# EXPERIENCES OF ELDERLY PEOPLE CARING FOR HUMAN IMMUNODEFICIENCY VIRUS POSITIVE ORPHANS ON ANTIRETROVIRAL TREATMENT IN SWAZILAND

by

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submitted in partial fulfilment of the requirements

for the degree of

**MASTER OF PUBLIC HEALTH**

in the subject

Health Studies

at the

**UNIVERSITY OF SOUTH AFRICA**

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**June 2010**

## DEDICATION

To my wife and three sons for their unwavering support and love always, especially during my studies.

Student number: 3601 654 3

## DECLARATION

I declare that: **Experiences of elderly people caring for human immunodeficiency virus positive orphans on antiretroviral treatment in Swaziland** 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 and that this work has not been submitted before for any other degree at any other institution.

…… ……

Kevin Makadzange Date

## ACKNOWLEDGMENTS

I wish to extend my heartfelt thanks and sincere appreciation to the following persons for their respective assistance and valuable contributions towards this dissertation:

- Dr BL Dolamo, my supervisor, for her professional guidance, intellectual support and valuable counsel, without whose assistance this project would not have been possible.
- The courageous elderly people who agreed to participate in the study.
- My extended family and friends for their encouragement and motivation.
- My wife, Vesta, for her love and companionship as well as her unwavering belief in my abilities and daily assistance during the difficult times of this investigation.
- My three sons, Kevin, Keith and Kelwyn, for their support and understanding.
- My younger brother, Panganai, for his advice and assistance.
- Mbabane Government Hospital antiretroviral clinic staff for their assistance and support.
- Dr David Levey for editing the manuscript.

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## ABSTRACT


The purpose of this study was to describe the experiences of elderly people caring for HIV positive orphans on antiretroviral treatment in Swaziland. An exploratory, descriptive and contextual qualitative study based on a phenomenological approach was conducted. Data was collected by means of semi structured interviews with twelve elderly people purposively selected at Mbabane Government Hospital antiretroviral treatment clinic. The findings of the study highlighted that the elderly people were giving care under compulsion with very little support from the government, the community or other organisations. Their care giving capacity was compromised by many challenges which included the heavy burden of caring for a number of dependents; economic constraints; poor infrastructure; food insecurity, and physical, psychological and social constraints. The elderly were employing a number of coping strategies to counteract the challenges that they were facing.

The researcher concluded that the elderly people were vital in ensuring the survival of sick orphans under the paediatric antiretroviral treatment programme in Swaziland if afforded sufficient support and empowerment.

**KEYWORDS**

Elderly Care, Orphan and Antiretroviral treatment

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## ABBREVIATIONS

**AIDS**: Acquired Immunodeficiency Syndrome

**ART**: Antiretroviral Therapy

**DNA**: Deoxyribonucleic acid

**EGPAF**: Elizabeth Glazer Paediatric AIDS Foundation

**HIV**: Human Immunodeficiency Virus

**MDG**: Millennium Development Goals

**NERCHA**: National Emergency Response Council for HIV/AIDS

**RNA**: Ribonucleic acid

**UN**: United Nations

**UNAIDS**: United Nations Joint Action on AIDS

**UNGASS**: United Nations General Assembly Special Session

**UNICEF**: United Nations Children's Fund

**WHO**: World Health Organization

# CHAPTER 1

# ORIENTATION TO THE STUDY

## 1.1 INTRODUCTION

> *Second, this time in Zambia, Graca and I were taken to a village where orphan population was described as out of control. As a vivid example of that, we entered a home and encountered the following: to the immediate left of the door sat the 84-year-old patriarch entirely blind. Inside the hut sat his two wives, visibly frail, one 76 and the other 78. Between them they had given birth to nine children, eight now dead mainly due to HIV/AIDS and the ninth alas was clearly dying. On the floor of the hut, jammed together with barely room to move or breathe, were 32 orphaned children ranging in age from two to sixteen. Graca and I looked at each other and wordlessly communicated the inevitable fear: What in God's name is the future for these youngsters?* Stephen Lewis, UN Secretary-General's special envoy for HIV/AIDS in Africa (Lewis 2003).

The above scenario gives a snapshot of how devastating the Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome (HIV/AIDS) has been in Southern Africa, from which Swaziland is not spared. This has left a trail of hopeless orphans, most of whom are taken care of by their grandfathers and grandmothers. Swaziland, with its HIV prevalence currently pegged at 26.6% among the 15 to 49 age group (Ministry of health and Social Welfare 2009; UNICEF 2007), is facing not only the task of reversing the growth of the epidemic, but also the huge challenge of mitigating its impact on the nation's children. There are currently almost 70,000 children orphaned by HIV/AIDS with the United Nations Children's Fund (UNICEF) predicting 120,000 orphaned children by the year 2010, a staggering 13% of the country's population. Besides being burdened by the task of taking care of these orphans, the country is also

grappling with the responsibility of taking care of its more than 16 000 children currently living with HIV. To date, the Government has only managed to place about 2 800 out of the 16 000 HIV positive children on antiretroviral treatment (ART) (UNAIDS 2004; Thembo 2008:2; UNGASS 2008).

Although the 2 800 HIV positive children on the ART programme at present represent a correct move towards lifting the burden, it is saddening to note that the majority of these children on such treatment are under the guardianship of their grandparents who live in poverty, experience ailing health and lack adequate knowledge, skills and resources to cope with this complicated responsibility (Dlamini & Eyeington 1997:71; Du Tlessis 2000:15; HelpAge International 2004). The poor living conditions of these grandparents, their age and low level of literacy, make it so difficult for them to ensure that these children take their medication on time and as prescribed, that they eat proper food and meet their appointments at the antiretroviral treatment clinics without fail. Their situation is worsened by their poor socio-economic status marred by the scarcity of nutritious foodstuffs, limited income, ever escalating transport costs and the poor rural transport system, all of which make it very difficult to provide efficient and effective care to these children (Calles & Schwarzwald 2006:39).

Gathering first hand information through a systematic and scientific process from these elderly caregivers with regards to the challenges they were facing in providing such a crucial service, as well as the strategies they were employing to deal with the situation, proved to be an urgent and a very important move that bas been hitherto lacking. The realisation of that urgent need prompted the researcher to carry out the study. The best way to understand the existing scenario was to conduct an exploratory qualitative phenomenological study which enabled the researcher to gain an inside perspective on the story.

This chapter furnishes an overview of the study by describing the source of and background to the research problem, formulating the problem statement, and

discussing the purpose and significance of the study as well as the research objectives. It subsequently discusses the philosophical foundation of the study as well as the assumptions underlying it. Key concepts involved in the study are also defined. The chapter also outlines the research design and the research methodology which encompasses the sample selection, methods of data collection, data analysis and measures to ensure the trustworthiness of the study. Ethical considerations and limitations of the study as well as the general outline of the research report are also covered.

## 1.2 RESEARCH PROBLEM

This section furnishes an outline of the research problem as well as the background to the problem and the statement of the research problem. A research problem is an area of concern in which there is a gap in the knowledge base which requires research to be conducted so as to generate the necessary knowledge and provide evidence that proves the existence of the problem. These research problems can be developed from clinical practice, the literature, interaction with colleagues, research priorities identified by funding agencies and theory (Burns & Grove 2005:85).

### 1.2.1 Source and background of the problem

The researcher identified this research problem from a presentation at a paediatric HIV/AIDS management workshop held in Swaziland in 2008. Based on the explanations from the workshop, the researcher assumed that it would be challenging to look after an HIV positive orphan who is taking antiretroviral therapy, more especially if the care is being given by an elderly person who does not possess adequate financial and / or material resources as well as the technical know-how and proper literacy. After a thorough reflection on the said presentation in Swaziland, it occurred to the researcher that a similar scenario might be a reality.

In Swaziland there is an increasing number of HIV infected orphans taking antiretroviral treatment under the care of older persons. This influx was stimulated by the roll out of a paediatric HIV treatment programme spearheaded by the Swazi Government with the help of the Elizabeth Glazer Paediatric AIDS Foundation (EGPAF) in 2005 (WHO 2005). The rapid response by most of the older persons in enrolling sick orphans for the programme can be attributed to the need to lessen the challenges they were facing in looking after the sick children in their custody. Upon the announcement of the programme, many elderly caregivers were compelled to enroll their sick children, anticipating that the services would bring relief to the agony and stress of taking care of a sick child who is not showing any signs of improvement.

However, the irony is, considering the complexity of the treatment regiments, that a programme which seemed to be a messiah turned out to be a mountain to climb for many of those elderly caregivers. As much as putting the child on antiretroviral treatment makes her or him feel better and seems to provide a green light to the caregiver's plight, on the other hand it can equally place a greater burden on the caregiver. The truth is that it is difficult for both the clinicians and the caregiver to look after a child on antiretroviral treatment, considering the complexity of the treatment regimes and the need for close follow up as regards adverse effects, treatment adherence and reviews. Once the child is on treatment it means that extra care is needed (Calles & Schwarzwald 2006:52).

One challenge which then waters down the benefits of this programme is the fact that most of these caregivers are poor, frail and illiterate, causing it to be extremely difficult for them to make sure that these children take their medication on time and as prescribed, that they eat proper food and meet their appointments at antiretroviral treatment clinics without fail. Their situation is worsened by high levels of poverty, economic hardship and drought gripping the country and hence the scarcity of nutritious foodstuffs, a limited income, ever escalating transport

costs and a poor rural transport system which makes it very hard for them to take the children to treatment clinics for review.

Considering the fact that, in reality, in Swaziland there were elderly caregivers of children taking antiretroviral (ARV) treatment, the questions were: What were their experiences? How were they dealing with the situation? What were the challenges they were facing? How were they coping, and what were the support systems at their disposal or lacking? These issues formed the basis of the research question for this study. Seeking answers to the questions above made it very important to explore and understand the experiences of the elderly caregivers while they looked after these children. A number of studies had mainly looked at the general care of HIV orphans by elderly people; however, evidence of care for HIV positive orphans on antiretroviral treatment was lacking. The realisation of the existence of such a scenario prompted the researcher to explore the present topic.

### 1.2.2 Statement of the research problem

Since the inception of the paediatric antiretroviral treatment programme in Swaziland, a total of 2 800 children had been enrolled. It came to the researcher's attention that the majority of those children were being taken care of by the elderly. However, it still remained a mystery as to what experiences the elderly caregivers were encountering. No platform had been provided for them to share their experiences and highlight their plight. The literature available did not clearly outline how they perceived the care they were giving to the orphans or the antiretroviral treatment itself for the young children. That gap remains a mystery in the history of the paediatric antiretroviral treatment programme in Swaziland, a condition which could only be truly unveiled through carrying out a phenomenological study, which was the aim of this study.

## 1.3 AIM OF THE STUDY

This section discusses the aim of the study. According to Burns and Grove (2005:86), the aim of any study concerns the research purpose and the objectives of the study. The said purpose is a concise, clear statement of the specific goal or aim of the study, indicating the type of study and its variables, population and settings.

### 1.3.1 Research purpose

The purpose of this study was to describe the experiences of elderly caregivers in taking care of HIV positive orphans on antiretroviral treatment in Swaziland.

### 1.3.2 Research objectives

The following objectives guided this study:

- To explore the experiences of the elderly caregivers in terms of how they have been taking care of HIV positive orphans on antiretroviral treatment in Swaziland.
- To describe the challenges being faced by the elderly caregivers of orphans on antiretroviral treatment.
- To describe the coping strategies employed by the elderly looking after the orphans.
- To establish support systems and the level of support or lack thereof rendered to the elderly caring for HIV positive orphans on antiretroviral treatment in Swaziland.

## 1.4 SIGNIFICANCE OF THE STUDY

The intention of this study was to generate information which would be useful for decision makers and programme planners and other stakeholders, such as non-

governmental organisations, the government, health professionals, social workers, faith based organisations, community health motivators and individuals who provide services and implement interventions, targeting the elderly and HIV positive children. These organisations could use the information to focus their activities on how to specifically meet the needs of elderly people caring for HIV positive orphans on antiretroviral treatment. The findings from this research project will contribute towards meaningful change in policy development and programme designs aimed at guiding the scaling up of the national paediatric antiretroviral treatment programme in Swaziland.

## 1.5 DEFINITION OF KEY CONCEPTS

- **Elderly**

According to the *Cambridge International Dictionary of English* (1995: 446), 'the elderly' refers to old people. Old age in developing countries is considered to begin at the point when an active contribution to society is no longer possible (Gorman 2000:15). For the purpose of this study the chronological age of 60 years was used as a guide for the working definition of 'old'.

- **Elderly care**

For this study elderly care refers to the process where grandmothers and grandfathers look after their HIV grand children because their parents are no more (are dead).

- **Care**

Care is defined by the *Longman Dictionary of Contemporary English* (2003:221) as the process of looking after someone, particularly because they are ill, old, or very young.

- **Orphan**

As defined by the *Cambridge International Dictionary of English* (1995:996), an orphan is a child whose parents are dead.

According to the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS (UNICEF 2006), an orphan is defined as a child under the age of 18 years whose mother, father or both parents have died from any cause. These orphans, whatever the reason for their status, can be specifically categorised as a single orphan, that is, a child who has lost one parent, or double orphan, that is a child who has lost both parents. They can also be categorised as a maternal orphan, thus a child whose mother has died, or a paternal orphan whose father has died.

- **Antiretroviral treatment**

This is treatment that suppresses or halts a retrovirus. One of the retroviruses is the Human Immunodeficiency Virus (HIV) that causes the Acquired Immunodeficiency Syndrome (AIDS). Retroviruses are so named because they carry their genetic information in the form of Ribonucleic acid (RNA) instead of Deoxyribonucleic acid (DNA) so that the information must be transcribed in a reverse direction – from RNA to DNA (*Webster New World Medical Dictionary*, 2000)

## 1.6 PHILOSOPHICAL FOUNDATION OF THE STUDY (RESEARCH PARADIGM)

The philosophical basis of qualitative research is interpretative, humanistic and naturalistic and is concerned with the understanding of the meaning of social interaction by those involved (Burns & Grove 2005:28). It is interpretative in the sense that it is concerned with studying reality as it is constructed by people when they interpret and give meaning to their lives and experiences from an insider perspective (that is, the perspective of the research participants). It is

naturalistic because it studies phenomena or people in their natural settings with no attempt to exercise control over the settings or variables (Streubert, Speziale & Carpenter 2003:18). It is humanistic because it rests on a perspective according to which humans are perceived to continuously construct, develop, and change their everyday interpretation of their worlds in order to make sense of their lives. The researcher describes and understands human experience and emotions holistically as part of the person's total living experience (Babbie & Mouton 2001:29).

### 1.6.1 Assumptions

Assumptions are statements taken for granted or considered true, even though they have not been scientifically tested.

#### *1.6.1.1 Methodological assumption*

The study was based on an interpretative methodological approach, studying the social actors or participants' subjective reality from an insider perspective. The researcher is the main instrument in the research process, actively involved with the participants and not detached from the study, thereby bringing in the element of intersubjectivity (Babbie & Mouton 2001:29). Non numerical analysis and interpretation of narrative data was carried out. The research process was inductive, resulting in the generation of new theory. It was noted that truth can be discovered only imperfectly and in a probabilistic manner (Burns & Grove 2005:23).

#### *1.6.1.2 Epistemological assumption*

Epistemology deals with the nature of knowledge and knowing by specifying according to which rules knowledge should be produced (Terre Blanche & Durrheim 1999:6). The study was based on a linguistic epistemology with the assumption that humans think, live and feel in terms of language. This supported

the collection and analysis of narrative data enabling participants to share their beliefs, perceptions and actions with the researcher in the form of stories (Brown, Crawford and Hicks 2003:174). The study was also based on the epistemological position that data are contained within the perspective of the people who are involved in looking after HIV positive orphans on antiretroviral treatment; because of this, the researcher engaged the participants in collecting the data (Groenewald 2004:7).

#### *1.6.1.3 Theoretical framework*

Exploring the experiences of the elderly caring for HIV positive orphans on antiretroviral treatment involves looking at the process of caring in the context of vulnerable and frail old people. The researcher decided to base the study on the framework of Tronto's ethics of care (1993). The latter is used as a framework for analysis of care and as a visionary ideal against which to evaluate the experiences of caring.

In this framework, Tronto defines good care as holistic practices involving four phases: 'caring about', 'taking care of', 'care-giving' and 'care receiving'. Caring about is the nominal willingness to care, while taking care of connotes mobilisation of resources. Care giving represents the particularisation of the intention to give with the caregiver in direct interaction with the care receiver. Care-receiving implies neediness, dependency, and functional inadequacy (Tronto 1993:105).

'Caring about' and 'taking care of' represent the public, the universal and the rational aspects of caring whereas 'care-giving' and 'care-receiving' represent the private, the menial and the emotional aspects of care. 'Ethics of care' emphasises the importance of relationships and is based on the interdependence of all individuals in order to achieve their interests. Care is a disposition and a process that fosters the growth of those participating in a caring relationship and

their willingness to adopt open-ended responsibilities in regard to each other (Tronto 1993:105).

This framework can serve as a guide to pinpoint issues and challenges in the caring process and relationships by raising questions related to the elements of care, that is, attentiveness, responsibility, competence and responsiveness, and the context of care which includes power, privilege and adequacy. An ethic of care and responsibility develops from an individual's feeling of interconnectedness with others (Tronto 1993:108).

Typically the powerful are more often in a position to receive or demand care than to provide it while those with less power often find themselves in situations in which they provide care without much power or conducive conditions to do so and occupy positions of invisibility and voicelessness (Sevenhuijsen 1998:24). The elderly are powerless, invisible and voiceless and are expected to provide care to demanding sick orphans in conditions of inadequacy experienced by the less privileged. These elderly people might be attentive to the needs of the orphans but the services they provide might not directly address these needs.

There might be constraints that negatively affect the responsibility and competence of these elderly people. For the provision of care to be effective and fair, those receiving the care must be able to articulate their needs, furnish input into shaping the care practices, and react to the care they receive (Tronto 1993:108; Levy 2006:554). HIV positive orphans are young and frequently so sick that they do not have a 'voice', thus making it more challenging for the elderly to provide effective care.

An exploratory study based on Tronto's ethics for a care framework detailed the experiences of elderly people caring for HIV positive orphans by addressing the above issues. It unearthed how attentive they were to the needs of the orphans and their competency as well as how they perceived the responsiveness of the

orphans to their efforts. It was expected that assistance from those in power would improve the competency of the elderly in the caring process; consequently, the extent of the help they were experiencing was explored. The ethics of care framework enabled the researcher to holistically explore the topic.

## 1.7 RESEARCH DESIGN

The study is a qualitative, exploratory, descriptive and contextual based on a phenomenological approach (see chapter 2).

### 1.7.1 Qualitative

Qualitative research refers to inductive, holistic, emic, subjective and process-oriented methods used to understand, interpret, describe and develop theory regarding a phenomenon or setting. It is a systematic, subjective approach used to describe and give meaning to life experiences. Qualitative research is mainly associated with words, language and experiences rather than measurement, statistics and numerical figures (Burns & Grove 2005:535).

### 1.7.2 Exploratory

Exploratory studies are aimed at gaining insight and understanding into a new interest, a relatively new subject of study or a persistent phenomenon. In order to acquire insight into the experience of participants the researcher explored the use of a semi-structured interview schedule which constitutes an open and flexible data collection strategy (Babbie & Mouton 2006:79; Uys & Basson 1991: 38).

### 1.7.3 Descriptive

Descriptive research refers to studies that have as their main objective the accurate portrayal of the characteristics of persons, situations or groups (Polit &

Hungler 1999:643). It is a non-experimental design that is used to observe and measure a variable when little conceptual background has been developed and concerns specific aspects of the variable under study. The intention of the study was to describe the experiences mentioned as authentically as possible.

### 1.7.4 Contextual

A contextual study focuses on specific events in natural settings (Burns and Grove 1998:331). The study focuses on the elderly, caring for sick orphans in Mbabane, Swaziland, without manipulating the situation.

### 1.7.5 Phenomenological

This study is a phenomenological one. It adopts a systematic, interactive and subjective approach to describe and give meaning to life experiences. The aim of the phenomenological approach to qualitative research is to describe accurately the lived experience of the people rather than generate theories or models of the phenomenon being studied (Leininger in Burns & Grove 2005:23).

## 1.8 RESEARCH METHODS

This section presents the research methods employed in this study. Research methods refer to specific research techniques which involve sample selection, data collection and data analysis techniques (Silverman 2000:79).

### 1.8.1 Population and sample

A study population is that theoretically specified aggregation of elements from which the sample is actually selected. A sample is selected from a target population by means of probability or non probability methods (Babbie & Mouton 2006:173). To match the research objectives, older persons defined as the target population are those who are at least 60 years of age looking after HIV positive orphans on antiretroviral treatment in Swaziland. A non random purposive sampling scheme was employed to select members of the target population who

were likely to provide the most valuable data addressing the research objectives (Leedy & Ormrod 2005:145). The number of participants in the sample was not predetermined. Sampling was carried out until data saturation, when no further new themes emerged from the data (Burns & Grove 2005:535).

### 1.8.2 Setting

The setting for the study was naturalistic, meaning that it was a real life situation where the informants naturally interacted without interference. No control or manipulation was imposed during the study. The naturalistic setting was the hospital in Mbabane, the capital city of Swaziland, where they normally obtain the medication.

Swaziland is a small land-locked country in southern Africa. Mbabane Government Hospital is the only referral government health institution in Swaziland; hence it caters for the entire country. Since Swaziland is small, all four of its administrative regions (Hhohho, Manzini, Shiselweni and Lubombo) are within a few hours' drive from the capital city, Mbabane.

### 1.8.3 Methods of data collection

To address the research problem above, the researcher employed semi-structured interviews for data collection, asking open ended questions which the participants answered in their own words yielding narrative data for qualitative, non numerical analysis (Burns & Grove 2005:547). The interview guide was developed in English and then translated into isiSwati and then back into English to make sure it meant what it was supposed to mean and thereby collected the required data. Pilot testing was conducted in Mbabane. Data were gathered in isiSwati by recording responses by means of a digital voice recorder and written field notes, recording observed non verbal behaviours and reflections.

Interviews took place at the Mbabane Government Hospital antiretroviral treatment clinic. Two research assistants with experience in conducting social science interviews were employed and fully briefed and trained regarding the research requirements.

### 1.8.4 Data analysis

Qualitative data analysis techniques employ words rather than numbers as the basis of analysis, moving from concreteness to increasing abstraction (inductive reasoning) (Burns & Grove 2005:535). In this study the researcher transcribed the interviews verbatim and produced interview scripts using MS Word. The scripts were then colour coded and analysed.

Analysis of the interviews was based upon the Marshall and Rossman (1994) framework which involved only three stages, namely:

a. Data formatting
b. Data organising
c. Generating categories, themes and patterns.

Stage four, which involves the testing of emerging hypotheses against the data, was not carried out since this was beyond the scope of this study.

## 1.9 MEASURE TO ENSURE TRUSTWORTHINESS

In qualitative research it is important to ensure trustworthiness, which refers to the neutrality of the findings. This helps to convince the audience that the findings of the inquiry are worth paying attention to or worthy of taking note. In this study, Lincoln and Guba's (1985:112) model was used to measure trustworthiness (for more information on trustworthiness – see chapter 2). Lincoln and Guba (1985) identified the following terms that describe operational techniques supporting rigour in qualitative research: credibility, dependability,

confirmability and transferability. A qualitative study must be dependable to be credible; and credible to be transferable (Babbie & Mouton 2006:277).

## 1.10 ETHICAL CONSIDERATIONS

A study should comply with the ethical principles of beneficence, respect for persons and justice, protecting the rights of the informants and the institution as well as the scientific integrity of the research. The researcher consequently took the following ethical measures into consideration: informed consent, confidentiality and anonymity, privacy and the right of participants to withdraw from the study.

Permission to conduct the study was obtained from the Swaziland Ministry of Health and Social Welfare after clearance from the Ethics committee in Swaziland (see annexure B). Written permission to conduct the study at the Mbabane Government Hospital was obtained from the National Antiretroviral Treatment Coordinator (see annexure C). Informed consent was obtained from the informants prior to the interviews (see annexure D).

Confidentiality and anonymity were guaranteed by ensuring that the data obtained could not be linked to the source. No names were attached to the information obtained and anonymous labelling was employed. The participants were informed that they were free to withdraw from the study at any time without prejudice (see chapter 2).

## 1.11 LIMITATIONS OF RESEARCH

The limitations of a study refer to the restrictions on, or in, the study that may decrease the generalisability or transferability of the findings. There are two types of limitations: conceptual and methodological. Conceptual limitations restrict the abstract generalisability or transferability of the findings while methodological

limitations restrict the population to which the findings can be generalised or transferred.

In this study, the participants were drawn from the Mbabane Government Hospital only and not the whole of Swaziland, thus limiting the transferability of the findings. The use of semi-structured interviews to discuss sensitive issues with regards to HIV positive people who may be reluctant, embarrassed or lack suitable language for discussion, could be a setback to this study by restricting the depth of the information obtained.

## 1.12 OUTLINE OF THE STUDY

This chapter comprises an overview of the study. Chapter 2 considers the research design, research methodology and the setting for the study while chapter 3 presents and discusses the data analysis and literature control. Chapter 4 discusses the conceptual framework; chapter 5 concludes the study and makes recommendations.

## 1.13 CONCLUSIONS

This chapter introduced the study by outlining the research problem, its source and the background to the problem. The aim of the study which included the research purpose and objectives was also outlined. The significance of the study, its philosophical foundations and definitions of key concepts were also covered. The research design and methodology, measures to ensure trustworthiness as well as ethical considerations were also discussed. Limitations to the study, and lastly the general outline of the study report, were also discussed.

Chapter 2 considers the research design and methodology.

# CHAPTER 2

# RESEARCH DESIGN AND METHODOLOGY

## 2.1 INTRODUCTION

Chapter one furnished an orientation to the study. This chapter outlines the research design adopted and the research methodology employed in the investigation. A description of the participants and the data gathering technique employed is provided, explaining how the data were gathered and analysed. The chapter concludes with details regarding ethical considerations and the measures employed to ensure the trustworthiness of the study.

## 2.2 RESEARCH DESIGN

A research design is a plan or blueprint for conducting the study that maximises control over factors which could interfere with the validity of the findings (Burns & Grove 2005:223). In order to fulfill the purpose of the research an exploratory, descriptive, contextual, qualitative and phenomenological study was conducted.

### 2.2.1 Qualitative research design

A qualitative research refers to a series of broadly divergent and related methodologies that cluster under a paradigmatic umbrella (Schneider, Whitehead & Elliot 2007:106). It takes its departure point that of the insider perspective on social action. Qualitative research is naturalistic since it studies phenomena or people in their natural setting, applying low control designs. The researcher visited the site of the research, that is, the antiretroviral clinic, to meet the participants. The research was conducted in a manner that did not disturb the context of the phenomena studied (Streubert Speziale & Carpenter 2003:18). A

qualitative research design is flexible, which enabled the researcher to adapt the inquiry as understanding deepened or the situation changed (Burns & Grove 2005:535; Marshall & Rossman 1995:98).

By employing a qualitative research design the researcher managed to gain in-depth understanding into the said experiences. The elderly managed to describe their experiences in their own words and convey their feelings through verbal and non-verbal communication.

### 2.2.2 Exploratory design

Exploratory studies are aimed at gaining insight and understanding into a new interest, a relatively new subject of study or a persistent phenomenon. They are conducted in order to satisfy the researcher's curiosity and desire for a better understanding and to explicate the central concepts and constructs of a study. The researcher wanted to explore and gain insight and comprehension into the experience of elderly people caring for HIV positive orphans on antiretroviral treatment: this was achieved by means of semi-structured interviewing of the informants. Through exploratory research the researcher managed to unearth other areas for future research in the area of orphan care and paediatric antiretroviral treatment (Babbie & Mouton 2006:79; Uys & Basson 1991: 38).

### 2.2.3 Descriptive design

A descriptive design, which is a non-experimental form of research design, was used in order to portray accurately, and as authentically as possible, the experiences mentioned. The main aim of a descriptive research design is to facilitate the description and the exploration of new issues and to explain why certain phenomena occur? (Neuman 2000:22). A qualitative research design enabled thick description of the context, the participants involved and the activities of interest.

### 2.2.4 Contextual design

Context denotes the conditions and situations of an event. A study is contextual when the phenomenon is studied for its intrinsic and immediate contextual significance. It focuses on specific events in specific 'naturalistic settings' or locations (Mouton 1998:133). The study was limited to exploring and describing the experiences noted. The context of the study including the background to and the settings in which it was conducted are also described in chapter 1.

### 2.2.5 Phenomenological approach

This is a phenomenological study which means it is systematic, interactive and subjective in approach, so as to describe and give meaning to life experiences. The aim of a phenomenological approach to qualitative research is to describe accurately the lived experience of the people concerned and not to generate theories or models of the phenomenon being studied (Leininger in Burns & Grove 2005:23). A phenomenological study seeks to understand people's experiences, perceptions, perspective and understanding of a particular situation (Leedy & Ormrod 2005:139). It searches for in-depth, contextualised understanding of phenomena, leading to gaining insight and comprehension using semi-structured interviews and the participants.

To understand the experiences of older persons looking after HIV positive orphans on antiretroviral treatment a phenomenological study is best so as to gain an insider perspective on the phenomena in a naturalistic setting with enough flexibility, being as non intrusive as possible. The primary source of data was the life world (Welman & Kruger 1999:189) of these persons; hence semi-structured interviews were conducted in order to understand the experiences from the perspective of the participants.

## 2.3 RESEARCH METHODOLOGY

This section presents the research methods employed in this study. Research methods refer to specific research techniques which involve sample selection, data collection and data analysis techniques (Silverman 2000:79). Therefore, the study sample and sampling process are described in this section, while the data collection method and procedures used as well as the data analysis process are also outlined.

### 2.3.1 Population and sample

A study population is that theoretically specified aggregation of elements from which the sample is actually selected. Sampling is the process of selecting a group of people, events, behaviours or other elements with which to conduct a study. An element is that unit about which information is collected and which provides the basis of analysis. A sample which consists of elements is selected from a target population by means of probability or non probability methods (Babbie & Mouton 2006:173).

#### *2.3.1.1 Population*

To match the research objectives, as mentioned, older persons are defined as those at least 60 years of age looking after HIV positive orphans on antiretroviral treatment in Swaziland, further defined as the target population. The target population is described as the entire population or individuals who meet the inclusion criteria. The researcher, however, used an accessible population which is the group to which he had reasonable access; these were elderly people looking after HIV positive orphans accessing their antiretroviral treatment at Mbabane Government Hospital. Since these were the source of the key participants, the persons were thoughtfully and purposefully selected because

they were considered to be knowledgeable and information rich with regards to the subject of inquiry (Leininger & McFarland 2002:93).

#### *2.3.1.2 Sampling technique*

The study utilised a non random purposive sampling scheme, that is, selecting members of the target population who were likely to provide the most valuable data addressing the research objectives (Leedy & Ormrod 2005:145). Since the study is qualitative in nature the researcher did not attempt to select a sample that was representative of the population. Purposeful sampling was used, as indicated.

Even though purposive sampling lacks predictive power as no statistical analysis can be performed, and because the sample is not statistically determined, such sampling was used mainly because of its simplicity (Patton 2002:40). It is based on the assumption that the researcher's knowledge about the population is complete enough to enable him or her to select cases deemed appropriate to the objectives of the study. Generalisation of results from a purposive sample is limited (Polit & Hungler 1999:284).

#### *2.3.1.3 Inclusion criteria*

In this study the aim was to ensure that the final sample included participants who met the following criteria:

- Elderly people 60 years of age and above, male or female.
- Attending Mbabane Government Hospital antiretroviral clinic.
- Elderly people who have been caring for HIV positive orphans on antiretroviral treatment for at least six months.

#### *2.3.1.4 Recruitment*

The participants were identified at the Mbabane Government Hospital antiretroviral clinic with the help of the staff at the clinic, especially the nursing staff and social workers. The researcher selected sample members based on the needs emerging from the early findings, hence sampling took place until data saturation when no new themes emerged from the data or when the inclusion of new participants did not lead to new information, but rather confirmed previously collected data (Gillis & Jackson 2002:190). The number of participants in this sample was not predetermined. Qualitative research normally involves a small sample size and the sampling is flexible (Burns & Grove 2005:535).

### 2.3.2 Data collection

A qualitative phenomenological approach was used to collect data through semi-structured interviews asking open ended questions which the participants answered in their own words yielding narrative data for qualitative, non numerical analysis. The researcher became immersed in the data in order to develop the insights necessary to scientifically analyse the data without losing sight of the subjective life-worlds of the participants as revealed by them (Burns & Grove 2005:547).

#### *2.3.2.1 Development of data collection instrument*

Findings from literature reviews and discussions with other professionals involved in HIV programmes guided the researcher in developing the data collection instrument. As already mentioned, the interview guide was developed in English, then translated into isiSwati and finally translated back into English to make sure it meant what it was supposed to and that the required data was collected.

#### *2.3.2.2 Pilot study*

The researcher conducted a pilot study in November 2009 in Mbabane with one elderly woman looking after an HIV positive orphan on antiretroviral treatment. The participant signed the informed consent and participated in an interview which lasted one hour and was captured by a digital voice recorder. The researcher transcribed the tape recording verbatim. Field notes and memos were completed during and after the interview. The researcher ensured that the environment was quiet with no distractions. Consultation with an expert concluded that the order in which the questions were asked was vitally important. Appropriate changes were made to the interview schedule. The pilot study helped to determine whether the researcher was going to use appropriate interviewing skills for elderly people.

#### *2.3.2.3 Characteristics of the data collection instrument*

The semi-structured interview schedule is a common instrument in qualitative research. With sufficient rapport, flexibility and time, a large amount of detailed information can be collected (Patton 2002:40). The interview question sequence lists core questions representing the research topics of interest, giving the interview some structure (see Annexure D).

The interview schedule consisted of general introductory demographic questions, followed by open ended questions introducing each thematic area of which there were four (general experience in caring, challenges, coping strategies and support systems) and recommendations. These questions were accompanied by probing questions. The participant's responses also determined what additional questions were asked, which varied from interview to interview.

#### *2.3.2.4 Data collection process*

The interviews took place at the said clinic. Care was taken to ensure that each interview took place in a quiet, private location with no one except the participants and interviewer present or within earshot. Two research assistants with experience in conducting social science interviews were employed, fully briefed and trained with regards to the requirements of the research. They were identified at the University of Swaziland and paid at a negotiated rate not exceeding 200 Emalangeni per interview.

With the assistance of the hospital staff at the clinic the participants were identified, approached by the interviewers who introduced themselves and asked for permission to conduct the interview (see Annexure D) or set an appointment to interview at a convenient time.

Data were collected in isiSwati. The interviewers asked open ended questions using a semi structured format and probed for further understanding of the phenomenon under study. The interview process was conversational with the responses being recorded on audio tape and written field notes, recording observed non verbal behaviours and reflections (see annexure E). The interviewers applied facilitative communication skills such as paraphrasing, probing, clarifying and summarising to ensure that participants were able to describe their experiences. However, while the participants were able and encouraged to respond in any manner they wished as well as to introduce new topics of importance, the interviewer directed the interview so as to remain focused. The interviewer maintained the flow of the conversation, kept the questions brief and simple and listened actively.

*2.3.2.4.1 Audio taping*

Permission was requested from the participants to use a digital voice recorder (see Annexure D). All interviews were captured in their entirety. Each interview was assigned a code such as ‘participant-A, 05 Dec 2009’. Each interview was recorded in a separate file and labelled with the assigned interview code. As soon as possible after each interview the researcher listened to the recording and made notes transcribing key words, phrases and statements in order to allow the voice of research participants to speak. The researcher made sure that the recording equipment was always in perfect working condition and that batteries were available at all times.

*2.3.2.4.2 Field notes*

The interviewers took field notes during the interviews. Field notes were used as a secondary data storage method since the human mind tends to forget quickly (Lofland & Lofland 1999:14). Field notes constitute a step towards data analysis (Morgan 1997:57). The writing of field notes during the research process compelled the researcher to further clarify each interview setting (Caelli 2001:279). During each interview the interviewers wrote observational notes to describe the underlying theme as well as the dynamics during the interview in order to assist in remembering all the aspects of the interview. The field notes were made while watching and listening and included direct quotations of what was said.

### 2.3.3 Data analysis

Qualitative data analysis techniques use words rather than numbers as the basis of analysis, moving from concreteness to increasing abstraction (inductive reasoning) (Burns & Grove 2005:535). Data analysis in qualitative research occurs simultaneously with data collection. In this study the researcher and

research assistants transcribed the interviews verbatim and translated the recorded interviews from isiSwati to English. Interview scripts were produced using MS Word. The researcher subsequently printed the transcriptions and read through the data several times in order to obtain a sense of the whole. Coding, which involves breaking up the narrative into smaller parts and clustering many related concepts into a manageable number of categories (categorising), followed. Subsequently the discovery of interrelationships between the categories, developing a number of unifying themes (synthesis) took place. Each theme and its many layers of underlying interrelated concepts were then used to describe the phenomenon under investigation (Burns & Grove 2005:548).

The analysis of the interviews was based upon the Marshall and Rossman (1994) framework which involves three stages, namely:

a. Data formatting
b. Data organising
c. Generating categories, themes and patterns.

Testing of emerging hypotheses against the data, which is stage four, was not performed since it was beyond the scope of this study.

#### *2.3.3.1 Data formatting*

All interviews were recorded using high quality recording equipment. Recordings were transcribed near verbatim, with important speech utterances (for example, pauses, sighs, laughter) and contextual comments (for example, mimes, hand signals) included. During transcription, discussions were translated into English, although any words or phrases not easily translated were kept in isiSwati. The transcripts were checked, anonymised and hard copies printed. Additional information was collated for each interview.

#### *2.3.3.2 Data organising*

The need for organising the data definitely became apparent when one was faced with the output from the interviews. Once formatted, the data was sorted, simplified, and summarised to aid the identification of categories and themes. The main organisational tool used was a comprehensive summary sheet completed for each interview. The researcher perused the transcripts in order to familiarise himself with the content and nature of the discussions and then constructed templates to identify and label the main themes in the research, with the choice of themes driven by the content of the discussions, after which he completed the summary sheet for each transcript.

#### *2.3.3.3 Generating categories, themes and patterns*

The identification and definition of categories and the examination of relationships between the categories underpinned much of the analytical procedure. The analysis rested upon a systematic reading of the text relating to each category or theme across all the transcripts. As new information emerged from the transcripts, new themes of interest and new variables were added. Each transcript reading was accompanied by ‘cut and pasting’ or summarising the relevant text. This was performed on a computer using MS Word in order to enable the identification, construction and description of themes based upon relevant data drawn from all the transcripts.

## 2.4 MEASURES TO ENSURE TRUSTWORTHINESS

In qualitative research, as mentioned it is important to ensure trustworthiness (Babbie & Mouton 2006:277). Its various aspects are discussed below.

### 2.4.1 Credibility

Credibility criteria involve establishing that the results of qualitative research are believable, from the perspective of the participants involved in the research. Credibility is high when compatibility exists between the constructed realities that exist in the mind of the participants and those that are attributed to them.

This research has achieved credibility through persistent observation and the prolonged engagement with the participants by the interviewers staying in the field until data saturation was achieved. The prolonged engagement enabled interviewers to build a good rapport with the participants. Sufficient time was allowed to enable the elderly to answer the questions as well as ask questions themselves. Triangulation was also applied by asking different questions, seeking different sources of data as well as checking with the supervisor to assist in achieving credibility. The researcher ensured referential adequacy by having enough materials and working equipment to document findings. Peer debriefing and member checks were also used to enhance credibility (Babbie & Mouton 2006:277).

### 2.4.2 Transferability

Transferability refers to the extent to which the findings can be applied to other contexts or with regards to other respondents. The researcher ensured thick descriptions of findings with sufficient detail and precision regarding the context and research process in order to ensure transferability. Purposive sampling was used to make sure that the informants who differed from one another were selected in order to maximise the range of specific information that could be obtained from and about the context (Babbie & Mouton 2006:277).

### 2.4.3 Dependability

Dependability ensures that the study would yield similar results if repeated with the same or similar participants in the same or similar context. It refers to the stability of the data over time and conditions. It emphasizes the need for the researcher to account for the ever changing context within which research occurs. According to Guba and Lincoln (1985), there is no credibility without dependability; in as much as there can be no validity without reliability. Therefore, the researcher employed the same measures as for credibility to ensure dependability (Babbie & Mouton 2006:278).

### 2.4.4 Confirmability

Confirmability is the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher. A confirmability audit trail was conducted involving the reviewing of the raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, instrument development information and materials relating to intentions and dispositions. An audit trail ensured that the conclusions and interpretations could be traced to the source and were a true reflection of them. An audit trail can determine both dependability and confirmability at the same time (Babbie & Mouton 2006:278).

## 2.5 ETHICAL CONSIDERATIONS

The study complied with ethical principles, beneficence, respect for persons and justice, protecting the rights of the informants and the institution as well as scientific integrity of the research.

The principle of beneficence means that the researcher does not harm others intentionally through lack of knowledge or by negligence. Interviewers were made aware of the importance of minimising the subjects' level of anxiety or stress and

the absolute requirement of not divulging any information obtained from the interviews. Experienced interviewers were engaged in order to minimise the risks that might have been posed to the participants. Training for the data collection included discussions and exercises regarding the meaning and process of informed consent, the importance of protecting the privacy of the subjects and the confidentiality of the information obtained. The researcher supervised all the data collectors on a continuous basis. Unscheduled supervision visits were made to ensure that the interviewers were following pre-defined protocols and guidelines. The researcher was also responsible for checking data quality and ensuring that data were stored in a safe and confidential location.

### 2.5.1 Informed consent and voluntariness

The principle of respect for persons acknowledges the autonomy and protection of those with diminished autonomy. The researcher ensured that all the participants were competent to give informed consent. The participants were supplied with accurate information concerning the purpose of the study and the procedures involved. After ensuring comprehension as well as voluntariness they signed an informed consent agreement (see annexure D). Fair treatment of others and avoidance of discrimination and exploitation was maintained in terms of the principle of justice. Fair procedures for the selection of participants were used, with no incentives being offered to attract participants (Herbst 2000:88).

### 2.5.2 Confidentiality and anonymity

Informational privacy and confidentiality is necessary to guarantee respect for persons and this was ensured during primary data collection and secondary data analysis. All participants were told that the information obtained in the study would be confidential. When recruiting, respondents were known by their first names only. All data were kept under secure conditions in locked files in an office. When interviews were being transcribed, names and other identifying

information were removed or replaced with anonymous, similar labels. Access to the research data was limited to the author. No identifying information was to be disclosed in the final report.

### 2.5.3 Termination

The participants retained the right to refuse to answer any questions or discontinue their participation at any time.

### 2.5.4 Ethical clearance

The research proposal was assessed and approved by the University of South Africa ethics committee (See Annexure A) which means that it met the requirements to maintain the integrity of the University. The researcher also presented the proposal to the Swaziland Scientific Ethics Committee in the Ministry of Health and Social Welfare and received approval and a clearance certificate to conduct the study in Swaziland (see Annexure B). A written request was sent to the National Antiretroviral Treatment Programme Coordinator who granted permission to conduct the study at the Mbabane Government Hospital (see Annexure C). The researcher sought informed consent from the participants as means to obtain permission to talk with them.

## 2.6 CONCLUSION

This chapter discussed the research design and methodology as well as ethical considerations. It also covered the strategies employed to ensure trustworthiness. The next chapter will address the issues of data analysis and literature control.

# CHAPTER 3

# DATA ANALYSIS AND LITERATURE CONTROL

## 3.1 INTRODUCTION

Chapter 2 discussed the research design and methodology of this study. This chapter describes the data analysis and literature control.

## 3.2 THE AIM OF THE STUDY

The purpose of this study has been defined. The objectives of the study are as follows:

- To explore the experiences of the elderly caregivers in terms of how they are taking care of HIV positive orphans on antiretroviral treatment in Swaziland.
- To describe the challenges being faced by the elderly caregivers of orphans on antiretroviral treatment.
- To describe the coping strategies being employed by the elderly looking after the orphans.
- To establish support systems and the level of support being rendered or lack thereof to the elderly caring for HIV positive orphans on antiretroviral treatment in Swaziland.

## 3.3 DATA COLLECTION AND ANALYSIS

To address the research objectives above, the researcher used semi-structured interviews for data collection, asking open ended questions which the participants answered in their own words, thus yielding narrative data for qualitative, non numerical analysis. Data were collected over a period of 3 months from 12 elderly people looking after HIV positive orphans on antiretroviral treatment in and around Mbabane. With the help of two research assistants with experience in conducting social science interviews, the researcher collected the data in isiSwati according to an interview guide, while capturing the responses by means of a digital voice recorder and written field notes, recording observed non verbal behaviours and reflections.

Analysis of the interviews was based upon the Marshall and Rossman (1994) framework as below:

a. Data formatting
b. Data organising
c. Generating categories, themes and patterns.

A detailed description of this method appears in chapter 2.

In this study, the researcher transcribed the interviews verbatim and produced interview scripts using MS Word. Subsequently, the scripts were colour coded one by one. Thereafter, similar topics were grouped together into categories. A number of themes and sub themes emerged from each category. These were used to describe the phenomenon under study.

Five main categories emerged from the data analysis process. Each category is discussed under the emerging themes and sub-themes with relevant narrations from the participants, while the relevant literature is also cited as a control procedure regarding the presented data. The researcher begins with furnishing the demographic profile of the participants.

## 3.4 BIOGRAPHICAL PROFILE OF THE ELDERLY CAREGIVERS

To meet the objectives of the study the researcher interviewed 12 participants who met the sampling criteria already mentioned.

Table 3.1 below furnishes the biographical information of the 12 participants who took part in the study, covering their ages, marital status, and area of residence and their level of education.

**Table 3.1.Biographical information of participants**

| Participant | Age | Marital status | Area of resident | Level of education |
|---|---|---|---|---|
| A | 62 | Divorced | Peri-urban | Primary |
| B | 70 | Widowed | Rural | Primary |
| C | 63 | Married | Rural | Primary |
| D | 64 | Widowed | Peri-urban | No education |
| E | 62 | Widowed | Rural | Primary |
| F | 63 | Married | Urban | Secondary |
| G | 61 | Widowed | Rural | No education |
| H | 68 | Widowed | Rural | Primary |
| I | 60 | Married | Rural | Primary |
| J | 65 | Married | Peri-urban | Primary |
| K | 67 | Married | Rural | Secondary |
| L | 64 | Widowed | Rural | Primary |

### 3.4.1 Summary of the table

The elderly people who were interviewed were all non-professional females who had acquired mainly a primary level of education and resided in rural areas under conditions of extreme poverty. This is consistent with the reports of HelpAge International (2005) ; Piot, Greener and Russell (2007:4); Baylies (2002:611) and Ssengonzi (2009:309) that poor women are the main caregivers of people living with HIV and AIDS.

## 3.5 CATEGORIES AND THEMES

Data collection and analysis identified five categories reflecting the participants' experiences as they cared for HIV positive orphans on antiretroviral treatment. The categories are: (1) experiences in caring before initiation of antiretroviral treatment, (2) experiences in caring after initiation of antiretroviral treatment, (3) challenges experienced during the caring process, (4) coping strategies, and (5) support systems available to assist during the caring process. These are presented together with the themes and sub-themes in table 3.2 below.

**Table 3.2** Categories and themes.

| **CATEGORIES** | **THEMES/SUB-THEMES** |
|---|---|
| 3.5.1 Experiences in caring before initiation of antiretroviral treatment | 3.5.1.1 Caring due to crisis<br><br>3.5.1.2 Caring for very sick children<br><br>*3.5.1.2.1 Persistent ill health*<br>*3.3.1.2.2 Not knowing what was wrong* |
| 3.5.2 Experiences in caring after initiation of antiretroviral treatment | 3.5.2.1 Beneficial effects of antiretroviral treatment.<br><br>*3.5.2.1.1 Improvement in health status*<br>*3.5.2.1.2 Reduced burden of caring for the* |

| | |
|---|---|
| | *sick financially, emotionally and physically*<br>*3.5.2.1.3 Marked increase in appetite*<br>3.5.2.2 More responsibility to monitor treatment<br>*3.5.2.2.1 Treatment administration*<br>*3.5.2.2.2 Ensuring adherence* |
| 3.5.3 Challenges experienced during the caring process | 3.5.3.1 Excessive responsibility<br>*3.5.3.1.1 Caring for more than one sick orphan*<br>*3.5.3.1.2 Caring for other adult family members*<br>3.5.3.2 Economic constraints<br>*3.5.3.2.1 Poverty*<br>3.5.3.3 Food insecurity<br>*3.5.3.3.1 Lack of adequate food*<br>*3.5.3.3.1 Inability to meet nutritional requirements*<br>3.5.3.4 Poor infrastructure<br>*3.5.3.4.1 Transport problems*<br>*3.5.3.4.2 Few centres for treatment collection*<br>*3.5.3.4.3 Poorly equipped health centres.*<br>*3.5.3.4.4 Shortage of drugs for opportunistic diseases*<br>*3.5.3.4.5 Lack of protective clothing*<br>3.5.3.5 Physical constraints<br>*3.5.3.5.1 Chronic ill health*<br>*3.5.3.5.2 Lack of strength*<br>3.5.3.6 Psychological constraints |

| | |
|---|---|
| | *3.5.3.6.1 Panic at having contracted the disease*<br>*3.5.3.6.2 Stress and depression*<br><br>3.5.3.7 Social constraints<br><br>*3.5.3.7.1 Abuse by husbands*<br>*3.5.3.7.2 Lack of time to meet friends, family and social events*<br>*3.5.3.7.3 Fear of stigma and discrimination* |
| 3.5.4 Coping strategies | 3.5.4.1 Income generating activities<br><br>*3.5.4.1.1 Buying and selling*<br>*3.5.4.1.2 Borrowing from money lenders and relatives*<br>*3.5.4.1.3 Part-time employment*<br><br>3.5.4.2 Activities to boost food security<br><br>*3.5.4.2.1 Small-scale farming*<br>*3.5.4.2.2 Backyard orchards* |
| 3.5.5 Support systems | 3.5.5.1 Type of assistance required<br><br>*3.5.5.1.1 Basic necessities*<br>*3.5.5.1.2 Resources for income generation*<br><br>3.5.5.2 Government assistance<br><br>*3.5.5.2.1 Grants are not enough*<br>*3.5.5.2.2 Food hampers selectively distributed*<br>*3.5.5.2.3 Orphan and vulnerable child grants ill-defined*<br><br>3.5.5.3 Non-government and faith based organisations<br><br>*3.5.5.3.1 International organisations* |

| | |
|---|---|
| | *3.5.5.3.2 Local churches*<br>*3.5.5.3.3 Volunteers*<br><br>3.5.5.4 Community and extended family<br><br>*3.5.5.4.1 Extended family*<br>*3.5.5.4.2 Community members* |

### 3.5.1 Experiences in caring before initiation of antiretroviral treatment

This category deals mainly with how the elderly people ended up caring for the sick HIV positive orphans. It is presented and subsequently discussed under two main themes, namely, caring due to crisis and caring for a very sick child.

#### *3.5.1.1 Caring due to crisis*

It emerged from the interviews that the elderly people took over the responsibility of looking after their grandchildren after the death of one or both of the latter's parents or when their parents were so critically ill that they could not take care of the children and felt that the grandmothers were in a better position to look after the children. One participant reported having to take over the care of a 2 week old neonate because the mother had died. The elderly people adopted the role of caregiving because there was a crisis and they had to intervene to avert disaster, as revealed by the narratives below:

> *I took care of the child because I saw that she was going to die. I decided to look after her because there was nothing I could do because even her mother had died and she was developing sores all over the body even in the mouth and throat. Her condition was bad.*

*Impilo ikahle kepha make wakhe wafa. Babe uyaphila kodvwa asimati kutsi ukuphi. {Life is fine but her mother died. The father is alive but we don't know where he is}.*

*I am the one caring for the orphans. The youngest was really sick and I had to take care of him from a young age, as his mother died when he was only a week old.*

*Kungoba bantfwana bami bebanebhadi emshadweni. Emadvodza abo afa babese babuya ekhaya nebantfwana babo. {This is because my daughters had bad luck in marriage. Their husbands died and then they returned home with their children}.*

The revelations from the narratives above actually concur with what Oleke, Blystand and Rekdal (2005:2628) found in their study: that orphan care usually occurs as a result of crisis fostering. Winston (2006:36) argued that many grandparents care for orphaned grandchildren out of compulsion rather than free will, which was actually the case with the participants in this study. This is therefore in contrast with Tronto's ethics of care framework (1993:105) which states that effective caring involves the willingness to care, with those participating in the caring relationship expressing their willingness to take open-ended responsibility with regard to each other. The elderly people's lack of free will in caring for the orphans compromised their effectiveness, attentiveness, competence and responsiveness in providing care to the sick orphans.

#### *3.5.1.2 Caring for very sick children*

The data analysis revealed that the participants took over the care of very sick children presenting with frightening medical conditions while some were in miserable and critical conditions.

*3.5.1.2.1 Persistent ill health*

The participants reported having to endure the stress of caring for persistently sick children with sores discharging pus all over the body, discharging ears, chronic diarrhoea, failure to thrive and malnutrition. Some of the children were so sick that they were in and out of hospital with pneumonia, convulsions and abscesses which would require being on intravenous fluids, intravenous antibiotics and oxygen therapy as stated by some of the participants:

> *I was in and out of hospital because the sores were developing now and then. I thought the child would die like her mother. I would come back here [hospital] even four times in one month.*

> *When she returned the child was 2 years old and could no longer walk. She was very sick with diarrhoea and wasting. Her tummy was also huge. I took her to clinics and hospitals until the nurses told me that the child was starving. They told me to feed her different foods and not one and the same thing. With the Lord's help she was better. Then later she kept on having stomach problems and I took her to a clinic nearby. There the nurses suggested that the child gets tested for HIV as they had tried everything else. When the results returned I was told that my grandchild had AIDS and was advised to take her to the Mbabane hospital for medication. I then took her there because I wanted her to recover. The doctor examined her and recommended that she take the medication. It was in syrup form at that time, now she is taking the pills.*

> *She would sweat a lot, the skin around the thighs was wrinkled and peeling off. We then decided to bring her to hospital and they found that she was HIV positive. They were then able to help us.*

Ssengonzi (2007:20), from a study in Uganda, discovered that elderly caregivers provide care to patients with AIDS at the terminal stages of the illness when the patient needs constant care in terms of feeding, cleaning, medication monitoring and at times tender loving care. The participants in this study found themselves in similar situations which were compounded by the fact that they waited too long before taking the children to be tested or to start antiretroviral treatment due to denial and the fear attached to this incurable disease as well as to ignorance.

*3.5.1.2.2 Not knowing what was wrong*

The participants indicated that they did not know what was wrong with the children initially and tried all means to make them better in vain until they were obliged to endure the pain and the anxiety of accepting the sad news of their grandchildren's HIV status.

> *Before you could not tell what was really wrong with him. I would take him to clinics and hospital and they could not tell what was wrong with him.*

> *The thing that led me to bring my grandchild here was that he was always sick. He was sick for a long time and we did not know what was wrong with him. We had gone to many doctors until we decided to take him to Mbabane Government Hospital where he was diagnosed with pneumonia. He was treated and recovered and the doctor told me that he had to start antiretroviral treatment for the rest of his life.*

> *I went with him to many hospitals until I was helped by a Zimbabwean doctor at the Mbabane Government Hospital. He advised me to take the child for an x-ray then told me to come to this section.*

Lehman, Hecht, Wartley and Fleming (1999:40) established that being afraid of finding out one's HIV status and lack of recognition of the need to test were

common reasons for delaying being tested, which was the case faced by the participants in this study.

### 3.5.2 Experiences in caring after initiation of antiretroviral treatment

The data analysis revealed that antiretroviral treatment was a life changing intervention in the lives of both the sick orphans and their caregivers. It brought with it a new set of experiences for the elderly people. Besides the fact that the children were put on lifelong medication which they would take twice daily, they were given a new lease of life. The participants reported the beneficial effects of the antiretroviral treatment as well as the added responsibility of monitoring and administering the medication.

#### *3.5.2.1 Beneficial effects of antiretroviral treatment*

The participants indicated that they were very pleased with what antiretroviral treatment had done to their grandchildren since there was a marked improvement in the children's health status, relieving a huge part of the burden of looking after the sick children.

##### *3.5.2.1.1 Improvement in health status*

The participants reported visible changes in the health status of the children as revealed by the narratives below:

> *As I am telling you this child was so skinny. Now she has gained a lot of weight. Even the doctors who know her were shocked to see her like this and they said that she had gained weight and she looked healthy and fresh. The doctor weighed her and found that she had gained a lot of weight and the doctor was very happy.*

> *The treatment has been very helpful, because now you can tell when the child maybe has flu. I am very grateful of the Zimbabwean doctor's help.*

*He also gained weight and his appearance is better. Now he falls sick like someone who is not HIV positive. His strength is much better now and he is able to run and do certain chores like weeding.*

*Yes it has been really helpful. I noticed an increase in strength and their bodies are returning to shape. They are also now able to help out at home. When sending them you can tell whether they are sick or not, like sending them to the store you can tell that they are healthy when they return quickly.*

According to Oswal (2002:112), weight gain, and feeling of wellbeing are some of the obvious beneficial effects of antiretroviral treatment which were also noticed by the participants in this study.

*3.5.2.1.2 Reduced burden of caring for the sick financially, emotionally and physically*

As reported by the respondents, antiretroviral treatment brought hope into their lives concerning the children's sickness. The elderly caregivers had such confidence in the medication that they did not hesitate to recommend it to other people in similar situations.

*He is my hope. Maybe someday there will be cure and I don't want to lose hope because I know that it is incurable now. It was never known how to treat it but now there are the pills to keep it slow and with time a cure for it will be found. I do have that hope.*

I *encourage those who still don't know, that they should bring their children because they can get help. It does not mean anything that they are positive; life still goes on.*

HelpAge International (2007), from studies undertaken in Thailand, Cambodia and Vietnam, reported these same encouraging effects of antiretroviral treatment in reducing the burden of caring for the sick children. The studies described significant differences in terms of caring responsibilities by reducing the financial, emotional and physical pressure on many caregivers which confirms the findings in this study. Mundia (2008:20) in his study established that antiretroviral therapy changed the home-based care needs of people living with HIV from being dependent and bedridden to being active and able to help themselves.

*3.5.2.1.3 Marked increase in appetite*

All the participants witnessed an increase in the children's appetite which they attributed to the medication. No one conveyed it better than these participants who said:

> *I try different means to get that little food and give it to him. A few moments later he then says he is still hungry and then I realized that it is the medication because they told me at the hospital that it makes them very hungry. This worries me a lot because we do not have enough food.*
>
> *Inkinga isekudleni, ngoba lamaphilisi abenta bafune kudla kakhulu manje loko kiyinkinga ngoba nalo kudla kuncane. Badzinga kudla nase mukhasini kwetikhatsi tekudla kepha loko akwenteki. {The only problem is with food, as their medication increases appetite which is problematic since we have a shortage of food. They need to eat between meals but this is not possible}.*

Oswal (2002:98) as well as Pakker, Praxedes, Bassani, Bakaki, Boelaert, Loeliger, Giuliona, Ndugwa and Lange (2003:25) in their studies observed an increase in appetite as one of the benefits of antiretroviral therapy in children which was also reported by the participants in this study. Though the increase in

appetite was a good sign it was also a source of worry for some of the respondents as their remarks indicate.

#### *3.5.2.2 More responsibility to monitor treatment*

The participants reported the new responsibility of making sure that the children receive the medication on time and as indicated by the health professionals on a daily basis without failure as well as honouring review appointments at the clinic.

##### *3.5.2.2.1 Treatment administration*

The participants experienced no difficulty with administering the medication, either syrups or pills.

> *What is good about that is that the young one reminds me every now and then about the time. The doctors told us to teach the children so that they know how to take their medication and the young one does just that. He even takes the medication by himself because the doctor encouraged us to teach them to take the medication because sometimes you may not be there to give him so he has to know how to do it.*

> *I just try my son. I have been to the hospital and I was taught I must give her the medication in the morning and in the evening. I understood that. I never went to school but I understood that very well. She started on the syrup then the pills. I had no problem in measuring because I was given measuring cups.*

> *I have no problem in giving my grandchildren their medication and they take it correctly. Only the two youngest are taking the syrup mixture. I do not have any problem in making the correct measurements because they teach me.*

Most of the participants reported no problems in administering the medication since they were taught by the nurses and were given measuring cups for medicines in syrup forms. The older children were less problematic since they actually assisted with taking of the medication.

*3.5.2.2.2 Ensuring adherence*

According to the Swaziland national guidelines for antiretroviral treatment and post exposure prophylaxis (Ministry of Health and Social Welfare 2006:68), adherence to antiretroviral therapy refers to the ability to follow instructions on how to take medication: this means taking the drugs at the same time, in the correct dosage and consistently (without missing a dose). Some of the participants understood the importance of adherence to antiretroviral treatment whereas some were not very strict in that regard as revealed by the narratives below:

> *She takes the medication all the time at 6.30. She also knows the times and she never forgets. She gets it everyday. She does not skip times.*

> *I don't just sit around. When they leave town at 6:30pm which is the time she has to take it, when she gets home I give her because she would have eaten something in town. I don't let her sleep without taking it. I don't think it would be right.*

> *I sometimes forget because sometimes I am thirty minutes late but that is not a problem. The only problem is when you are late with five hours. If it's like that, then you don't give him. You should not get used to it because the virus develops more in the body. You should always be on time.*

The above narratives are actually in contrast to what Mellins, Brackis-Cott, Dolezal and Abrams (2004:10350) reported in their study where adherence to

paediatric antiretroviral treatment was compromised by a number of factors related to the caregiver, a finding which was also echoed by Polisset, Ametonon, Arrire, Aho and Perez (2008:23). Adherence was not a major problem in this study, which could be the result of the reported health professionals' support, in agreement with what Brown, Lourie and Pao (2000:81) found in their study. Yu, Della Negra, Queroz and Pacola (2004:101) also established that adherence to antiretroviral treatment was better in children living with adoptive parents, other relatives and in foster care institutions than in those living with biological parents.

### 3.5.3 Challenges encountered during the caring process

According to Kamya and Poidexter (2009:4) as well as Sorrell (2007:17), the elderly caregivers look after orphans in rudimentary villages, facing a number of challenges. The participants in this study likewise reported confronting many difficulties when they were looking after the orphans on antiretroviral treatment, which included excess responsibilities, economical constraints, food insecurity, poor infrastructure, physical constraints, psychological constraints, and social constraints. This is consistent with what Mayer (2000:14) found in her study.

#### *3.5.3.1 Excessive responsibilities*

The data analysis revealed that the respondents were responsible for taking care of sick orphans as well as other sick adult members of the family, so much so that the burden on their shoulders was really heavy. Research undertaken by UNICEF in seven sub-Saharan Africa as reported by HelpAge International (2007) also reveals the excessive responsibility placed on the shoulders of the elderly due to orphaning.

*3.5.3.1.1 Caring for more than one sick orphan*

The participants were caring for more than one orphan including those taking antiretroviral treatment as the narratives below reveal:

> *Batukulu bami labane badla lamaphilisi ekudzindzibalisa ligciwane lembulalave. {Four of my grandchildren are on antiretroviral treatment} The first is 9 years old, followed by 6 years old then 5 years and finally 3 years old.*

> *Only two of my grandchildren are taking antiretroviral treatment. They are aged 12 and 13 years old respectively. The other two aged 9 and 7 years are not on the treatment.*

> *Four of them lost their mother and only one is on the treatment. He is 7 years old now. He started the treatment in 2004 and before taking the pills, he first took the medication in syrup form. I first went to Good Shepherd and they gave him the syrup medication.*

These narratives support what HelpAge International (2006) reported, which is reiterated by Landsberg (2007:104), UNICEF (2007) and HelpAge (2007): that older people actually in most instances care for at least two people living with HIV with others caring for more than three HIV positive children. Ssengonzi (2007:7) also reiterated the fact that the elderly provide physical and emotional care to one or more orphans, which supports Gibbs' (2008:19) argument that households headed by an elderly female, in particular, have higher dependency ratios.

*3.5.3.1.2 Caring for other adult family members*

Some of the adult family members were actually a cause for concern as they constituted a source of stress for the participants as revealed by these narrations:

> *I am caring for the orphans. One is 9 years and is on treatment. My relationship with him is fine, but I was affected by my grandchild who is 21 years old and is now in hospital and going to start antiretroviral treatment. Our relationship was very strained such that I ended up in hospital and was told that I had a heart problem. I was admitted for 2 weeks but now I am much better. I tried to advise her on her ways but she would not listen.*

> *Like I said too, he [husband] too has become a burden for me because I look after him. He is not well as he usually complains about his joints being stiff, thus he cannot walk. He can no longer do anything like harvesting. All he does is sit.*

> *The four girls are all sick. Only one had been hired here in Mbabane, hoping that she would then be able to care for her children. She has four children. The problem now is that her employers no longer pay her. I too was hoping that her working would improve our standards of living, but now she has to return home.*

The narrative above support what Chazan and Whiteside (2007:165) as well as Schatz (2007:147), established in their studies: that older women were caring for multiple people due to the HIV pandemic increasing the number of dependents on shrinking incomes.

### *3.5.3.2 Economic constraints*

The elderly were caring for orphans under challenging economic conditions. Poverty was the main challenge.

*3.5.3.2.1 Poverty*

The participants revealed that they were heading poverty stricken households so that in their old age they were the main breadwinners. They were too old to obtain any gainful employment or perform any other meaningful income generating activities.

> *The main problem is that I sometimes do not have money to take her to hospital when she is sick. Sometime I cannot take her where she is supposed to go because I am not working. That is the problem I have.*

> *The biggest problem is that of money, because you need money for everything. Another problem is clothing. My grandchildren have no clothing. I usually ask from relatives for clothing. Some offer their assistance and some do not. They just insult me and it is very heartbreaking.*

> *The biggest challenge was money. Like I stated before, he started taking medication at Good Shepherd Hospital. I then experienced financial problems which is why I asked for his treatment to be transferred to Mbabane, which is nearer. This was after the death of the child's father as the mother died first.*

This is in agreement with what HelpAge International (2005) reported: that 100 million older people live on less than a dollar a day while 80% of older people in developing countries have no regular income. According to Meursing (1997:27),

HelpAge International (2002), UNICEF (2003) and UNAIDS (2006), the elderly in Africa do not possess the economic resources to care for orphaned children. The participants actually lacked the resources for income generation and dealing with the needs of the children.

The death of their economically active children robbed them of the people who were supposed to be taking care of them as dependants. Their condition was made worse by the fact that caring for a sick person is very expensive considering the direct costs (medical, food, clothing) and the indirect costs (loss of income support, lack of time to earn money) involved (HelpAge International, 2004). Foster et al (2005:16) and Landsberg (2007:104) have argued 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 only exacerbated by caring for a sick orphan.

According to Tronto's ethics of care framework (1993:105), caring involves mobilisation of resources in a context of power, privilege and adequacy. Poverty undermined the capacity of the elderly to provide adequate care to the needy, dependent and functionally inadequate sick orphans. The situation of the elderly people in this study was similar: they needed someone to assist them with resources for providing care.

#### *3.5.3.3 Food insecurity*

The participants reported that the children under their care did not have enough food, thereby failing to meet the nutritional requirements prescribed by the health professionals.

*3.5.3.3.1 Lack of adequate food*

Some of the participants could not even provide adequate food so that certain children were actually sleeping on empty stomachs. Adding to the frustration of insufficient, food some of the children were choosy since they were used to good food when they were living with their parents in town.

> *Ngalesinye sikhatsi siye silale singakadli, nabo makhelwane bami lebebasipha kudla abasasiphi. {We sometimes sleep on empty stomachs and our neighbours who used to give us maize no longer do so*}.
>
> *My problem is that I sometimes do not have the food they need to keep them healthy. I sometimes fail to give them what they need. The food comes with money which I do not have.*
>
> *The medication helps them a lot but the only problem is that there is not enough food. I try to give them vegetables. If they were eating well they would have been looking even healthier than now.*

The unavailability of food was a real problem in the households headed by aged people, in agreement with what Landsberg (2007:104) reported in his study. Help Age International (2005) argued that despite older people's right to be free from hunger, lack of food is a serious problem in their households, to such an extent that some go for days without food which could lead to malnutrition in the family. Gibbs (2008:19) also established that households headed by the elderly are at a greater risk of being food insecure.

3.5.3.3.2 *Inability to meet nutritional requirem*ents

The interviews revealed that owing to poverty the elderly caregivers found it difficult to meet the nutritional requirements of the sick children. The participants

could not provide the required foods (fruits, protein rich foods like eggs and milk) due to lack of money to buy them. The children ended up eating whatever was available.

> *The huge problem is when it comes to food. I usually give them soft porridge sometimes with cabbages or umbhidvo and anything available. Though I was told that I should also give them apples and oranges, I never do that because I do not have the money to buy them.*
>
> *The problem is that she does not get the right food.*
>
> *Here at hospital they tell us that the children should get oranges, bananas and apples which are good for the body, but when you do not have money how are you going to buy them.*

Matshalaga (2004:62) identified an inability to meet the dietary requirements of HIV positive patients as a major problem faced by caregivers which was the case with the participants in this study.

#### ***3.5.3.4 Poor infrastructure***

Another challenge reported by the respondents which frustrated their efforts as caregivers was poor infrastructure since they lived mainly in rural areas with limited accessibility.

##### *3.5.3.4.1 Transport problems*

The road infrastructure is poor in rural Swaziland as revealed by the following narrative:

> *During rainy seasons I have problems in collecting my grandson's treatment on time. This is due to the fact that there is no transport since rivers are full and there are no bridges. I do not know if something can be done about this. Though I encounter problems with transport, I have never missed the date for fetching the child's treatment. I always find means to get here.*

In other words, the elderly were facing difficulties in travelling to obtain their grandchildren's medication but this was not a deterrent as regards their collecting it on time.

*3.5.3.4.2 Few centres for treatment collection*

The respondents also reported having to stand in long queues waiting to be attended to by healthcare professionals after traveling lengthy distances to the hospital. They wished there were more centres for collecting the drugs near their homes to avoid travelling.

> *Kute tibhedlela langihlala khona. {There are no hospitals where I stay}.*

> *We do have problems even though they may be few but they are there. Sometimes when you come here it takes a long time before you get the medication. I was here at 7:30am but I have just received the medication now at 11 o'clock.*

*3.5.3.4.3 Poorly equipped health centres*

Malfunctioning laboratory equipment at the hospital, so that investigations like liver function tests, full blood count and chest x-rays which are important for initiation and monitoring of antiretroviral treatment could not be undertaken, was reported as a concern by the participants.

*It is very important that the government helps us especially with the equipment because it is not nice to wait a long time only to find out that there is no test result because the equipment is not working. The government should improve the equipment because when the doctor wants the test results the test can not be done because the equipment is not working.*

*That is very important because it is giving us a hard time when doctors do tests on her when she is sick. One day she was supposed to do two tests but when we were to get the results we did not get those of the second test because the equipment had faults so I had to stay the whole day up until 2pm. I went and told the doctor and he said that was a problem because the test was important so as to see what was wrong with the child.*

Makoae and Jubber (2008:35) reported that caregivers were not satisfied with poor services at the hospital, specifically if turned away due to poor facilities when they felt they needed help. This was also the case with the participants in this study.

*3.5.3.4.4 Shortage of drugs for opportunistic diseases*

Some of the participants were worried about the shortages of drugs for opportunistic infections in the hospital dispensary which meant that they had to buy these in the expensive private pharmacies in town.

*And another thing is when you tell the doctor the problem he writes you a prescription and when you go to the pharmacy they tell you they don't have the medicine and that is painful. We are forced to buy from expensive chemists in town.*

Makoae and Jubber (2008:40) in their study in Lesotho reported that caregivers expressed frustration at the lack of consistent provision of HIV related medication in the hospitals and clinics; participants in this study expressed the same.

*3.5.3.4.5 Lack of protective clothing*

Lack of protective clothing such as gloves was also reported as a worry for the caregivers who had to clean some children with sores.

> *I do not use any gloves now because there is no need to. When she was very ill with diarrhoea and septic sores all over the body, I also did not use gloves then, as I had none. I just used my bare hands.*

The elderly were putting themselves at risk by cleaning the children without wearing gloves. Exposure to body fluids can result in HIV transmission.

### *3.5.3.5 Physical constraints*

As one grows old the body starts failing, resulting in chronic illnesses and lack of strength.

*3.5.3.5.1 Chronic ill health*

Data collection and data analysis revealed that the participants complained of failing health having a huge bearing on their caring roles. Hypertension, joint and back pains, poor eyesight and sleeplessness were commonly reported ailments that began or became worse during the caring process.

> *Eissssh I used to make mats and sell them. Now that my health has deteriorated I can no longer do so. I now have BP and my body is painful*

*all over. Now we easily lack food, whereas before I was able to support my children through selling the mats.*

According to HelpAge International (2005), the caring role severely strains the elderly caregivers and causes much emotional stress, leading to weight loss and vulnerability to illness and disease. Providing care during the night and worrying a great deal lead to sleepless nights and physical exhaustion. Joslin and Harrison (2002:383) discovered that the stress of raising HIV infected children precipitated chronic medical conditions in the elderly caregivers.

*3.5.3.5.2 Lack of strength*

The elderly people were less energetic and excessive responsibilities ran them down. The respondents reported experiencing difficulties undertaking labour intensive tasks for the purpose of earning extra income and saw this as the main contributor to poverty in the household.

*Besides growing maize, there isn't much that I do. I am now old and often sickly, thus my strength is not the same as before. When I was stronger, I was very hard working and found other means to make a living.*

*My market is small because what kills me is that I have to go to the mountains to get the grass to make them and that is so strenuous and at home I am alone and I have to look after cattle and most of the time I am not able to do that.*

HelpAge International (2005) reported that the elderly lack the strength to carry out strenuous tasks such as carrying sick children out of bed, bathing them, and chopping firewood. The narratives' revelations are in support of what Juma, Okeyo and Kidenda (2004:3) established in their study: that the elderly were doing arduous household chores without any assistance.

#### *3.5.3.6 Psychological constraints*

The caring role was straining the caregivers psychologically, causing much stress and worry.

##### *3.5.3.6.1 Panic at having contracted the disease*

Some of the participants reported being worried about exposing themselves to the virus while they looked after the children, so much so that they were living in persistent fear.

> *I too have tested a number of times because I look after my grandson and sometimes assist during child delivery. When I am sick I always think that maybe I too am now HIV positive.*

> *I have brought my granddaughter today, but I too have to get tested as I suspect that I too could be infected. Another reason is that my husband died of AIDS. Furthermore some of my grandchildren's parents also died of AIDS and I did not use gloves because my hands are too big.*

Maharaj (2008:656) reported that 50% of the respondents in a study in Kwazulu Natal, who had ever cared for someone living with HIV, perceived themselves at medium to high risk of HIV infection because of their caregiving activities. The elderly were justified in being worried because they were acting without proper protection.

##### *3.5.3.6.2 Stress and depression*

The findings of the study indicated that the elderly caregivers suffered considerable emotional pain due to caring for the sick children. They identified the following as the contributors to their distress: the loss of their sons or

daughters, the poor health of their grandchildren, a precarious financial situation, the difficulty of specific caring duties, the uncertainty about the future of the household and the reality of being compelled to care without any assistance.

> *No, everything is fine so far. The only problem is with me because now I have a problem of high blood pressure. I think the cause of this is that I have been suffering and stressed for so long. Sometimes my mind is very forgetful. I misplace a lot of things. My granddaughter does assist me in other things especially in her medications, but I have to be near her so that she is motivated.*

> *I had a lot of stress because I was thinking a lot and my blood pressure rose. When you have too many problems and have no way of solving them you end up having sleepless nights.*

> *I do have a lot of stress. I sometimes lie down because of the stress and have panic attacks.*

According to Howard, Phillips, Matinhire, Goodman, McCurdy and Johnson (2006:24), financial, physical and emotional stress levels are high among caregivers of orphans especially if the child is sick. Taking care of HIV positive orphans drains the elderly caregivers emotionally (Du Plessis 2000:15). The narratives above also concur with what Lecler, Grinstead and Torres (2007:333); and Ice, Juma and Yogo (2003:2), established in their studies: that the elderly caring for someone living with HIV/AIDS experience such emotional or psychological fatigue due to their caregiving activities that they have high levels of caregiving stress, resulting in lower levels of physical, social and mental health.

Difficulties and stress in adapting to the new parenting role which involves the elderly's relationship with their grandchildren and lack of understanding between

grandchildren and grandparents due to the generation gap was reported by HelpAge International (2005) and Oburu and Palmerus (2005:273), as a common problem. Fortunately, on a positive note, the participants in this study reported enjoying good relationships with their grandchildren which they attributed to the fact that the children were still young.

> *Budlelwane bami nebatukulu bami buhle fitsi ngicabanga kutsi lokungetela loku kutsi basebancane. {My relationship with my grandchildren is good and I think the most contributing factor is because they are still young}*.

#### ***3.5.3.7 Social constraints***

The participants reported facing many social difficulties which included physical abuse, isolation and fear of stigma and discrimination.

##### *3.5.3.7.1 Abuse by husbands*

The data analysis revealed that some caregivers faced abuse from their husbands due to their caregiving roles as shown by the narratives below:

> *Home is at Mhlangeni around Bhunya just before LaMgabhi. I have a long problem, I was married at Maseko homestead but I had a child from another surname and my husband never treated me well. I had two children from him but they died and the one with which I came into the marriage lived. She was the mother of this child and she later died as well. My husband then said I was killing his children so that I could take care of mine. He then chased me away from his home and said he did not want this child because he did not want him to die at his home. He said he should go to where he belongs but the bad thing is that I don't know where I can take the child because I don't even know the father of the child.*

> *The biggest challenge I have at the moment is with my husband. He has developed some psychological problems, so things have become very challenging. He abuses me physically everyday and this affects me a lot.*

The elderly caregivers were being abused even by close family members due to caring for the sick children.

*3.5.3.7.2 Lack of time to meet friends, family and social events*

The participants were ever busy looking after the sick children, so that they did not have time for other social activities.

> *I am always with the children since they require my help. I make sure that they eat before taking their medication. I fail even to go to church.*

The participants furthermore reported social isolation as a major challenge, mainly due to their workload interfering with social interaction. Their ability to visit friends and attend community events was restricted as spare time was used to search for food. This is in accord with what Meursing (1997:14) also identified in her study. Butler and Zakari (2005:45) and Ssengonzi (2009:309) reported that elderly caregivers face disruption in social activities and altered family relations. Juma et al (2004:3) and HelpAge International (2008) also reported that caring limits the elderly's time for socialization, attending social events and carrying out income generating activities.

*3.5.3.7.3 Fear of stigma and discrimination*

The participants reported such fear of the stigma attached to HIV infections that they could not reveal the child's sickness to neighbours. They were afraid that community members would spread the news, resulting in discrimination, as Ssengonzi (2009:309) also noted in his study.

The participants had this to say:

> *If somebody asks if the child is sick I never say what the child is suffering from because they can talk about you all over the place and they would make fun of you when you are with the child. It can also go as far as school and other children will laugh at her at school. Other kids at school would even say to her she is so thin with the wounds all over so that is not good as health workers say it is not right to despise someone when they are sick.*

> *Yebo bayasati simo sakhe kepha abamubandluli. Bangani bakhe bamuphetse kahle.{Yes, they know of his status and they do not discriminate him. His friends also treat him well}.*

The narratives revealed that some of the participants were afraid of experiencing discrimination due to their grandchildren's HIV status whereas others were not experiencing any discrimination at all. Knodel (2006:49) found, in a study conducted in Thailand and Cambodia that positive responses to households affected by HIV far outweighed negative reactions, mainly attributed to the fact that improved knowledge about the disease and its high prevalence in some communities meant that the people were more familiar with HIV. This however contradicts reports by HelpAge International (2007) and Maharaj (2008:17) of widespread discrimination and negative reactions levelled against the elderly and those caring for someone with HIV. Swaziland records a high prevalence of HIV; hence one would expect its people to be supportive of those affected by the disease.

### 3.5.4 Coping strategies

This category covers the means employed by the elderly caregivers as regards survival. This is discussed under two themes: income generating activities and activities to boost food security in the family.

#### *3.5.4.1 Income generating activities*

The elderly people were placed under much pressure to engage in income generating activities so as to raise money for daily living and for transport to hospital. These included buying and selling, and even borrowing from money lenders.

##### *3.5.4.1.1 Buying and selling*

The participants were engaging in running small scale businesses whereby they sold goods by the roadside and markets but were also forced to sell productive assets such as land and livestock as reported by HelpAge International (2008).

> *I usually sell some goods so that I can fetch my grandson's medication on the specified date. I have avocado trees at my homestead, so I usually sell them.*

> *I sometimes buy and sell goods. This helps me a lot.*
> *I sometimes sell things at my market and I sometimes use all the money I make as profit.*

> *Ngale sinye sikhatsi ngiye ngitsengise inkhunkhu kute ngitfole imali yekumuyisa esibhedlela. {I sometimes sell a chicken so that I get the money to take her to hospital}.*

The participants reported realising small amounts of money from their businesses to be used to collect medication for their grandchildren.

*3.5.4.1.2 Borrowing from money lenders and relatives*

Some of the participants resorted to borrowing from money lenders, friends and relatives.

> *The shylocks cause problems when they want their money. They do not care about your problems because they are in business.*

> *To speak the truth there are market stalls next to my home. I try so that it does not take a long time for her to get what she needs. I then ask for food items on credit. The market owner knows my situation so she is very patient with me. I give her the money after getting the grant for the elderly.*

Borrowing in fact caused the elderly caregivers to experience greater financial problems, considering the interest rates the money lenders charge, as supported by what Sundar and Varghese (2003:7) established in a study carried out in Tamil Nadu, India: that older caregivers for people living with HIV reported selling their property, or pledging it to money lenders for interest rates ranging from 36 to 120% per annum, to provide healthcare to treat family members. This act depletes the family's resources, plunging it into severe poverty.

*3.5.4.1.3 Part-time employment*

Some of the respondents were obliged to take up part time employment to try and boost the household income,

> *I am a community health worker and when I get paid the situation becomes better. I am able to do something with the E200 I get even if I don't get the elderly grant for the elderly.*

The elderly are expected to be resting and being looked after by their children and grandchildren but due to HIV they are forced to seek employment.

#### *3.5.4.2 Activities to boost food security*

Food insecurity is a major problem in households being headed by the elderly; the participants reported having to do small-scale farming to increase the food supply in the home.

##### *3.5.4.2.1 Small-scale farming*

The participants had the following to say concerning efforts to boost food security in their homes:

> *The major problem is food. I usually grow vegetables and maize to make a living. I also face challenges in buying fertilisers. I do everything by myself though some of my grandchildren do help me.*

> *Ngine ngadze lencane lengilima kiyo tidhidvo letinje ngemaklabishi, umbila naletinye nje, lengibese ngiyatitsengisa. {I have a small garden where I grow vegetables like cabbages, maize and others which I then sell}.*

The participants reported resorting to farming as a way of boosting food security in the family and meeting the nutritional requirements of the sick children. The produce of farming and gardening was for domestic consumption, with little

surplus for sale. Lack of fertilisers, seed and manpower limited the amount of produce. The elderly received no assistance in their farming activities.

*3.5.4.2.2 Backyard orchards*

From the interviews it emerged that the participants were complaining of being unable to obtain enough fruits for the children; hence some had to resort to back-yard orchards.

> *What I have at home she gets like mango. I have mango, banana and peaches trees at home. When the bananas are ready we cut a bunch and she eats when it is ripe. This is something I don't buy.*

Instead of buying fruits some participants were trying to meet the nutritional requirements of the children from home-grown fruits.

### 3.5.5 Support systems

The participants reported a strong need for assistance, which was really lacking as the following narrative reveals:

> *If there could be any help, the way that it can come I would be happy with it because I don't have anything.*

From what the participants reported it seemed there was no significant assistance specifically intended for the elderly who are looking after HIV positive orphans, which meant they were competing with everyone else for the available assistance. There was no constant help from anywhere. These findings are in agreement with what was reported by Umchumanisi Link Action Research Network (2003): that support for the elderly in Swaziland was sporadic, inadequate and was only reaching very few destitute elderly people. According to

HelpAge International (2007), the harsh reality is that the elderly are invisible when it comes to allocation of resources in the fight against HIV/AIDS.

#### *3.5.5.1 Type of assistance required*

The data analysis revealed that as the result of poverty the elderly caregivers were begging for assistance in terms of meeting basic necessities, resources for income generation and even financial assistance.

##### *3.5.5.1.1 Basic necessities*

The interviews revealed that some of the participants were in great need of necessities such as shelter and clothing, as the narratives below indicate:

- *Shelter*

  *Something that I really need is a place to stay. If I can get the grant I would build myself a two roomed house so that it would be known that I stay in that place and anyone who wants to see me would find me there.*

  *The house is in bad condition. It may fall on us anytime, as it was built from wood. When it rains it pours into the house. We also need a new house. We all live in that house and it is not that big. We have blankets because we were given by the volunteers. I also used to buy in Johannesburg for selling here, when my son who was gunned down was still alive.*

- *Schooling*

  *Ngingabonga kakhulu umangabe kungaba nemuntfu longangifundzisela yena, loko kungangetfula umftwalo emahlombe.Ngingazama ngibone kutsi ngentanjani kulolokinye. {I would really appreciate it if someone was able to educate her, which would lift a huge burden from my shoulders. I can then maybe try and see what to do with the rest}.*

  *Yes, I would really appreciate the help in the form of books, uniforms, and any other school material for my two eldest grandchildren. Money though would be gladly received.*

- *Food*

  *I would like to get the support in the form of food. I once talked to them and asked if they can help us with beans and milk.*

  *As you know a child can be helped with food and if somebody is able they could even help us with money.*

- *Other necessities*

  *There is also a need for clothing and blankets, but I cannot mention everything. We do have a house but we don't have anything to sleep on. We sleep on mats.*

  *I would also appreciate clothing, blankets and sponges. This is because they all sleep on one mat on the floor and only have a few blankets. Only the youngest sleeps with me in bed.*

*We would be happy if government would give us something. It may be the food or at least money to take care of the children and provide them with everything they need.*

Due to poverty and dwindling income the elderly in this study were in dire need of basic necessities. Tsheko, Segwabe, Odirile and Tlou (2007:19) established that housing was a major issue of concern for orphans and vulnerable children in Botswana, leading to overcrowding, which is consistent with what the narratives above reveal. Tsheko and Kabanye-Munene (2007:57) also reported that caregivers are unable to provide food, clothing and school fees for orphans under their care.

*3.5.5.1.2 Resources for income generation*

The elderly caregivers were also pleading for resources with an eye to income generation and sustaining their households. Some of them wished for land for farming while those that possessed land needed inputs for farming in the form of seeds, fertilisers and tractors.

*First and foremost would be food. It could be fertilizer and seeds, as I have the land but do not have the fertilizers and seeds. I can ask my grandchildren to help me in planting.*

### *3.5.5.2 Government assistance*

Most of the elderly caregivers in this study felt that the government was actually neglecting them as expressed by these narratives;

*Hulumende akenti lufto. {The government does not do anything}.*

> *There is nothing that the government helps us with. There was a request by those who are sick that they should be given money at the end of each month for transport to get to hospital but that has not been granted up to now. Instead of giving them the money they actually brought VCT closer to Sigangeni, but when I took my little girl there they said I should bring her here at the hospital because there are no doctors there.*

The situation in which the participants in this study found themselves was like that faced by elderly women in Cambodia, wherein they were unlikely to benefit from government support that directly mitigates the impact of providing care as reported by HelpAge International (2005). None of the elderly caregivers involved in the study reported receiving significant socio-economic support from government sources. Campbell (2007:5) reiterated that public sector support services for elderly caregivers are inadequate and unsympathetic in most cases.

*3.5.5.2.1 Grants not enough*

> *There is no one here in Swaziland who can do that, it would be better if I was getting the elderly grants because I would be able to take care of him.*

According to IRIN (2007), the Swazi government disburses grants to the elderly pegged at US$15, which in most cases is their only, meagrer, monthly income: it is not enough to cover the household needs. In addition, from the narratives above it seems not all the elderly are receiving the money.

*3.5.5.2.2 Food hampers selectively distributed*

Some of the participants were collecting food hampers from the Mbabane government hospital antiretroviral clinic. As certain elderly caregivers reported, though, they were not benefiting from some of the help because of corruption and nepotism practised by those in charge.

*I have never taken that. Never, I usually look at them taking it. I once queued for registration. I just have temper. The person who was registering us called somebody that was behind me and I left at that moment because it was like they were selective. I was shocked because I did not understand why they were doing favours. If I am in front you should finish with me first. You don't have to look for your relatives first or your friend or whatever so I left just like that.*

#### *3.5.5.3 Non-governmental and faith based organisations*

A number of organisations are helping vulnerable children in Swaziland but it seemed some of the participants were not aware of them.

*Angikase ngalutfola lusito kuba ngoba angitati naletinhlangano. {No, I have not received any help because I do not even know these organisations}.*

These included international organisations, churches and volunteers.

##### *3.5.5.3.1 International organisations*

Some of the participants were receiving assistance from international non-governmental organisations as indicated by the narratives below:

*NERCHA sometimes brings fertilisers and seeds for all orphans and not HIV positive orphans specifically.*

*I have been registering many times with these organisations for the past three years, but I have not received any help. There are some organisations that usually come to our place. Some of the organisations*

*are Bakamshwandane (Disaster Task Force) and World Vision. As of yet I have not seen them helping us.*

*No, together with Red Cross they haven't. They do not give us anything. When they lie to us they usually tell us that, some people from their companies came to access the Maphalaleni area and concluded that it had enough food. Families or homesteads are not the same. There are some men who are able to grow crops such as maize but they do not give us.*

It seemed that assistance from these organisations was erratic so that the deserving beneficiaries were not receiving the much needed help. Matshalaga (2004) reported that registration for assistance from aid organisations was not adequate since only a few households in a village were assisted, resulting in needy households receiving no assistance at all.

*3.5.5.3.2 Local churches*

Churches were helpful in terms of orphan care; some of the participants were receiving help from them as the narratives below show:

*Last month Roman priests from Malkerns helped us. They gave us groceries. Since we were many they could not provide for all of us.*

*No there is nothing but at church they provide the elderly with mealie meal, beans, sugar. It's just that three only.*

*We thought they would give us at the end of the month. It is not like they will give us at the end of each month. It takes time.*

> *The Roman Catholic Church gave us food for the sick children I am caring for. This was about 2 months ago. They do not do this every time though. This year they only supplied us once.*

The religious groups were providing help, though not consistently and adequately. The participants appreciated that and wished more help would arrive.

*3.5.5.3.3 Volunteers*

The participants reported having received support from volunteers:

> *Emavolontiya avamisile kuta landzaweni, basiphe tingubo. Beta kanye ekhaya kami. {Volunteers usually come to my area and have given us blankets. They only came once at my place}.*

> *The only other time we were assisted was last year when some Chinese volunteers came by and gave everyone rice irregardless of whether they were needy or not.*

According to Campbell (2007:308), in rural South Africa volunteers provide significant support to those affected by HIV and AIDS.

### *3.5.5.4 Community and extended family*

It is expected that the elderly caregivers receive support from the community and extended family.

*3.5.5.4.1 Extended family*

The elderly caregivers reported lack of adequate support from the extended family.

The participants commented as follows:

> *The others only help when they want. It may be after four months sometimes but I stay with the people here at home but they don't care and you cannot force them to help you because they are supporting their wives and children in their houses, you see. They say I had chance with their father and nobody was bothering me. It is like that.*

> *The only person that helps me is my sister in law. If I have problems I usually go to her and she gives me money. She does tell me her problems because she also has children but she gives me the little she can afford.*

> *I ask from their aunts, two of them who are married. They give me the little they can because their husbands do not want as they also have their own needs. They sometimes call me so that we meet and they give me something. It happened one day, as we were buying groceries, we met her husband and it almost brought problems because she had not informed him. I just get that kind of help when they get the chance but these chances are so slim. My concern is the young one.*

These narrations show that the extended family members were concentrating on their nuclear families and not adequately assisting the elderly people looking after the orphans. These revelations are consistent with those of Matshalaga (2004), who found that the traditional extended family, which used to be a pillar of support for households in need, has disintegrated due to HIV related high mortality so that the elderly are caring for orphans entirely unsupported.

According to Aiyeko (2005:4) and; Karim and Karim (2005:12), relatives are no longer available to cope with the rising number of orphans and each family fends for its own survival.

*3.5.5.4.2 Community members*

The community was not a source of sufficient support for the elderly caregivers as they complained of abandonment by their political and community leaders as well as neighbours. This is evidenced by the following comments from the elderly caregivers:

> *There is nothing from them. We tend to be forgotten by those whom we elected into parliament. After electing them they never give back to us. I will never go for election again, never. The present Member of Parliament we have does not help us with anything. In other places the Members of Parliament have called the elders to receive some food parcels but he has not done anything. He can not even help young children who have lost their parents when they come up to him to ask for his assistance. They lie and say when they get to parliament they will do this and that which they never fulfill. This one promised to fence our gardens but up to now nothing has been done. The year is almost over but there is nothing.*

> *We would benefit from those through our Member of Parliament but he only helps those he knows and even our zone leaders do not care about us they don't know that we need help.*

> *Tihlobo tami netakhamiti abangisiti ngalutfo ngoba angiluceli lusito kubo. {Relatives and the community do not help me because I do not ask for their assistance}.*

*I can't do that because I am afraid to ask from somebody I am just afraid to ask I can't so it is hard to ask from my neighbour. I just try on my own to find something because you can never ask for anything from your neighbour when you are all the same.*

*No, they don't offer me any assistance. They just tell me that they can't offer me anything. They are arrogant and look down on me. I usually ask for assistance from distant people. This may be in the community or elsewhere, as long as it is not my neighbours.*

In contrast to what Lecler, Grinstead and Torres (2007:333) established in their study, that neighbours are a valuable source of support, in the present instances neighbours and other members of the community were not very helpful in terms of assisting the elderly participants in this study. Some of the participants were not receiving any help from the community because they were not asking for it.

## 3.6 SUMMARY OF ANALYSIS OF FIELD NOTES

Field notes were used to record what the participants were saying non- verbally. The data analysis revealed that the elderly caregivers looking after the orphan as a result of crisis wore gloomy faces with tears in their eyes as they narrated the conditions of the chronically and persistently sick children. Other participants used open hands indicating that there was no food in the house. There was slight brightness in the faces of some participants as they spoke of the beneficial effects of antiretrovirals which they experienced when the children started antiretroviral treatment. This showed that antiretroviral treatment was their hope. The elderly caregivers were in need of support which was not available.

## 3.7 CONCLUSION

This chapter presented the data categories and the themes and sub-themes that emerged from the data analysis. Relevant literature was also referred to as a control for the research findings.

In the next chapter, the conceptual framework is analysed and the research findings are presented in the form of a mind map.

# CHAPTER 4

# CONCEPTUAL FRAMEWORK

## 4.1 INTRODUCTION

Chapter 3 dealt with data analysis and literature control. This chapter analyses Tronto's ethics of care framework in relation to the study's findings and develops a mind map on the challenges and experiences of the participants.

## 4.2 TRONTO'S ETHICS OF CARE FRAMEWORK

As has been pointed out, according to Tronto (1993), good care consists of holistic practices involving four phases: 'caring about', 'taking care of', 'care-giving' and 'care receiving'. Tronto's ethics of care framework can serve as a guide to pinpoint issues and challenges in the caring process and relationships by raising questions related to the elements of care which are identified as: attentiveness, responsibility, competence and responsiveness and the context of care which includes, power, privilege and adequacy (Tronto 1993:105).

### 4.2.1 Caring about

Based on Tronto's ethics of care framework (1993:105), 'caring about' is the nominal willingness to care involving the cognitive or the knowing aspect on the part of the caregiver. The caregiver ought to be well prepared to accord full attention to the needs of the one cared for out of free will. According to the findings of the study the elderly caregivers looking after orphans on antiretroviral treatment were doing so out of compulsion in a crisis situation with no choice because there was no one else to provide the care. This situation was not conducive to providing holistic care since this compromised the 'caring about' phase of such care.

### 4.2.2 Taking care of

According to Tronto's ethics of care framework (1993:105), 'taking care of' connotes the mobilisation of resources focusing on the needs and concerns of those cared for. The study findings revealed that poverty was one of the major challenges faced by the elderly people. Owing to poverty, the elderly people did not have enough food and were finding it very difficult to meet the nutritional requirements of the sick children. Obtaining money for transport to visit the clinic for the children's medication and review visits was difficult. As indicated earlier, antiretroviral treatment causes an increase in appetite, resulting in the children demanding more food which was difficult to provide.

Failure to provide for the children negatively impacted on the 'taking care of' aspect of the provision of holistic care.

### 4.2.3 Caregiving

An ethic of care and responsibility develops from an individual's feeling of interconnectedness with others (Tronto, 1993: 108). 'Care giving' represents the particularisation of the intention to give with the caregiver in direct interaction with the care-receiver. This involves the relationship between the caregiver and the care receiver. It also involves the actual care, not merely being sympathetic and attentive. The elderly people were in fact the ones cleaning, feeding the children and monitoring their medication.

For effective interaction between the caregiver and the care receiver, those receiving care must have a voice and be able to articulate their needs, provide input into shaping the care practices and react to the care they receive (Tronto 1993:108; Levy 2006:554; White 2000). The young age of the children and their helplessness due to ill health resulted in their being voiceless, making it difficult

for the caregivers to judge whether their efforts were being recognised. The children were not able to respond in a confirming way as to whether they were appreciating the care they were receiving.

### 4.2.4 Care receiving

According to the said framework, 'care-receiving' implies neediness, dependency, and functional inadequacy. Their age and chronic ill health rendered the orphans needy, dependent and functionally inadequate. They were in need of all forms of care since they could not provide for themselves and the disease made them unable to perform activities required for daily living.

The introduction of antiretroviral treatment actually improved the condition of the children. The progress in their health status lifted the burden of caring by rendering the children less dependent. They gained strength to perform other activities of daily living, which meant that they did not need to be carried in and out of bed: they were able to feed and clean themselves and less monitoring was required. The care receiving phase of the holistic care was altered by the children's response to antiretroviral treatment.

### 4.2.5 Elements of care

Tronto's ethics of care framework, as noted, encompasses attentiveness, responsibility, competence and responsiveness. The constraints the elderly were facing negatively affected these elements of care.

Attentiveness refers to the process whereby a person concentrates on certain features of the environment to the exclusion of others (*Longman Dictionary of Contemporary English* 2009:94). It means paying particular notice or being observant. During the caring process one is supposed to be attentive to the needs and concerns of the care receiver. Although the caregivers were

conscientious regarding the needs of the children, their efforts might not have addressed these owing to the lack of resources as well as the fact that the children did not have a ‘voice’ to articulate their exact needs. The attention of the elderly caregivers was focused on a number of individuals including the sick children and other family members, resulting in the spreading of the caregiving efforts rather than concentrating on one individual. This distracted their attention and thereby compromised the quality of care given (Tronto 1993:108).

The social force that binds a person to the courses of action demanded by that force is termed responsibility. The elderly were morally obliged to look after the sick orphans and were accountable for all the decisions they made and the actions they took. Due to the crisis created by the HIV, whereby there was no one else to care for the children, the elderly were left with the huge responsibility of looking after the children, at times even more than two in addition to other aged members of the family. That sense of responsibility drove them to keep providing the care (Tronto 1993:106).

According to the *Longman Dictionary of Contemporary English* (2009:388), competence is the quality of being able to perform a task. This quality permits or facilitates achievement or accomplishment and requires that one is well qualified physically and intellectually. The elderly caregivers were chronically unwell due to degenerative conditions of old age and were also less educated. They were weak and not able to be involved in gainful income generating activities to sustain their household and meet the children’s needs. These physical, psychological, intellectual and economic constraints disqualified the elderly as competent caregivers. By applying several coping strategies they tried to improve their competence but the lack of support let them down. Their caregiving ability was compromised even though they were doing a good job.

The elderly caregivers were responsive to the health and social needs of the children. Responsiveness denotes the quality of readily reacting with one’s

emotions to appeals from other people (*Longman Dictionary of Contemporary English* 2009:1488). The orphans were in need of care while the elderly were the only ones in a position to respond to or answer their call for help. The responsiveness of the elderly caregivers to the needs of the children was compromised by the challenges they faced and furthermore by the fact that they were facing social isolation, a fear of stigma and abuse from relatives due to their caregiving roles. The other caregivers were afraid to reveal their grandchildren's HIV status, which raises the element of a lack of the openness necessary for effective caregiving. This in reality denied them the opportunity to receive assistance from the community and family members because they did not bring their concerns to them.

### 4.2.6 Context of care

Provision of care should be carried out within a suitable context. This includes a degree of power, privilege and adequacy. The elderly caregivers were, however, operating in an environment of poverty and lack of support from the government, community and family.

Caregiving is normally carried out by the less powerful. As pointed out, typically the powerful are more often in a position to receive or demand care than to provide it while those with less power often find themselves in situations in which they provide care without much power or are in positions of invisibility and voicelessness (Sevenhuijsen 1998:24). The elderly caregivers, who were mainly less educated women, were not sufficiently empowered to fulfil the role of a caregiver which compromised their competence and responsiveness to the needs of the children. Their caregiving roles were unnoticed and the community needed to empower them.

The elderly caregivers were physically as well as economically inadequate. Their condition was not very conducive to providing holistic care in that resources were inadequate while in addition they were also physically not strong.

## 4.3 EXPERIENCES OF THE ELDERLY PEOPLE CARING FOR HIV POSITIVE ORPHANS

The findings of the study are summarised and presented in figure 4 below:

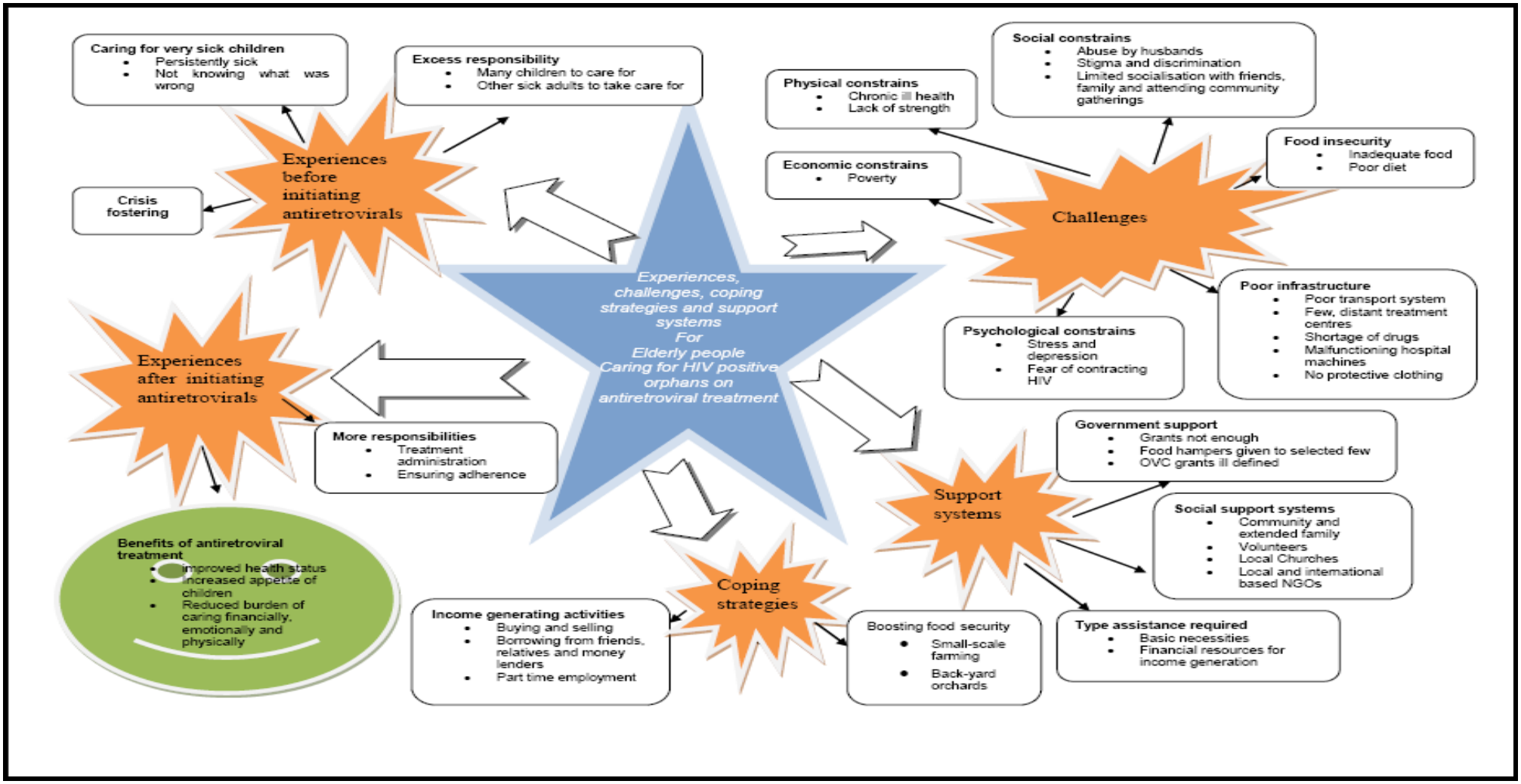


**Fig 4: A mind map of the findings giving a visual picture assisting in identifying areas for intervention strategies**.

### 4.3.1 Experiences before initiating antiretroviral treatment

The elderly caregivers were experiencing crisis fostering which was very difficult because they were looking after extremely sick children who were persistently ill without a clear picture and knowledge of what was wrong. This was even more difficult because they were actually caring for more than one child as well as other sick adult family members. These events forced them to take the children for testing, which led to a different set of experiences.

### 4.3.2 Experiences after initiating antiretroviral treatment

The elderly caregivers had to endure the pain of HIV testing on behalf of their grandchildren. Besides the caring duties, the treatment brought the added responsibilities of ensuring that the children were taking their medication daily at the right time and correct dosages, which is essential for a good response to antiretroviral treatment.

The elderly caregivers experienced and witnessed the beneficial effects of antiretroviral treatment on their grandchildren, evidenced by the improvement in their health status and increase in appetite. There was a reduction in the burden of caring financially, emotionally and physically. A healthy child who plays with other children and eats well is less costly and less stressful to look after. While this was something to smile about, many other challenges were encountered during the caring process.

### 4.3.3 Challenges

The elderly caregivers faced many hurdles which interfered with their caring roles. They were economically challenged since they lacked income generating potential, while sickness deprived them of time to generate income and depleted the few resources at their disposal. They were living in abject poverty which resulted in the lack of food in their households and hence, difficulties in meeting the nutritional requirements of the sick children. Even though they made an effort to obtain medication for their grandchildren, they

were faced with yet another major challenge, namely, the poor infrastructure in their areas of residence in terms of the unsatisfactory road network and only a few distant treatment centres. At the centres, drugs for opportunistic infections were in short supply, while laboratory and radiology equipment malfunctioned. At home they lacked protective clothing such as gloves so that they continuously exposed themselves to the virus.

The elderly were physically frail with chronic ill health owing to diseases associated with old age and they lacked the strength to work and carry out their caregiving roles. Their health was also affected by the psychological constraints they faced, which included stress and depression, resulting in constant fatigue. Stress levels were also raised by the social constraints they faced, which included abuse by husbands, stigma and discrimination by their society and limited time for socialisation with friends, family and other community members.

### 4.3.4 Coping strategies

The elderly attempted to employ coping strategies to deal with the challenges they were facing. These included developing means of income generation in order to alleviate the suffering due to poverty. They bought and sold goods as well as borrowed from friends and relatives. Others even took up part time employment in spite of their age. They also attempted small scale farming in the form of gardening and backyard orchards in order to improve the food security in the households and meet the nutritional requirements of the children.

### 4.3.5 Support systems

In their quest to make the lives of the children comfortable, it appeared that the support they were receiving was not sufficient for them to realise their goals. They required assistance in the provision of basic necessities such as clothing, food, education and shelter.

They expected assistance from the government which was not forthcoming. The little support that the government did offer, such as grants for the elderly, food hampers and grants for orphans and vulnerable children, was insufficient. Social support from the community and family members, volunteers, local churches, local and international non governmental organisations was not adequate to meet the requirements of the elderly caregivers. Often the assistance did not reach them.

## 4.4 CONCLUSION

Based on Tronto's ethics of care (1993: 105), the elderly caregivers functioned under circumstances of crisis which limited their willingness to 'care about'. They lacked the resources to mobilise whilst 'taking care' of the children, although they were in a position to give the care since they were interconnected with the children. The needy, dependent and functionally inadequate children were ready to receive care.

Although the elderly caregivers were attentive and responsible in caring for the children, their competency and responsiveness were negatively affected by the context in which they were providing the care, which was a state of little power, a lack of privilege and inadequacy.

The mind map depicts the experiences, the challenges they faced, the coping strategies and the support systems available to the elderly caregivers. This serves to summarise the findings of the study as well as reveal areas for intervention strategies.

In the next chapter, the summary of the findings, the conclusions drawn by the researcher, the limitations of the study and recommendations are presented.

# CHAPTER 5

# SUMMARY OF FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

## 5.1 INTRODUCTION

This chapter summarises the study, discusses the findings, outlines the limitations and makes recommendations according to the research findings.

## 5.2 SUMMARY OF THE STUDY

The study was an exploratory, descriptive and contextual qualitative one, based on a phenomenological approach. Its purpose was to describe the experiences of elderly caregivers in looking after HIV positive orphans on antiretroviral treatment in Swaziland. The researcher interviewed 12 elderly caregivers, purposively selected at the Mbabane government hospital antiretroviral clinic. The interviews were conducted in isiSwati, captured by a digital voice recorder, transcribed, translated into English and analysed. Categories and themes that emerged from the data were used to describe the phenomenon being investigated.

The objectives of the study were as follows:

- To explore the experiences of the elderly caregivers in terms of how they are taking care of HIV positive orphans on antiretroviral treatment in Swaziland.
- To describe the challenges being faced by the elderly caregivers of orphans on antiretroviral treatment.
- To describe the coping strategies being employed by the elderly looking after the orphans.

- To establish support systems and the level of support being rendered to, or the lack thereof, the elderly caring for HIV positive orphans on antiretroviral treatment in Swaziland.

## 5.3 FINDINGS

Five categories emerged from the data with themes and sub themes emerging under the categories. The findings were discussed under the five categories that emerged from the data, namely:

Category 1 Experiences in caring before initiation of antiretroviral treatment
Category 2 Experiences in caring after initiation of antiretroviral treatment
Category 3 Challenges experienced during the caring process
Category 4 Coping strategies
Category 5 Support systems

### 5.3.1 Experiences in caring before initiation of antiretroviral treatment

The findings of the study revealed that the elderly caregivers took over the care of very young HIV positive orphans mainly out of compulsion to intervene in a crisis situation so as to avert a catastrophe since the children's parents were dead and there was no one to look after them. Most times children acquire HIV infection vertically from the mother so that without any intervention, they become ill during the early stages of life. If they happen to lose their parents at that stage, their grandparents normally take over their care.

The participants reported that the HIV positive orphans were initially very sick, requiring a great deal of attention, thus exerting a heavy burden on the elderly caregivers and interrupting their normal social functioning. The elderly caregivers were not sure of what was wrong with the children until they were eventually tested and consequently started antiretroviral treatment.

These findings imply that the elderly people were the main providers of holistic care to the orphans which, according to Tronto's ethics of care framework (1993:105), involves 'caring about', 'taking care of', 'care giving' and 'care receiving'. 'Caring about' involves the nominal willingness to care (Tronto 1993:105). This willingness appeared to be lacking.

The sick children were chronically unwell, expressing neediness, dependency and functional inadequacy which, according to Tronto's ethics of care framework (1993:105), are elements of the care receiving component of holistic care. This meant that the children were in great need of care and the responsibility fell on the shoulders of the elderly people. They were required to be attentive and responsive to the needs of the children although they were facing many challenges with no significant support from anywhere.

### 5.3.2 Experiences in caring after the initiation of antiretroviral treatment

The turning point in the lives of both the elderly caregivers and the sick children occurred when antiretroviral treatment was initiated. The intervention brought a new set of experiences. The participants reported a marked improvement in the health status of the children as well as a considerable increase in appetite which alleviated suffering, and lifted the burden of caring from the caregivers, emotionally, physically and financially. The children were more functionally adequate, more independent and required less attention, meaning a reduced need for 'care receiving', which enabled the elderly caregivers to concentrate on other activities such as income generation and acquiring resources for 'caring about'. According to Tronto's ethics of care framework (1993), caring about involves the mobilisation of resources as the caregiver interacts with the care receiver.

The introduction of antiretroviral treatment exerted such a huge impact on the lives of the caregivers that they were very grateful, although it was accompanied by the extra responsibility of daily administration of medication and close monitoring to ensure adherence. The elderly were not experiencing any difficulties with the medication while the older children were actually

assisting in taking their medication, which raises the importance of involving the children in their treatment. The children did not experience many side effects which could have compromised adherence.

The findings imply that involving the children in the antiretroviral treatment and care plan shifts the responsibility of ensuring adherence to medication from falling entirely on the shoulders of the caregiver. This improves adherence and the success of the intervention. According to Brown, Lourie and Pao (2000:81), adherence to antiretroviral treatment in children also increases if the general context of caring for a child with HIV improves. This context involves the level of household income, social and family support as well as that of the healthcare provider. The participants were not experiencing any difficulties in administering the medication because they were receiving education and support from the healthcare providers, although support from the community and family members was not adequate.

### 5.3.3 Challenges experienced during the caring process

It also emerged from the study that the caring capacity of the elderly people was compromised by the challenges they endured on a daily basis without much support and employing ineffective coping strategies. The elderly were faced with a situation whereby they often cared for more than one child on antiretroviral treatment, which was demanding. Some were also looking after other adult members of the family who were either sick or too old to care for themselves. Due to the huge demand for their care, the elderly carried a huge responsibility which had a negative bearing on their attentiveness and responsiveness to the needs of the children, consequently compromising their competency as care providers.

Poverty was a major problem in the elderly headed households, resulting in a lack of basic necessities. The elderly were economically inactive and were unable to engage in any gainful income generating activities while the sickness in the family drove them deep into poverty (Foster et al, 2005). This shows that the elderly were giving care in a context of reduced power,

underprivilege and inadequacy with few resources at their disposal for mobilisation to provide holistic care (Tronto 1993:105).These research findings also have important implications in as far as development and the Millennium Development Goals (MDGs) are concerned. The MDGs commit the world to eradicate extreme poverty and hunger; hence, targeting these impoverished elderly people could go a long way toward achieving that goal.

Food insecurity was also reported as a challenge, resulting in lack of sufficient and nutritionally adequate food necessary for the quick recovery of the sick children. Assisting the elderly to boost their household food security would enable them to possess the resources, as they interact with the sick children in their caring relationship, to improve their nutritional status and their response to the antiretroviral treatment, thereby reducing child mortality due to opportunistic infections and illnesses related to malnutrition. Specific targeting of elderly people with support and information on nutrition could greatly help to reduce infant and child mortality, which is the aim of MDG 4. Nutrition is important in HIV positive children; therefore the elderly need support to meet the nutritional demands of the sick children, which has a major bearing on their response to medication and survival.

The findings of the study also revealed that efforts by the elderly caregivers to ensure that the children receive their medication were frustrated by the poor road network in Swaziland, lack of money for transport, as well as the fact that only a few centres offer paediatric antiretroviral treatment. There were long queues at the clinics, resulting in lengthy waiting times. Shortages of drugs for opportunistic infections and malfunctioning equipment for investigations were also cited as major problems experienced by the caregivers at the clinics. The travelling and the queuing presented a burden to these elderly people considering their old age, physical frailty and chronic ill health.

The elderly caregivers were living in persistent fear of being infected with the virus since they were exposing themselves to bodily fluids due to lack of protective clothing, such as gloves. The caregiving role was also very stressful due to its demands and the fact that there was no support and

assistance at their disposal. The stress they experienced resulted in an aggravation of their chronic ill health. This was also made worse by social isolation, abuse from their husbands and fear of stigma and discrimination. These findings actually imply that the elderly caregivers are really strained psychologically while psychological support is in fact lacking, thus leading to burnout.

The challenges faced by the elderly caregivers negatively affect their responsibility and competency as care providers as they try to fulfill the duty of caregiving as a social and moral practice, reiterating what Bozalek, Henderson, Lambert, Collins and Green (2007:31) found in their study in the Western Cape, South Africa.

### 5.3.4 Coping strategies

The elderly caregivers faced many challenges as they rendered their caregiving duties, mainly owing to poverty. They attempted to engage in buying and selling to boost the income of the family. Although this occurred on a small scale they realised some money for transport and necessities. Some supplemented their income by borrowing from money lenders, friends and relatives; however, they faced problems when it was time to pay back the loans. Some took up part time employment to earn a living.

The findings revealed that there was no time for rest for the elderly caregivers in contrast to the social norm that retirement should be enjoyed as one advances in age. The elderly carried a huge concern which required them to be economically active. They were engaging in all sorts of strenuous activities to cope with the harsh economic situation prevailing in their households.

Food insecurity was a major problem among the households headed by the elderly: as a way of improving this status they were obliged to conduct small scale farming in the form of gardening and backyard orchards. They were producing sufficient for domestic consumption as well as a little surplus for sale. The major problems were the lack of labour, implements and fertilisers

with their caring duties taking up much of their time. Often, no assistance was available since the children were young and other family members and community members were concentrating on their own concerns. All these compromised the production of food.

The elderly caregivers, who were mainly women, needed economic empowerment to boost the income generating activities as well as their agricultural activities. Most societies normally concentrate on the young, offering them economic support in terms of loans and education while neglecting the elderly. HIV has altered this scenario to such an extent that the neglected elderly should be the major target for support and empowerment.

### 5.3.5 Support systems

The elderly caregivers needed much support in the form of meeting their basic needs and those of the orphans under their care. There was a great need for financial support since there was not enough forthcoming from the government, non-governmental organisations, faith based organisations, the community and the extended family. The elderly were fighting a lone battle even though they were playing a very essential humanitarian role.

The government was not doing enough for the elderly and there was lack of dissemination of information regarding aid organisations, so much so that the deserving people like the elderly were being left out when aid was distributed. The elderly were even afraid to ask for help, even from their neighbours. Where aid was available there was a great deal of corruption and nepotism. Some elderly people actually considered it best to suffer in silence on their own than waste time begging for assistance.

The elderly people were at the centre of the survival of the sick orphans and if supported with sufficient resources from the government and aid organisations and the community, they could be mobilised and play a very crucial role in meeting the MDG of reducing child mortality.

## 5.4 LIMITATIONS OF THE STUDY

One of the limitations of the study was that the sample of participants was selected by means of purposive sampling, resulting in a sample comprising mainly female caregivers from the vicinity of Mbabane. The sample did not represent the caregivers of the whole country, so that the results cannot be generalised. However, it is worth noting that a small sample was a convenient way of conducting the study, considering the type of the research and the costs entailed for a larger sample.

Furthermore, under-reporting or over-reporting might have occurred as a result of the sensitive nature of HIV and AIDS.

## 5.5 RECOMMENDATIONS

This study recommends the following as part of the paediatric antiretroviral treatment programme in Swaziland:

**Paediatric antiretroviral treatment programme**

- Older people should be provided with information and training on HIV/AIDS as well as paediatric antiretroviral treatment through appropriate media to ensure an increase in the caring capacity of the elderly people to alleviate suffering among the children concerned.
- The paediatric antiretroviral treatment programme should be decentralised so that that there would be more treatment centres closer to where the elderly live in the rural areas.
- A constant supply of drugs for opportunistic infections should be ensured while also ensuring that equipment at the health facilities is functional at all times.

**Caregiver support**

- The elderly looking after HIV positive orphans on antiretroviral treatment need to be given specific attention with regards to policy and programme interventions.
- Policy and programmes designed to meet the needs of families affected by HIV/AIDS include older people and orphans.
- Aid organisations and the Government should provide direct income support to address the financial needs of the elderly caregivers of orphans on antiretroviral treatment through the development and expansion of social protection mechanisms, such as foster-care and child support grants for the orphans on antiretroviral treatment. There is a need to ensure that the elderly have access to credit schemes and appropriate training to ensure the viability of small businesses. These efforts will greatly help in lifting them out of extreme poverty.
- Assistance and support should be consistent and adequate, concentrating more on strengthening the caring capacity of the elderly to protect and care for the children by the provision of economic, material and psychological support and the development of life skills of children and carers.

- From the findings of this study, it is evident that the elderly caring for HIV positive orphans should be targeted in order to escape the abject poverty in which they currently live. HelpAge International (2005) argued that the MDGs specifically target children and youth but are silent on issues of age, ethnicity and disability, thus resulting in the elderly being an invisible group unlikely to benefit from efforts to eradicate poverty. Elderly people can actually be effective agents of change and contribute to the aims and aspirations of the MDGs through their caring roles and the contributions they make to the household and national economy.

**Further research**

- A relatively larger sample size including male caregivers should be used in future studies covering a wider geographical area with respect to this group of emerging caregivers, especially since it is enlarging each day.
- A qualitative study could be conducted to explore the psychological impacts of caring for the said orphans on the wellbeing of elderly caregivers.

## 5.6 CONCLUSION

The researcher was able to meet the objectives of the study by establishing that the elderly were the main caregivers of children on antiretroviral treatment whose parents were dead. They were doing so under compulsion with very little support from the government, the community and other organisations. Their caregiving capacity was compromised by many challenges. They were employing a number of coping strategies to counteract the difficulties they were facing.

The researcher concluded that the elderly are vital in ensuring the success of the paediatric antiretroviral treatment programme, but only if they afforded enough support and empowerment.

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# ANNEXURES

## ANNEXURE A: APPROVAL FROM THE UNIVERSITY

**UNIVERSITY OF SOUTH AFRICA**
**Health Studies Research & Ethics Committee**
**(HSREC)**
**College of Human Sciences**

**CLEARANCE CERTIFICATE**

Date: 29 September **2009** Project No: **3601 654 3**

Project Title: **EXPERIENCES OF ELDERLY PEOPLE CARING FOR HUMAN-IMMUNO DEFICIENCY VIRUS POSITIVE ORPHANS ON ANTIRETROVIRAL TREATEMENT IN SWAZILAND**

Researcher: **Kevin Makadzange**

Supervisor/Promoter: **Dr BL Dolamo**

Joint Supervisor/Joint Promoter:

Department: **Health Studies**

Degree: **MPH**

**DECISION OF COMMITTEE**

**Approved** [√] **Conditionally Approved** [ ]

Date: 29 **September 2009**

**Prof VJ EHLERS**
**RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**

**Dr BL Dolamo: SUPERVISOR**

## ANNEXURE B: APPROVAL LETTER FROM SWAZILAND ETHICS COMMITTEE.

*Telegrams:*
*Telex:*
*Telephone: (+268 404 2431)*
*Fax: (+268 404 2092*

***MINISTRY OF HEALTH***
***&***
*SOCIAL WELFARE*
*P.O. BOX 5*
*MBABANE*
*SWAZILAND*

**THE KINGDOM OF SWAZILAND**

**TO:** Mr Kevin Makadzange
UNISA

**DATE:** 19th October, 2009

**REF:** MH /701

**RE: EXPERIENCES OF ELDERLY PEOPLE CARING FOR HIV POSITIVE ORPHANS ON ART IN SWAZILAND**

The Scientific and Ethics committee would like to appreciate your response to the comments raised in our last meeting.

In view of the fact that you have addressed all the issues that were of concern to the committee and you have approval from the ART coordinator of Mbabane Government hospital, you are therefore granted authority to conduct the study.

You are kindly requested to adhere to the processes outlined in the protocol and if there are any changes, you are advised to notify the chairman of the committee before you effect any changes.

The committee is looking forward to the findings of the study to inform decision making in this area.

**DR S.V MAGAGULA**
**CHAIRMAN OF SEC**

DIRECTOR OF HEALTH SERVICES
MINISTRY OF HEALTH & SOCIAL WELFARE
P.O. BOX 5
2009 -10- 19
MBABANE
SWAZILAND

## ANNEXURE C: PERMISSION LETTER TO CONDUCT STUDY AT MBABANE GOVERNMENT HOSPITAL

*Telephone: (+268 404 2431)*
*Fax: (+268 404 2092*

*MINISTRY OF HEALTH*
*P.O. BOX 5*
*MBABANE*
*SWAZILAND*

**THE KINGDOM OF SWAZILAND**

07 October 2009

To: ART Site Co-ordinator, S.M.O.
Mbabane Government Hospital

RE: PERMISSION TO CONDUCT RESEARCH PROJECT

This letter serves to inform you that Dr Kevin Makadzange, who is a final year Masters of Public Health student at the University of South Africa, has been granted permission to carry out a research project at Mbabane Government hospital ART clinic. He will be conducting a study on **"The experiences of elderly people caring for HIV positive orphans on antiretroviral treatment"**. He is going to identify the elderly people at the clinic and carry out interviews at the clinic and at their homes.

The study will provide valuable information on how aid organisations and the Government can meet the specific needs of the elderly people caring for these orphans. The findings from this research will also contribute towards meaningful changes in policy development and programme designs aimed at guiding and facilitating the implementation of an effective national paediatric antiretroviral treatment programme.

Any assistance rendered to him will be highly appreciated.

Yours faithfully

MINISTRY OF HEALTH
12 OCT 2009

**DR. VELEPHI OKELLO**
National ART Co-ordinator

**ANNEXURE D: INTERVIEW QUESTION ROUTE (English and isiSwati versions)**

**Experiences of elderly people caring for Human immunodeficiency Virus positive orphans on antiretroviral treatment in Swaziland**

**Interview: Informed consent agreement**

Good morning/afternoon. I want to thank you for taking time to meet with me today. My name is..... from the University of South Africa. We are conducting interviews with elderly people caring for HIV positive orphans on antiretroviral treatment about their experiences as they look after these children. The significance of the study is to gather information that will be useful for aid organisations and the government to focus their activities on how to meet the needs of elderly people caring for these orphans specifically. The findings from this research will contribute towards meaningful changes in policy development and programme designs aimed at guiding and facilitating the implementation of an effective national paediatric antiretroviral treatment programme.

I would like your permission to talk with you today about your ideas and experiences related to caring for these children. It is up to you if you wish to answer any or all of my questions. You may end our discussion at any time. Everything you say will be kept private and confidential. To ensure I have a complete record of everything you say, I would like to tape record our conversation. But do not worry, only the researcher will listen to the tape and no one will be able to identify you. Similarly your name will not be used in any research findings.

If you agree to participate in this interview, please sign this page. If you do not wish to participate thank you for your time.

Signature .....

Date .....

| Question | Instructions |
|---|---|
| **INTRODUCTION**<br>First I would like to ask you a few questions about yourself | |
| 1. How old were you on your last birthday? | |
| 2. What level of education did you complete? | *Probe for primary, secondary, or tertiary and grade/form.* |
| 3. What is your religion? | *Probe for traditional, Christian or none.* |
| 4. Where do you live? | *Probe for town and suburb, village only*. |
| 5. Who do you live with? | |
| 6. Do you have any children? If yes how many sons and daughters do you have? | *Probe for relationship with children, whether supportive.* |
| 7. Are you currently married? If yes how long have you been married? | |
| | |
| **THEMATIC AREA 1: GENERAL EXPERIENCE IN CARING** | |
| Could you tell me about your experiences in caring for orphans? | *Probe for causes for caring for orphan, relationship with child, competency*. |
| **THEMATIC AREA 2: CHALLENGES**<br><br>What are the challenges you are facing as you look after the child/children since treatment was initiated? | *Probe for financial constraints, dietary requirements, administering medication, psychological support for child*. |
| **THEMATIC 3: COPING STRATEGIES**<br><br>Can you elaborate on the strategies you are employing to cope with these challenges? | *Probe for ways of improving competency.* |
| **THEMATIC 4; SUPPORT SYSTEMS** | *Probe for assistance in cash or kind (NGO,* |

| | |
|---|---|
| What is your source of support for looking after these orphans? | *Government, Community, relatives, other organisations).* |
| **RECOMMENDATIONS**<br>If it happens that help comes your way what areas would you need assistance and in what way?<br><br>What are your views in terms of the antiretroviral treatment programme? Is it helpful? In what sense?<br><br>What are your recommendations? | |
| **CONCLUSION**<br>Thank you for sharing your thoughts and experiences with me. How did you feel during the conversation? What did you expect before we started? | |

## INTERVIEW QUESTION ROUTE (isiSwati version)

Sawubona. Ngitsandza kubonga ngesikhatsi sakho lositsetse, washiya umsebenti wakho ekhaya kute utewuhlangana nami lamuhla. Ligama lami ngingu..... ngisuka kulelinye lemakolishi ekufundzela eningizimu ne Africa. Site lapha ngelucwaningo lesilwenta kubantfu labadzala, bogogo nabomkhulu labahlala netintsandzane letineligciwane lembulalave, ngalebakwatiko nalesebakubonile mayelana nalamaphilisi ekudzindzibalisa ligciwane labawasebentisa nabasanakelela bona bantfwana emakhaya. Bumcokwa balolucwaningo kutsi kucokelelwe lwati lotawu setjentiswa kusita tinhlangano naHulumende ekusiteni bantfu labadzala ngetidzingeko labahlangana nato basanakelela bantfwana labatintsandzane. Lesitakutfola kulelicwaningo kutawusita ekutfutfukiseni tinhlelo noma tindlela letisetjetiswako ekubuketeni kusetjentiswa kwalamaphilisi ekudzindzibalisa ligciwane lembulalave esiveni kubantfwana.

Ngicela imvumo yekukhuluma nawe kulelilanga lanamuhla mayelana nemibono nelwati lwakho loluphetselene nekunakekela labantfwana. Kusemvumeni yakho kutsi uyafuna kuphendvula lemibuto lengitakubuta yona nome chake. Usenekuyimisa lenkulumo yetfu nome nini nawufuna. Konkhe lotakukhuluma sisacocisana kutawuba yimfihlo. Kubanesiciniseko kutsi konkhe lokushoko kuyagcineka, ngingatsandza kwenta lilekhodi lalenkhulumo yetfu. Ungakhatsateki lelilekhodi lilalelwa bacwaningi kuphela futsi ngeke kwateke kutsi ngubani lokhulumako. Futsi ligama lakho ngeke lisentjetiswe kulolucwaningo.

Uma uvuma kutsi sichubeke nalolucwaningo,ngicela usayine lapha. Uma ungafisi, ngiyabonga sikhati sakho longinikete sona.

Signature .....

Date .....

| Imibuto | Indlela yokwenta |
|---|---|
| **SINGENISO**<br>Kwekucala, ngingatsandza kukubuta imibuto lephatselene nawe. | |
| 1. Ngelusuku lwakho lwekutalwa lelutsandza<br>kwengca wawuhlanganisa iminyaka lenganani? | |
| 2. Esikolweni ufundze wagcinaphi? | *Ngabe igcine esikolweni lesincane nobe lesikhulu nobe ekolishi lekufudzi.* |
| 3. Ukholwa kuphi? | *Ukholwa Nkulunkulu nobe inkholelo yesiSwati.* |
| 4. Uhlala kuphi ? | *Uhlala edolobheni noma emakhaya.* |
| 5. Uhlala nabani ? | |
| 6. Unabo yini banftwana? Nawunabo,<br>nginikete inombolo/sibalo sebafana neman-<br>tfombatane? | *Nangabe unabo bantfwana bayakusita yini lakhaya.* |
| 7. Ushadile yini ? Sekuphele iminyaka<br>Lenganani ushadile? | |
| **<u>THEMATIC AREA 1: LWATI LONALO NGEKUNAKELELA</u>**<br><br>Ngicela ungitjele kabanti ngelwati lonalo ngekukhulisa uphindze unakekele tintsandzane? | *Kwentiwe yini kutsi kube nguwe lohlala nabantfwana, uyakhona yini kuhlala nabo, fitsi niyakhona yini kuphilisana nebantfwana.* |
| **<u>THEMATIC AREA 2: TINKINGA</u>**<br><br>Yini tinkinga lobhekane nato usakhulisa labanftwana kusukela kwacala loluhlelo | *Ngabe tinkinga tetimali, nobe tekudla, nobe tinkinga ngemaphilisi* |

| | |
|---|---|
| lokusebenta lamaphilisi? | *kulomntfwana, ngabe unato tinkinga yini umntfwana asakhulanje emphilweni.* |
| **<u>THEMATIC AREA 3: UNCOBA KANJANI</u>**<br>Ngicela ungichazele kabanti ngetindlela lotisebentisako kute uncobe letinkinga lobhekene nato. | *Ngabe yini tindlela tenhlala kahle.* |
| **<u>THEMATIC AREA 4: TINDLELA TELUSITO</u>**<br><br>Ingabe ulitfola kuphi lusito lekunakekela labantfwana? | *Ngabe lolusito ulitfola kuHulumende, etihlobeni, emumangweni nobe etinhlanganwemi.* |
| **<u>TINCOMO</u>**<br><br>Uma ungaba nelusito lolubakhona, ungaludzinga ngakutiphi tinhlangotsi futsi ngayiphi indlela?<br><br>Ingabe yini longayisho mayelana nalamaphilisi ekudzindzibalisa ligciwane, ngabe ayasita yini? Futsi asita ngayiphi indlela?<br><br>Itsini imibono yakho? | |
| **<u>SIPHETFO</u>**<br><br>Ngiyabonga kococisana nawe ngalokucabanga ko nalokubonile. Uve kunjani sisacocisana? Bewugadzeni | |

| | |
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| sisengakakhulumisani? | |

## ANNEXURE E – EXAMPLE OF A SEMI-STRUCTURED INTERVIEW ON ELDERLY LIVING WITH HIV POSITIVE ORPHANS

### PARTICIPANT E

**Introduction**

**I: We are doing a survey on orphans who are living with HIV; we are doing this so that we may be able to help the government and other non governmental organizations about means to help the young children. We are going to talk and everything we will talk about will be recorded.**

E: There is no problem.

**I: There are no names to be said, your name will not appear and when you want to stop the interview there is no problem with that too; you can say you are not able to go on with the interview. We will first talk about you; firstly I would like to know how old are you?**

E: I am sixty two years old.

**I: How far did you go with your education?**

E: I passed standard five.

**I: Where do you go to church?**

E: I go to Anglican sometimes called Sheshi.

**I: Is it a traditional or modern church?**

E: It is one of the old churches.

**I: Where do you stay?**

E: I stay at Siphocosini.

**I: Who do you stay with there?**

E: I stay with my grandchildren, my husband died.

**I: You stay with your grandchildren, what about your own children?**

E: No the only one I had was born in 1978 and they died.

**I: How many grandchildren do you stay with?**

E: They are four.

**I: Any girls or...**

E: There are no girls at home it's only boys.

**I: Were you married?**

E: Yes.

**I: How long have you been married?**

E: From 1966.

**I: From 1966, now can you tell me how life is as you are taking care of the child?**

E: It is very difficult because the life sometimes is not good because one should always have money and the food has to be different from the others. We try to cultivate some crops but some of them aren't good for them and you find that you can't afford other things.

**I: You said life is not good, do you mean at home or to the child?**

E: Especially to the children because they are not the same as mine, those did not have a problem because they would even eat vegetables and these want nice things and that becomes a problem.

**I: How is your relationship with the child?**

E: This one, I think she is much better than mine because we get along very well. She is so good and I don't have a problem with her because I have been raising her even when her mother was still alive, she could not take care of her. I have been the one who took care of her up until she took the medication.

**I: Her mother died, what about her father?**

E: He is also trying because he is also taking the medication.

**I: does he work?**

E: He does sometimes he stops because he is also not very healthy.

**I: When he has been able to go to work does he help with the child?**

E: Yes he does because he has been paying her school fees. This year she is going for second grade, she has been delayed because she has not been well.

**I: What are the challenges that you come across while still taking care of the child?**

E: The main problem is that I sometimes don't have money to take her to hospital when she is sick. Sometime I cannot take her where she is supposed to go because I am not working, that is the problem I have.

**I: What do you normally do when you don't have the money?**

E: I sometime sell a chicken so that I get the money to take her to hospital.

**I: What other things do you do in order to keep the child healthy?**

E: I make mats to sell so that I always have the money and take her to hospital when there is a need because they can get sick anytime; you just put your hope on the pills alone because they can just have a headache and sometimes she can bleed through the nose so you have to take her to hospital anytime.

**I: Do the other sicknesses come at a time when you don't have the...**

E: The money, no it has never happened I don't want to lie to you.

**I: It comes at a time when you have the money?**

E: Yes and I am able to come to the hospital with her and after treatment we go back home and her father usually comes.

**I: When you get to the hospital what do the doctors do or say?**

E: They treat her and this is where we normally start because she used to stay at her mother's home when she started to get sick, I sometimes brought her to hospital when she started staying with me and she was admitted and when she was discharged they said she should start taking the medication.

**I: She has been admitted?**

E: Yes.

**I: How long?**

E: Two weeks and when she was discharged she started with the medication and after that she would be sickly and I would bring her here or take her to Sigangeni clinic and at the clinic they refer her here all the time and ever since she has never been admitted I go home with her all the time. It has since been better.

**I: How does she get sick?**

E: She sometimes has a headache and she would be hot all over the body and bleed through the nose or sometimes it's stomach ache.

**I: Do they help her here?**

E: They help her so much because they give her pills.

**I: Does she get the nutrition she needs?**

E: That is something she does not get that well but her father also helps out with that because she has to get everything such as eggs but when that gets finished then I cannot give her more.

**I: You said you make mats to have money; do you have a sufficient market for that?**

E: My market is small because what kills me is that I have to go to the mountains to get the grass to make them and that is so strenuous and at home I am alone and I have to look after cattle and most of the time I am not able to do that.

**I: You can't go to the mountain?**

E: Yes I can't and now that she goes to school she has to find me when she gets back home.

**I: Does she take the medication on time, don't you sometimes forget to give it to her?**

E: It happens because sometimes when they go to town and come back late but in the morning I give her and she also know her time to take the medication.

**I: When she has not taken the medication what do you do?**

E: I don't just sit around, when they leave town at 6:30pm which is the time she has to take it, when she gets home I give her because she would have eaten something in town. I don't let her sleep without taking it; I don't think it would be right.

**I: Doesn't that give problems because they usually say she should not be late to take the medication?**

E: There has never been any problem maybe it's because she never exceeds an hour without the medication.

**I: So you can say it does not have to be a long time not having taken the medication?**

E: Yes, I can't give her when she gets home at 9pm they will be followed closely by the morning medication. That is what I think.

**I: Don't you sometimes get worried as to what to do?**

E: It happens that I don't know what to do especially in the evening it happens that at 6:30pm the food is not ready but since we are given food packs here she prepares that and then takes the medication, I am going to get her food when I finish.

**I: What do you do in order to provide the right food for the child?**

E: I stand up and sometimes I call her father's older brother who lives in Matsapha and he helps us out.

**I: Doesn't he also tell you his problems?**

E: He does but he gives us what we ask for or sometimes gives us money until we are able to do something for ourselves, they have never gone to sleep on an empty stomach although it happens that we don't have anything but they never go to sleep on empty stomachs and even for a day to go by it does not happen as I said that I sell a chicken and we get something to keep us going for a while.

**I: Does the one who helps you bring food or money?**

E: He brings food and money to take care of the others when they are sick.

**I: What means do you use to keep the child healthy?**

E: There are many things because I am old I am able to get the little I can and because I am a community health worker when I get paid the situation becomes better and I am able to do something with the E200 I get even if I don't get the elderly grant it's not that much of a problem. Milk and sour milk must always be there so that her situation does not get bad.

**I: How often do you get the E200 you are talking about?**

E: At the end of each month.

**I: Is it the grant for the elderly?**

E: No, it's for being a community health worker.

**I: What about the grant?**

E: I also get that and it's far better because there is something that keeps me busy.

**I: Are there any organizations that help to take care of the child, which would provide with food?**

E: They do give us but it has been sometime now because they last gave us last year at eSigangeni Inkhundla.

**I: They last gave you last year?**

E: Yes at the beginning of the year now we don't have anything.

**I: Before that what did they do? Did it take time for them to give you?**

E: Yes it takes time, when they did it last year there was Hospice at Home and one of the King's wives after that there was nothing.

**I: Does the government ever help you with anything?**

E: Aw nothing, there is nothing that the government helps us with, there was a request by those who are sick that they should be given money at the end of each month so that they would be able to get transport to get to hospital but that has not happened up to now.

**I: What was the response from government when you asked for that?**

E: They said they will see because it was those that are infected that said they don't have money, even if they want to go to hospital. Instead of giving them the money they took the VCT closer to them because they were complaining about travelling (laughs) they took the VCT to Sigangeni but when I took my little girl there they said I should bring her here at hospital because it's the doctors that usually see her.

**I: Does anybody ever help you in your community?**

E: Nobody, there is just nobody nothing happens I can say NERCHA sometimes brings fertilizer and seeds and they are doing that for orphans but not HIV positive orphans.

**I: Does it happen that you ask for help from your neighbor?**

E: I can't do that because I am afraid to ask from somebody; I am just afraid to ask. I can't; so it is hard to ask from my neighbour. I just try on my own to find something because you can never ask for anything from your neighbour when you are all the same. Are we done now?

**I: No we are not but it is going there. If there could be anybody who may want to help you how would you want help to come?**

E: With the kids?

**I: Yes**

E: There is nothing I don't need (inaudible) I also need the food; I need the food very much.

**I: You said NERCHA brings fertilizers...**

E: If they bring it this year just like now they gave me they will come again after maybe ten years because there are many homesteads, it goes to others you may get it again after ten years.

**I: What they usually give you, do you cultivate with it?**

E: Yes I do, even now I am from the fields I am going back in the afternoon I cannot play with it.

**I: Has the pills helped her when you look at the way she is now?**

E: They have helped her so much and if those that stayed with her could see her they would be shocked. They have helped her so much.

**I: How if you can explain a bit more?**

E: The situation is not the same as before when she used to be on and off, now she even eats well and she plays so freely. There are many things that I see in her.

**I: What would you want to say about taking care of the children, anything that comes from your heart?**

E: Must I talk about government or what you should do as a mother to take care of the child?

**I: You can talk about government or as a mother.**

E: I am not happy about government because her father is not able to provide and sometimes it is a burden to him because as an orphan they want us to pay a lot of money or meet half way with school fees so how will you do that because her father is not in a condition to work so that he can pay at school. That is where the government should improve and about life it does not mean that now that they are sick it does not mean it is the end of life, life goes on just take the child to hospital to do blood tests, take care of them and feed them well and give them their medication but the bad part of it is that there is not the right food for them to eat.

**I: Thank you for talking to me, have a good day.**

## ANNEXURE F: REQUESTS FOR PERMISSION

University of South Africa
Department of Health Studies
P.O.Box 392
UNISA
0003

23 July 2009

Ministry of Health and Social Welfare
Government of Swaziland
Mbabane

Dear Sir/Madam

**Re: Permission to conduct a research project**.

I am an MPH student at UNISA. I am conducting a study on the experiences of elderly people caring for HIV positive orphans on antiretroviral treatment. The study will benefit aid organisations and the government to focus their activities on how to meet the needs of elderly people caring for these orphans specifically. The findings from this research will also contribute towards meaningful changes in policy development and programme designs aimed at guiding and facilitating the implementation of an effective national paediatric antiretroviral treatment programme.

I hereby request permission to conduct a research project in Swaziland in areas surrounding Mbabane between August and December 2009.The study is done in partial fulfillment of the requirements for the degree of Masters of Public Health at the University of South Africa. I intend to interview elderly people identified at Baylor Children's Hospital.

Anonymity and confidentiality will be ensured at all times and the findings will be communicated to you.

I will be grateful if you consider my request.

Yours faithfully

Kevin Makadzange
MPH student

University of South Africa
Department of Health Studies
P.O.Box 392
UNISA
0003

07 October 2009

The Co-ordinator
Swaziland National Antiretroviral Treatment programme
Mbabane

Dear Sir/Madam

**Re: Permission to conduct a research project.**

I hereby request permission to conduct a research project at Mbabane Government Hospital antiretroviral treatment clinic between November 2009 and January 2010.The study is done in partial fulfillment of the requirements for the degree of Masters of Public Health at the University of South Africa. The study is on the experiences of elderly people caring for HIV positive orphans on antiretroviral treatment. I intend to interview elderly people identified at the clinic with the help of the clinic medical staff.
Anonymity and confidentiality will be ensured at all times and the findings will be communicated to you.

I will be grateful if you consider my request.

Yours faithfully

Kevin Makadzange
MPH student