-structured questions allowed the researcher a framework in which necessary open-ended questions were posed to encourage the participants to talk freely about their experiences and allowed the participants to respond in their own words, thus enabled richer and more complex data to be collected (Polit &Beck 2008:69).

### **3.8. Pilot Study**

The pilot study refers to the mini version of a full scale study. It is also known as a trial run or a feasibility study (van Teijlingen & Hundley 2001:4). Pilot studies are done as preparation for the major study to assist the researcher with an advance warning about where the main research project could fail, where research protocols may not be followed or whether the proposed methods or instruments are inappropriate or too complicated (Polit, Beck & Hungler 2001:467).

In this case, an informal pilot study was conducted with three participants within the study area i.e. Umlazi, and with the older caregivers of adult AIDS-III children. The participants in the pilot study were precluded from the main study. Conducting this pilot study allowed the researcher to eliminate bias and to test the instruments to be used.

### **3.9. Data Analysis**

Data analysis, according to the Business Dictionary (2013: 1), is the process of evaluating data by using analytical and logical reasoning to examine each component of the data provided. This process entails gathering, reviewing and sorting data from various sources in order to reach findings or conclusions. In this study, the data analysis method used was thematic analysis.

According to Rubenstein (1988:186), the best way to analyse data (tapes and transcriptions) is to identify key themes that emerge from the discussion under each of the discussion headings. The researcher used thematic analysis to analyse data. Themes are defined as units derived from patterns, such as conversation topics, vocabulary, recurring activities, meanings, feelings or folk sayings and proverbs (Taylor & Bogdan 1989:14). The researcher interpreted and categorised in terms of common themes all the raw data collected.

Analysis of the data collected followed the steps mentioned below as highlighted by (Taylor & Bogdan 1989:12; Rubin, 1995:18-19; Braun & Clarke (2006:83-89). Data analysis begun while an interview was still underway. The first step was to collect the data. Audiotapes were used for this purpose.

**Phase 1:** During this stage, the researcher familiarized herself with the data, transcribed it where it was necessary. She also read, and re-read the data and note down initial ideas.

**Phase 2:** This is the stage of generating initial codes. During this phase, the researcher coded interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.

**Phase 3:** This is the phase of theme searching. Codes were collated into potential themes, gathering all the data relevant to each potential theme. Patterns of experience were listed from the transcribed conversations, which came from direct quotes or paraphrases of common ideas. Quotations were selected to validate the themes identified as older caregivers describe their situations and feelings.

**Phase 4:** Themes were reviewed during this phase. The researcher identified all the data that relate to the already classified patterns. All the tasks that fit under the specific pattern were identified and placed with the corresponding pattern. This was followed by combining and cataloguing related patterns into subthemes. Themes were identified by bringing together components, fragments, ideas or experiences which were often meaningless when viewed in isolation.

**Phase 5:** During this phase, the researcher defined and name themes, and continued with analysis to refine the specifics of each theme and the overall story that the analysis tells.

**Phase 6:** This was the researcher's final opportunity for analysis. This phase involved the selection of vivid, compelling, extract examples and the final analysis of selected extracts, relating back to the research question and literature so as to produce the final report. When reporting the findings, examples from the participants' verbatim statements were included so as to engage the reader in consensual validation of the text (Leornado 1989:40-41).

### **3.10. Ethical Considerations**

Ethics are generally considered to deal with beliefs on what is right or wrong, proper or improper, good or bad (McMillan & Schumacher 2001:196). It is the researcher's responsibility to ensure that the ethical standards are adhered to.

The following measures were taken in both planning and conducting the study to ensure that the rights and welfare of the participants were protected.

Participants' right to self-determination, confidentiality, privacy and anonymity was respected.

To ensure that the information was relevant and a true reflection of the information obtained from the participants, verbatim transcripts were presented to participants for scrutiny prior to analysis.

To protect the participants' confidentiality the computer where the data are kept is password-protected to ensure that all the data is secure. Participants and the board members were informed about the findings of the report that was generated from their answers and it was shared with them. The report-back session was conducted and the copy of the report was left with the organization for reference purpose.

### **3.11. Trustworthiness and Credibility**

The researcher strived with everything in her power to do a truly valid, reliable and objective study. This was done by ensuring the trustworthiness, credibility and transferability of the study. The researcher considered the four criteria as proposed by Guba (1981: 75-90). These criteria were credibility, transferability, dependability and confirmability.

To ensure the credibility of this study, the researcher followed the following procedures as cited by Babbie and Mouton (2001:277).

The researcher had a prolonged engagement with the participants to ensure data saturation and referential adequacy, for example, the use of audio tapes to document her findings. Lastly there were member checks, to check data and interpretations with the participants.

The credibility of this study will prove that the study has the quality of dependability, which implies that if it was to be repeated with the same or similar respondents (subjects) in the same or a similar context, its findings would be similar (Babbie & Mouton 2001:278; Lincoln & Guba 1988: 346-347).

To ensure the transferability of this study, the researcher collected sufficiently detailed descriptions of data in context and reported in sufficient detail and precision to allow judgments about transferability to be made by the reader (Babbie & Mouton 2001:277). Confirmability, according to Babbie & Mouton (2001:278), is the degree to which the findings are the products of the focus of the inquiry and not the biases of the researcher. To ensure confirmability, the researcher conducted an audit trail that enables the auditor (the person conducting trustworthiness or validity of the research) to determine whether the conclusions, interpretations and recommendations can be traced to their sources and whether they are supported by the enquiry (Babbie & Mouton 2001: 278).

To conduct such a trail, the following data is available for audit i.e. raw data which is the audiotapes recorded, data reduction and analysis products, which are write-ups; field notes; summaries and condensed notes; data reconstruction and synthesis products, i.e. themes that were developed; findings; conclusions and a final report; material relating to intentions and depositions, i.e. inquiry proposals; personal notes and expectations; and instrument development information (Interview schedules).

### **3.12. Summary**

The chapter has outlined the research methodology that was followed in conducting this research study. It further outlined the population that was studied; the sampling procedure; the research setting; gaining access into the research setting; data collection and analysis; and the ethical issues. The next chapter (Chapter Four) will discuss the analysed data.

## **CHAPTER 4**

### **DATA INTERPRETATION AND ANALYSIS**

#### **4.1. Introduction**

This chapter presents the data analysis based on the objectives of the study as indicated below:

The objectives are:

- To gain an understanding of the lived experiences of the older caregivers for their adult AIDS-III children.
- To investigate how the older caregivers cope with their caregiving tasks.
- To explore the older caregivers' service needs.

The chapter begins by discussing the profile of the sample studied and its characteristics in order to better understand the nature of the findings. The sample profile will be followed by the presentation of results and the discussions of the main trends and patterns in the data, with reference to the research objectives and questions. Finally, there were other important findings that carry significance even though they may not have been themes. They will therefore be discussed as part of the findings. The researcher begins by furnishing the biographical profile of the participants.

#### **4.2 BIOGRAPHICAL PROFILE OF OLDER CAREGIVERS**

To meet the objectives of the research, the researcher interviewed ten participants in the focus group and further identified three participants from the focus group who were interviewed individually. All ten participants interviewed in the study were female. The majority of the participants (seven) were in the age group 55-65, while two were aged 66-70 and only one was in the group aged 71-81.

Four of the participants had never been married, three were married, and two were widows, while one had separated from her spouse owing to marital problems associated with the commitment of caring for the adult sick child.

Regarding the educational level of the participants, it was found that two had no formal schooling, four had passed Grade 8, three had passed Grade 10 and only one, a retired nurse, had a tertiary qualification.

Eight of the ten participants were unemployed; two were doing casual domestic jobs.

Three of the caregivers were caring for two care recipients; two were caring for four care recipients; two had two care recipients; and three were caring for one care recipient. Three were caring for biological sons and a daughter in law; two were caring for biological daughters and their husbands (sons in law); two were providing care for biological sons and daughters simultaneously; and the other three were providing care for their adult grandchildren.

Most of the caregivers interviewed resided in informal settlements under conditions of extreme poverty. This is consistent with the reports by Help Age International (2005:4), Piot, Greener and Russell (2007:4) and Ssengozi (2009:309) that poor women are the main caregivers for people living with HIV and AIDS.

#### **4.3. THEMES AND SUBTHEMES**

The researcher identified the following themes and subthemes as the reflectors of the participants' lived experiences in caring for adult AIDS-III children. Three major themes that emerged were:

- Challenges facing older caregivers during the caring process.
- Coping strategies used by the older caregivers in dealing with the challenges of caregiving.
- Support systems and service needs cited by caregivers.

Another important finding in this study that does not fall within the theme was the discussion of the route or circumstances that led to older parents becoming the sole caregivers for their adult AIDS-III children. This will be discussed under the findings.

The following table presents the main and subthemes that emerged from this study.

THEME	SUBTHEMES
<p>4.3.1. Challenges facing older parents who are caregivers.</p>	<p>4.3.1.1. Emotional challenges</p> <p>4.3.1.2. Physical challenges</p> <p>4.3.1.3. Financial constraints</p> <p>4.3.1.4. Psychological constraints.</p> <p>4.3.1.4.1. Depression and stress.</p> <p>4.3.1.4.2. Fear of contracting the disease</p> <p>4.3.1.5. Social challenges</p> <p>4.3.1.5.1. Isolation by family and community and time constraints</p> <p>4.3.1.6. Fear of stigmatization and discrimination.</p>
<p>4.3.2. Coping strategies utilized by older caregivers</p>	<p>4.3.2.1. Accepting caregiving as a natural part of their parental responsibility and viewing the sick child positively</p> <p>4.3.2.2. Maintaining hope or accepting the inevitability of loss</p> <p>4.3.2.3. Seeking help from within the family and outside</p> <p>4.3.2.4 Adjusting their time</p>

<p>4.3.3. Identified support systems and services.</p>	<p>4.3.2.5. Social relations as the source of support</p> <p>4.3.2.6. Religion as a coping mechanism</p> <p>4.3.2.7. Negative coping mechanism</p> <p>4.3.3.1. Home-based care services</p> <p>4.3.3.2. Provision of free education for Orphaned children</p> <p>4.3.3.3. Economic, Emotional and spiritual support</p> <p>4.3.3.4. Upgrading of existing government services</p> <p>4.3.3.5. Full involvement of older caregivers in issues that affect them.</p> <p>4.3.3.6. User-friendly material</p> <p>4.3.3.7. Housing as an urgent need</p> <p>4.3.3.8. Self-help initiatives and income-generating activities.</p>
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The presentation of the findings will be according to the following pattern: it will begin by discussing the challenges faced by elderly parents who are caregivers for their adult AIDS-III children. Then the discussion will turn to how older parents cope with the stresses associated with caregiving. This will be followed by the needs identified by the older parents who are caregivers for adult AIDS-III children.

Finally the study will discuss the circumstances that often lead elderly parents to become caregivers for their adult AIDS-III children.

### **4.3.1. CHALLENGES FACING OLDER PARENTS WHO ARE CAREGIVERS**

#### **4.3.1.1. EMOTIONAL CHALLENGES**

According to most participants in this study, a major source of happiness for older parents is that of seeing their adult children leading a good life, making a decent living, and raising their own families.

Realizing that an adult son or daughter has a debilitating and fatal illness, observing the progressive decline in the individual's physical and mental condition and witnessing the suffering that accompanies it is emotionally wrenching for a parent.

Almost all participants stated that, because of the stigma associated with the disease, and fear of negative reactions from neighbours and acquaintances in the community, they often hesitate to share their feelings or seek emotional support in their normal social network. Psychological and emotional strain was commonly mentioned as an unavoidable aspect of parental caregiving.

Among the circumstances cited that often cause emotional strain, older parents listed the following: facing the worsening condition of their child and the inevitability of death; adjusting their life to accommodate the caregiving role; and trying to do their best to provide this and alleviate their child's suffering.

*I don't want to witness this disease again in my life , not even with my worst enemy, I nursed both my adult children myself, without anyone coming to my rescue. This disease tortures your heart terrible and causes trauma. (Participant 3).*

*In my heart I always wondered how much more he would be tortured as he had suffered a lot, how long I would have to take care of him in that situation. It is very hurting too see your own child suffering like this. (Participant 8).*

Another major source of emotional strain highlighted by the parents was the negative reaction they received from other community members. Most of the time elderly parents felt that emotional exhaustion set in, especially when they had to repeat the role as the caregiver for another infected son/daughter, which was very common among the members of my focus group.

*I didn't have any time to rest after the death of my daughter last year because within a month my last born son was also sick to death and even today I am still providing full time caregiving to him and his condition is on and off. I feel that I am cursed maybe I have wronged my Lord I have no time of my own. (Participant 10)*

The hurt and pain of looking after their own children and those very close to them like in-laws because of an illness like HIV and AIDS is seen to be a painful and traumatic experience for the older caregivers.

Some of the participants broke down and cried when relating to the plight of their AIDS-III children and those already deceased. Fortunately the center has a full time social worker to provide counselling and debriefing.

*It is very painful and we even have no enough time to have proper bereavement for our lost adult children because we have to be emotionally and physical strong for our orphaned grandchildren. (Participant 2)*

The data analysis revealed that some of the caregivers faced abuse from their care recipients and their spouses which also caused lot of emotional strain to the older caregiver.

*My own son has been a very respecting child but now he is very emotional and short tempered , at one instance I gave him food and he threw the plate at my face swearing at me that I am serving him food that is not warm enough and had no meat in it whereas he is receiving his disability grant. (Participant 1)*

*My husband is always complaining that I have no time for him now as I am a full time caregiver of my two children that have returned home after contracting the disease, he does not even assist me in my caregiving tasks. He told me that he will now have an extra marital affair because I am no longer playing my role as his wife but a slave of my children. (Participant 7)*

*My grand child is a very troublesome child and it was worse after the death of his parents, he never finished schooling and was once a street kid for years and he only returned home few years ago. He is currently bed ridden and very sick and always demands me money to buy cigarette and alcohol.*

*When I refuse he abuse me physical and last year he stabbed me here (the older caregiver showed a healed wound on her arm with 5 stitches). I did not tell anybody what he did to me I had to lie to my family that I was attacked by a robber because I feared that they might chase him away in that condition as sick as he was and he has nowhere to go. I always hope and pray that one day he will realize that he is doing wrong things to me. (Participant 8)*

According to the Thailand study conducted by Saengtienchai and Knodel (2001: 28), there is probably no stronger emotional bond than that between parents and their children. In their study in Thailand among older caregivers, they reported that psychological and emotional strains were commonly mentioned as a part of parental caregiving. This theme is supported by Keen Reder (2003: 14) who reports that caregivers and PLWA experience what is termed anticipatory grief which is associated with the development of symptoms that people perceive as life threatening. Pakenham, Dadds and Terry (1995:192) noted that caring increases distressing emotions.

#### **4.3.1.2. PHYSICAL CHALLENGES**

The data analysis revealed that most participants were responsible for taking care of more than one care recipient, which placed a heavy burden on the shoulders of older caregivers.

Older caregivers expressed physical stress arising from doing washing, lifting up the bedridden, supporting or bathing the sick son or daughter and changing and washing the bedding. Eight out of the ten participants stated that they were losing weight and had problems with getting enough sleep as a result of caregiving.

*At least at his earlier stages of suffering he could walk. Later, when his condition started to decline, he could no longer walk...I needed to support him to get up, dress, and eat. I had to spoon-feed him and shower him. I did everything for him. I was getting thinner and thinner day by day because I didn't have enough sleep and time to eat. (Participant 4)*

*At my age it is very strenuous that I have to take care of my son and his wife for 24 hours a day. The worse part of it is to bath them lifting them is not easy and I can feel that my back is cracking. I sense it that I am soon going to die an untimely death because I have no time to relax. (Participant 10)*

These narratives support what Ssengozi, Konde Lule, Sewaankambo & Mawe (1996:7) reported that the elderly provide physical and emotional care to one or more people living with AIDS.

This is further supported by Gibbs (2008:19), who says that households headed by an elderly female in particular have higher dependency ratios.

In Thailand, Knodel (2001:31) reported that, while exhaustion was common amongst the elderly caregivers, many appear to have been able to avoid severe strains by calling on younger or stronger family members for the most demanding physical tasks.

Most of the older caregivers stated that they had no energy for carrying out all the tasks related to caregiving owing to their own state of health, which was deteriorating with age. They said they lacked the strength to do washing, bath the sick, cook, and most of all to meet the needs of the adult child's children.

*It is really taxing to stand on my sore feet for the whole day, to rush up and down. I am in my golden years where I must relax and wake up after sunrise, but circumstances are against me I must be a mother again to my sick child. This is a real role reversal. (Participant 2).*

*I will never forget the day when my sick child was supposed to go to hospital in the middle of the night. I called the ambulance because my house is inaccessible by transport I had to carry him on my back to reach the ambulance I fell three times with him on my back, he is very heavy I cannot carry him but I had no option. (Participant 7)*

In the study conducted by Makadzange (2010: 73), it is argued that elderly people were less energetic and excessive responsibilities were a drain on them. This is further supported by Juma, Okeyo and Kidenda (2004:3) in their study showing that the elderly were doing arduous household chores without any assistance.

The theme of physical challenge is supported by Flaskerud and Tabora (1998:26), who noted that caregivers experienced health problems associated with depression, anger and the number of care recipient's illness symptoms. This theme is further supported by Leblanc, London and Aneshensel (1997:919) who noted that caregivers reported symptoms of poor health that were associated with care related demands and stressors.

#### 4.3.1.3. FINANCIAL CONSTRAINTS

The elderly parents experienced numerous financial challenges in their occupation of giving care to adult AIDS-III children. Caregiving took significant time away from income-generating activities for the elderly caregiver.

Most of the parents said that, if the adult sick child had been contributing to the parents' income, assisting them in their economic activities, or providing other services that facilitated the parents' ability to earn an income, such assistance was forgone once the child became too debilitated to function normally.

Financial stress was also further generated more directly through the various expenses associated with caring for someone living with AIDS. These expenses included food and other costs of daily living, medication, health care fees and hospitalization. Immediately following their child's death, parents were faced with the costs of the funeral, typically an important and expensive affair in the African culture. Moreover, if the child with AIDS had dependents, the older parents may need to take over their support during the debilitating phase of the illness, and often afterwards as well.

*My son was very expensive, during his sickness he wanted to eat expensive fruits, and he told me to buy only 100 percent juice and A grade meat. I tried hard to please him I knew he wouldn't be able to live any long but to be honest I was drained financially. (Participant 9)*

*My daughter is very demanding, every week she demands that I top up her cellphone with airtime that she wastes within a minute. If I don't do it she shouts at me telling me that she has all the rights to use her disability grant the way she wants to. I eventually do as she demands to be at peace. Most of the time I had to use my pension to meet her never ending demands. (Participant 5)*

*We had to replace bed sheets clothes that we had thrown away once he had soiled them beyond use. We also bought nutritious mixtures, instant porridges and disposable napkins for him and they are very expensive. (Participant 10)*

Some parents admitted that they bought expensive traditional medicines from outside the modern health system.

Other expenses parents bore were transportation and school fees for grandchildren. Most of the caregivers felt that if it was not for the food parcels and protective clothing they received from the organization of which they were members, they would not have managed to survive that far.

*I am so lucky that I joined this Gogos' support group, that is the reason why I am still surviving even under difficult conditions because I get food hampers every fortnight and some clothing and emotional support from other gogos.*  
(Participant 5)

*There are times when I fail to collect her ARV's from the local clinic because of lack of taxi fare. I am the sole bread winner and I need money for everything and I cannot administer her medication on an empty stomach.*  
(Participant 2)

This is further confirmed by Foster, Levine & Williamson (2005:16) and Landsberg (2007: 104) that illness in a grandmother-headed household does not cause poverty but rather worsens its legacy, meaning that the elderly live in severe poverty which is exacerbated by caring for a sick person.

Borrowing to help meet the health care and funeral expenses was also fairly common to many older parents, who reported that most of the time they were unable to clear the debt or were struggling to do so later.

*We never had debts before. We only started lending when she got sick. We are struggling to pay our debtors back.* (Participant 6)

Some of the participants said that at times they and their care recipients actually slept on empty stomachs. Adding to this frustration was a fussy sick adult child who demanded the expensive and unaffordable food they were used to when they were employed. The participant's failure to provide them with food posed a challenge to taking medication.

*I am sometimes forced to skip his treatment because I cannot give him medicine on an empty stomach and that often causes complications. At times I give them unbalanced food which is not nutritious.* (Participant 3)

Matshalaga (2004:62) highlighted the inability to meet the dietary requirements of HIV positive patients as a major problem for caregivers, which is also seen in this study.

Most of the participants reported that they did not have access to protective clothing like gloves, linen savers and disinfectants to protect them from infection.

Most preferred to buy food first then protective clothing. Others deliberately didn't want to use protective clothing as revealed in the narratives below:

*I would rather save my hard earned pension for food rather than to buy gloves it is a waste of money. (Participant 6).*

*I always prefer not to use gloves with my sick child because she will think that I am now scared of touching him because of the disease, she must feel comfortable and not discriminated at, that's why I will never use any protective clothing. (Participant 9)*

In the study conducted in Thailand by Saengtienchai and Knodel (2001:42), it was shown that families were very supportive of each other. They pooled resources and took advantage of various formal mechanisms that could help. This shows a great deal of support in comparison with the situation in our country, where most of the time the caregivers are left to fend for themselves, while the family members distance themselves. In the present study it is noted that older caregivers are unemployed and are dependent on social grants which is disability grant and old age pension. Brouwer, Lok, Wolffers and Sebagalls (2000: 536) and Flaskend and Tabora (1998:29) in their studies noted that poverty increased the worries of caregivers as they might not have enough money for a balanced diet and regular medical check-ups especially when the person is bedridden.

#### **4.3.1.4. PSYCHOLOGICAL CONSTRAINTS**

Most of the caregivers confirmed that their caregiving role was strenuous and very demanding, and consequently caused a great deal of stress and anxiety. Caregivers reported that providing care for a sick adult child caused lot of psychological pain as they witnessed the suffering and decline of their children.

##### **4.3.1.4.1. Depression and Stress**

Most participants revealed that caring for an adult AIDS-III child is very depressing and stressful. Caregivers had regarded their adult children as pillars of strength, but illness had reversed their role. Parents were now finding themselves providing for their sick children.

Many factors contributed to their depression and stress, such as a very demanding sick adult child; ill-disciplined grandchildren; the high cost of school fees; providing nutritious food for the sick child; the deteriorating health of grandchildren; attending school meetings for grandchildren; and supervising homework.

*I do not mind taking the responsibility of raising my grandchildren but what I hate most is attending these never ending school meetings at night and monitoring of homeworks, Awu Awu I feel like dying. (Participant 4)*

*I thought this time I will be enjoying my golden years of aging and my children will be looking after me as I did when I raised them but now I am faced with a new challenge of becoming a mother again to my adult children and their children who are orphaned. (Participant 6)*

#### **4.3.1.4.2. Fear of Infection**

Some of the participants admitted that they were extremely afraid of contracting HIV while looking after their care recipients and were thus living in fear of the unknown.

*As I indicated before that I do not use gloves so as to avoid frustrating my child, but deep down I know I am risking my life as a result there too I am scared that I might be infected. I am even scared to do an HIV test what if I test positive. (Participant 9).*

*I have provided care to lot of people with AIDS that is why I always test myself when I go to the clinic. I want to be certain of my status and always scared to get my results after testing. (Participant 2)*

*I thought this time I will be enjoying my golden years of aging and my children will be looking after me as I did when I raised them but now I am faced with a new challenge of becoming a mother again to my adult children and their children who are orphaned. (Participant 6)*

Care workers in many studies have reported fear of infection. In a study done by Horsman and Sheeran (1995:1544), results revealed that HIV and AIDS care workers reported fear of infection. Melnick (2002:89) also found that caregivers expressed concerns regarding being infected. In this current study many caregivers never thought of being infected although some revealed the fear of contagion. Most older caregivers were eager to assist their loved ones hoping for improvement in their health condition.

#### 4.3.1.5 .SOCIAL CHALLENGES

Eight out of ten participants reported the various social challenges they encountered caring for to their adult AIDS-III children. They cited challenges that included isolation, stigmatisation and discrimination.

##### 4.3.1.5.1. Isolation from family and community and time constraints

The participants all agreed that they felt isolated and excluded from all social activities because of their busy schedules. They no longer attended community gatherings, church services, funerals, weddings and traditional ceremonies.

The only avenue to socializing available to them was their organization where they met to support each other on certain days.

The participants had this to say:

*I have never been to church for about two years now as I have no one to relieve me in my caregiving role even on weekends. I have missed out on meeting other mother's union members for support and advices. I am now living a solitary life. (Participant 5)*

“

*I cannot even attend my close relative's funerals as I cannot leave my sick child all by herself. I must always be there for her to administer her medication, change her nappy, feed her and respond to her demands at all times. (Participant 3)*

*My other son who is HIV negative does not eat any food that is prepared by me because he believes that he will contract HIV in my food as I am providing care to my AIDS-III grandchild. He does not even want me to touch his children and they are not allowed to come closer to my house and I feel rejected and isolated. (Participant 10).*

A number of the participants found that they were no longer in control of their time because the demands on them were dictated by the needs of the person they were taking care of. At the terminal stage of the illness, when the adult child's health had severely deteriorated, demands on the caregiver's time and effort could be particularly overwhelming.

*I am not able to do anything; I even forget to bath myself and even to eat, because she wants to be with me all the time, either to sit or to lie down with her. She use to read newspapers almost every day and now due to her eyesight problem he always ask me to read daily newspapers for her every morning and evening. I always provide time for reading in my busy schedule. (Participant 7)*

*I couldn't go anywhere, I had to abandon going to church, community meetings, I couldn't do anything else except to watch him for 24 hours I had to cook for him, feed him, bath him, and give him medicines. I had to take care of everything for him. No one assisted me I worked very hard day and night. (Participant 2)*

Most of these elderly caregivers said that time demands were exacerbated when they were also looking after other family members, such as when two or more children were sick and there were other grandchildren to take care of.

*"I had to take care of my son, his wife and a very sick newborn baby for ten months. It was really difficult and very taxing emotionally and physically, and eventually I was financial drained". (Participant 6)*

Other studies, such as that by Neursing (2009:309) and Ssengozi (2009: 309), reported that elderly caregivers face disruption in their social activities and altered family relations, and caregiving often limits the elderly's time for socialization, attending social events and carrying out income-generating activities. The findings of this research also support the findings of Katz (1981:29), which connected isolation and rejection together with subsequent prejudice and discrimination to attribution of stigma.

In this current study most caregivers cited that they experienced emotional strain due to rejection of both the caregiver and care recipient by family and community members. This often led older caregivers to become isolated from their potential support structure. Most caregivers resorted to secrecy and defensiveness due to uncertainty about those around them (Poindexter 2005:68).

#### **4.3.1.6. Fear of stigmatisation and discrimination**

The participants reported that they feared the stigma attached to HIV caregivers, as most of them were experiencing it in their households. They preferred to keep the illness secret from the community. Negative reactions by others in the community to the caregivers for AIDS-III could cause psychological, economic and social distress.

*I have kept my children's sickness as a secret even to my own family members because I know their attitude towards this disease. (Participant 7)*

*I told them that my son was bewitched at work because of his position of authority, I attributed his sickness to jealousy whereas deep down I knew he was suffering from this dreadful disease I did not want to be ridiculed and discriminated by my community. (Participant 10).*

Use of opportunistic infection to keep the diagnosis a secret was supported by several research findings in the field of HIV and AIDS and caregiving (Powell –Cope & Brown: 1992: 578).

Two out of the ten participants reported that the support they received from their neighbours was amazing and that the neighbours were always there for them, providing emotional, material and financial support when they needed it.

*I am very lucky to have supportive neighbours, they know that I am struggling financially and have provided care to more than three adult children of my own. They are always there for me, they provide transport to hospital when I need it for free, they buy nutritious food for my care recipients, and they also buy protective clothing like gloves and for me. I am very grateful to have such neighbours. (Participant 6)*

Most older caregivers cited rejection and discrimination and felt helpless and at times hopeless and unable to maintain this situation. This was in line with what was observed by Powell-Cope & Brown (1992:579) who observed that the caregiver and the care recipients are vulnerable to the effects of stigma, such as isolation, emotional turmoil and shame.

The impression gained from the participants is that giving care to an adult AIDS-III child does present challenges, particularly when it comes to the health of older caregivers, since they are affected emotionally, physically, financially and socially.

The next focus is on how the older caregivers coped with all the challenges they mentioned.

#### **4.3.2. HOW OLDER CAREGIVERS COPE**

The parents had developed a wide range of strategies for coping with the long-term term caregiving situation with their adult AIDS-III children. They experienced many stressful situations and reported that they responded in various ways to coping with the challenging tasks of caregiving. They stated that, in some instances, it was possible to assertively change the situation, or leave it or alternatively adapt in order to live with it so as not to feel even more frustrated.

Some coping strategies were positive and others were negative but most of the participants opted for positive coping mechanisms.

#### **4.3.2.1. ACCEPTING CAREGIVING AS A NATURAL PART OF THEIR PARENTAL RESPONSIBILITY AND VIEWING THE SICK CHILD POSITIVELY**

Eight out of the ten participants admitted that the caregiving period was difficult for them, but they indicated that they had willingly undertaken the role. Also, most of the participants did not think of caregiving as a burden but rather as part of their responsibility as parents. They wanted to do their best to help their sick son or daughter.

*Anyway she is my daughter; I had to look after her if I don't who will provide care for her. It is my responsibility and I cannot shift it to someone else. . I didn't think about the troubles like infection, I am her mother. I would do anything for my daughter. (Participant 2)*

*As a mother I was prepared to pay all his expenses I just wanted my son to be cured and spend my entire pension on him. My children would never be a burden to me. For my children I would do anything to save their precious lives. (Participant 1)*

Most participants maintained a generally positive attitude towards their sick child. Accepting the demands and sacrifices that often accompanied caregiving was probably made easier by the positive view that many parents had of their son or daughter. Folkman (1997:16) found that caregivers experience positive psychological states during caregiving and bereavement, with positive reappraisal being one of the coping strategies employed by them.

A positive psychological state is associated with searching for and finding positive meaning. In this study commitment to caring was associated with accepting caregiving as part of natural parental responsibility and viewing the sick child positively.

Most parents stressed that their child was of good character and had behaved normally before the onset of the illness. Six parents blamed bad fortune or other people such as the son's or daughter's spouse as the source of the infection.

*My son married an old widow. He must have got AIDS from his wife. I have no doubt that she infected my innocent son. (Participant 7)*

*My daughter was a good person and had only one man in her life. She didn't hang out with bad friends and was always at home at all times. I do not know how she caught this disease. (Participant 1)*

The other four participants mentioned problematic aspects of their child's character or behaviour, although their attitude towards caregiving was more positive. One participant, who appeared to be a devoted caregiver, also mentioned that she had tried to hide her son's condition from his father for as long as possible because she feared her husband's reaction.

*I kept it as my secret and did not want my husband to know my son's status because I know he would ill-treat him he is a very cruel person and can verbally abuse my son. (Participant 9)*

All the parents interviewed seemed to have devoted themselves fully to the care of their children to the very end. Several researches have observed the issue of self-control in caregiving. Melnick (2002:81) found that caregivers were trying to control feelings as a way of coping. According to Lazarus and Folkman (1989:11), one factor that influences an individual's coping strategy is self-control. Putting on a brave face and concealing their hurt, anger and disappointment or anxiety helped the older caregivers to function best.

This is also evident in the study conducted in Thailand by Knodel et al (1996: 43) that parents viewed it as normal when their single adult sons patronized prostitutes.

Infection was thought to stem from premarital behavior, and it was unlucky that the child had been infected. Thai parents always blamed their sons' wives for being the source of infection (Saengtienchai & Knodel (2001:43).

#### **4.3.2.2. MAINTAINING HOPE OR ACCEPTING THE INEVITABILITY OF LOSS**

Another coping strategy cited by almost all the participants was the hope that the sick child would get better. This hope helped to keep up some parents' morale during the illness and motivated them to do their best in giving care.

This hope is reflected in the constant search for treatment to improve their child's health, as reported by at least five parents.

*I only wanted my son to get better. I took best care of him because I wanted him to be cured. I wanted his life more than anything else.* (Participant 5)

Most of the parents recognized the inevitability of their child's death. They knew that AIDS is incurable and fatal.

Eventually, most of them considered that their child's death was a foregone conclusion that they could not change, and it was unavoidable.

*I know that this disease was not curable; I tried to get over it. I expected they (her son and daughter in law, who both had AIDS) would die eventually.*

(Participant 10)

According to Mullan (1998:716) caregivers experience a lot of difficulties that have to do with care recipients comfort especially when care recipients are acutely ill. The fear of death of those they care for is a constant threat .In this study it has been noted that death was also a constant threat to older caregivers.

#### **4.3.2.3. SEEKING HELP FROM WITHIN THE FAMILY AND OUTSIDE**

Most of the participants stated that the practical implications of the substantial physical, emotional, financial and time demands created by AIDS caregiving meant that those who assumed primary responsibility for it could not cope with everything on their own without the support of the family.

*I always ask my husband to help me lift up my son when I bath him and change his bed linen. He is always willing to assist in physical chores. At times he even fetches medication for my sick son from the clinic.* (Participant 4)

Due to the stigmatized nature of AIDS, most of the parents in the study stated that they were forced to limit the call for help to within their own immediate family. The family members helped with the tasks of caregiving, but financial assistance was often needed to cover the range of additional expenses associated with the situation in which an adult child became ill, with and died of AIDS.

*My other children are very helpful, they always deposit some money every month end into my account as they are aware that my pension is too minimal and almost all of it goes to my sick child's nappies and medication. (Participant 2)*

Two participants stated that insurance mechanisms eased the burden, although such assistance was not enough to fully alleviate the financial strain. Assistance was in the form of loans from loan sharks. Most of the time, the caregivers failed to pay the loans back and accrued high interest.

*Last year when three of my children were sick simultaneously I did not have enough money to bury two that died within two days I had to get money from the loan sharks to pay for the funeral expenses. I couldn't pay them back and they came home and took my lounge suite, fridge, television set and my two big pots. They told me that they will sell them to defray their expenses.*

*That was a really drawback and I couldn't report them in the South African Police Service (SAPS) because I am scared of the loan sharks and their shrewdness and they warned me that should I report the matter to the police they will teach me an unforgettable lesson. (Participant 2)*

The findings revealed that assistance from other family members (especially their other children), in terms of visiting, keeping the parents company, lending or contributing money, or offering transportation reduced the parents' sense of being alone.

Most of the parents in this study highlighted that, while seeking family assistance was very important in helping them cope with the situation, the success of this strategy depended on pre-existing relations and was not necessarily guaranteed.

#### **4.3.2.4. DEALING WITH FEARS OF CONTAGION.**

According to Gregory and Longman (1992:336) and UNAIDS (2000a:4), the fear of contracting AIDS can cause considerable anxiety on the part of the caregivers, especially if they are not well informed. In Umlazi, the extensive campaign to educate the public about AIDS has probably reduced this problem. Most, but not all of the parents who were the caregivers in this study were reasonably well informed about their low risks of contracting HIV from the tasks they performed for their sick son or daughter, especially if they took the proper precautions.

About seven of the elderly parents indicated that they were not afraid of becoming infected through the presence of their AIDS-III child, or through caregiving tasks. Very few, only three, seemed to have been truly worried.

*I took care of everything; I applied cream to her mouth sores, bedsores, and cleaned her teeth. Our counselor and social worker in Qondokuhle Gogos' association warned me to wear gloves and I always do. (Participant 2)*

*I washed her buttocks after she excreted. I did this with glove. I was taught of universal precautions in our association and how to avoid being infected. (Participant 9)*

Using gloves was frequently mentioned as a recommended practice, especially when dealing with bodily fluids.

In the Thai study, parents also stated that, at times, they intentionally avoided using gloves because they felt it would signify that they had an aversion to their son or daughter and might hurt his or her feelings (Saengtienchai & Knodel 2001: 46).

#### **4.3.2.5. ADJUSTING THEIR TIME.**

To some older parents, parental caregiving was typically very time-consuming, particularly during the final stages of the illness. Amongst the older parents interviewed, four were still economically active and caregiving was seriously competing with the time required by their work. They all agreed that the financial strain resulting from their child's illness meant that more income was needed. Thus, they all needed to make adjustments in their working life to accommodate the demands of caregiving.

These adjustments ranged from stopping work completely to increasing the time spent working in order to earn extra income to meet the extra costs incurred by caregiving.

One common solution was for the main caregiver simply to stop working during the period when intensive caregiving was required and spend all their time with their adult AIDS-III child. This was made easier if someone else could take over the work or others in the household were still earning an income.

*It's a mother's responsibility, as her mother I am duty bound to provide care for her. I have no option I had to quit my job so as to watch her on full time basis. At least her siblings are still employed and are supporting us".* (Participant 10)

*I had to stop selling my fruits as a street vendor for several months. I had to stop because my son wouldn't eat until I got home; there was nobody to cook for him.*

(Participant 7)

One employed participant stated that, because she was poor, she could not afford to stop working, even though she also had to maneuver the situation. Another solution was to seek the assistance of someone else during the periods when it was necessary and unavoidable to work.

*I couldn't quit my job as I was the sole breadwinner I had to rush home during my tea time to give her something to eat and to administer her medication. In some other days I would seek assistance of someone to assist with his caregiving needs whilst I am away.* (Participant 2)

This was also evident in Thailand, where older parents had to stop or reduce work to meet the demands of caregiving (Knodel 2004: 49).

#### **4.3.2.6. SOCIAL RELATIONS AS THE SOURCE OF SUPPORT.**

Almost eight of the caregivers stated that the maintenance of social relationships was a strong source of support that enabled them to cope with grief and poor emotional health, personal health issues, time constraints and financial stress. Social networks are very common in this study area i.e. in Umlazi. There are burial clubs, savings clubs, sewing clubs and small garden clubs, as well as a service for caring for each other's children when parents are at work.

However, owing to the increase in caregiving, many caregivers have found it hard to maintain their social relations ties as strongly as they used to. In cases where other family members or friends assist with caregiving, older people are able to find time for social interaction.

The Qondokuhle Gogos' Association support group was regarded as a positive social network that is vital to the support of older people. They felt that they themselves could be part of the solution by volunteering to help care for others and by leading a group to educate the community about HIV/AIDS and how to care properly for the sick.

*Many of us have gone through the grieving process and understand the sadness we can share our experience and help others to overcome their situation. (Participant 4)*

*We can be a voice to improve others ability to cope and to reduce the level of problems associated with HIV/AIDS in our communities. (Participant 8)*

#### **4.3.2.7. RELIGION AS A COPING MECHANISM**

Some of these older caregivers expressed satisfaction with the role played by their religion and its contribution in helping them to cope with their caring roles. They felt that their constant belief and trust in God kept them motivated.

*I like helping my children, my belief and trust in God kept me going. My pastor and the church members have been praying for us they sometimes come here to pray with us. (Participant 10)*

*I have set my trust in God; since I joined church things have been much easier. (Participant 3)*

#### **4.3.2.8. NEGATIVE COPING MECHANISMS**

This study also shows that certain caregivers were sometimes engaging in negative coping strategies, some of which are questionable. They defended themselves for resorting to these unacceptable strategies. This is evident in the following narratives:

*Looking after my two children at the same time made me a real alcoholic, I was a casual drinker but after engaging myself into full time caregiving I started drinking a lot and this has helped to release the stress as I sometimes forget about all the worries whilst am drunk. There is no single day that passes without me being drunk and I am enjoying it. (Participant 2)*

*Provision of care to my adult child has pushed me fast into the brink of poverty. I am unemployed as I was retrenched at work for absenting myself frequently after assuming the caregiving role. I had no option but to supplement my lost job with something. That is the reason why I am selling illegal home brewed beer so as to make the ends meet. I am in and out of jail for selling this alcohol, I will not stop brewing it as it is my major source of income. (Participant 6)*

#### **4.3.3. OLDER CAREGIVER'S IDENTIFIED SUPPORT SYSTEMS AND SERVICES.**

The caregivers identified a wide range of needs and services that they felt might lessen their burden of caregiving and eventually lead to coping positively with the tasks ahead of them.

##### **4.3.3.1. Home-based care services**

They expressed the need for home-based care services that were designed to meet the needs of older people who are caregivers for AIDS-III people.

*We must be provided with home based care training since most care is provided by us and we are the silent victims and unsung heroes who sufferers in silence in the four corners of our homes. (Participant 4)*

*The community health workers must be monitored constantly and be taught to ensure confidentiality; most of them are our neighbours who often spread news in the neighborhood about our care recipient's health condition and HIV status. (Participant 7)*

##### **4.3.3.2. Provision of free education for orphaned children**

Most of the participants repeatedly stressed their concern about education for the grandchildren in their care. Older people frequently prioritize school fees above their own basic needs. They felt that the introduction of free schooling for orphaned children could have a major impact on the burdens they face as caregivers.

*I just wonder why some schools are a no fee paying schools and others are fee paying, I strongly believe that the government need to consider that all orphaned children be exempted from school fees and some schools school fees are ridiculously high and unaffordable. (Participant 3)*

The older caregivers also revealed that it is not an easy task to raise their grandchildren, as they are faced with a great deal of resistance and many challenges because of the generation gap.

*I always find it very difficult to raise these children, I so wish that we can have a support group of the orphaned children here in the center so that they can help each other as peers. (Participant 7)*

#### **4.3.3.3. Economic, Emotional and Spiritual Support**

The respondents reported that there was a great need for economic support for older caregivers and their dependents, including regular cash transfers for the most vulnerable.

*The child support grant is not sufficient enough to maintain the orphaned child and the cost of living is very high and I cannot afford all their basic needs and I end up using my pension. I cannot even afford to pay my bills on time as I have to prioritise my grand children's needs. (Participant 1)*

The respondents further reported that they need emotional and spiritual support for themselves and caregivers which, includes bereavement counseling after the death of a care-recipient.

*My grandchildren and I are still mourning the death of our loved ones, I still feel that we did not get enough counseling and spiritual support to face this situation, the picture is still fresh in my mind from caregiving to death and their funerals as if it was yesterday. (Participant 9)*

#### **4.3.3.4. Upgrading of existing government services**

Better support for accessing the existing government service was needed for e.g. help with transportation costs and poverty relief, like fair distribution of food packages. The general feeling amongst the participants was that the government support services are there but they need upgrading.

*We are expected to get food parcels every fortnight in our councilor's office but at times when you get there you are told that they have been all distributed on first come first serve basis. This is unfair because what they should do is to keep a checklist of people who qualifies for food hampers because some of these people who come early do not have the sick person at home.*

*The reason why we often come late for collection is because we must first bath and feed the sick person before leaving for the collection. (Participant 6)*

*There must be an urgent upgrading of government transport system (ambulances) to transport the sick to hospital. Last year my son died because I didn't have transport to take him to hospital immediately when he started to complicate. I called the ambulance it only arrived three hours later and was told that have only three ambulances to service the whole township. My son's life would have been saved if the ambulance had arrived on time. (Participant 4).*

#### **4.3.3.5. Full involvement of older caregivers in issues that affect them**

Older caregivers should be involved in the design and implementation of policies and programmes, particularly home-based care programmes. The caregivers pointed out that they should not be discussed unless they were present, as they understood their plight better than anyone else.

*We are the ones that are directly hands on in these caregiving tasks of our AIDS-ILL adult children and their orphaned children, so why are we not consulted if any policy pertaining to us is designed? As from now on the planners and the government must know that there must not be anything about us without us being part of it as the custodians. (Participant4)*

#### **4.3.3.6. User friendly material**

The caregivers said it was very difficult to find material written in Isizulu, as it is very scarce. This did not really matter, as they were illiterate.

*Even if I want to learn more about this disease and how to assist my ill children better I am struggling to get the materials in my language. Lot of material in my local clinic is in English and Afrikaans. We are not educated and cannot understand these languages I do not have time to sit down and watch TV programmes on HIV and AIDS and to listen to radio programmes due to my tight schedule. (Participant 4)*

#### **4.3.3.7. Housing as an urgent need**

Another major concern was that of housing. The parents stated that they often found themselves acting as heads of households, but having to live in an inadequate space. They wanted safe, affordable housing. They reported that, in most of their houses, they couldn't ensure privacy as they had to share a one-roomed house with four or five people.

*I am forced to bath my son naked in front of children because we have only one room that we share with more than five people. I have teenagers both boys and girls that share this one room with me, my husband and my sick son. There is no privacy at all. (Participant 5)*

*The house that we live in is of mud and is dilapidating and can fall at any time and does not have enough ventilation and worse we have no running water that is a major concern to have a house with running water and a flushable toilet. (Participant 4)*

#### **4.3.3.8. Self-help initiatives and income generating activities**

They also identified the need for the introduction of more self-help initiatives whereby the elderly who were still active could support each other. They also said they lacked land for "one home one garden", the project of the government.

*I enjoy farming and I lack enough land to practice it and money to buy seeds and fertilizers. (Participant 3)*

They also felt that they needed greater empowerment and education on their roles as caregivers. Empowerment included equipping them with the skill to evaluate demands on the available resources within themselves and in the home, to set clear priorities and realistic goals, and to plan appropriate action.

*There is nothing as stressful as being responsible for important tasks or people's comfort and lives and not being properly equipped with the resources, knowledge and skills needed to feel confident about a successful outcome. (Participant 1)*

*Education should also empower us about problem-focused approach as compared to an emotional approach we often resort to so as to lead to effective coping strategies. (Participant 8)*

*They must also teach us about the normal emotional experiences and feelings associated with our work, such as exhaustion, frustration and anger. (Participant 3)*

#### **4.4. HOW AND WHY DO OLDER PEOPLE BECOME CAREGIVERS;**

##### **CHOICE OR CIRCUMSTANCE?**

A number of reasons were cited by the caregivers to explain the older person's increasing role as the main caregiver for adult AIDS-III children and ultimately their orphaned children. The older caregivers mentioned three main forms of caring:

- The first scenario: An adult AIDS-ILL child would be living with parents before the onset of the sickness and would continue to live with them even during the illness.

*My son had been living with us for the rest of his life, he never got married and did not want to leave us and rent flats like other children do in this neighbourhood. That is why I ended up being the sole caregiver of my sick son because he had nobody except me. (Participant 4)*

*We are a very close knit family all my children both married and single ones live with me here in the same yard ,that is why I found myself as the caregiver of my daughter in law and my son when they became bedridden. (Participant 6)*

- In the second scenario : An older person would be forced by circumstance to leave her household for that of an adult AIDS-III child to take care of him or her during their terminal stage.

*My eldest daughter was an educator by profession and she was teaching at Manguzi about 200km away from home. She bought the house there and had children. When she got sick and couldn't do some of the chores I had to relocate.*

*I left my husband behind because I had no option I couldn't let my own biological daughter die a lonely death after suffering so much with this dreadful disease. Her children too needed someone to take care of them as they were still very young to fend for themselves. (Participant 2)*

*My son called me and told me that his wife's sister who had just moved in to take care of them, is ill-treating him, she is verbally and physically abusing him as she believes he is the one who infected her sister. As they were both bedridden my daughter in law and my son, his wife couldn't help him. I had to leave my household so as to take care of my son since his sister in law was just taking care of my daughter in law and abandoned my son. My son had to tolerate the sister in law's verbal abuse and torture everyday. (Participant 1)*

- The third scenario: This is when the older person decides to take responsibility for her adult child owing to neglect or abandonment by the spouse.

*My daughter was married for 12 years and had three children and they were a very happy family until this monster disease came with the curse in their happy life. She was living with her in laws and their extended family in another section of this township. I only learnt after six months that my son in law left my only daughter to die in his home and no one was taking care of her. Her husband is now cohabitating with another young woman and I had no option but to take my child back home. I am by now her full time caregiver and I am happy because I am there for her. (Participant 8)*

The general consensus amongst the participants was that taking care of their adult AIDS-III children was their responsibility and they regarded caring as a sign of love, believing that the sick were "too young to die".

#### **4.5. DISCUSSION**

The results of this study were derived from the collected data. The participants answered the research questions adequately. A great deal of information was obtained about the lived experiences of older caregivers of adult AIDS-III children. Although it was noted that the caregivers cited some experiences and coping strategies more than others, no attempt was made to look for consensus.

According to Jones and Hunter (1995: 378), in qualitative research, consensus does not always mean that the correct answer has been found, as there is a danger in deriving collective ignorance rather than wisdom. However, for the sake of conceptualization, common trends were used to describe the themes.

Financial constraints were common to nine of the participants. These participants cited lack of money for meeting the basic needs of their sick adult child and orphaned grandchildren. They also cited insecurity over food. Only one participant was financially stable and was receiving support from her family. This confirms that most of the older parents who assume the role of caregiver are eventually poorer, as they are drained financially by the expenses of caregiving and are often left to fend for themselves.

This reveals that more financial and material aid is needed to assist older caregivers in their task. Almost all the participants were living in informal settlements and their houses were dilapidated, untidy and overcrowded. This finding concurs with those of other studies on caregivers, which showed that older caregivers are already struggling. They live in dire conditions, and urgent intervention in terms of infrastructure, especially that of adequate housing, is needed.

Most of the participants were breadwinners, living with other family members, employable but unemployed and financially dependent on the older caregiver. This finding highlights the importance of designing interventions for uplifting the economic status of older caregivers. This could include the provision of care and support grants and food parcels for needy households. This finding concurs with that in the study by Fleck (2003:327), which states that many households have become poorer as a result of the HIV/AIDS pandemic. Rutayaga (1992: 65) also argues that increasing numbers of orphans are exerting tremendous pressure on the fragile economies and existing social and health services of developing countries. Freeman and Nkomo (2006:505) further argue that capacity and resources are stretched to breaking point, and those who are providing the necessary care are, in many cases, already impoverished, often elderly, and might themselves have been dependent on that very same sick adult child.

All ten of the caregivers reported emotional and physical constraints which were detrimental to their own health. This finding clearly shows that older caregivers need some respite, care and constant relief from their caregiving tasks so as to be able to attend to their own deteriorating health.

The introduction of day care centres might lessen the burden on the shoulders of the older caregivers. The provision of such centres for older people would also go some way to drastically reducing the disruption of living arrangements caused by prolonged travel and absences from their homes to care for the sick. Older caregivers and their care recipients need to be educated on the services that facilities like hospices and nursing homes provide. They could be encouraged to send their sick children to such centres.

Another form of relief that the older caregivers needed was the support of their family members, especially their spouses, who could assist them in strenuous physical tasks. For this reason, more interventions and advocacy ought to target males and encourage them to be involved in caregiving. This indicates an urgent need for strengthening support systems used by the government, NGOs, families and the community in giving support to older caregivers. Most caregivers preferred to remain silent victims and avoid seeking help from other family members, because they did not want to trouble other people. They also felt ashamed of being dependent. The participants reported that they needed family and community support in their caregiving tasks. D'Cruz (2004:10) states that social support (formal and informal) is an important buffer for family caregivers for people living with AIDS. He found that caregivers' perceptions of their experiences with the informal support from extended family varied along a continuum ranging from satisfaction to dissatisfaction.

The caregivers had no fear of contagion, as they were capacitated by their organization when it came to universal precautions and said they were using protective measures like gloves. One participant reported that she was deliberately not using gloves when working with her sick child because it would be like discriminating against the care recipient. It is clear that the older caregivers still needed more training and information on care and support.

Such training should target the care recipients, too, so that they would be able to understand the precautions relating to caregiving as opposed to discrimination by the care giver.

The researcher's findings showed that most of the caregivers were experiencing stress and depression. This poses a challenge to health care professionals to assist families affected by HIV and AIDS when it comes to family stress throughout the illness trajectory.

The older caregivers also indicated inadequate supervision on the part of health care personnel. This eventually led to a lack of care guidance, directions, motivation and quality of caregiving by older caregivers.

This indicated the need for health workers to visit the households frequently in order to supervise older caregivers, to counsel them so as to eventually improve their caregiving contribution and enhance their coping strategies.

Eight of the ten participants reported that they were following positive coping strategies to help them in their caregiving tasks. Only two caregivers reported making use of negative coping strategies as solutions to their demanding task. It is clear that most of the older caregivers had a positive attitude to fulfilling their role, but what they needed most was support from the government in the form of training, resources, infrastructure, grief support and stress reduction strategies.

The participants in this study also employed numerous support systems and services that might make their caregiving tasks much easier. They were in dire need of training in various aspects of caregiving. They needed to see an upgrade in the existing government services, and wanted to be consulted on the issues that affected them. They also wanted free education for orphaned children, but, more than anything, they needed adequate housing. The findings of this study hold implications for future HIV and AIDS interventions in South Africa. These include programs and interventions that PLWA and their families, especially older caregivers, require, information on family coping skills and more supportive local community networks.

This study was based on the caregiver identity theory, which was developed by Montgomery, Rowe and Koloski (2007:1). In this study most of the older caregivers experienced caregiving as a dynamic process of change, which included change in care activities and the relationship between the caregiver and the care recipient (Montgomery et al 2007:43). All the participants in this study changed their identities from being the mother of their adult AIDS-III children to being a caregiver. According to Montgomery et al (2007:2), these changes in identity eventually influence the type and level of stress or burden.

This becomes evident in this study, as the researcher reported that most of the older caregivers experienced depression and stress. According to the caregiver identity theory, caregiving is governed by norms and social values as well as by a person's ethnic and cultural background, because each culture has its own norms relating to the caregiving responsibility. In this this study, almost all the participants valued their caregiving as part of their parental obligation and regarded it as a natural part of their parental responsibility. They thus viewed the sick child positively. This is the tendency in the African culture, to extend help to family members in need.

Three important aspects of caregiver theory highlighted by Montgomery and Kwak (2008:12) are caregiver stress, great diversity among caregivers and a variation in perception of the services that the caregivers do not think they need. All the above aspects have been identified in this study. Nearly all of the older caregivers reported extreme stress and depression, and a great deal of diversity was seen, especially in the circumstances that led the older parents to assumption of the caregiving role. The services used vary as well, as the older caregivers used only the services that they perceived to be necessary or useful for them.

Montgomery et al (2007:43) have identified five phases of the caregiving career that are linked to the changes in the care recipients' needs. Most caregivers in this study reported that they had been through all these phases, beginning by being unaware of their caregiving identity (Phase 1). Then they moved on to Phase 2, during which they gradually recognized that they were assuming the caregiving role. They noticed changes in the escalation of the care recipients' demands.

The caregivers then progressed to the third stage, which they judged to be the most demanding and strenuous (Phase 3). All the participants reported that this stage was characterised by the increased intensity of the care. The fourth phase is, according to the participants, the most intense of all, as most adult AIDS-III children in this phase are bedridden and are a great burden. They need a great deal of attention from the caregivers. None of the participants in this study moved on to the fifth phase, which involves moving the care recipient into an institution for care like a nursing home or somewhere that would relieve the caregiver of all the primary responsibilities.

All the participants in this study were providing care for their adult AIDS-III children in their own settings and did not move them into any institution of care. As pointed out above, caregiving is governed by norms and values and also a person's cultural background. All the participants regarded the hospice and other nursing facilities as a suggestion of abandonment or letting down the loved one. That is why most of the sick adult children chose to go back to their parents' home or else a parent moved in to their adult child's home to look after them.

#### **4.6. SUMMARY**

In this chapter, the sample studied was explained, followed by the challenges facing the older parents who were caring for their adult AIDS-III children. The coping strategies that older parents often follow when faced with this challenging task were discussed, as well as the needs and services that the older caregivers identified as the key to the solution of their problems.

The chapter also discussed the circumstances that often led to older parents becoming caregivers for their adult AIDS-III children. The data, themes and subthemes that emerged from the data analysis were set out. Relevant literature was also referred to as a control for the research findings.

In the next chapter the researcher will discuss the summary of the findings, the conclusion and the recommendations.

## CHAPTER 5

### CONCLUSION, RECOMMENDATIONS AND SUMMARY

#### 5.1. INTRODUCTION

In this chapter, the researcher will present the summary of the study; the recommendations for interventions; future research; and the conclusion. The study had certain limitations which will also be discussed. Some light has been shed on how to better understand the lived experiences and coping strategies of the older caregivers of adult AIDS-III children and the type of support services that would assist them in their caregiving work. The study has further identified possible remedies for some of the challenges experienced by older caregivers which could complement the already existing support services available to them.

#### 5.2. SUMMARY

This study was exploratory and qualitative. Its purpose was to investigate the lived experiences of older caregivers who are providing care to AIDS-III adult children in the Umlazi Township in the province of KwaZulu-Natal. The researcher interviewed ten older caregivers from the Qondokuhle Gogos' support group. The interviews were conducted in Isizulu, captured by a digital voice recorder, transcribed, translated into English and analysed.

The objectives of the study were as follows:

- To gain an understanding of the lived experiences of the older caregivers of adult AIDS-III children.
- To investigate how the older caregivers cope with their caregiving task.
- To explore the older caregivers' support and service needs.

Categories and themes that emerged from the data were used to describe the phenomenon being investigated. The findings were discussed under the four themes that emerged from the data:

1. Challenges facing older caregivers as they provide care for their AIDS-ILL adult children.
2. Coping strategies that the older caregivers follow to deal with the challenges of caregiving.
3. Support systems and service needs cited by the older caregivers.
4. Routes and circumstances that led to the older parents becoming the sole caregivers for their adult AIDS-III children.

### **5.2.1. Challenges faced by older caregivers as they provide care to their AIDS-III adult children**

The findings of the study revealed that the older caregivers faced a lot of challenges in their caregiving tasks for adult AIDS-III children. These tasks range through the emotional, physical, financial, psychological, social and time constraining. Most of the older caregivers said that the worsening condition of their sick adult child caused much emotional strain. The physical activities, coupled with caregiving, such as lifting the care recipient, changing their soiled bed linen and bathing them, also caused a great deal of physical strain. Nine of the ten participants reported financial constraints as the major barrier to their pursuit of positive and stress-reduced caregiving. Almost all the participants highlighted social exclusion as one of their major challenges, owing to the heavy demands of caregiving, which consumed most of their "me" time. All the above challenges had psychological effects and caused a lot of stress and depression for the older caregivers.

### **5.2.2. Coping strategies utilised by older caregivers**

This study revealed that the caregivers had developed a wide range of strategies for coping with the long-term caregiving for their adult AIDS-III children. They used mainly positive strategies like accepting caregiving as their God-given responsibility, viewing the sick adult child positively, maintaining hope or accepting the inevitability of loss, seeking help from others, joining the Gogos' support group and other social contacts, holding a strong religious belief and adjusting their time to get some relief.

Two out of the ten caregivers reported that they used negative coping strategies, engaging in illicit activities like brewing beer and selling it illegally. One caregiver was by now a self-confessed alcoholic owing to the stress and demands of caregiving.

### **5.2.3. Support systems and service needs of older caregivers**

The older caregivers cited a wide range of needs and services that they felt could lessen the burden of care. They highlighted the need for home-based care services; free education for orphaned children; economic support like regular cash transfers; emotional and spiritual support; and upgrading of the existing government services. Most of the caregivers expressed their wish for full consultation and involvement in issues that affected them. They also mentioned the need to balance caregiving and their “me” time; training on the management of care-recipient behaviour; and user-friendly training material. Most of the caregivers reported that they needed a lot of support in the introduction and sustainability of self-help and income-generating activities.

### **5.2.4. Route or circumstances that led to the older people becoming the sole caregivers for their adult AIDS-III children**

Older parents cited three main reasons that eventually led them to becoming the sole caregivers for their adult AIDS-III children.

The first was the case of the adult child living with the older parents even before he/she became ill.

The second reason concerned the circumstances that forced an elderly parent to leave her household and move into the adult child’s home to provide care.

The third reason was the older person’s decision to voluntarily take on the responsibility owing to the abandonment of the sick child by the spouse.

### 5.3. RECOMMENDATIONS

Based on the findings cited above, the study recommends the following:

Abandoning the practice of continuously excluding older caregivers from programmes that involve them. Most caregivers expressed their dissatisfaction with this practice.

Communities and families at large should be educated on the important role played by the older caregivers and the challenges facing them so that they can be appropriately assisted. Furthermore, the communities should be assisted by both government and non-governmental organisations in the establishment of community support networks that will target older caregivers, who take care of their adult AIDS-ill children.

Capacity building for the older caregivers to cope with HIV and AIDS issues should be prioritised so as to alleviate their stress and equip them with skills for positive coping, which the study showed to still be lacking.

The findings also revealed that older caregivers had no knowledge of the support services available to them. The study therefore recommends that the government structures tasked with the welfare of the elderly should continuously conduct workshops in communities to sensitise their members, especially the older caregivers, about the support services available to them to alleviate the burdens involved in care.

Churches and other community structures should form the basis of emotional and psychological support for the older caregivers, as spirituality and religious services often play an essential role in health and healing offering hope in the midst of life's challenges. The study has revealed that older caregivers suffer considerable psychological and emotional stress.

Older caregivers should be empowered continuously with information on HIV and AIDS; the mode of transmission; home-care support; and strategies to prevent infection. Empowerment programmes should be age and culturally appropriate. That is, they should appeal to their level of maturity.

The study has revealed that most materials and workshop awareness programmes conducted often exclude older caregivers and the material is in a language foreign to them.

Older caregivers' income-generating activities should be fully supported by NGOs and the government in order to make up for the deficit caused by caring for an adult AIDS-III child.

The government should formalise the system followed for older caregivers of adult AIDS-III children and support them financially in their caring endeavours, as the study has revealed that they are financially crippled by the expenses of caregiving.

The government should include family caregiving for AIDS patients as an integral part of HIV and AIDS program planning, as this would ensure that all members of the family were involved. Older caregivers would receive family support and would not be left to fend for themselves in their caregiving role.

#### **5.4. LIMITATIONS OF THE STUDY**

The main limitations of the study are the small area studied and the sample size. A qualitative study does not need a large sample.

The study is limited to older caregivers who are members of the Qondokuhle support group. The lived experiences of other older caregivers who are non-members might differ from those in the findings. It was impossible for the researcher to carry out a larger study owing to time constraints, and the nature of the research, which is of a limited scope (mini dissertation). Lack of funding also played a part.

There is racial bias, as all ten of the older parents who participated in the study were African. The study therefore lacks cross-cultural research. It was impossible to include all races, because the study was conducted in a black township,

There is also gender bias, as all ten of the older parents who participated in this study were female. The study lacks male perspectives on lived experience as caregivers of an adult AIDS-III child. This could not be avoided as all the caregivers in the Qondokuhle Gogos are female.

## 5.5. CONCLUSION

This research investigated the lived experiences of older caregivers for adult AIDS-III children. Interviews were used to collect data, which was analysed using the thematic categorization. The participants' lived experiences and coping strategies contained four major dominant themes, which held the essential meanings of the participants' accounts. The findings suggest that caring for an adult AIDS-III child can be emotionally, physically, socially, psychologically and financially draining, although later it can fit into the daily lifestyle.

Most of the older caregivers experienced caregiving as a dynamic process of change, which is characterised by changes in care activities and the relationship between the care recipient and the caregiver. All the older caregivers in this study had to change their identity from that of mother to that of caregiver. The theoretical framework for this study is based on Montgomery's caregiver identity theory.

This study adds to the body of knowledge that informs policies, programs and training of older caregivers in the HIV and AIDS arena. The study has provided a core list of possible intervention targets, providing valuable information for the systematic design and evaluation of educational interventions to assist older caregivers with their caregiving tasks. The researcher maintains that the information gained from this research impacts on the social work and health field, as it could give an understanding of the lived experiences, coping mechanisms and needs of older caregivers for adult AIDS-III children.

The researcher was able to meet the objectives of the study by identifying some of the challenges, coping strategies and needs of older caregivers for adult AIDS-III children. The study further revealed that, although older caregivers are faced with numerous challenges, most of them still manage to cope positively and are often fully prepared to assume their new role identity of the sole caregiver for adult AIDS-III children. Their willingness, preparedness and dedication means that they will continue to help their adult AIDS-III children, which further illustrates that they are still going to be the silent victims, unsung and unsupported heroes of HIV and AIDS.

It is therefore important to note that the older caregivers are crucial to providing care for the adult AIDS-III children, but the role they have assumed lacks sufficient support and empowerment.

The study therefore suggests that, as HIV and AIDS continue in their foothold as one of the leading causes of adult mortality, there is a need to support the older caregivers, who are often left with no choice but to shoulder the burden of caring for their adult AIDS-III children and eventually orphaned grandchildren. To alleviate the struggles of older caregivers, the policy-makers, government sectors, non-governmental organisations and HIV and AIDS program planners should consult with and involve older caregivers in their policies and services.

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## APPENDIX A

P.O.Box 61132

Bishopsgate

4008

8 September 2013

The Managing Council

Qondokuhle Gogos'

P.O. Box 36030

Ntokozweni 4089

Attention : Managing Director

Dear Madam

### APPLICATION FOR PERMISSION TO UNDERTAKE A RESEARCH STUDY.

I hereby apply for permission to conduct a research study with the QONDOKUHLE support group members. I am conducting the study for partial fulfillment of Master's Degree.

I therefore need your assistance and co-operation. My research topic is "The Exploration of the lived experiences of the older caregivers of their AIDS-ILL ADULT CHILDREN".

Hoping that my application will be favourably considered.

Thanking you in anticipation.

Yours faithfully

Mantombi Nala – Preusker

## APPENDIX B

### INFORMED CONSENT FORM

THE EXPLORATION OF THE LIVED EXPERIENCES OF THE OLDER CAREGIVERS OF THEIR AIDS-ILL ADULT CHILDREN IN UMLAZI. (KWAZULU-NATAL)

**RESEARCHER: MANTOMBI NALA-PREUSKER, UNISA (0837468110)**

#### RESEARCHER'S STATEMENT

I am asking you to participate in the focus group for the older parents who are caregivers of their AIDS –ill adult children. The purpose of this consent form is to give you information you will need to help you decide whether or not to participate. You may ask questions about anything related to the focus group, /interview which is not clear to you. When all your questions have been answered, you can decide if you want to participate or not. This process is called “informed consent”.

#### PURPOSE AND BENEFIT

The purpose of the focus group discussion and in-depth interviews is to obtain information so that the older parent's plight is understood from their own perspectives. The benefits of participating in the study include contributing to the world of knowledge about challenges, coping strategies and needs of older caregivers.

#### PROCEDURE

If you choose to be in the study, I would like you to attend the focus group. The discussion will take 60 minutes. The focus group questions will center around on your perceptions on the lived experience, coping strategies and needs as older caregivers of an ill adult children. For example I will ask:

“What is it like to be the caregiver of your AIDS-ILL Adult Child”?

“How do you cope with identified challenges?”

“What can make your caregiving task more easier”?

I will be taking notes during the focus group, but I would also like to audiotape record the focus group discussion and interviews so that I can have an accurate record. Audiotapes will be kept in a locked file cabinet and will only be accessible to the researcher. Tapes will be used to compensate for incomplete notes and to ensure accuracy of direct quotes. The researcher will transcribe any quotes she would like to use. Please indicate whether you give your permission to be audiotaped recorded or not.

#### RISKS,STRESS OR DISCOMFORT

Although it is unlikely that there will be any risks, stress or discomfort involved in the focus group, some people feel uncomfortable participating in the focus group, or feel that being in a study is an invasion of privacy. I will do all that I can to make you feel comfortable, but at any time you may withdraw from the study without any risk to you.

#### OTHER INFORMATION

Taking part in the study is voluntary. You may refuse to participate or withdraw at any time without penalty .All this information from this study will be confidential and only the researcher will have access to any identifiable data. I will keep the audiotapes and data will be retained until the research report is approved. There after all information related to the research will be destroyed. The report will not identify you, but will provide general findings and suggestions for improvement. However, the researcher cannot safeguard against focus group participants sharing information learned from the group with outsiders. The researcher, therefore ask that focus group participants keep information that has been shared with the group confidential to ensure individual's privacy.

Researcher's signature :

Date :

## **APPENDIX C**

### **INTERVIEW GUIDE**

#### **THE EXPLORATION OF THE LIVED EXPERIENCES OF OLDER CAREGIVERS OF THEIR AIDS- ILL ADULT CHILDREN.**

Greetings and introduction of researcher and her assistant.

Outline the purpose of the research.

1. What circumstances led you to become the primary caregiver of the person you are taking care of?
2. Please describe, in as much detail as you would like, your caregiving experience.
3. Please describe how your caregiving experience affects other aspects of your life.
4. How do you cope with the challenges that you encounter?
5. What according to your opinion would make the caregiving task easier and effective?
6. Is there anything else you would like to add about, your experience of being a primary caregiver of your AIDS-ILL Adult Child?

## TRANSLATED VERSION OF APPENDIX C

### IMIBUZO NGESIZULU

Umcwangingi uyabingelela kwi qembu logogo abazobandakanyeka ocwangingweni, abese ebazisa ngaye kanye nomsizi wakhe.

Umcwangingi uphinde acacise ngenhloso yocwangingo.

Imibuzo izoma kanjena:

1. Kungani wagcina usungumbheki/ umnakekeli ngqo walomntwana wakho okhulile ogulayo na?
2. Ake uchaze unabe kabanzi ngokubheka nokunakekela kwakho lo ogulayo , konke nje okumayelana nosizo omnikeza lona.
3. Kungabe ukuba ngumbheki / umnakekeli kwakho kukhona yini lapho okukukhinyabeza khona, ngenxa yalomsebenzi wokuba ngumbheki womntwana wakho osekhulile ogulayo na?
4. Kungabe ubhekana kanjani nezinqinamba ohlangabezana nazo kulomsebenzi wakho wokuba ngumbheki womntwana wakho na?
5. Ake uchaze unabe ngakho konke okubona kungaba usizo nokungenza lula lomsebenzi obhekene nawo wokuba ngumnakekeli/ umbheki womntwana wakho osekhulile ogulayo ?
6. Kungabe kukhona yini okunye ofisa ukukuxoxa ngokuba umbheki/ umnakekeli engingakubuzanga ngakho kodwa okungenza ukuba umsebenzi wakho ngiwuqonde kangcono?