

**EXPERIENCES OF OLDER WOMEN CARING FOR HIV/AIDS AFFECTED
HOUSEHOLDS IN ATTERIDGEVILLE**

by

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I Kudzai Otilia Zheve student number 47091177 declare that ,***Experiences of older women caring for HIV/AIDS affected households in Atteridgeville*** 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.

SIGNATURE

(Ms)

DATE

Dedication

I dedicate this dissertation to my mother Mrs Priscilla Gladys Zheve, your words and love never failed me and to my dear sister Silence. May your soul rest in peace

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“For with God nothing is impossible”. I would like to extend my gratitude to the following persons:

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ABSTRACT

The aim of this qualitative study was to understand how older women experience their roles as care-givers to HIV/AIDS affected households in the Atteridgeville community and to identify specific problems they encounter. Twelve older women attending three elderly day care centres in Atteridgeville participated in the study. Purposive sampling was done and data was collected through two focus group interviews. Colaizzi's seven-step method of data analysis yielded the following four main themes: Caring for adult children with HIV/AIDS, Caring for HIV affected and infected grandchildren, Multiple role players involved in caring for HIV/AIDS persons, The impact on the lives of care-givers. Factors with a positive and negative impact on caring for HIV/AIDS households were identified. The study raises awareness for the need for social workers in Atteridgeville to intervene in assisting older women in their challenging role of caring for HIV/AIDS households.

KEY CONCEPTS:

Experiences, caring, Colaizzi seven step method, data analysis, older women, HIV and AIDS, households

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ABBREVIATIONS

AIDS	-	Acquired – Immune Deficiency Syndrome
ARV	-	Anti – Retro Viral
ART	-	Anti – Retro Therapy
HAART	-	Highly Active Anti – Retroviral Treatment
HIV	-	Human Immune Virus
KZN	-	Kwa-Zulu Natal
NGO	-	Non – Governmental Organisation
NSNP	-	National Schools Nutrition Programme
UN	-	United Nations
UNDP	-	United Nations Developmental Program
UNICEF	-	United Nations Children’s Fund
WHO	-	World Health Organisation

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

This chapter is an introduction to the dissertation of limited scope and gives a brief overview of each phase of the study. The chapter covers the source and background of the research problem, statement of the problem, aim and significance of the study definition of key concepts, the foundation, design and methodology and the layout of the research.

Human Immuno-deficiency Virus and Acquired Immuno-Deficiency Syndrome (HIV/AIDS) is one of the most serious and urgent global problems facing the world today. The HIV pandemic has a multifaceted impact on individuals, their households, families and communities. This multifaceted impact is felt directly by those who contract the disease and indirectly by those who are related or associated with them (Veenstra & Whiteside 2005:9). HIV impacts on older people in two basic ways; being infected and living with HIV and being affected, in the sense that they have to care for children living with HIV/AIDS or grandchildren orphaned by AIDS. In Eastern and Southern Africa, the care giving role is an issue of scale with 40-50 % of the estimated twelve million children orphaned by AIDS being cared for by an older person (Help Age International 2010). The deaths of prime age adults are likely to alter household composition and family structures and in particular the positioning of older persons in the households who have to provide care for orphaned children, (Tadele & Kloos 2013:123, Ostfeld, Keesing & Eviner 2008:297, Gosney, Harper & Conroy 2012:4).

Schatz, Madhavan and Williams (2011:598) state that nearly 50 % of households in South Africa are headed by women. In Atteridgeville, a community located west of Pretoria, a large number of older women who attend the Elderly Day Care Centres are caring for families affected by HIV/AIDS. This study examines the experiences of older women who care for their HIV/AIDS affected households.

1.2 BACKGROUND OF THE STUDY

The background of the study is derived from the increasing HIV/AIDS epidemic in South Africa and some research done previously on older women caring for HIV/AIDS affected households.

The increasing HIV/AIDS epidemic in South Africa poses a substantial burden on older people, in particular, women who mainly provide care for sick children and their grandchildren who have become orphaned and vulnerable by the death or illness of their parents. Previous research in South Africa has shown that older people live in extended family situation with their children, grandchildren and sometimes other dependents with an average of four dependents per caregiver (Boon, James, Ruiter, Van den Borne, Williams & Reddy 2009:19).

According to Schatz (2007:148), adult children are mostly unemployed, sick or have passed away leaving full care and responsibility of grandchildren in the hands of the older generation, especially older women. With little or no support, older caregivers endure emotional, physical, financial and social costs that arise from these circumstances.

Studies done in South Africa by the Medical Research Council (Ashton 2011:55 and Van Dyk 2008:45) show that older women caring for HIV/AIDS affected households depend, to a large extent, on their old age grants to care and provide for their families.

Atteridgeville is a community where older persons receive a government old age grant of R1 350 every month, which is announced yearly in the yearly budget. Many of these older women have a burden of caring for HIV/AIDS affected households and they are financially strained with the care giving role.

1.3 RESEARCH PROBLEM

The researcher is a social worker providing services to the elderly in Atteridgeville community, which includes three Elderly Day Care Centres. The older women attending the centres meet and interact with social workers and social auxiliary workers and get involved in age active programs from Monday to Friday from nine in

the morning to three in the afternoon. The older women receive three meals per day because the old age pension they receive every month is not enough to provide for them and their extended family. In South Africa older women of sixty years and above, who meet the criteria are eligible to receive a pension grant as stipulated in the Social Assistance Act (Act 14 of 2004), (South Africa 2004:5). Currently this amounts to R1 350 per month. They may also apply for foster care grants as stipulated in the Children's Act (Act 38 of 2005), (South Africa 2005:35) which currently amounts to R830 per month per child for their orphaned grandchildren so that they can be able to care for them. The pension and foster care grant is used to take care of their grandchildren and other extended family members, so the money is barely enough.

Social workers often witness the financial strain of older women in Atteridgeville. As confirmed by research done by Chant (2007), cited in Schatz, Madhavan and Williams (2011:598), the researcher also observed that the older persons, especially women, are emotionally strained as they sometimes do not engage in all the activities in the centres; they arrive late to collect food for their orphaned children and leave the centres early. Some of them open up and tell the social workers and social auxiliary workers that they are experiencing care giving problems.

This leads to the following research question:

What are the experiences of older women who care for HIV/AIDS affected households in Atteridgeville?

1.4 AIM OF THE STUDY

The aim of the study is to understand how older women experience their roles as caregivers to HIV/AIDS affected households in the Atteridgeville community and to identify specific problems they encounter.

1.4.1 Research purpose

The purpose of the study is to formulate recommendations that will assist social workers in Atteridgeville to support older women caring for HIV/AIDS affected households with their specific problems. This may strengthen community-based care

mechanisms in supporting older caregivers with their responsibilities in caring for HIV/AIDS affected households.

1.4.2 Research objectives

In order to answer the research question the objectives of the study were set:

- To explore the older women's experiences in caring for HIV/AIDS affected households.
- To identify factors that impact on older women caring for HIV/AIDS affected households.

1.5 SIGNIFICANCE OF THE STUDY

Research on the experiences of older women caring for their HIV/AIDS households has not been done, specifically in the Atteridgeville area. The information gained from this study will assist social workers in Atteridgeville to support older women who care for their adult children or grandchildren with HIV/AIDS and orphaned grandchildren with their specific problems.

Awareness of the findings will also be valuable to health practitioners, programme managers and coordinators managing HIV/AIDS to focus on older people and HIV/AIDS thereby assisting them with their roles and responsibilities as care-givers.

1.6 DEFINITION OF TERMS

This section gives theoretical and contextual definitions of the key terms used in the study.

1.6.1 Experiences

Wierzbicka (2010:31) defines experiences as an accumulated knowledge or current perception of a situation. In this study, the researcher sought to understand the experiences of older women caring for HIV/AIDS affected households.

1.6.2 Caring

Jasmine (2007:9) defines 'caring' as an act or behaviour that expresses and demonstrates empathy, love and support to another person. In this study older women care for, assist and support their HIV/AIDS affected household members according to their anticipated needs.

1.6.3 HIV affected households

HIV/AIDS - The Human Immunodeficiency Virus is an organism which causes AIDS (Acquired Immunodeficiency Syndrome). HIV is passed from a person to person through sexual contact, blood exposure, childbirth or breast feeding. When not treated, HIV infection causes progressive damage to the immune system, leading to AIDS.

Household refers to a basic residential unit where economic production, consumption, inheritance, child rearing and shelter are organised and carried out (Haviland, Prins, Walrath & McBride 2010:250).

In this study HIV affected household means a residential unit where an older woman lives and cares for adult children or grandchildren with HIV/AIDS or grandchildren orphaned because of AIDS.

1.6.4 Older women

According to the South African Older persons Act 13 of 2006 (South Africa 2006), an older person means a person who, in case of a male is sixty five years of age or older and in case of a females, is sixty years of age or older. In this study an older person refers to women of ages 60 and above.

1.6.5 Orphan

According to the Children's Act 38 of 2005 (South Africa 2005) an orphan means a child who has no parent caring for him or her. In this study an orphan is a child who lost one or both parents due to HIV/AIDS who is being taken care of by an older woman.

1.7 FOUNDATION OF THE STUDY

The philosophical base of the study is naturalistic, humanistic and interpretive. This means the researcher tries to understand the meanings of social interactions in their natural settings without an element of control (Burns & Grove 2010:34). According to Polit and Beck (2013:265), the naturalistic methods of inquiry deal with the issue of human complexity by exploring it directly. The researchers in naturalistic traditions emphasize the inherent depth of humans, their ability to shape and create their own experience and the idea that truth is a composite of realities.

The experiences of older women as they live in their homes caring for HIV/AIDS affected households will be explored and described as reported by the women themselves.

Through an inductive process, researchers integrate information to develop a theory or description that helps explicate the phenomena under observation. Inductive reasoning moves from the specific to the general. According to Moule and Goodman (2013:324), inductive reasoning is a process of starting with details of an experience, observations or something using these to develop a general understanding of a phenomenon.

The researcher will gather detailed and specific information from older women on caring for HIV/AIDS affected households to understand and describe the phenomenon in a more general sense.

1.8 RESEARCH DESIGN AND METHOD

A research design refers to the structured approach followed by researchers to answer a particular research question (Joubert & Ehrlich 2007:77). Following is a brief summary of the design and methodology followed in this study, with a detailed description in chapter 2.

The research design of this study is qualitative, explorative and descriptive in nature.

- It is qualitative as the research aimed for a deeper understanding of older women's experiences on caring for their children or grandchildren with

HIV/AIDS or grandchildren orphaned because of HIV/AIDS, especially by interpreting behaviour and verbal responses.

- It is exploratory as it aimed to explore the experiences of older women on their care giving responsibility for their HIV/AIDS affected households.
- It is descriptive as the researcher took into account the opinions of older women concerning their care giving experiences and described these experiences as shared by the participants.

1.8.1 Population

Burns and Grove (2010:342) define population as an entire set of individuals having some common interest. The population of this study consists of older women caring for HIV/AIDS affected households.

1.8.1.1 Target population

Moule and Goodman (2013:142) define target population as the total population that forms the focus for the study. In this study the target population was older women who are caring for HIV/AIDS affected households in the Atteridgeville community.

1.8.1.2 Accessible population

Grove, Burns and Gray (2013:352) defines accessible population as the portion of the target population to which the researchers have reasonable access. In this study the accessible population refers to older women, caring for HIV/AIDS affected households who attend the elderly day care centres in the Atteridgeville community. Refer to section 2.3.2.

1.8.2 Sampling

Sampling is the process of selecting a portion of the population to represent the entire population so that inferences about the population can be made (Polit & Beck 2013:283). A total number of seventy two older women attend the three Elderly Day Care Centres and twenty of them are caring for HIV/AIDS households. A sample of fifteen older women was selected to participate in the study from all three Elderly

Day Care Centres; five older women were selected from each Elderly Day Care Centre.

Purposeful selection of respondents was done because it allowed the researcher to select typical individuals from the spectrum in which they are interested (Joubert & Ehlich 2007:101). A non-probability sample reflected the target population through the careful use of inclusion and exclusion criteria as described in section 2.4.3.

1.8.3 Data collection

Data collection entails precise, systematic gathering of information relevant to the research purpose, research question and specific objectives of the study (Burns & Grove 2010:733). The researcher used focus group interviews to collect data from the participants, in order to meet the set objectives. One focus group interview was planned with representation of five older women from each of the three Elderly Day Care Centres. Eventually two focus group interviews were conducted. Data collection is described in section 2.5.

1.8.4 Data analysis

The purpose of data analysis is to organize, provide structure to and elicit meaning from research data. In qualitative studies, data collection and analysis usually occurs simultaneously (Polit & Beck, 2013:305). Data analysis includes identifying categories or themes of data, interpreting data, validating data and writing the qualitative report. A seven-step data analysis method by Colaizzi (1978), described in Polit and Beck (2013:315), was used by the researcher to analyse data. Refer to section 2.6.

1.8.5 Ethical considerations

Ethics is defined as a system of moral values, the study of the general nature of morals and the specific morals and choices to be made by a person. It sets rules and standards of governing the conduct of a person or the members of a profession (Joubert & Ehlich 2007:30). Clearance and consent to conduct the study was sought from the University, the management of Pretoria Care for the Aged and the individual participants.

The research participants remained anonymous; the principle of confidentiality was upheld.

1.8.6 Trustworthiness

According to Polit and Beck (2013:321), trustworthiness of qualitative research is the degree of confidence by researchers in their data collection and analysis. It is assessed using the criteria of credibility, transferability, dependability and confirmability. The researcher used different strategies to ensure that the study is credible, transferable, dependable and conformable. Refer to Table 2.1.

1.9 STRUCTURE OF THE DISSERTATION

CHAPTER 1 – Orientation to the study.

CHAPTER 2 – Research design and methodology.

CHAPTER 3 – Data analysis and literature control.

CHAPTER 4 – Discussion of findings, evaluation of the study and recommendations.

1.10 CONCLUSION

This chapter described the background of the research problem, presented the statement of the problem, purpose of study, research objectives and significance of the study. It also defined key concepts used in the study, provided an overview of the research methodology and the layout of the dissertation. Chapter two discusses the research design and methodology for the study in more detail.

CHAPTER 2

RESEARCH DESIGN AND METHODOLOGY

2.1 INTRODUCTION

This chapter outlines the research design and methodology used in the study. It includes a description of the participants, data gathering and data analysis. The chapter concludes with ethical considerations for the study.

The research question of this study was: *What are the experiences of older women who care for HIV/AIDS affected households in Atteridgeville?*

The objectives of this study were to explore the experiences of older women on caring for HIV/AIDS affected households and to identify the factors that impact on older women caring for HIV/AIDS affected households.

2.2 RESEARCH DESIGN AND METHODOLOGY

A research design refers to a structured approach followed by researchers to answer particular research questions. A research design specifies the questions to be studied, the data to be collected and the methods of data collection and analysis. The research design of this study is qualitative, explorative and descriptive in nature (Joubert & Ehrlich 2007:77, Shi 2008:460).

The researcher explored and described the experiences of older women caring for HIV/AIDS affected households by means of qualitative strategies.

2.2.1 Qualitative design

Creswell (1994), cited in Klenke (2008:7) defines qualitative research as being interpretive and naturalistic in nature. This means that qualitative research takes place in the natural setting, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. This study is qualitative as it focuses on the experiences of older women who care for HIV/AIDS affected households in their daily lives.

According to Polit and Beck (2013:265) and Moule and Goodman (2013:171), qualitative research is an investigation of a phenomenon, typically in an in-depth and holistic manner, through the collection of rich, narrative materials using a flexible research design. This study aims for a deeper holistic understanding of older women's emotional, financial and social experiences when caring for their HIV/AIDS affected households. Data collection was conducted through a focus group interview to record the behaviour and verbal responses of the women.

Qualitative research is characterised by inductive reasoning. Inductive reasoning is a process of starting with the observations and details of an experience followed by interpretations to develop a general understanding of a phenomenon (Moule & Goodman 2013:170). The specific information collected during the focus group interviews was interpreted to understand and describe the phenomenon of older women caring for their HIV/AIDS affected households.

2.2.2 Explorative design

Explorative designs are usually undertaken when relatively little is known about a phenomenon (Salkind 2010:1254). According to Grinnell and Unrau (2010:23), the goals of exploratory research are:

- To become familiar with the basic facts, people and concerns involved.
- To develop a well – grounded mental picture of what is occurring.
- To generate many ideas and develop tentative theories and conjectures.
- To determine the feasibility of doing additional research.
- To formulate questions and refine issues for more systematic inquiry.
- To develop techniques and a sense of direction for future research.

This study is exploratory as it explored the unique experiences of older women caring for HIV/AIDS affected households in Atteridgeville community to form a mental picture of the realities of such households and recommended further research in this field.

2.2.3 Descriptive design

A descriptive design attempts to describe a group of people, a phenomenon or event. It describes who is experiencing the problem, how widespread is the problem and how long the problem existed (Salkind 2010:1254). This study is descriptive as the researcher will take into account the verbalised experiences and non-verbal expressions of older women concerning their care giving responsibilities and describe these experiences, including their problems, as shared by the participants.

2.2.4 Methodology

Shi (2008:460) defines research method as the general approach of identifying the population, selecting the sample, data collection and analysis and the standards used for interpreting data and making reach conclusions.

In the following sections (2.3-2.7) the methods used to explore the experiences of older women caring for HIV/AIDS affected households are described in detail.

2.3 POPULATION

A population is an entire set of individuals having some common interest (Burns & Grove 2010:342, Mcnee & Mc Cabe 2008:118).The population of this study are older women caring for HIV/AIDS affected households.

2.3.1 Target population

The target population is a group from which the researcher wants to draw conclusions (Grinnell & Unrau 2010:576, Boswell & Cannon 2014:180). The population under study consists of older women caring for HIV/AIDS affected households in the Atteridgeville community.

2.3.2 Accessible population

The accessible population is that portion of the target population that the researcher can reasonably reach (Boswell & Cannon 2014:180). In this study the accessible population consists of older women who are caring for HIV/AIDS affected households attending any of the three Elderly Day Care Centres in Atteridgeville which report under a Non-Profit Organisation, which is, Pretoria Care for the Aged.

2.4 SAMPLING

Sampling is the process of selecting a portion of the population to represent the entire population. The selected elements are then referred to as the sample (Polit & Beck 2013:283).

2.4.1 The non-probability sampling

Grinnell and Unrau (2010:569) define non-probability sampling as sampling procedures in which all of the persons, events, or objects in the sampling frame have an unknown and usually different probability of being included in the sample. In this study the researcher made use of the non-probability sampling. Inclusion in the sample was determined by a set of inclusion criteria as well as the attendance of Elderly Day Care Centre on the days the researcher recruited participants. Older women who were not at the Day Care Centre were not considered for participation in this study and those who did not volunteer to participate were not included in the sample.

2.4.2 Purposeful sampling

According to Cottrell and Mc Kenzie (2010:133), purposive sampling, also known as judgemental sampling is a method in which researchers select participants that they perceive to be “typical” individuals possessing a given trait.

Purposive sampling actively seeks to obtain the data by including participants who have a particular type of experience, characteristic and understanding to share (Macnee & McCabe 2008:122). The participants of this study are all older women who care for HIV/AIDS affected households. Thus, the participants are particularly knowledgeable about the issue under study, and therefore purposefully chosen to participate in the study.

Five older women meeting the inclusion criteria were selected from each of the three Elderly Care Centres to make a total sample of fifteen older women for the study. On the day of the interview, only twelve older women came for the focus group interviews, thus the actual participants. No new participants were added in the process of the research.

2.4.3 Inclusion criteria

According to Holloway and Wheeler (2013:144), an inclusion criterion states that particular people are included in research while other participants are excluded. In this study the inclusion criteria were:

- Women older than 60 years.
- Caring for HIV/AIDS affected households.
- Attending any one of the 3 elderly day care centres in Atteridgeville.
- Who could speak Sotho and understand English.

Participants were selected from three Elderly Day Care Centres. The researcher clearly explained the study to all possible participants and gave them consent forms. The first five participants from each of the three Elderly Day Care Centres to return the consent forms to the researcher were selected for the study. Twelve participants attended the focus group interview. The other three participants could not attend the focus group interview due to personal reasons.

2.4.4 Ethical issues pertaining to sampling

Ethics are a critical element that runs through a research process. The researcher strived to make the selection of the study population fair; therefore, the risks and benefits could be fairly distributed (Burns & Grove 2010:189). The following were considered.

Voluntary Participation

Participation in the study was completely voluntary. According to Seidman (2012:50), voluntary participation means that participants are not coerced to participate in the study and they may at any time during the research, withdraw their participation. The researcher made it clear to the participants that participation in the study is voluntary. Participants were free to decline or participate in this study, or to withdraw participation at any point without penalty. Participants were told that the decision whether or not to participate in this research study was not going to have any influence on their relationship with the Elderly Day Care Centre.

Informed consent

Informed consent is crucial when recruiting participants for the study and must be obtained in all forms of research. This requires informing participants about the overall purpose of the research, the process of data collection as well as the risks and benefits of participation. Consent can be given in a written format, verbally, audio-taped or video-taped. Informed consent is intended to ensure that participants are placed in a situation where they can decide about their participation, in full knowledge, of the risks and benefits of the study. Informed consent should be gathered before the study commences (Boeije 2010:43, Seidman 2012:50). Informed consent was sought before commencement of the study. In this study consent was given in written format, the participants signed consent forms which clearly stated the purpose of the study. Refer to Annexure 3.

Vulnerable sample

According to Boswell and Cannon (2014:99), vulnerable populations are always a concern in research. In this study, the age of participants and the HIV/AIDS factor constitute them as vulnerable. Older women are a vulnerable group. Further, the responsibility of caring for HIV/AIDS affected households makes them more vulnerable because they are financially, emotionally and physically strained (Schatz 2007:147-154). HIV/AIDS households experience stigmatisation, lack of community support, rejection and isolation making them vulnerable (Campbell, Andersen, Mutsikiwa, Madanhire, Skovdal, Nyamukapa & Gregson 2014:13).

As a professional social worker, the researcher is trained to work with vulnerable individuals, to help them help themselves and maintain their social functioning. The older women in the study were treated with utmost respect and dignity.

2.5 DATA COLLECTION

This study used a focus group interview as a method of data collection. According to Joubert and Ehlich (2007:318), data collection allows the researcher to understand how the participants perceive their situation and their role within the context. Bryman and Bell (2007:511) state that in a focus group interview, people known to have a certain experience could be interviewed in a relatively unstructured way about that

experience. In this study twelve older women's experiences of caring for HIV/AIDS affected households were explored and discussed during the focus group interview. The women were given a platform to discuss their experiences freely in a warm and comfortable environment.

During the analysis of the transcript, the researcher realised that the issue of grandchildren was not explored enough in the first focus group interview and as a result, another follow-up focus group interview was conducted with seven of the original twelve participants who were available. The follow-up interview focused on their experiences in caring for their grandchildren with and without HIV/AIDS.

The processes of data collection are described in detail in the following sub-sections 2.5.1-2.5.4.

2.5.1 Focus group interviews

Focus groups are characterised by interactions between the participants from which the researcher discovers how people think and feel about particular issues. These groups are set up to explore specific, rather than general topics. The ultimate goal of the researcher is to understand the reality of the participants (Holloway & Wheeler 2010:126).

Focus group interviews are conducted to obtain specific types of information from a clearly identified set of individuals. This means that individuals who are invited to participate in a focus group must be able and willing to provide the desired information and must be representative of the population of interest (Stewart, Shamdasani & Rook 2007:51).

The group of participants for this study was selected because of their situation, which is, caring for HIV/AIDS affected households.

There are five characteristics of a focus group (Krueger & Casey 2008:10). These are mentioned and then explained in the context of this study.

- The typical focus group size is five to ten people, but depending on the topic and other arrangements it can be as many as twelve people. In

this study the researcher conducted a focus group interview with twelve older women caring for HIV/AIDS affected households.

- Homogeneity - the participants should possess similar characteristics that are relevant to the purpose of the study. In this study, the participants are older women who have experience in caring for HIV/AIDS affected households.
- Focus groups provide qualitative data. Focus group interviews allow researchers to understand a phenomenon from the discussion that ensues. The researcher used the data gathered through the focus group discussion to understand the phenomenon of older women caring for HIV/AIDS affected households.
- Focus groups are indeed a “focused discussion”. The researcher’s guide is carefully crafted to answer the research questions. In this study, the researcher had an interview guide which included questions to direct the discussion of the participants.
- Focus group interviews assist the researcher in understanding the topic in detail. In this study, the focus group interview generated data which made the researcher understand the experiences of older women caring for HIV/AIDS affected households in Atteridgeville.

According to Babbie (2010:323), focus group interviews have three advantages which are relevant to this study:

- It is a socially oriented research method capturing real-life data in a social environment. The participants in this study were older women who care for HIV/AIDS households. These women discussed their different experiences within their social context.
- It has flexibility. The researcher responded to emerging issues from the discussion. Although an interview guide was used, the unique contributions of the participants were captured.
- It is low in cost. It was low cost for the researcher because the venues were there for free; the participants live in different areas near the Elderly Day Care Centres, so no extra transport costs were incurred.

2.5.2 Interview schedule

The researcher developed an interview schedule before conducting focus group interviews. Flick (2009:145) defines an interview schedule as a written list of questions, open ended or closed, prepared by an interviewer for a person to person interaction. In this study the interview schedule, (annexure D) consists of three sections namely;

- section 1 , which includes a checklist, objectives and introduction,
- section 2, which includes interview questions and
- section 3 which includes a conclusion.

In section 1, the researcher designed a checklist to ensure that the environment was suitable for the interview. The objectives of the focus group interview were formulated to guide the researcher during the focus group sessions. It was followed by an introduction which included welcoming the participants, an overview of the discussion and ground rules, as recommended by Hasse-Biber & Leavy (2011:166).

In section 2, the researcher formulated the broad interview questions, exploring the experiences of older women caring for HIV/AIDS affected households. Discussions were done according to the interview schedule and according to emerging issues, as they were brought up by participants.

In section 3, the session was concluded by the researcher, summarising the main points shared by the participants and thanking them for participating in the study.

Pre-testing of the interview schedule

According to Stewart et al (2007:66), pretesting of the interview guide provides an opportunity to determine whether wording of questions is appropriate, to determine whether questions elicit discussion and to identify questions that are not easily understood.

The pre-testing was done using three individuals, meeting the sampling inclusion criteria, from an Elderly Day Care Centre in another area of the Pretoria Care for the Aged. These three participants were not included in the actual study.

Pre-testing enabled the researcher to plan follow up prompts based on the initial response to generate further discussion in the final focus group interview. It also served as a preparation for the researcher to conduct the focus group interview.

2.5.3 Conducting the focus group interview

Boswell and Cannon (2014:278) explain that in focus group interviews a group of individuals are led in the discussion of a selected topic at the same time. Each session tends to last approximately one to three hours. To facilitate the data collection process, the sessions are audio taped or video-taped for analysis. The focus group interview for this study lasted seventy two minutes. The follow up interview lasted forty seven minutes.

The venue

According to Roberts and Priest (2010:155), an appropriate venue that is accessible to participants needs to be identified; it needs to be a place that is warm, comfortable and without distractions of noise. Refreshments, at least water, should be available and other equipment like a watch, tape recorder, and list of topics / interview schedule.

The boardroom of one of the Elderly Day Care Centres was chosen for the focus group interview since these older women were familiar with it. They always conduct their meetings there, it is spacious, warm and far from any distractions like noise. The researcher, the assistant and participants were seated on chairs around a table; this was to enable everyone to have a face to face contact with each other. Water and tissue paper were provided for the participants. The researcher used her own watch to keep track of time and a tape recorder was used to record the interview.

Roles of the interviewer and the assistant during the interview process

The researcher interviewed the participants with the assistance of a social auxiliary worker at one of the Elderly Day Care Centres. The roles of each were clarified and defined prior to the interview.

Morgan and Krueger (1998), cited in De Vos, Strydom, Fouche and Delport (2011:306) explain that a researcher should have the necessary communication and

group facilitation skills. In this study the researcher is a professional social worker with the necessary listening and communication skills and is familiar with facilitating groups. The researcher facilitated the group discussion, directed, encouraged and probed participants as on the topic. The researcher made sure that no participant dominated the group, and that all participants had a chance to discuss their views. The researcher also constantly observed and noted the participant's non-verbal behaviour such as their attitudes and emotional components of responses. The researcher was well prepared mentally to conduct the focus group interview, with knowledge of the objectives of the study.

The researcher is well known to the participants and this made it easier to establish a trust-relation within the research context, thus the environment was warm and friendly. The researcher built rapport in the group, ground rules were set and introductions were brief. The researcher explained the objectives of the study to the participants and the information which the researcher wanted to elicit from the participants (King & Horrocks 2010:75).

The participants' contributions were valued by the researcher, as they expressed themselves without any fear of criticism. The researcher tapped into the participants' experiences by probing deeper into their experiences to get a clear understanding of what they go through in their day to day lives (Ulin, Robinson & Tolley 2012:112).

The assistant was asked to handle possible distractions which emerged in the group, for example, when a participant's cell phone rang. The assistant operated the tape recorder and took field notes, including a socio-gram which was used in the analysis of data. The researcher used a socio-gram to identify participants who were either dominating the discussion or not responding. By doing so, it was ensured that the participants could voice their experiences.

At the end of the interview, the researcher summarised the main issues discussed and verified with the participants. Lastly, the researcher expressed gratitude to participants for dedicating their time to the study (Roberts & Priest 2010:158).

After the participants had left, the researcher and the assistant discussed the interview, comparing field notes and discussing the limitations (Cresswell 2014:186).

2.5.4 Ethical considerations related to data collection

Ethics is defined as a theory or a system of moral values, the study of the general nature of morals and the specific moral choices to be made by a person and the rules and standards of governing the conduct of a person or the members of a profession (Joubert & Ehlich 2007:30). The researcher and the assistant were guided by social work ethics and research ethics as described below.

Ethical clearance to do the study was given by the University of South Africa, Health Studies Higher Degrees Committee. Refer to Annexure A. Consent to conduct the research was obtained from the management of Pretoria Care for the Aged and individual participants. Refer to Annexure B and C.

Respect for participants

The researcher treated the participants with respect and dignity and was mindful of their differences in cultural and ethnic diversity. The participants are older women, and older people are respected people in the black community, so the researcher treated them in a caring and respectful manner. According to Grinnell and Unrau (2011:80), cultural issues must be considered at every step of the research process, from developing the research question to disseminating the study findings. Socio-cultural issues such as extended families and the role of Sangomas were dealt with respect and acknowledgement. In this study the researcher realised that people do not discuss issues of HIV/AIDS publicly because of the sensitivity and stigma around the matter. Having an established trust relation with the participants, the researcher managed to encourage the participants to discuss their experiences, explaining to them the goal and potential benefit of the research. Since the researcher is a social worker by profession, it was easy for her to refer these older women to support groups and counselling when need arose.

Anonymity

Anonymity, the most secure means of protecting confidentiality, occurs when the researcher cannot link the participants to their data (Polit & Beck 2013:84). Anonymity refers to concealing the identity of the participants in all research

documents, therefore actively protecting the identity of research participants (King & Harrocks 2010:117). The identities and names of the participants will not be published or given to anyone; hence the information will be anonymous. During the researcher did not use real names of participants, alphabetical codes were used. The names which were accidentally used and captured on the recorded tapes were not transcribed, hence anonymity was ensured in the study.

Confidentiality

Polit and Beck (2013:85) define confidentiality as a pledge that any information participants provide will not be publicly reported in a manner that identifies them and will not be made accessible to others. All records and identities of the participants were maintained as confidential. By ensuring confidentiality, the researcher agrees not to report private data that identifies the participants (Klenke 2008:50). In this study, the data collected were kept confidential and will only be available for the researcher and the participants. The researcher ensured this by:

- Asking the field worker to sign a confidentiality agreement.
- Keeping all information that is in the form of interview notes, tape recordings and transcriptions in the researchers' cabinet which is always locked. It is only the researcher who has access to this cabinet.
- Not disclosing the participants' names, identities and information gathered to other colleagues at the Elderly Day Care Centres or in the research report.

2.6 DATA ANALYSIS

The researcher collected verbal data through tape recording the focus group interviews and prepared them for analysis through verbatim transcription. According to Moule and Goodman (2013:410), qualitative data is initially prepared through verbatim transcription providing a written record of the conversation to include verbal interactions noted between the researcher and the participants. Field notes made by the researcher and the assistant were also added to the transcription to become the final data document for analysis.

The researcher used Colaizzi's seven-step method of data analysis (Profetto-McGrath, Polit & Beck 2013:328, Holloway & Wheeler 2013:223, Moule & Goodman 2013:414) as follows:

- The researcher read the transcript of the focus group interview with the older women caring for their HIV/AIDS affected households to acquire a feeling for the content.
- Each transcript was re-read many times to extract significant statements. The statements were underlined.
- The researcher gave meaning to each significant statement as she understood what the participants meant and their feeling attached to it.
- The meanings were grouped or organised in sub-categories and categories. This step revealed common patterns or trends in the data.
- Related categories were grouped into themes. A detailed, analytic description was then compiled of the participant's experiences and ideas on each theme. This is called an exhaustive description. The exhaustive description was done to gain insights into the structure of the experiences of older women caring for HIV/AIDS households.
- The researcher then identified the fundamental structure for each exhaustive description.
- Because of the continued contact with the participants at the Elderly Day Care Centres, the researcher was in a position to do a follow up discussion to verify the transcription as a true reflection of the focus group interview.

Literature control

As sub-categories and categories were identified, the researcher also did a literature control. This was to compare existing literature with concepts and meanings identified in the current study. Literature sources included textbooks, journal articles and internal sources. The UNISA subject librarian assisted with a literature search using the following key terms: experiences, older women, caregivers, HIV/AIDS households. This was done using the e-journals, e-books and e-thesis and dissertations. The following data bases were used: CINAHL with full text, MEDLINE.

2. 7 TRUSTWORTHINESS OF THE STUDY

Table 2.1 represents an overview of how the strategies to ensure trustworthiness of the study by Krefting (1991), cited in Followell (2008:54), were applied in this study.

Table 2.1

Strategies to ensure trustworthiness (Followell 2008:54)		
STRATEGY	CRITERIA	APPILCABILITY OF CRITERIA IN THIS RESEACH
Credibility	Prolonged engagement	The researcher had a trusting relationship with the older women at the elderly day care centres before the research was done. This opened the door for honest explanation of their experiences of the phenomenon.
	Member checking	Follow-up discussions with the participants after focus group interview were done to ensure the interview information was understood.
	Pre-test of the interview schedule	A pre-test of the interview schedule was done in preparation for the focus group interview to determine whether the wording of questions was appropriate and whether questions elicited relevant discussion.
Transferability	Nominated sample	Purposeful sampling method was used to ensure that participants had experience on the research topic
	Dense description	Researcher described the complete methodology in detail.
Dependability	Audit trail	Keeping raw data and recorded tapes.
	Code and re-code procedure	Consensus between researcher and the research expert.
Confirmability audit	Confirmability audit	Records include field notes and tape recordings
		Focus group interview schedule to organise and analyse data.

Credibility

Credibility means a link between participants' views and how the researcher presents them. A study has credible findings if the findings reflect the experience and perceptions of participants (Gerrish & Lacey 2010:139).

The relationship between the researcher and participants was based on trust that existed even before the research was done. The researcher opened up to the participants about the motives and purpose of the study to ensure valid and credible results. The older women trusted the researcher; hence they gave honest explanations of their experiences of the phenomenon during the focus group interview.

The researcher also ensured that there was credibility through member checking. The researcher did a follow-up on the focus group interview to ensure that the interview information was correctly understood. The participants reviewed the information which they gave to the researcher during the focus group discussion to ensure that the researcher was accountable to the participants.

The researcher pre-tested the interview schedule with three participants to check whether the questions for the focus group interview were appropriate to address the phenomenon under study. This formed the basis for credibility of the research findings.

Transferability

Transferability is when findings in one context can be transferred to similar situations or participants (Holloway & Wheeler 2010:303). For the findings of this study to be transferable to other populations, there was need for application of accurate and detailed descriptions of methodology. Thus, the researcher described the context and methodology in detail.

Dependability

Qualitative data cannot be seen as credible unless its dependability is known, that is, its ability to stand the test of time (Moule & Goodman 2013:189). Dependability relates to reliability in qualitative research, which refers to the consistency and accuracy of the data.

Dependability is enhanced by keeping field notes and tape recordings and transcribing them into a meaningful data documents. There was consensus between the researcher, the assistant and the qualitative research expert on the process of

the study, the congruency of the emerging findings and the interpretations with the raw data.

Confirmability

Confirmability is a measure of the objectivity of data. To confirm objectivity, the researcher presents an audit trail of the methods, presentation of data and analytical processes. In this study, data interpretation was subjected to external audit by a qualitative research expert towards the end of the study (Moule & Goodman 2013:190). The expert verified that the findings and interpretations by the researcher were grounded in the data provided by the participants and not in the bias or interest of the researcher.

2.8 CONCLUSION

This chapter discussed the research design and methodology followed. Further, data collection and analysis were discussed, along with the relevant ethical considerations. The next chapter focuses on data analysis and literature control.

CHAPTER 3

DATA ANALYSIS AND LITERATURE CONTROL

3.1 INTRODUCTION

In the previous chapter, the methodology followed in conducting this study was discussed. This chapter focuses on data analysis of the focus group interview conducted with twelve older women caring for HIV/AIDS affected households, attending the three Elderly Day Care Centres in Atteridgeville community during September 2013 as well as a follow-up focus group interview during January 2014. Both interviews were transcribed and analysed. Significant statements identified during the analysis are discussed. See table 3.1 below. Literature review is also done to compare what is known about the study field with the findings of the study.

The objectives of this study were to explore the older women's experiences in caring for HIV/AIDS affected households and to identify the factors that impact on older women caring for HIV/AIDS affected households.

3.2 ANALYSIS OF THE TRANSCRIPTS

As the researcher read and re-read the transcripts of the interviews, thirty six sub-categories emerged. The sub-categories were then grouped into categories. Thirteen categories were formulated to give meaning to the sub-categories by grouping them into different relevant categories. Lastly, four different themes were formulated from the grouped categories. These themes are now briefly summarised and discussed in detail in Table 3.1.

The first theme is "Caring for adult children diagnosed with HIV/AIDS". Under this theme, four categories are described, and these relate to expression of feelings: strained relationships between older women adult children, coping strategies and ongoing duties. The older women in this study expressed their feelings about caring for their adult children diagnosed with HIV/AIDS in different ways. Feelings of anger, hurt, fear, worry and helplessness were identified. Most of the older women had strained relations with their sick adult children and this was because the adult children did not disclose their status and the fact that they were a burden to their

caregivers. The older women in this study developed coping strategies like acceptance and belief in God while caring for their sick adult children. In caring for adult children diagnosed with HIV/AIDS, older women also had ongoing duties such as giving them emotional support, personal caring and self-protection.

The second theme is “Caring for HIV affected and infected grandchildren”. Three categories are discussed under this theme, and they relate to challenges encountered: social life of grandchildren and education/schooling. The older women are faced with challenges such as finances, dealing with the development of sexuality of the teenagers and disrespectful and unacceptable social behaviour of the children, in their responsibilities of caring for grandchildren. The social life of the grandchildren is discussed in terms interaction with friends and relatives. Education also emerged as a category since children need encouragement and support, which depend on the relations between teachers and caregivers. The food schemes at schools were also discussed by the older women.

The third theme focused on the “Multiple role players involved in caring for persons with HIV/AIDS”. Four categories were identified: health care team, the person diagnosed with HIV/AIDS, the community and the care-givers (older women). The participants mentioned that health care professionals played an important role in the treatment of the persons diagnosed with HIV, with traditional healers having an insignificant role to play. The role of the person diagnosed with HIV/AIDS was mostly described in terms of compliance with treatment. Community involvement seems to be lacking because of the stigma attached to HIV/AIDS. Despite hardships and burdens, the caregivers (the participants) themselves portrayed a positive attitude in caring for HIV/AIDS households.

The final theme is “The impact on care-givers everyday lives”. Two categories are discussed under this theme, and these are: financial strains and biophysical impact. The participants had financial strains in caring for HIV/AIDS affected households, but receiving old age grant and the foster care grant assisted them. The responsibility of caring for HIV/AIDS infected or affected households had a huge biophysical impact, since this was an ongoing duty. The women suffer emotional stress and physical strain.

Table 3.1 represents the major themes, categories and sub-categories identified during the analysis of data from the focus group interview of older women caring for HIV/AIDS infected and affected households in Atteridgeville.

Table 3.1: Identified themes, categories and sub-categories.

THEMES	CATEGORIES	SUB – CATEGORIES
3.3 Theme one : Caring for adult children diagnosed with HIV/AIDS	3.3.1 Expression of feelings 3.3.2 Strained relations between older women and adult children 3.3.3 Coping strategies 3.3.4 Ongoing duties	3.3.1.1 Anger 3.3.1.2 Hurt 3.3.1.3 Fear 3.3.1.4 Worry 3.3.1.5 Helplessness 3.3.2.1 Disclosure 3.3.2.2 Being a burden 3.3.2.3 Dependency 3.3.3.1 Belief in God 3.3.3.2 Acceptance 3.3.4.1 Emotional support 3.3.4.2 Personal caring 3.3.4.3 Self protection
3.4 Theme two: Caring for HIV/AIDS affected and infected grandchildren	3.4.1 Challenges encountered	3.4.1.1 Responsibility to support 3.4.1.2 Financial responsibilities 3.4.1.3 Sex education 3.4.1.4 Disrespectful from grandchildren 3.4.1.5 Unacceptable social behaviour

THEMES	CATEGORIES	SUB-CATEGORIES
	3.4.2 Social life of grandchildren	3.4.2.1 Interaction with friends 3.4.2. 2 Interaction with relatives
	3.4.3 Education / Schooling	3.4.3.1 Encouragement and support 3.4.3.2 Teacher / caregiver relationships 3.4.3.3 Food schemes
3.5 Theme three: Multiple role players involved in caring for persons with HIV/AIDS	3.5.1 Health care team	3.5.1.1 Health Professionals 3.5.1.2 Sangomas
	3.5.2 The person diagnosed with HIV/AIDS	3.5.2.1 Co-operation 3.5.2.2 Compliance and non- compliance
	3.5.3 The community	3.5.3.1 Stigma 3.5.3.2 Secondary stigma
	3.5.4 The caregiver	3.5.4.1 Positive attitude
3.6 Theme four: Impact of HIV/AIDS on caregivers everyday life	3.6.1 Financial strains	3.6.1.1 Old age grant 3.6.1.2 Foster care grant
	3.6.2 Biophysical impact	3.6.2.1 Ongoing tasks 3.6.2.2 Physical strain 3.6.2.3 Emotional strain on the caregiver

The following sections, 3.3-3.6, describe the different themes, categories and sub-categories that emerged through the analysis of the transcribed interviews. The discussions are supported by examples of raw data presented in italic font. Furthermore literature is included to confirm or contradict findings of the study.

3.3 THEME ONE: CARING FOR ADULT CHILDREN DIAGNOSED WITH HIV/AIDS

According to the inclusion criteria all twelve participants were caring for sick adult children. Five older women even cared for more than one adult sick child. According to Benson and Haith (2009:21), older women are often the primary care-givers for

HIV/AIDS infected persons in the household. Refer to Table 3.1 for a summary of the four categories and thirteen sub-categories of theme one that follows.

3.3.1 Expression of feelings

From the data gathered during the focus group interview, older women expressed different feelings about caring for their sick children. Tshililo and Davhana-Maselesele (2009:142) reveal that family members experience negative feelings characterised by sadness, pain, anger, depression and frustration as they care for their loved ones with HIV/AIDS, in their study of family experiences of home caring for patients with HIV/AIDS in rural Limpopo province, South Africa.

The participants in this study expressed feelings of anger, hurt, fear, worry and helplessness. It is not always possible or easy to describe these feelings separately. The sources and manifestations of the feelings often overlap. According to Cunningham (2009:32), a wide range of emotions come up whenever a person is wounded, and these include anger, confusion, worry, rage, frustration, fear and embarrassment. Pfeiffer (2009:40) contends that people act out what they feel; that unresolved hurt can turn into anger and that fear is another root of anger.

Chidre and Rozman (2006:48) are of the opinion that people cannot transform negative emotions until they learn to admit what they are feeling. By admitting their feelings, people slow down the emotional energy running through their systems. Being honest about stating what one is feeling helps regulate one's emotional energy and gives one more power.

The sub-categories of feelings are described in sections 3.3.1.1-3.3.1.5.

3.3.1.1 Anger

According to Hunt (2013:33), anger is typically started and fuelled by at least one of the four sources, which are: hurt, injustice, fear or frustration. Anger is therefore a secondary response. One sometimes experiences hurt or fear but expresses it in anger. This is often because people are not in control of their emotions and they find it difficult to communicate their emotions.

According to O'Connor and Earnest (2011:44), the impact of HIV/AIDS complicates family care giving responsibilities which causes anger and frustration. Foyster (2013:101) states that anger is often a result of hurt feelings and if not expressed in a healthy way, it can turn into a disease or illness.

The participants in this study expressed feelings of anger as they discussed their experiences of caring for their sick adult children. They were angry and bitter for different reasons.

One of the reasons why they were angry was the attitudes of their sick children towards them as their care-givers. Participants explained that their sick children were rude and did not show them any respect.

'I was always there helping her with everything, but she never stopped shouting at me and...she abused me with words that came out of her mouth. (field note observation: participant was crying)' Participant E.

'...my daughter was very rude to me even on her death bed...' Participant H.

Participants expressed their anger because it seems the sick children expected to be cared for. From the raw data it is clear that some adult children did not have much contact with their parents until they became sick. They then came home to be cared for by their parents.

'She ran away to Brits, came back again, very sick with a baby' Participant F.

'She came home thin and very sick...and...my other daughter came from wherever she was, I don't even know...' Participant L.

Financial problems were another reason for their anger. In the process of caring for their sick children the older women lost their jobs or in some cases. One should keep in mind that the old age grant that these women receive is not enough to sustain a family (Van Dyk 2008:45, Ashton 2011:55). The women expressed their anger about the financial burden they had because of their sick adult children.

'I was doing a piece job and I even lost it because I had to care for a sick child' Participant C (field note observation: *looked very angry*).

'I am now doing a piece job, two days a week because my income per month is not enough to take care of this big family.' Participant H

They were also angry as they used their pension grant to take care of their sick children and their orphaned grandchildren.

'I used my pension...did a lot for my sick child, I used money for transport, food, paying rent and everything in the house'. Participant L

'I was receiving an old age grant of R1000. I had to buy food, for my children and grandchildren.' Participant F

Being left with the burden of orphaned grandchildren was also mentioned by the participants as one of the factors that caused anger. The older women were angry because their adult children had HIV/AIDS and then came home to receive care from their parents, and when they died, their children (HIV positive/negative) became a burden to them.

'...unfortunately she died leaving her baby infected with HIV' Participant F.

'My son's girlfriend came to dump her child, my grandson, when he was only six months old and she disappeared...the I found out that the child was HIV positive' Participant G.

Some of the women expressed their anger with the disease itself and not with their sick adult children.

'I am left with two children out of six. They were all taken away by HIV. I am very angry today' Participant J.

The feelings of anger towards the sick adult children expressed by the participants correspond with findings from previous research. The increasing dependence of HIV/AIDS infected patients on the care-giver requires adjustment in family, work and social commitment. This may result in care-givers having feelings of anger and resentment about changes in their loved ones or their care giving roles (Lashely & Durham 2010:351, Maezzo 2008:81).

Human anger is seldom experienced in isolation from other emotions and the defensive structure of the individual is intimately tied to the way that anger is experienced. To deal with anger effectively is to engage in therapy. The therapeutic engagement of anger includes identification of adaptive, maladaptive and ego defending responses to anger and implementation of specific treatment approaches

(Gupta 2008:213). The participants of this study need professional assistance for them to experience such therapeutic interventions.

3.3.1.2 Hurt

According to Smith and Wilson (2010:222), hurt is regarded as a feeling that occurs when an individual is emotionally injured by another. People feel hurt when they believe that another individual or group of individuals communicated or behaved in a way that caused them emotional pain. A prototype analysis of emotional concepts conducted by Shaver, Schwartz, Kirson and O' Conner (1987:1062) revealed that hurt is associated with emotional terms such as anguish and agony and that people associate hurt with sadness.

The data shows that these older women were hurt in different ways. Knowing that their children were infected with HIV/AIDS brought hurt to most of the older women.

'This is very hurting (her adult children dying of AIDS), I would rather keep quiet, because our children do not listen to what we tell them' Participant B.

'When I discovered that my other daughter was also sick, I was devastated...' Participant E.

Some of the participants expressed poor relationships with their adult children. In the study, the data revealed that most of the sick adult children were not staying with their families, that they only came home when they were sick and needed care and that they were not willing to tell the truth about their diagnosis. This lack of trust in their parents demonstrates poor relations and it emotionally hurt their parents. Poor interpersonal relations in HIV/AIDS families are also described in a study by Feng, Lu, Feng, Ko, Chen & Chen (2009:480).

'She ran away to Brits, came back again very sick with a baby. I was very hurt because I knew that she was HIV positive and now she comes with a baby' Participant F.

'...but one thing children always come back home when they are sick, but when they are working and getting their own money and enjoying life, they never think of home...' Participant L.

The older women perceived the sick adult children as being disrespectful towards them as their parents and as their care-givers. The way their sick children spoke to them really hurt them.

'I was always there helping her with everything, but she never stopped shouting at me'. Participant E

'I would tell her to go to the hospital at least to get tested and she would say "are you the one who infected me?"...' Participant H.

The older women were also hurt by their children's death from AIDS. Death is unbearable and hurting for everyone especially if parents bury their own children. In this study some participants had more than one child dying of HIV/AIDS in the family.

'... I then received a call from the hospital that she is dead. It hurt me; even though I knew that in her condition she was not going to survive' Participant E.

'My three daughters died of HIV...' Participant H. (field note observation: looking sad)

According to Koenig, Weatherford and Weatherford (2012:94), it hurts families, caregivers and partners to witness a loved one's physical decline and to know that they are going to die. It hurts to care for a loved one that you realise will eventually die.

3.3.1.3 Fear

Shomande (2008:4) describes fear as the instinctive emotion aroused by impending or seeming danger, pain or evil. Whitehead (2013:22) also defines fear as a biological adaptive physiological and behavioural response to the actual or anticipated occurrence of an explicit threatening stimulus. The emotion of fear is generated by specific things; fear of something, someone or some imagined object. The participants in this study expressed the feelings of fear for caring for more than one child with HIV/AIDS as it gave them a lot of work. Caring for someone who is sick involves feeding, bathing, cleaning and lifting them up, which is hard work. This is not easy to anyone, especially older women.

'My other daughter died, and with this other one who is sick now if I think what I went through with my other daughter, I became very scared because its hard work' Participant F.

'The situation (the adult child being sick) was very bad because I had to wash her, feed her and look I am also sick with old age' Participant L.

One of the participants mentioned her fear of contracting HIV/AIDS. Another one mentioned that she contracted HIV through caring for her sick adult child. When caring for someone with HIV/AIDS precautionary measures of wearing gloves have

to be considered when bathing and cleaning sores or being in contact with blood or bodily fluids.

'I cared for my daughter and it's not a nice experience, I was scared to also get HIV' Participant C.

'I also got infected with HIV as I was caring for my sick child. I never used any gloves...' Participant K.
(field note observation: beating the table)

As they were caring for their sick adult children, the participants feared that their children may die anytime.

'...but it is not easy taking care of a sick child because you are always thinking that maybe something will happen' Participant F.

'Taking care of someone sick knowing they will eventually die is not easy..., especially at this age...'
Participant I.

Fear is also described in other HIV/AIDS studies. A study conducted by Feng, Lu, Feng, Ko, Chen and Chen (2009:480) reveals that family members of people living with HIV/AIDS also experience fear of infection transmission and fear of stigma related to HIV/AIDS.

According to Gollhofer (2011:52), managing fear essentially means that we try to carve out a space in our lives - a comfort zone, where we experience as little emotional pain as possible. We should find a workable balance where our fears manage us a little and we manage them a little. We manage our emotions by creating the illusion of feeling safe while living a productive life in an uncertain, fear-ridden world.

In this study the researcher found that the older women who felt comfortable in the group were willing to express their fear as they care for their sick adult children with HIV/AIDS. There is therefore a need for social workers to provide opportunities for the older women to share their stories and experiences and receive counselling to alleviate their fear and also to equip them with skills to care for those infected with HIV/AIDS.

3.3.1.4 Worry

Wilkinson, Mearse and Freeston (2011:4), Borkovec, Robinson, Pruzinsky and DePree (1983:10) and Freeston and Mearse (2012:6) describe worry as a chain of uncontrollable thoughts and images that negatively affect us. Worry represents an attempt to engage in mental problem-solving of an issue whose outcome is uncertain. People have to learn to deal more effectively with uncertain situations by finding other things to do instead of worrying.

According to Lashely and Durham (2010:493), disclosure of HIV/AIDS to family may cause parents to worry about the child's ability to cope with the disease, which may lead to parental distress.

In this study, older women were worried about how their adult sick children were going to cope with HIV/AIDS. They were also worried that their sick children were not getting better.

'Things got really bad, I went back to the hospital with her and now I could see that she was dying'
Participant E.

'...but unfortunately she died ...' Participant F. (field observation: sad face)

The participants were also worried as their adult children were not complying with their treatment. They realised that if the sick adult children did not take their treatment, it meant that their condition was not going to get any better.

'...she was put on treatment but she did not want to take her medication' Participant F.

'...she was on treatment but was refusing to take her medication...' Participant H.

Compliance with treatment is discussed in more detail in section 3.5.2.2

In a study conducted by the United Nations (UN) (2009:56), on old-age parents and the AIDS epidemic in Thailand, parents reported major reductions in their own worries about the health of their HIV/AIDS-infected adult children, when the children started following antiretroviral therapy. In the same study, worry was also reduced when the children started to comply with treatment. However, in this study, older women became more worried since their children were not complying with treatment and as a result, their health was deteriorating.

Ssengonzi (2007:340) describes the plight of older persons as care-givers to people infected with or affected by HIV/AIDS in Uganda, that respondents reported frequent worrying, because of the fact that they knew that their sick relative would ultimately die.

3.3.1.5 Helplessness

Helplessness is the inability to act or succeed or a feeling of being depleted of strength (Knaus & Ellis 2012:134). In a study by Hussein & Manal (2008:890), on psychological profiles of people with AIDS and their care-givers in Egypt, HIV/AIDS patients and their care-givers experienced traumatic stress which left them helpless due to the seriousness of the disease. Although the family care-givers may not experience the physical pain personally, the situation of their loved ones with AIDS causes a sense of helplessness which leads to various social and emotional problems.

The participants in this study also felt helpless because their children were HIV positive. They took their sick children to hospital, but often their sick children did not follow prescribed treatment and some eventually died. The feeling of helplessness was brought about by the fact that no positive results came out, regardless of the efforts made by these women to help their children.

'My problems will not end...I am now caring for my other daughter who is also HIV positive, she was also secretive, she started taking her medication, but it was late...' Participant E.

'There was nothing that I could do; I took the child to hospital' Participant F

'I took her to the hospital, but it was too late...on delivery she passed away' Participant L.

Participants also felt helpless knowing that when their sick adult children died, they were left with the responsibility of looking after the grandchildren. Further, the fact that the orphaned grandchildren left in their care were also infected with HIV caused a feeling of helplessness for older women. In such a situation, one is likely to be helpless as one would start thinking of the traumatic experiences and responsibility of caring for the sick adult children.

'My grandchild got very sick and I had to take him to the hospital, then I found out that the child was HIV positive' Participant G

'My daughter passed away and after that I had to take my grandchild for testing, he is also HIV positive'. Participant A

One participant expressed that she developed a feeling of helplessness when she heard from other participants that their grandchildren complied with their treatment and they were getting better, while her grandchild did not comply with his treatment and his health was deteriorating.

'...he doesn't want to drink his medication, now he could be healthy like other kids I am hearing about here'. Participant A

The issue of compliance to treatment is discussed in more detail in section 3.5.2.2.

3.3.2 Strained relations between older women and adult children

When a family member is infected with HIV/AIDS, family functions and processes change. Some family relationships change from caregiver to care receiver and it is usually women and girls who care for the sick people (DeFrain & Asay 2012: 53).

The care for a child naturally lies in the hands of a mother who is usually the centre of every household (Schumann 2013:112). However, sometimes this normal, happy relationship is often strained during the middle adolescent stage of development (Edelman & Mandle 2006 :510) or when chronic illness has a negative effect on the relationships in the family (Morrison-Valfre 2012:168).

In this study, it is revealed that HIV/AIDS also strains relationships. Inherently the adult children know that they need to go back to the primary care-giver, the mother. They know that they need support and care, but they feel embarrassed or guilty. At the same time, the primary care-givers, who are, in this case the mothers, know that they are expected to assist and care, but they are not prepared or equipped to do so in these circumstances.

A study by Ssengonzi (2007:348), about older persons as care-givers to people infected with or affected by HIV/AIDS in Uganda, highlights the issue of strained relationships between care-givers and the patients.

In this study, the strained relations could be attributed to the sick children not disclosing their status to their care-givers. Also, the fact that the children were

dependent on the older women and had become a burden to them also caused strained relations. Each of these is discussed below in section 3.3.2.1-3.3.2.3.

3.3.2.1 Disclosure

Disclosure of HIV/AIDS status is a process of informing people of a disease diagnosis (Swanson 2009:376). On a personal level the tendency not to disclose the diagnosis of HIV is closely related to the stigma and discrimination attached to the disease. It is however also a human right not to disclose the HIV diagnosis. The South African Constitution protects the right to privacy and confidentiality of all citizens as cited in Reid & Visser (2013:177). Medical practitioners are under ethical duty to act in the best interest of their patients. A patient's HIV status may only be disclosed to a person or a group of people if the patient gives consent to such.

Literature shows that HIV-positive women face more acute discrimination in society. Once their HIV-positive status is disclosed, women face being physically abused and sometimes the threat of being chased away from their homes (Kirk-Duggan & Torjesn 2010:188).

There is, however, also a positive side to disclosure of a HIV diagnosis. Disclosure contributes to a person's ability to take care of themselves and plan ahead for their care and treatment. People who are HIV positive are encouraged and sometimes required to disclose their status as a way to improve public health and to improve their own mental and physical health (Aulette-Root, Boonzaier & Aulette 2013:58).

A study conducted by Sun, Sun, Wu, Lin, Wu and Yan (2007:307), reveals that disclosure has a positive impact on family. It strengthens family relations and allows family members to help people living with HIV/AIDS with medical care and the opportunity for a family to receive counselling.

In this study, it seems that the adult sick children had difficulty in disclosing their status, even to their mothers who were caring for them. Most of the participants mentioned that their adult sick children could not disclose their status to them. This could be due to the fact that the sick adult children were ashamed of their HIV/AIDS status or they feared discrimination or simply because they had strained relations with their parents.

The statements below show that the participants assumed that these children knew their status, but did not want to disclose it to anyone.

'This child was very sick staying in Tzaneen and then she came back home, but did not want to disclose what she was sick of' Participant F.

'My child was very secretive, I could see that she was sick, but she did not say it' Participant E.

'My daughter also had HIV, she was very secretive about it, she kept it a secret until she died' Participant H.

The findings in this study concur with findings by Van Dyk (2008:282), that most people do not disclose their HIV positive status because they fear rejection, isolation, stigma, discrimination, gossip and victimisation from family and friends.

The positive effect of disclosure was also expressed by participants in this study.

'She went on treatment and now she has fully recovered.....' Participant L

'She is responding well and recovering now because she is now serious about her medication.' Participant E

'ARVs work...people with HIV drink medication and they get better' Participant J.

The following was found in the literature: In a study done on women and HIV prevention in Canada (Gahagan 2013:113), women described how secrecy about their HIV-positive status created barriers to access support and services. Hall, Hall and Cockrell (2011:65), state that with (ART), patients live longer feeling better. Due to better medications that have been developed, patients are living longer and experiencing less severe symptoms until they reach the final stages of the disease (Moini 2013:130). The findings above are reflected in this study, as older women mentioned that some of their adult children disclosed their status, that they take their medication and that they got better.

Although the word “stigma” was not used by the participants, they describe the phenomenon within the community context and this is explained in detail in section 3.5.3.1.

Stigma makes people reluctant to disclose their status, even to their caregivers. Most people living with HIV/AIDS do not want their families to know that they are HIV

positive for, fear that their family members will be afraid to look after them (Dageid, Sliiep, Akintola & Duckert 2011:132). According to Mooney, Knox and Schacht (2010:60), HIV/AIDS stigma and discrimination can scare people from getting tested for the disease and it can make them less likely to acknowledge their risk of infection. The same was described by Greef, Phetlhu, Makoe, Dhlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2008:312), Akintola (2008 :362) and Liamputtong (2013 :283), that delay to disclose the diagnosis might interfere with early treatment preventing the person from receiving education, medical care and social support.

Most countries, including South Africa, have established advocacy groups that can assist people with HIV/AIDS to protect their rights against discrimination. It is, thus a pity to find in studies that HIV infected persons keep their diagnosis a secret.

3.3.2.2 Being a burden

Caregiver burden relates to the overall impact of the physical, psychological, social and financial demands of caregiving (Ungar 2011:223, Dageid at al 2011:299). According to Lashely and Durham (2010:350), many factors contribute to the physical, financial, emotional and social challenges. Care-giver burden can be assessed in terms of the objective and subjective impact upon their lives. Objective burden relates to the extent to which care-giving disrupts daily routines and social relationships. Subjective burden relates to the care-giver's perceptions of and reactions to the demands of care giving. In this study, the older women expressed both objective and subjective burden in their care for the adult children diagnosed with HIV/AIDS. These are discussed as physical, emotional, financial and social factors

Physical factors

Older women face problems of exhaustion as they look after their sick children. The strain they face while caring for their children living with HIV/AIDS in the last stages of the illness can be harrowing and tiring and as a result, it takes its toll on the older person's health (Maharaj 2013:152). The physical caring for sick adult children reported in this study includes the need for the sick children to be taken to hospital, the need to be fed, bathed and clothed and the need to be attended to all the time.

As much as participants know that caring for one's own child is one's responsibility, it eventually becomes a burden and impacts on the health of the participants.

'I had to wash her, feed her, and look I am also sick with old age' Participant L.

'I used to go to go the hospital three times a day; this was very hard because I had to walk sometimes' Participant E.

'...when she eats she vomits...Taking care of someone sick is not easy, especially at this age, when you also have your own problems and you are also not healthy' Participant I.

'I bath her, feed her, clean after her and lifting her up and I am not physically strong, I have blood pressure and sugar diabetes' Participant F.

Some of the older women in this study said they are caring for more than one sick adult child.

'I took care of my child who was sick...I am also caring for an adult daughter infected with HIV/AIDS' Participant F.

'My child was sick, she came home...my other daughter who was sick also came from wherever she was...' Participant L.

'...I was resting from taking care of the first one then the other one comes sick with this disease' Participant L.

The participants of this study are older women with their own physical ailments and health problems related to old age. Because of their age, it is even hard for them to take care of themselves, let alone taking care of someone who is HIV positive.

Emotional factors

Caring for a sick child / person is emotionally draining for everyone, as one does not know what to do or think especially if the condition does not get better or if the sick person does not comply with treatment (Garner & Christiansen 2008:11). In this study the older women were emotionally drained by different feelings as described in section 3.3.1. In addition, they reported that they feel stressed to witnessing their adult children suffer until death.

'This issue (caring for the sick child) really stressed me, I could not even eat sometimes' Participant F.

'...I was also stressed and sick, I have blood pressure...' Participant L.

'I was admitted in hospital for almost a month I was very stressed...' Participant J.

According to Dagied et al (2011:299), emotional stress comes from the traumatic effects of caring for sick patients and witnessing their death. This is also the reality described by participants in this study.

Financial factors

Maharaj (2013:152), states that caring responsibilities have financial implications that include meeting the costs of daily living, providing food, treatment and shelter. The older women in this study had to use their own pension grants to care for their HIV/AIDS affected households and it was not enough.

'...I went to a loan shark for my daughter's funeral expenses...it took me a lot of months paying the debt' Participant H.

'It affected me badly financially because I had a big family to care for with little income' Participant F.

In the African culture, older parents rely on their adult children to support them financially and to take care of their needs. The era of HIV/AIDS has a negative impact on this social arrangement. According to Dening and Thomas (2013:41), African older parents suffer the loss of crucial and expected economic support from wage-earning adult children who become too sick to work, who instead return home seeking care and eventually die.

In this study, the older women are the heads of the households responsible for food, rent and electricity, amongst others. The older women receive a government old-age grant of R1350 every month (Social Assistance Act No. 18 of 2004), (South Africa 2004:5). The grant is not enough for them to take care of themselves and HIV/AIDS infected/affected households, hence they struggle financially.

Social factors

Everyone has a social life with friends, relatives and the community, which needs to be revived by socialising and sharing time with others. When caring for a sick child/person, it is very difficult to be involved in social occasions or to socialise with people because of the caregiving responsibility (Umunna 2011:136). Care-giving for sick people presents a role to most people, which neither socialises nor prepares

them to fulfil. To meet the demands of care-giving, caregivers must restructure their pre-existing obligations and social activities. The increasing dependence on the caregiver may require significant adjustments in family, work and social commitments (Lashely & Durham 2010:351).

The participants in this study also described the impact of having to care for a HIV affected household on their social life.

'I could not socialise with people because I had to do a lot for my children' Participant J.

'... neighbours...if they know your child has HIV, they will gossip and talk...' Participant H.

'I do not tell anyone my problems, so I do not get any support from anyone' Participant H.

Schatz (2007:150) stresses that older care-givers are burdened by care-giving roles. For females in Southern Africa, care-giving can lead to physical, emotional and psychological, financial and even social stress as it disrupts ordinary social life.

3.3.2.3 Dependency

Johnson (2012:10) defines dependency as a condition of receiving assistance for necessities from someone and includes seeking support and security. In this study, the sick adult children were dependent on their mothers (older women) for everything, including care and support. In a study conducted by Schatz (2007:152), on older women's relations with their households in rural South Africa, a large number of the older women's adult children were living with their parents when they became sick, instead, they only came back "home" for care. The same was found in this study as described by the other women.

'This child was very sick staying in Tzaneen and then came back home...' Participant F.

'...she came home thin and very sick...' Participant L.

'When my daughter came home she was very sick...' Participant A.

'...but one thing children always come back home when they are sick, but when they are working and getting their own money and enjoying life, they never think of home' Participant L.

According to Cohen and Menken (2006:55), adult children return home when they become sick with HIV/AIDS. HIV/AIDS has made sick adult children to be more dependent on their older parents. This is confirmed by the older women in this study.

3.3.3 Coping strategies

Carver and Scheiver (1994) and Gurung (2014:141), cited in Rodman (2010:112) describe coping and coping strategies as follows: 'Coping' is anything that people do to manage problems or emotional responses. 'Coping strategies' refers to the specific behavioural and psychological efforts we make as we try to master, tolerate, reduce or minimize stressful events. In this study coping strategies refer to the strategies which were used by older women when caring for their HIV/AIDS affected households. For this study the coping strategies which were described were a belief in God and acceptance of HIV/AIDS as a disease.

3.3.3.1 Belief in God

In this study the researcher did not determine the religious status of the participants prior to the group interview. Using the term "God" may or may not refer exclusively to the Christian religion. However, none of the participants used names to suggest other religions, for example, Buddha. Therefore, any reference to "God" in this study is defined in the following information found in literature:

Dawkins (2008:52) defines God as superhuman, with supernatural intelligence that deliberately designed and created the universe and everything in it. God has been conceived of as supernatural, immortal and having special power over lives and affairs of people and the course of nature. God has revealed himself to be a moral being. Many terms have been used to describe the moral nature of God such as holiness, righteousness, justice truthfulness, mercy, love and others (Famodimu 201:47, Millikin 2010:29).

A belief in God can help a person deal with tough life struggles. The participants in the focus group interview believed in God in their responsibilities of caring for their sick children. One participant was grateful to God that the daughter died and did not leave any children for her to look after because it could have been stressful for her,

but most of them believed that God will give them strength in caring for their HIV/AIDS affected households.

'No I thank God because if she had left children I could be in problems now taking care of them, maybe they could have been infected with HIV' Participant I.

'When I discovered that my other daughter was sick , I was devastated and even lost weight, but God keeps me going' Participant E.

'God is there' Participant H.

'I am a Christian I took everything easy and waited upon the Lord' Participant H.

These statements show that these older women get their strength from God and they believe in God. According to Belgrave and Allison (2009:284), studies have shown that spirituality is an influential factor in helping African Americans cope with problems and stressful events. A belief that one's final destiny is in God's hands provides hope and inspiration. Interviews conducted with caregivers of African American children with chronic illnesses like HIV/AIDS revealed that spirituality helped the caregivers to reduce stress and it increased positive coping among caregivers.

The findings of a study conducted by Makoe, Greeff, Phetlhu, Uys, Naidoo, Kohi, Dlamini, Chirwa and Holzemer (2008:138) in five African countries, concur with the findings of this study that belief in God is a coping strategy in stressful situations. In their study the coping strategy of turning to God focused on spirituality and included activities such as praying, joining religious groups and building hope in God in response to the illness.

Believing in God helps the older women caring for HIV/AIDS affected households to cope with their situation and to get through difficult times.

3.3.3.2 Acceptance

According to McCracken (2011:189), acceptance is the willingness to experience unpleasant internal phenomena (thoughts and feelings) without attempting to avoid, escape or terminate them, in the service of pursuing valued goals. Liamputtong (2013:60) states that family is a major source of support for most people living with

HIV/AIDS, as they fight as a unit against stigma and other social pressures. HIV/AIDS is a lifelong disease and it takes time for the entire family to accept the diagnosis and to live with it. The process from rejection to acceptance may take many years. Once the family accepts the fact that their close family member has been infected with HIV/AIDS, they develop an understanding and accepting attitude towards people living with HIV/AIDS.

The issue of acceptance is very important when caring for an HIV/AIDS infected child. Acceptance reduces pressure on the caregiver as they will perform their duties knowing that the person is sick (Aggleton, Davis & Hart 2013:23).

The participants in the focus group interview described different experiences as some had accepted that their adult children were infected with HIV/AIDS.

'It hurt me even though I knew that in her condition she will not survive' Participant E.

'I know and accept that she had HIV' Participant F.

Some of the older women in this study expressed that it is better to accept that you have HIV/AIDS and take on treatment as they have seen their sick adult children and other people getting better because of treatment.

'She went on treatment and now she has fully recovered....' Participant L.

'She is responding well and recovering now, because she is now serious about her medication' Participant E.

'Other people with HIV drink medication and get better...' Participant J

Punpanich, Gorbach and Detels (2011:718) conducted a study on the care for children with HIV/AIDS. They found that not accepting the diagnosis had a negative impact on the well-being of the care-giver.

3.3.4 Ongoing duties

In this study, older women expressed in many ways the responsibilities which come with caring for their sick adult children on a day to day basis. These duties include ongoing support and personal caring as described in the following section.

3.3.4.1 Emotional support

According to Westall and Liamputtong (2011:32), emotional support is defined as feeling validated and understood by others and having someone to talk to when difficult times arise. Emotional support includes empathy, encouragement, recognition of competence and nurturance. Haber (2013:221) maintains that emotional support provides people with a sense of love, reassurance and belonging.

Older women in this study were always supportive of their children, despite their strained relations.

'When a child is sick you must always be supportive, not shout at them because they will go to strangers and confide in them' Participant F.

'...I was helping her with everything...' Participant E.

'...but I had to do everything to support her' Participant H.

'I gave my children all the care I could give them when they were sick...' Participant J.

Greater emotional support is associated with positive effect on people living with HIV/AIDS. In a study conducted by Gordillo, Fekete, Platteau, Antoni, Scheiderman and Nostlinger (2009:523) on emotional support and gender in people living with HIV/AIDS, they found that many people living with HIV/AIDS have high levels of stress. Receiving support from family members help to alleviate or prevent the extent to which they experience psychological distress. In this study, older women provided emotional support to their sick adult children to avoid distress.

3.3.4.2 Personal caring

Smith, Turkel and Wolf (2013:218) define caring as a nurturing way of relating to persons toward whom one feels a personal sense of commitment and responsibility. It involves individual attention to and concern for another individual, responsibility for or providing for at some level. In terms of illness and disease, personal care is described as the provision of non-professional services for patients in their place of residence. These include home making, food preparation and bathing (Durgin & Hanan 2010:38).

According to Lashely and Durham (2010:351), care-giving responsibilities may include many different types of tasks, such as lifting, bathing, dressing, feeding, listening, talking, providing emotional care, completing household chores that include changing bed linen and laundry, arranging for health care and interfacing with the health care system, providing all around the clock supervision of the care recipient and supervising medical schedule.

The older women caring for their sick adult children perform these tasks at all levels. Emotional caring was discussed earlier in section 3.3.4.1. The physical caring done by the older women includes cleaning, bathing, cooking, feeding, washing and caring for their children and they do all these tasks wholeheartedly.

'She was very sick, I did everything I could to care for her, I bathed her, gave her medication and did everything in my power to help...' Participant K.

'I took care of her at home, cleaning, washing and cooking' Participant I.

'I did everything that I could to take care of her, she got to a stage when she could not even go to the toilet, but I was cleaning her, giving her food' Participant H.

The findings of a study done on older women's relations with their households in rural South Africa concur with what the older women discussed in the focus group interview. Older women described care-giving as a responsibility that includes many activities, and these include feeding, bathing, fetching and preparing treatments, washing soiled clothing and blankets, helping the ill person to a pit latrine, travelling with the sick person to the traditional healer, clinic, private doctor, hospital and receiving care and treatment (Schatz 2007:150).

3.3.4.3 Self-protection

When caring for HIV/AIDS patients, precautionary measures should be observed, and these include washing hands and wearing gloves when handling or coming into contact with blood and other body substances to avoid being infected with HIV/AIDS on the part of the care-giver (Pomeroy, Mitchell, Roerig & Crow 2008:48, Swanson 2009:19, White, Duncan & Baume 2012:1005).

In the focus group interview, the participants did not dwell much on the issue of protective clothing. Participant K indicated that she does not use any gloves when attending to her sick adult child and as a result, she contracted HIV/AIDS.

'I never used any gloves bathing her'. Participant K

According to Dageid et al (2011:233), care-givers who provide care to patients without using gloves or other protective devices are at risk of contracting HIV/AIDS through contact with patients' body fluids.

The WHO has recommended a set of precautions for medical professionals for prevention of HIV infection and one of them is wearing gloves if there is a risk of contact with blood and body fluids while examining a person (Savitri 2008:44). This precautionary measure should also be considered by HIV/AIDS home care-givers to prevent HIV infection (Alarid 2009:114).

3.4 THEME TWO: CARING FOR HIV/AIDS AFFECTED AND INFECTED GRANDCHILDREN

As more people get infected with HIV/AIDS globally, more grandchildren are left in the care of their grandparents and care-givers. In Sub-Saharan communities, grandparents provide the most support to HIV/AIDS orphans. They have to buy food, clothing, take them school and take care of their health needs (Mapp 2014:123, Murphy, Cooper & Moore 2012:31, Tadele & Kloos 2013:112). According to Karim and Karim (2010:375), in South Africa, the number of orphans under the age of eighteen who have lost one or more parents is expected to rise in 2014 to an estimated level of six million.

In line with the literature, this study found that in some cases older women take care of their grandchildren while the parents are still alive. This theme is described under three categories and ten sub-categories. Refer to Table 3.1.

3.4.1 Challenges encountered

In this study, the older women had a duty to support their orphaned grandchildren, (some diagnosed with HIV/AIDS and others not). These women encountered many challenges in caring for HIV/AIDS affected and infected grandchildren. They took

responsibility of these children and they had to meet their educational and other social needs. The financial struggles to meet the needs of the grandchildren were described. The challenges are described in sections 3.4.1.1-3.4.1.5.

3.4.1.1 Responsibility to support

According to Lund and Tannehill (2010:165), responsibility is defined as personal acceptance for our conduct concerning others, our surroundings and ourselves. This includes fulfilling our obligations, keeping our commitments and nurturing and supporting one another. According to Madhavan, Schatz and Clark (2009:37), older women are likely to take much of the responsibility of care giving and sustaining households after an AIDS death occurs within their own household.

In this study, older women took responsibility of their grandchildren orphaned from AIDS on different levels. They took a role of nurturing and supporting the grandchildren because there was no one to care for them after their parents had died. From the researchers' question "who took the child after the mother died?" one of the participants responded:

'It's me isn't it that I am her grandmother, I took the child to hospital and she is now on treatment'
Participant K.

'These children are like our own children, they are our own responsibility...' Participant F.

'These children are like any other children despite their sickness, they need love, support' Participant F.

One of the specific responsibilities described during the interview was that of taking their grandchild/children to hospital when they get sick, and also, for routine medical check-ups.

'...I took the child to hospital and she is now on treatment'. Participant K

'My grandchild got very sick and I had to take him to the hospital, and I found out he is HIV positive'
Participant G.

'...I had to spend two weeks with him in hospital' Participant G.

'I take her to the hospital every month for medication and check-up' Participant K.

3.4.1.2 Financial responsibilities

Studies show that the high death toll of adult children in their prime years because of the HIV/AIDS epidemic greatly affects older women. It leaves older women as sole providers for the orphaned grandchildren (Dening & Thomas 2013:41, Fonchingong 2013:91).

Older women in this study expressed that their responsibility of caring for their grandchildren costs them a lot of money. The participants mentioned that they spend a lot of money on transport, school costs and nutrition.

'I am now doing piece jobs two days a week because my income per month is not enough to take care of this big family' Participant H.

'It's costing me money because when he gets sick I need to hire transport to take him to the hospital' Participant A.

'We have money problems, caring for grandchildren needs money, especially those who are sick' Participant H.

'Doctors write them a long list of the food that we should buy them. Some of the food there is very expensive' Participant L.

'...she loses things at school; jerseys, shoes and I have to replace them each time and again' Participant F.

'These kids need money when they go to school, you give them R1 and it's not enough' Participant L.

The South African Children's Act 38 of 2005, (South Africa 2005:104), provides foster care grants to eligible persons. Some of the older women said that they receive this grant, but the money is still not enough.

'...the grant is not enough, but I have to budget it' Participant L.

'...their grant with mine does a lot, but it is not enough to do the best for the children' Participant H.

'It is very difficult to depend on the grant because it is not enough' Participant F.

The participants were asked if they received any other support to alleviate financial burden. They all responded that they did not. Some of them indicated that they were

part of a food scheme, but they were now being excluded from the scheme because they receive foster care grants.

'There was an organisation which was giving food parcels but it stopped' Participant K.

'...but when they heard I was getting the grant they stopped giving me' Participant F.

'...I never got assistance there' Participant E.

The participants also reported wide spread irregularities in the food schemes.

'The people in these organisations take food to their families and we do not get anything' Participant L.

'...they are even opening shops' Participant I.

On a more positive note, some participants reported that there are school food schemes, which provided food for all school children.

'But schools are helping, they give them breakfast and lunch' Participant A.

'My grandchildren do not want to eat at school they say the food is not nice' Participant I.

'The teachers encourage us to give them empty lunchboxes and they get food from school' Participant F.

3.4.1.3 Sex education

The older women also mentioned their responsibility in sex education of their grandchildren. Grandchildren need this kind of guidance to prevent them from going astray especially during the adolescence. Adolescence is a time of great change and development and how people handle it depends on a host of factors which include family and social relationships, hence family is very important for children going through this stage (Carroll 2010:201).

One could detect a tone of concern in the remarks of the older women about the adolescent grandchildren.

'I found a condom in D's pocket...' (name of the child) Participant A.

'...I think it is adolescence messing with her head' Participant F.

'I sat down the other as I saw that one of the girls was now going around with men. I told them that these days there is HIV...' Participant F.

Sexual and reproductive health problems are extremely prevalent among adolescents. Reports from the United Nations Educational, Scientific and Cultural Organisation (UNESCO) and the International Guidelines on Sexuality Education (2008:1) show that young people who are not educated about HIV prevention are at an increased risk of contracting HIV because they do not know how to protect themselves. In this study, the older women played the role of educating and guiding their grandchildren on sexuality.

3.4.1.4 Disrespectful behaviour from grandchildren

Respect means valuing the person as a whole and it relates to attitude. It also includes an aspect of behaviour of one person towards another. Respect links to the person's worth and value (McSherry, McSherry & Watson 2012:49).

During the focus group interview four older women spoke about their grandchildren not showing any respect for them. This is a challenge to them as they do not know what to do with the situation. Some participants reported extreme negative measures, such as beating and chasing a grandchild away.

'In our tradition, after a parent dies, we sit down with the orphaned children left and tell them that their parent is no longer there and now they have someone who will care for them and they should respect that person, but the orphans in my care do not listen to anyone' Participant H.

'That child does not listen at home and he does not take orders from anyone' Participant A.

'I used to beat him, but I am now tired' Participant A.

'...I used to stay with my other grandchildren when their mother passed away; I chased them away to their father because of disrespecting me' Participant I.

'Orphans are not co-operative, they give us headaches...' Participant L.

The disrespect of grandchildren towards their grandmothers is also evident in the children's refusal to assist with ordinary household tasks. One would expect them to assist in some household chores, considering the age of their grandparents.

'...my grandchildren do not help me with anything in the house ...they bath and leave their clothes on the floor I have to clean after them' Participant H.

'...he does not even want to do anything, not even dishes...' Participant A.

The above statements support what was found in a study conducted by Hearle and Ruwanpura (2009:424) in Kwa-Ximba Community in Kwa-Zulu Natal Province. Despite the fact that the care-givers provide everything that their grandchildren need in their daily lives, grandchildren do not respect them. This leads to resentment on the part of the care-givers who feel that they are tired and too old to deal with the children's behaviour.

3.4.1.5 Unacceptable social behaviour

School aged children and adolescents go through a process of socialisation, which means they develop social skills and competences to foster appropriate and acceptable behaviour (Edelman & Mandle 2006:492). The older women in the study expressed their concerns about orphaned children who portray behavioural problems. These orphaned children do not listen to their guidance.

'At home he is always moody' Participant L.

'This boy is giving me problems; he even goes out at night' Participant A.

'That child does not listen at home and he does not take orders from anyone' Participant A.

'...I think its adolescents messing with her head' Participant F.

In a study conducted by Govender, Penning, George and Quinlan (2012:715), on care-givers for orphaned children in Amajuba district in South Africa, care-givers indicated that children in their care needed help for mental or behavioural problems. However only 3, 4% of all households had contact with child welfare agencies. This is also found in this study. The older women caring for HIV/AIDS affected and infected grandchildren in Atteridgeville did not report or seek help from social workers about behavioural problems of their children.

3.4.2 The social life of grandchildren

Socialisation is the process that starts within the family, extending to the broader society as children grow up. Socialisation is the process through which children

become a functioning part of society as they learn society's rules and values (Essa 2011:392). According to Berns (2013:15), socialization involves many experiences, interactions and environments that affect children's development. The way people are socialized affects their attitudes, values, motives and attributes, self-esteem, behaviour and morals.

In this study, the orphaned children with or without HIV/AIDS, were born and raised in the environment where parents and other family members were infected with HIV. Most of these grandchildren are raised by their grandmothers in an unstable family environment.

Literature shows different views on how children in HIV affected households socialise with friends and family members. Studies by Friemel (2008:166) and Boyden & Bourdillion (2012:192) show that orphaned children try to cope with stressful life through mutual help from friends. Interacting with friends, playing and going to school make orphaned children forget about their personal problems, hence they develop and maintain their self-worth. However, Ssenigozi (2007:258) maintains that HIV/AIDS orphaned children are stigmatized by their peers and other community members. They are also despised and often given nicknames as social outcasts, isolated and even shunned. They suffer rejection and discrimination from some relatives and friends.

Social interaction with friends and relatives is described below. It should be mentioned that at this stage of the interview, the participants were very quiet and seemed emotionally drained.

3.4.2.1 Interaction with friends

Some of the participants indicated that their grandchildren interacted well with friends.

'My grandchild is still young and there are no problems' Participant F.

'My grandchildren do not have any problems interacting with friends' Participant F.

However, it seems from the interview that some of these friendships were problematic for the older women and may even suggest peer pressure. From the

statements below, grandchildren spend most of their time on the streets and they go out at night.

'They like it more with their friends, they spend most of the time on the streets playing, and they even get home late' Participant H.

'He has friends that he plays with and even goes out at night' Participant A.

'...she has bad influence from friends. I am afraid something can happen to her at night' Participant F.

In a study by Xu, Wu, Rou, Duan and Wang (2009:25), on psychosocial well-being of children in HIV/AIDS affected families in South West China, findings show that older children tend to spend less time at home and more time with peers.

Some participants in this study reported that the grandchildren did not have problems in socialising, but other parties often had problems to relate to the children, because of the HIV factor. This sometimes led to isolation of the children.

'...they (people) suspect that these children have HIV, so it is a problem now because children are being told by their parents not to play with my grandchildren, so they are isolated...' Participant C.

3.4.2.2 Interaction with relatives

According to Karim and Karim (2010:375), in South Africa, many HIV/AIDS orphans are left in their maternal grandparents care after their parent's death. Likewise, in this study the grandchildren were left in the care of their maternal grandparents. The statements below show that the grandchildren in this study do not have much interaction with their relatives.

'My grandchildren do not have any know relatives from the fathers side whom they can interact with, but their mother's close relatives like me, aunts we interact well with them' Participant A.

'But on the issue of relatives, no relative interfered in this issue'. Participant C

One participant even reported that she cares for her son's child, who is HIV positive because the father is not interested in his child anymore.

'The first year when the child was left with me, he (the father) was coming to see him, but from then until now, I cannot get hold of him and he never come, I don't even know if he is dead or alive...' Participant G.

The participants in this study indicated that the grandchildren infected with and affected by HIV/AIDS they were caring for did not interact with nuclear relatives. Findings in this study do not concur with the findings of Xu et al (2009:26), who maintain that all children interacted with members of their nuclear and extended families. 75% of children believed they were in good relationship with their family caregivers because they received better care and emotional support from their family caregivers; they relied heavily on their adult caregivers to growing a sense of economic, emotional and social security.

3.4.3 Education/Schooling

According to Ball and Forzani (2007), cited in Aurthur, Waring, Core and Hedges (2012:11), education is a deliberate activity of helping learners to develop understanding and skills. This occurs in schools or similar institutions characterised by interactions among four elements: teachers, students, content and environment. Findings from the current study relates mostly to the support by teachers and the older women as caregivers. Content and environment were not explored.

Ssengonzi (2007:257) states that orphans often perform academically poor due to grief, hard labour, poverty, lack of proper nutrition and lack of guidance. This often results in school drop-outs. A high rate of school drop-outs leads to delinquent behaviour, street gangs, criminal activities, prostitution and drug abuse. On the contrary, consistent schooling supports children's morale and preserves a degree of equilibrium in their lives during transition periods (Karim & Karim 2010:384).

A study done by Wiseman and Glover (2012:175) on the impact of HIV/AIDS on education worldwide, teachers identified the most pressing needs of orphans in their classes. Psychologically, children need to be prepared to come to terms with their circumstances. They need to have control over their lives and they need to look forward to building a bright future like everyone else. Orphans need to continue going to school not only to learn but also to maintain a daily routine and a stable lifestyle.

Care-givers for orphans should have a good relationship with teachers at school to ensure that children's needs at school are well taken care of. By establishing a good

relationship with teachers, the care-givers should emphasize on children getting better education and they should reveal the backgrounds of the children to teachers. Children who do not do well at school should be involved in special skills classes and extra classes after school.

Maintaining discipline for grieving, impoverished orphans can be a problem for an older guardian. In most cases children are confused as they do not understand the disease and the circumstances around the loss of their parents. Even willing care-givers of HIV affected and infected orphans have reported the situation to be a complex one (Kamya & Poindexter 2009:5).

Encouragement and support offered by both the teachers and grandmothers as their care-givers were described in this study.

3.4.3.1 Encouragement and support

Encouraging someone means to reassure and support them when they are having difficulty with a task or experience (Mac Naughton & Williams 2009:68). Older women in this study never reported on their orphaned grandchildren dropping out of school. Statements below show that the older women, as care-givers, accepted the responsibility to encourage and support the children to excel in their education.

'They need encouragement to do their school work seriously, at home tell them to do better' Participant F.

'...the teacher told me to encourage and support her at home' Participant E.

Two participants made it clear that having HIV should not prevent children from performing well at school.

'Yes being HIV positive does not mean your mind is crippled' Participant I.

'At school they called me, they were surprised that the child was on treatment because she is very clever in her class' Participant K.

Despite the encouragement most of the older women reported that children are not performing well at school.

'...at school they are not doing well' Participant H.

*'D (name of child)...is not doing anything at school, he is in Grade 10'*Participant A.

'I am trying, but this child is not doing well at school'. Participant L

'M... (name of child) failed, she doesn't study' Participant F.

'Yes, some children behave well at school and some they do not, so at the end teachers give up'
Participant F.

'Let's support and encourage our children at home so that they can be better people at school and teachers can assist them' Participant I.

The encouragement and support found in this study contradicts findings from a study conducted by Kareith, Egesah & Kong'ong'o (2008:147) on the challenges of orphan foster-age in the era of HIV/AIDS in Kenya. They found that it is difficult for orphans to get their foster parents to provide for them with the support they need in their education to the extent that some had to drop out of school.

3.4.3.2 Teacher- care-giver relationships

The focus group interview revealed that participants and teachers have very good relationships. There is contact between teachers and care-givers about the children's behaviour or progress at school .The statements below show the contact between teachers and care-givers to ensure support for the children at school.

'I have a good relationship with the teachers; they call me at school, especially with the little one who is sick, because sometimes she sleeps in classes' Participant F.

'At school they called me they were surprised that the child was on treatment because she is a very clever in her classes' Participant K.

'When we go to school teachers have time for us, telling us the progress of the children, their behaviour, how they are supporting them and how we should handle them at home' Participant F.

'I was even called to school about this boy and it was bad news' Participant H.

'I have good relations with D...'s (name of child) teacher, she told me to encourage and support her at home' Participant E.

'The teachers are co-operative...' Participant A.

'I was even called to school twice to discuss about this issue (the grandchild disrupting class)'
Participant F.

Teachers have an important and positive role to play in the children's day to day lives, as they spend most of their time at school. This is supported by a study conducted by Wood and Goba (2011:275) on care and support of orphaned and vulnerable children at school in South Africa. The findings make it clear that there is a need for all teachers in school to work together in addressing the care and support of orphaned vulnerable children. The study also states that the relationship of teachers and care-givers is of paramount importance to children's education and well-being.

3.4.3.3 Food schemes

In this study, older women mentioned that there are food schemes operating in their communities and in schools, providing breakfast and lunch to learners. According to the Department of Basic Education, National School Nutrition Programme (NSNP), South Africa (2011:1), the primary school nutrition programme was introduced in 1994 by Nelson Mandela. The feeding schemes provide food to relieve child hunger and also to relieve poor care-givers when they are unable to provide enough food for their children. The nutritional programme also promotes healthy lifestyles amongst learners. During the 2012 State of the Nation address, President Jacob Zuma announced that over eight million learners benefit from the government's school feeding scheme (South African Government News Agency 2012).

Food schemes, as described by the participants, were discussed in detail under the financial challenges. Refer to section 3.4.1.2.

3.5 THEME THREE: MULTIPLE ROLE PLAYERS INVOLVED IN CARING FOR PERSONS WITH HIV/AIDS

HIV/AIDS treatment greatly relies on relationships among patients, families and health care providers. Rapport should be established as early as possible (Yu – Te & Huang 2013:221). Health professionals, the persons diagnosed with HIV/AIDS and the communities should work together and support each other so that the patients adhere to their treatment, making it easier for their caregivers. The four categories and six sub-categories of this theme are discussed below. Refer to table 3.1. In the

health care context, a person diagnosed with HIV/AIDS is called a patient. This is the term that will be used in this section.

3.5.1 Health-care team

The health care team provides health care services in order to promote, preserve, restore or improve a patient's state of health or in order to support a dying patient, (Nys 2010:95). In the current study, the health-care team was involved. Older women mentioned taking their sick adult children and grandchildren to hospital for treatment and support. During the follow-up member checking interview, the older women also spoke about Sangomas. All participants agreed that Sangomas cannot heal HIV, they believe HIV infected persons can get help they need in hospitals. These categories of health care are discussed in the following section.

3.5.1.1 Health professionals

According to Riegelman and Kirkwood (2014:178), there are formal requirements that define a health professional. These include admission prerequisites, coursework requirements, examination competency, and official recognition of education achievements and granting of permission to practice. The categories of health professionals include nurses, doctors, dieticians, pharmacists and others. The important role of health professionals in the lives of patients and care-givers includes treatment and health education to patients and information to care-givers on how to support patients.

In a study conducted by Sacajiu, Raveis and Selwyn (2009:1530), on the experiences of patients and family care-givers about Highly Active Antiretroviral Therapy (HAART), the findings show the importance of involving both patients and their care-givers in discussions in order to improve their understanding of the medication and to ultimately contribute to the patient's adherence to treatment. The study also suggests that healthcare teams may enhance dialogue with patients and caregivers to create therapeutic decisions to accommodate priorities and values of patients and their families.

The current study shows that despite strained relationships, disrespect, financial problems and other challenges, the older women diligently took their HIV affected

children and grandchildren to hospital. They also reported success stories about children taking their treatment.

'I took her to hospital and the doctor told me to support her because she had HIV, she was put on treatment' Participant L.

'I went to the hospital with my daughter ...' Participant E.

'I took her to hospital and they told her that she was HIV positive' Participant A.

'I took the child to hospital and the child is now on treatment responding very well' Participant F.

'She went on treatment and now she has fully recovered' Participant L.

'She is responding well and recovering now because she is now serious about her medication, but if she had taken it earlier she could have not been disabled' Participant E.

'...my daughter followed the doctor's instructions now she is fresh' Participant F.

'When I got to the hospital nurses praise me that I am taking good care of myself (the participant told the group that she was HIV positive) and my grandchild...' Participant K.

In this study, the participants mentioned nurses and doctors by name. However, other important team members such as pharmacists and dieticians were not mentioned.

3.5.1.2 Sangomas

Plummer, Mshana, Wamoyi, Shigongo, Hayes, Ross and Wight (2006:460) studied the sexually transmitted infection treatment seeking behaviour in rural Mwanza, Tanzania. Their study found that HIV/AIDS patients preferred traditional healers over health facilities for treatment because of familiarity, trust, accessibility, expense, payment plans and the perceived cause, nature and severity of illness because only traditional healers were believed to successfully treat bewitchment. HIV/AIDS was attributed to witchcraft and some traditional healers claimed to cure witchcraft and HIV/AIDS - like illness. Most individuals repeatedly visited traditional healers and stopped attending health facilities as they believed that they could be cured by traditional healers.

On the contrary, in this study older women caring for HIV/AIDS affected households in Atteridgeville relied on hospitals to get help from doctors with their sick adult

children and grandchildren. They discussed Sangomas, but none of them mentioned consulting a Sangoma about their children's illnesses. Participants are all of the opinion that if one is infected with HIV/AIDS, they have to go to hospital and receive treatment. They also believe that Sangomas cannot assist with anything regarding HIV/AIDS treatment, instead, they lie to them, wasting their money and their children end up dying.

'...but she got very sick and ended up telling me that we must not go to Sangomas and prophets. I am HIV positive' Participant F.

'Sangomas will waste your time; you will just wake up your child dead' Participant I.

'...if you want your child to die early with HIV take them to those Sangomas. I will never go to a Sangoma with a child diagnosed with HIV; it is just a waste of money' Participant E.

Audet, Blevins, Moon, Sidat, Shepherd, Pires, Vergara and Vermund (2012:1133) conducted a study on HIV/AIDS-related attitudes and practices among traditional healers in Mozambique. They found that traditional healers used razors to cut and rub herbs into the skin, they did not refer their HIV patients to the clinic because they did not recognize the HIV symptoms since they thought that they could treat the illness effectively themselves. The authors found that HIV-related practices of traditional healers probably increase the chance of infection through the reuse of razors and compromises successful treatment of persons already infected with HIV. This supports the participant's view that it is not advisable to take someone with HIV/AIDS to a Sangoma rather take them to hospital for treatment.

It has been proven that antiretroviral treatment assists many HIV patients to live a better and longer life. Skovdal, Campbell, Madanhire, Nyakupa and Gregson (2011:1006) maintain that treatment availability gives many antiretroviral users a renewed sense of social value, that include confidence in their previously compromised abilities to engage in housework, subsistence farming or formal work where available. If a patient responds well to treatment and recovers, then it means that they can maintain their social functioning and live their lives normally.

Older women in this study also acknowledged that it is safer to go to hospital for treatment when diagnosed with HIV/AIDS than seeking help from Sangomas. Thus,

if one is diagnosed with HIV/AIDS and put on treatment, one is expected to get better if treatment is adhered to.

3.5.2 The person diagnosed with HIV/AIDS

The term 'person diagnosed with HIV/AIDS' in this study refers to infected adult children and infected grandchildren under the care of older women in Atteridgeville.

A successful management of HIV/AIDS depends largely on the extent to which persons diagnosed with HIV co-operate and comply with and take responsibility for their treatment regimens. 'Adherence' is defined broadly as the extent to which a person's behaviour corresponds with medical advice, Meichenbaum & Turk (1987), cited in Gehlert & Browne (2011:534). Adherence and compliance are often used as synonyms. Crucial to adherence is acceptance of the illness, understanding the role of medication and a positive sense that taking medication will help (Ka 'o pua & Linsk 2007:136). HIV/AIDS treatment entails a combination of various types of ARVs in order to slow down reproduction of the virus. ARVs do not cure HIV/AIDS, but they simply prevent the virus from destroying the immune system, allowing infected people to live healthier and longer.

3.5.2.1 Co-operation

Anandarajan and Anandarajan (2010:17), define co-operation as acting together in a co-ordinated way at work, leisure or in social relationships, in the pursuit of shared goals to further the relationship.

In the current study, participants described co-operation in terms of adult children who acknowledge their diagnosis and work with health teams and the care-givers to improve the quality of their lives. Participants mentioned that they experienced problems with their sick children/grandchildren concerning their co-operation. Children mostly refused admitting that they were sick and they refused to seek medical help.

'..she didn't want to disclose what she was sick of...' Participant F.

'My child was very secretive, she could see that she was sick, but she did not say it... she did not even want me to know her status...' Participant E.

'My daughter also had HIV, she was very secretively about it, she kept it a secret until she died...and she was in denial but I could see that she was sick and she was dying' Participant H.

'I took her to hospital but it was too late' Participant L.

'...the other one who spoke out about it...is on treatment responding well and working for her children' Participant L.

'She started taking her medication but it was late, now she is disabled because of that disease' Participant E.

One participant stated that her grandson did not want to co-operate at all. He told her:

'I don't know why you people care so much because if there is a person to die it's me not you' Participant A.

HIV/AIDS patients should co-operate with health professionals and their care-givers on taking treatment. They should be diagnosed and put on treatment. If there is co-operation, there is a positive outcome as HIV/AIDS is manageable if the infected person adheres to treatment.

3.5.2.2 Compliance and non-compliance

According to Muller-Mahn (2013:112), adherence is often used as a synonym for compliance and concordance. Compliance refers to a more 'classic' hierarchical doctor-patient relationship where doctors/physicians give treatment directions which patients are supposed to follow unchallenged. In this study older women reported that some sick adult children/grandchildren adhered to treatment as they followed the doctor's advice. The lives of sick adult children/grandchildren changed because they were taking medication accordingly.

'My daughter who was sick had no children, she went on treatment and now she has fully recovered' Participant L.

'...the other one who spoke out about it is on treatment responding well and working for her children' Participant L.

'ARVs work because my grandchild is drinking them and she is living a happy life' Participant C.

Globally, rapid expansion and early access to ARV treatment services have resulted in a dramatic decrease in HIV related mortality and morbidity. However, the current regimens are to be taken continuously and require strict compliance by patients to achieve treatment success, to prevent drug resistance (Barton & Friedman 2008: 176).

A study conducted by Hiko, Jemal, Sudhakar, Kerrie and Degene (2012:58) on determinants of non-compliance to ARV among adults living with HIV/AIDS, concluded that successful antiretroviral treatment is dependent on sustaining high rates of compliance, that is, correct dosage taken on time and in the correct way. This was hinted by the participants who said that children and grandchildren who were taking their medication got better.

In a study conducted by Machado-Alba and Vidal (2012:360) on the effectiveness of ARV treatment in Columbia, one third of the patients had problems maintaining continuity of treatment therapy and this non-compliance resulted in treatment failure.

In the focus group interview some of the older women indicated that they were frustrated as their HIV/AIDS children and grandchildren were not complying with treatment. The children might have had their reasons for non-compliance, but the participants were concerned because taking their medication is the only way to live a better and normal life.

'I ended up giving up on her because she was refusing to take her medication' Participant H.

'Most people die because they do not want to take their medication' Participant L.

'This boy coughs that we won't even sleep, but he does want to take his medication' Participant A.

Non-compliance to ART is a major public health concern as it leads to virological, immunological and clinical failure as it increases the risk of transmission of the drug resistant virus. According to literature, the major factors leading to non-compliance to ART are thought to be forgetfulness, lack of understanding of treatment benefits, severity of adverse events and the level of complexity of the drug regimen. In a study conducted by Tran (2013:198) on HIV/AIDS care and treatment in Vietnam, barriers to ARV effective treatment included non-adherence to treatment, forgetting to take pills along when travelling and sleeping through the dose.

Because this study focused on older women as care-givers, it was not possible to determine the reasons why adult children/grandchildren did not co-operate or adhere to treatment.

3.5.3 The community

A community is a group of people living in the same place having a particular characteristic in common. The general safety and values of a community are a responsibility of every member of the society (Okpara & Idowu 2013:148). In this study, older women who are caring for HIV/AIDS households in Atteridgeville live in a community affected with HIV/AIDS. The community has a very important role to play on HIV/AIDS and on HIV/AIDS households. The values, responsibilities and roles of the community change because of HIV/ADS. HIV/AIDS infected/affected households are being stigmatized and isolated by the same community which is expected to provide support (Fuller 2009:137).

According to Karim and Karim (2010:157), the problem of HIV/AIDS in communities is being tackled through participatory peer education, community mobilisation and condom promotion in South Africa. This is done by different community based and non-profit organisations.

Even though the participants did not use the word 'stigma' during the interview they hinted that stigma exists in the community.

3.5.3.1 Stigma

According to Boesten and Poku (2013:30), HIV/AIDS related stigma can be defined as any negative thoughts, feelings and actions against people infected with or affected by HIV/AIDS.

Many authors describe how stigma causes persons diagnosed with HIV/AIDS to experience conflict, shame, prejudice and strained relations with community members. The family of persons with HIV/AIDS also falls victim to stigma (Pequegnat & Bell 2012:8, Jonas & Morton 2012:241).

Children are also affected by stigma. According to Corr and Balk (2010:343), stigma affects children and continues to threaten children's adaptation in communities after

the parents have died of AIDS. The stigma often leads to children's increase in social isolation and results in a decrease in their self-worth.

Evans and Becker (2009:200), describe how young people in Tanzania experienced 'stigma by association' including bullying and ostracism from their peers and others in the community. This impacted on their emotional well-being and led to social isolation. In this study, the older women did not report bullying of grandchildren, but rather isolation.

'...because the community knows that my children died of HIV, they suspect that these (grandchildren) children have HIV...other children are being told by their parents not to play with my grandchildren' Participant C.

'...some family members I was staying with were even scared to help sometimes...' Participant L.

'Neighbours and other people started talking ...because my four children died of HIV' Participant J.

Contrary to the discussion above, some communities can overcome stigma. This is described by Esu-Williams, Schenk, Geibel, Motsepe, Zulu and Bweupe (2006:890) in Zambia where the community overcame stigma through assisting and interacting with people living with HIV/AIDS. Thirty anti-AIDS club members received training to become adjunct caregivers to families in their communities. They helped with domestic chores; bathed HIV infected persons and dressed their wounds and provided information and support to family members. The study found that as a result of observing the activities of the youth caregivers and interacting with them, family members became more involved in the care of the sick relatives. Community members started visiting people with HIV/AIDS.

3.5.3.2 Secondary stigma

The findings by Ogunmefun, Gilbert and Schatz (2011:85) illustrate different forms and expressions of HIV/AIDS-related secondary stigma and their impacts on older female caregivers. These include physical stigma in the form of isolation and separation from family members, social stigma in the form of voyeurism and social isolation and verbal stigma in the form of gossip, finger pointing and jeering at people living with HIV/AIDS.

Mandelstam (2011:45) states that neglect means a lack or failure to care for. Isolation can be understood as a desire to have contact with others, but because of social, emotional or geographic barriers, people might not be able to do so (Glicken 2009:163). In this study, the older women mentioned that they were neglected and isolated because of the HIV/AIDS status in the households.

'Some other family members I was staying with were even scared to help (with the caring) sometimes'
Participant L.

'I could not socialise with people because I had a lot to do for my children, neighbours and other people started talking and I was very hurt'. Participant J

Neglect and isolation are very common in HIV/AIDS infected/affected communities. A community needs to have knowledge on HIV/AIDS in order to deal with the stigma attached to the disease. Social workers and health professionals should engage in workshops, training and awareness campaigns to educate communities on HIV/AIDS and to mobilise the communities to assist those infected and affected by HIV/AIDS.

The participants did not report any positive interaction with the community, neighbours and family members. However, one participant encouraged the group:

'Do not listen to what people say, many people are sick out there. I do not care about neighbours because they talk' Participant F.

Based on this study, it is evident that as the epidemic spreads and older women become care-givers to sick adult children, there is a growing need to address the issue of secondary stigma. Stigma can make the responsibilities of a caregiver more burdensome as they struggle to cope with loss of the loved ones as well as with the shame associated with the fact that their loved ones died of HIV/AIDS.

3.5.4 The care-giver

The caring role of the older women has been described in detail in the first two themes. Despite the fact that children and grandchildren are diagnosed with HIV/AIDS and all the challenges associated with in caring for them, they accepted caring role. Some participants even expressed a positive attitude.

3.5.4.1 Positive attitude

A study by Tran and Nguyen (2012) highlights the importance of family members in supporting patients during the course of ARVs. HIV/AIDS patients need encouragement and support, emotionally, socially, psychologically and financially. These aspects are visible in the data collected from the older women caring for HIV affected households in Atteridgeville. Most of them were discussed in theme one and theme two.

The statements below show that the older women caring for their HIV/AIDS infected adult children and HIV/AIDS affected and infected grandchildren did so with a positive attitude despite all the challenges they faced.

'You should have love for your sick children because with no love they feel it...' Participant F.

'...it is your child and you have to take care of them despite what people say...' Participant F.

'When my children died of the disease...I have not accepted it and it's still hurting me...this thing eats my heart' Participant J.

'This really hurt me because I also loved my daughter and didn't want her to die...' Participant L.

'I feel more responsible because these children (grandchildren) tell me that I am their only parent they know' Participant F.

Positive interaction with people living with HIV/AIDS should be emphasised within family members, neighbours and communities. There is no other source of support than family, neighbours and communities. This should be emphasised for the sake of the persons diagnosed with HIV/AIDS and the caregivers. Opportunities to share positive thoughts and hope should be created in communities.

3.6 THEME FOUR: THE IMPACT OF HIV/AIDS ON THE LIVES OF CARE-GIVERS

As care-givers, participants in this study reported that they experienced emotional and financial stress, deterioration in their health, increased loneliness and isolation due to changing family structures and stigma from the community. Although most of these aspects were discussed in themes one and two, the researcher found important to briefly summarise how these impact on the everyday lives of the older women.

3.6.1 Financial strains

HIV/AIDS has a financial impact on the everyday lives of the older women as they have to buy food, pay rent and take their sick adult children and grandchildren to hospital. Refer to sections 3.3.2.2 (financial factors) and 3.4.1.2.

3.6.1.1 Old-age grant

According to Folbre, Shaw and Stark (2013:109), the elderly, particularly black women, are increasingly assuming the role of primary care-giver, as the middle generation is either forced to migrate out of the household in search of scarce employment opportunities or have died of HIV/AIDS. Old-age grants are an important source of income together with the child support and foster care grants, from which the elderly care-givers are able to meet all the additional expenses. Most poor elderly South Africans receive a small means-tested non-contributory government pension which was expanded to the black population in 1994, Social Assistance Act (Act 13 of 2004), (South Africa 2004). Pension income helps to diminish the impact of economic shocks, such as cost of illness, funerals and caring for fostered and orphaned children and may contribute to families' reliance on the elderly (Schatz 2007:150).

Since the participants are older women (sixty years and above), they qualify for an old age grant which is currently R1 350 every month. Statements below indicate that despite the grant they receive monthly, they still incur financial difficulties as they use the money to care for the sick, to maintain their families and to provide basic needs.

'I had a big family to care for with little money, at that time I was receiving an old age grant of about R1000' Participant F.

'I used my pension, did a lot for my sick child I used money for transport, food, paying rent and everything in the house' Participant L.

'I went to a loan shark for my daughter's funeral expenses, so it took me a lot of months paying the debt with my own pension' Participant H.

3.6.1.2 Foster care grant

In South Africa, child fostering is culturally well sanctioned and a long-established practice, with biological parents (single or both), allowing the child to be raised by

another adult, usually a grandparent (Karim & Karim 2010:384, Children's Act (Act 35 of 2005), South Africa 2005:35. The current foster care grant is R830 every month and some of the participants reported that they were caring for more than one grandchild with or without HIV/AIDS. In view of HIV affected households, the foster care grants is of utmost importance since parents, sick or deceased, no longer contribute financially.

The grant provides a much higher payment than the child support grant and it is not easy for one to register for the grant since it involves court orders and referrals to social workers. It has increasingly been used to support families that foster children orphaned through HIV/AIDS. Among households that have managed to access the grant, it appears to be reserved for AIDS-affected families.

'...the grant is not enough, but I have to budget it' Participant L.

'They are five and I am getting foster care grants for two, I am in the process of applying for the other three' Participant H.

Participants indicated that they knew about the foster care grant and that they have applied for it as it will assist them to cover expenses for the grandchildren, though it is not enough to cover all the expenses.

3.6.2 Biophysical impact

Older women caring for HIV/AIDS households in Atteridgeville have the responsibility of care-giving as an ongoing duty. This is supported by a study conducted by Boon, Ruiter, James, van den Borne, Williams and Reddy (2010:48) on older adults caring for children and grandchildren in South Africa. Besides taking care of themselves and their households, older persons face ongoing tasks such as bathing, dressing and taking sick adult children to a doctor.

3.6.2.1 Ongoing tasks

For the older women who participated in this study, caring for their adult children and grandchildren with HIV/AIDS was an ongoing duty. These issues were discussed in detail in sections 3.3.4.1, 3.3.4.2 and 3.4.1.

Statements below show different tasks performed by these older women on a daily basis.

'I take the child to hospital every month for check-up' Participant F.

'I used to go to the hospital three times a day' Participant E.

'When he was sick I had to spend 2 weeks with him in hospital, now I pray that he grows up healthy' Participant G.

'I had to wash her, feed her...' Participant L.

'I took my daughter to the hospital when she was sick...' Participant K.

'...I was touching blood, saliva, human waste, everything' Participant K.

Their everyday tasks are also discussed by Ogunmefun, Gilbert et al (2011:85) in a study on female care-givers and HIV/AIDS in South Africa.

3.6.2.2 Physical strain on the care-giver

During the focus group interview, participants indicated that they experienced physical strain when caring for their HIV/AIDS infected children and orphaned grandchildren. The participants are all older women of sixty years and above, who are likely to have physical strains and diseases related to old-age. Caring for a sick child comes with many responsibilities which require physical strength, for example, bathing, lifting and feeding the sick child, amongst others. Statements below indicate that these participants were physically strained.

'I also took a strain physically as I had to do everything for the sick child...' Participant F.

'I bath her, feed her, clean after her, and lifting her up and I am not physically strong, I have high blood pressure and sugar diabetes' Participant F.

'Taking care of someone sick is not easy, especially at this age, when you also have your own problems and you are also not healthy' Participant I.

'When my children died of this disease I was admitted in hospital for almost a month I was very stressed...' Participant J

A study conducted by Ssengonzi (2007:349) shows that elderly care-givers experience physical strain when caring for adult patients. Elderly female respondents

reported more physical ailments such as chest pains, leg pains, back-ache, blood pressure and hypertension and these were attributed to frequent changing, lifting and washing of adult patients. More female participants reported sleep deprivation and weight loss because of the constant care giving needs; they also felt fatigued and frail more often than their male counterparts.

3.6.2.3 Emotional stress

Emotional stress refers to the immediate emotional responses of a person to stressful life events (Dobson 2010:203). According to Dageid et al (2011:233), emotional stress on the caregiver comes from the traumatic effects of caring for the sick or dying patients and witnessing their death.

The participants' statements indicated that they were emotionally drained by their care giving responsibilities as they had to be there for the sick children all the time, doing everything for them. The care-giving responsibility stressed them and affected their daily lives.

'But, it is not easy taking care of a sick child' Participant F.

'I used to go to the hospital three times a day, this was very hard on me because I had to walk sometimes, I became thin and I was stressed' Participant E.

'I am also sick, old and emotionally drained' Participant J.

'I was very frustrated at some point because my daughter was very rude to me, even on her death bed' Participant H.

A study conducted by Ssengozi (2007:254) also reveals that emotional strain of care-giving can lead to physical and emotional complications such as insomnia, chronic fatigue, tiredness, high blood pressure, depression, anxiety, poor appetite, helplessness and chronic pain all of which have detrimental effects on the health of the carer-giver.

Death affects people emotionally and psychologically. In this study, the deaths of children affected the older women. It was not only the death of their children, but also the responsibility to look after their grandchildren that affected the participants.

'She did not want to take her medication, but unfortunately she died leaving her baby with HIV/AIDS'
Participant F.

'When I went back home to cook for her I then received a phone call from the hospital that she was dead' Participant E.

'Two of my children died of HIV...those were the only children I had..., that is why I am saying it's hurting' Participant B.

In this study, the researcher did not explore the grieving process or unresolved grief. However, literature reveals that when a family member dies of AIDS, the surviving family members may feel that they have done something wrong in having a family member dying this way (Bersoff & Silverman 2013:646). A study by Demmer (2011:878) on experiences of families caring for HIV-infected children in KZN in South Africa reveals that many care-givers have unresolved grief stemming from the loss of children and family members to AIDS.

3.7 INTERPRETATION OF FIELD NOTES

The field notes taken during the focus group interview, highlighting the non-verbal responses of participants are discussed in this section. These responses were considered during the analysis of the transcripts and the discussion of the findings.

There were many emotions on the participants' faces when they shared their experiences in caring for their sick adult children. Participant F shared her experiences with a very sad face and Participants H, D, L and G were uneasy and sad as they listened. Participant H always seemed to agree with others through expressions like (awwwww, ummmmh) as she listened to other participants telling their experiences. The group also agreed as the discussion went on; they would shake their heads, nod their heads, hold their chins or touch their mouths in surprise. Participant D, A and G showed sad faces as Participant L related her experiences. The researcher also consoled the participants who broke down in tears, like Participant E. The participants often asked for permission from the researcher to talk. The participants consoled each other, showing sympathy to one another, for example, Participant H was patting Participant G on the back telling her not to cry.

When participant K was sharing her experiences in caring for her sick grandchild, she revealed her own HIV positive status. All the other participants looked surprised and Participant H showed some sympathy. When participant G was talking about her grandchild with HIV, she cried. Participant A showed a feeling of helplessness when relating to the group about her grandchild who was not complying with his treatment. The participants encouraged and supported one another throughout the focus group interview.

As the participants discussed how doctors were helping their sick adult children and giving them treatment, they sounded hopeful. Some participants who had seen results of children getting better gave other participants hope. Participant F also showed some regret as she was explaining that if her daughter had taken her medication she could be alive. Participants K, D, L, F and E were very confident to talk about HIV treatment that works for their children and grandchildren. Participants H, I and A showed some disappointment as they related their experiences about their children who refused to take medication and eventually died.

Participants L, K and I sounded stressed as they described the tasks they had to do for their sick adult children, which involved cleaning, washing, cooking and feeding. According to Participants E, K, L, H, I, D and A, the issue of their children eventually dying and leaving HIV-infected children behind really hurt them.

However, participants showed respect, sympathy, love, encouragement and support for each other throughout the focus group interview.

The researcher also had to deal with unexpected situations. Participant L's phone rang in the middle of the session and the researcher kindly told her to switch off the phone. Participant F's grandchild also cried and she took her outside.

The researcher could sense the value of sharing experiences as participants shared their different experiences (Hasse-Biber & Leavy 2010:296). The participants ended up sharing and even giving each other advice comfortably as they shared similar problems.

3.8 CONCLUSION

The chapter focused on the analysis of data from the focus group interviews. The information from the focus group was transcribed and themes, categories and sub-categories were identified. Data was analysed and literature control was done based on the themes, categories and sub-categories. The next chapter discusses the findings of the study and the recommendations.

CHAPTER 4

DISCUSSION OF THE FINDINGS, EVALUATION OF THE STUDY AND RECOMMENDATIONS

4.1 INTRODUCTION

The researcher explored the experiences of older women caring for HIV/AIDS affected households in Atteridgeville. Findings, recommendations, limitations and conclusions from the study are discussed in this chapter.

4.2 RESEARCH OBJECTIVES

The objectives of this study of limited scope were:

- To explore the older women's experiences on caring for HIV/AIDS affected households.
- To identify the factors that impacts on older women caring for HIV/AIDS affected households.

In order to meet the first objective, the researcher explored the experiences of older women caring for HIV/AIDS affected households through a qualitative, explorative and descriptive study using focus group interviews conducted with twelve older women from three different Elderly Day Care Centres in Atteridgeville. A follow-up focus group was conducted with seven participants to gain more information on the issues pertaining to caring for HIV/AIDS infected or affected grandchildren. The participants were given a platform to discuss their experiences freely in a warm and comfortable environment in a trustful relationship. The researcher took into account the verbalised experiences and the non-verbal cues to analyse the experiences as shared by the participants. The meaning thereof were structured and described according to sub categories, categories and themes (refer to Table 3.1).The first research objective was met, as described in detail under four main themes in chapter 3.

The factors that impact on older women caring for HIV/AIDS affected households in Atteridgeville are discussed in the summary and interpretations of the findings in section 4.3 below, to fulfil the second objective.

4.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

A number of factors that impact on the lives of older women caring for HIV/AIDS affected households in Atteridgeville were identified. The findings of the research are summarised according to the four main themes and factors that affect the lives of the participants are highlighted accordingly.

4.3.1 Theme one: Caring for adult children diagnosed with HIV/AIDS

The study participants described different **emotional feelings** that include anger, hurt, fear, worry and helplessness as they care for their adult children diagnosed with HIV/AIDS. Refer to sections 3.3.1.1-3.3.1.5. The older women shared their negative feelings about caring for HIV/AIDS households. These feelings were a result of knowing that the adult children were HIV positive and the fact that the adult children did not acknowledge the diagnosis, leading to their death.

Despite all the media coverage on HIV/AIDS, older people in Atteridgeville who are directly involved in HIV/AIDS affected households are not prepared to deal with the emotional impact caused by the disease. There are no structured forms or platforms for older women to discuss their problems related to caring for HIV/AIDS affected households to allow them to vent their emotions. This is the reason why members of the multidisciplinary health team had to plan and implement different ways to assist older women to deal with their emotional feelings on a continuous basis.

Strained relationships between older women and their sick adult children were evident from the data. Refer to sections 3.3.2.1-3.3.2.3. The findings revealed that the adult children only went back home when they were sick and needed care from their parents. The strained relationships which existed between the older women and the sick adult children resulted in the sick adult children not disclosing their HIV-positive status to the care-givers. This led to delayed treatment and death. Poor communication between sick adult children and the participants was evident. The sick adult children could not disclose their HIV status to their mothers and some of them were rude to their parents. Caring for sick adult children became a burden for the care-givers. The role of the care-giver entails a lot of daily responsibility. Older women bathed, washed, cleaned, fed and took their sick adult children to hospital.

These are not easy asks, especially for people of their age. Normally the accepted socio-cultural behaviour will be that adult children take care of aging parents. However, HIV/AIDS has changed this social practice, as the sick adult children depend on the older women for care.

The researcher found that good relationships and communication skills should be enhanced in families to prevent situations where a child and a mother cannot discuss certain issues like HIV/AIDS because it affects everyone in the family. Social workers should be involved through family group conferencing in assisting families to improve their communication and problem solving within the families. Furthermore, older women should get help from family and relatives to make their caregiving responsibility easier. This could be done through co-ordinated home-based care services within the community, to assist older women in their tasks of caring for their HIV/AIDS affected households.

Older women use two **coping strategies**. These include believing in God and accepting that their adult children were sick. Refer to section 3.3.3.1 and 3.3.3.2. The spiritual component gave them the strength to move on with their caring responsibility. These older women believe God made their care-giving responsibilities easier because they trust that God gives them strength to pull through.

It seems that church leaders within the community should engage in guiding the older women in HIV/AIDS in a spiritual way. It is evident in this study that their belief in God and their acceptance of the situation gave them courage and strength to carry on with their caregiving responsibility. Older women can be assisted in identifying and using different sources of spiritual encouragement and church leaders and church members in the community have a role to play spiritually in assisting these older women to deal with HIV/AIDS households.

Acceptance plays an important role. Accepting that their children were diagnosed with HIV/AIDS assisted the older women to be positive in their care giving roles. Despite the sick adult children not accepting their status, the older women accepted the status of their adult children and they kept on supporting them.

The researcher is of the opinion that social workers should also be engaged in counselling and equipping the older women with coping mechanisms for them to be able to deal with the demands of HIV/AIDS households.

The older women described their **ongoing duties** in caring for their HIV/AIDS affected and infected households. These include; giving emotional support, caring for the personal needs of the adult children and protecting themselves against contracting HIV. Refer to sections 3.3.4.1-3.3.4.3. It became clear that the responsibilities of caring for sick adult children placed a high demand on the physical strength of the older women. Most of the women suffer from chronic diseases which affects their stamina and energy. It seems that the participants are unaware of issues relating to self-protection when caring for an HIV/AIDS person. They expressed surprise when they heard that one of the participants contracted HIV from her adult child because she did not use proper protection.

The researcher is of opinion that older women should get help from family and relatives to make their caregiving responsibility easier. Social workers should also co-ordinate home based care services within the community so that they can assist older women in caring for their HIV/AIDS affected households. It is very important that health care practitioners should be made aware of the fact that home caregivers should be informed of the risks that go with the responsibility of caring for individuals with HIV/AIDS and that they should be equipped with the basic protective gear such as gloves, especially towards the last stages of AIDS.

4.3.1.1 Factors that impact positively on older women caring for their adult children diagnosed with HIV/AIDS

The two factors which impact on the older women positively are:

The spiritual belief that God gives them the strength to carry out their responsibilities towards their HIV/AIDS children and,

Women accepting that their adult children are diagnosed with HIV/AIDS taking care of them and making the best of the situation.

4.3.1.2 Factors that impact negatively on older women caring for their adult children diagnosed with HIV/AIDS

The study found that there are a lot of factors that impact negatively on older women and these include:

Older women failing to identify and express emotions they experience as care-givers to the HIV/AIDS adult children,

Older women are not guided and assisted to deal with their negative emotions which leads to unresolved emotional feelings,

Poor or non-existent communication between parents and children, leading to more negative emotions, and

Suffering from chronic diseases associated with older persons makes it difficult for the women to render the needed on-going care to their sick adult children on their own.

4.3.2 Theme two: Caring for HIV/AIDS affected and infected grandchildren

The older women in this study **encountered challenges** in caring for affected and infected grandchildren. The older women agreed that culturally and from a family perspective, they are the ones expected to take on the responsibility of supporting their grandchildren after their adult children died of HIV/AIDS. The grandchildren (with or without HIV/AIDS) needed to be cared for. Refer to 3.4.1.1.

It seems that the major challenge the older women faced was lack of funds to meet all the needs of the grandchildren and the extended family. The women need money to buy food and clothing, school fees and transport to take the sick children to hospital for monthly check-ups. However, the women manage the financial responsibility by using their old age grants and, in some cases, the foster care grants they receive on behalf of the children. Refer to section 3.4.1.2

There were also sex-related issues mentioned by older women. They reported that their teenage granddaughters are now involved with men and that some grandsons carry condoms in their bags. One could sense that the older women are concerned that their grandchildren might contract HIV as they suspect that they are now sexually active. Refer to section 3.4.1.3.

It is evident from the data that grandchildren are disrespectful to the older women and they display generally unacceptable social behaviour. The older women reported that children come back home late at night and they do not assist with house chores. In the absence of the primary care-givers (parents), the older women found it difficult to control the grandchildren, especially teenagers. Refer to sections 3.4.1.4 and 3.4.1.5.

The huge age gap makes it difficult for the old women to give sex education to the adolescent grandchildren. Therefore, the researcher suggests that there should be a sustainable plan of action for orphaned children, to guide and maintain the social morals and to mould the behaviours of these children. Social workers can mobilise health-care workers from community clinics to talk to teenagers and teach them on sex education, to prevent them from contracting HIV/AIDS.

Caring for HIV/AIDS affected and infected grandchildren also involved the **social life of grandchildren** which includes their interaction with friends and relatives. From the data gathered, it seems the grandchildren easily interact with their friends, but they hardly interact with their relatives. Refer to sections 3.4.2.1-3.4.2.2. In this study, older women reported that their grandchildren interacted more with their friends and not with their relatives. The older women kept their problems (as care-givers) to themselves.

This could be due to fear of embarrassment and stigmatisation by relatives. Although the women never used the word stigma, it may be due to the stigma attached to HIV/AIDS that they found it difficult to share the HIV status of a family member with the extended family or even friends. HIV/AIDS awareness programmes should be revised to meet the current needs. In most programmes, the focus is on the spread and prevention of the disease. It seems necessary to inform the families and community at large about the need for support to HIV/AIDS infected and affected households.

The **education or schooling** of grandchildren seems to be important for the older women. They want success for their grandchildren at school that is why they are concerned about their education/schooling. Refer to sections 3.4.3.1-3.4.3.3. The women emphasised that their grandchildren need encouragement from them as their

caregivers and at school from their teachers. The older women confirmed that teachers play an important role in these children's lives. From the discussion, it is clear that there is a good relationship between grandmothers and school teachers. Teachers often report on the grandchildren's performance and progress and to the grandmothers. Older women also mentioned that schools play a big role in providing food to children during school hours.

The researcher concludes that there should be co-operation between school bodies and social services, to increase the number of role players in caring for HIV affected or infected school children. Social workers need to work together with other social workers in schools and teachers so that they can identify problems at home which affect children at school, to assist in maintaining the children's social functioning and educational progress.

4.3.2.1 Factors that impact positively on older women caring for HIV/AIDS affected and infected grandchildren

The researcher identified three issues that impact positively on older women caring for HIV/AIDS affected and infected grandchildren and these are:

Positive relationships between teachers and care-givers, which is an advantage to grandchildren,

Food schemes from school serve a dual purpose, that is, as financial relief for the care-givers and to sustain the energy levels of children to be able to perform well at school and,

Despite all the challenges that they face, participants show a positive attitude in encouraging and supporting their grandchildren

4.3.2.2 Factors that impact negatively on older women caring for HIV/AIDS affected and infected grandchildren

Factors with a negative impact on the care-givers include:

Financial problems, as the old age and foster grants are not enough to meet all the needs of the household,

Disrespectful, unacceptable bad behaviour of grandchildren towards their grandparents, is directly the opposite of what society expects from them and, The fact that nuclear and extended families are not involved in the care for HIV/AIDS affected households has two negative implications. There is a lack of positive role models for the children to be raised within acceptable social norms. Secondly, the older women do not get the necessary assistance to relieve them from the physical and emotional strains of raising children at their age.

4.3.3 Theme three: Multiple role players involved in caring for HIV/AIDS persons

In the interview, the older women mentioned health professionals and Sangomas as the only **health-care team**. Refer to sections 3.5.1.1 and 3.5.1.2. Health professionals play an important role in caring for persons with HIV/AIDS. The older women took the responsibility to take their sick adult children and grandchildren to hospital for check-ups and treatment. It is evident that the older women are happy and satisfied with the assistance they get from nurses and doctors. Most of them agreed that if HIV patients follow the advice from doctors and nurses, they can live longer. However, the women only focused on nurses and doctors, whose services are used regularly. They did not mention any other category of health professionals.

Sangomas were mentioned by the older women, but not in a positive sense with regards to HIV/AIDS treatment. The older women ruled out the idea of going to Sangomas for HIV/AIDS treatment.

The researcher sees the need for social workers to familiarise themselves with the role of all categories of health-care professionalism hospitals and clinics in the community so that they can be able to refer older women facing HIV/AIDS problems in their households for professional advice and assistance.

The women described the role of **persons who are diagnosed with HIV/AIDS**, thus the sick adult children and grandchildren, in their own treatment and care in terms of co-operation and compliance. Refer to sections 3.5.2.1 and 3.5.2.2.

Women reported that sick adult children and grandchildren who took their medication got better. Most of the grandchildren with HIV were reported to be complying with

their treatment; hence they are living normal lives. It seems adult children with HIV/AIDS were, in many cases, not willing to co-operate and to comply with treatment regimens. This led to the death of adult children which caused a lot of stress and sadness for the older women.

The research has shown that stigma is still attached to HIV/AIDS and social workers, doctors and nurses should work in a team and have a coordinated plan to offer counselling to persons diagnosed with HIV/AIDS. During their treatment they should be motivated to co-operate and to comply with their treatment.

In **the community** where the older women stay with their HIV/AIDS affected households, they experience stigma and secondary stigma. Refer to sections 3.5.3.1 and 3.5.3.2. The older women described that after the deaths of their adult children their younger grandchildren experienced stigma and could not play with others in the community as they were thought to be HIV positive. The secondary stigma is evident in gossip from neighbours which led to social isolation of older women.

The important role of the **care-giver** was portrayed in a positive way. Refer to section 3.5.4.1. Despite all the challenges, the older women had a positive attitude in caring for their HIV/AIDS adult children and HIV/AIDS affected and infected grandchildren. Even in the absence of good support structures, the loving and nurturing role of a mother came out very strongly.

The researcher realised that there is still a need to eliminate stigma. Social workers should engage with community leaders and forums and set up procedures to educate the community about HIV/AIDS to encourage discourse about the condition. Doing so will reduce the stigma of HIV/AIDS. Furthermore it will lead to formal and informal support structures to assist older women caring for HIV/AIDS affected households.

4.3.3.1 Factors that impact positively on multiple role players involved in caring for HIV/AIDS patients

In this theme the factors with a positive impact include:

Women's trust in the treatment prescribed by doctors and nurses, to ensure a better quality of life for their loved ones,

Participants agreeing that Sangomas cannot treat the disease; this is very important as it links directly with compliance with prescribed treatment and,

Women highlighting the importance of a positive attitude, as they continue to support, encourage and help their sick adult children and grandchildren.

4.3.3.2 Factors that impact negatively on multiple role players involved in caring for HIV/AIDS patients

The negative factors concerning the role players in caring for HIV/AIDS persons include:

Limited categories of health professionals involved in the diagnosis and treatment of HIV/AIDS; involvement of pharmacists and dieticians would make it easier for the older women to care for their HIV/AIDS affected households,

Lack of co-operation and compliance from some sick adult children and grandchildren has an impact on the emotions of the older women as they cannot bear to see the health of their adult children and grandchildren deteriorating and,

The stigma attached to HIV/AIDS leads to discrimination and isolation for the person affected and the family.

4.3.4 Theme four: The impact of HIV/AIDS on the lives of care-givers

Most of these issues were discussed in the previous themes. The two main issues highlighted are financial strain, as well as the biophysical impact on the older women

The older women **face financial strains** in caring for HIV/AIDS households. Refer to sections 3.6.1.1 and 3.6.1.2. The older women have many dependants that include extended family, their sick adult children and dependant grandchildren. The older women said they receive old age grants from the government, which help them to sustain their families. Some also receive foster-care grants. However, their total income is lower than what they spend.

The researcher interpreted this in terms of assessment of the household situation of each older woman to work out a realistic budget from the available old age grant

income. The older women must be encouraged to report to social workers if they care for orphaned children so that they can get assistance in applying for a foster care grant. Social workers could also assist older women to engage in income generating programs so that they can get extra income to help them care for their HIV/AIDS affected households.

The older women perform on-going tasks in their responsibility of caring for the HIV/AIDS affected households. These tasks include day to day duties of bathing, washing, cooking and feeding the sick amongst others. Refer to sections 3.6.2.1-3.6.2.3. The above mentioned duties strain them physically and emotionally. These older women reported health problems which normally come with old-age. They were also taking physical and emotional strain with their daily tasks because it is not easy taking care of a sick person.

As mentioned before, the social worker had to assess the situation and plan with other family members or home based care workers in the community, to assist the older women with these ongoing tasks to reduce the physical and emotional strain.

4.3.4.1 Factors that impact positively on the lives of care-givers

Receiving the government old age grants and foster care grants is a positive factor, even if it is not enough to meet all the needs of the family.

4.3.4.2 Factors that impact negatively on the lives of care-givers

The grants are not enough to cover all the basic needs of HIV/AIDS affected households,

Because of their age, care-givers (older persons) do not have the strength to carry out the on-going activities of caring for the sick adult children and,

Stress and emotional hurt caused by the death of a loved one.

4.4 RECOMMENDATIONS FOR FUTURE RESEARCH IN ATTERIDGEVILLE

In this research the researcher focused on the experiences of older women caring for HIV/AIDS affected households in Atteridgeville. To get a holistic picture of

HIV/AIDS affected households, the following research can be undertaken in Atteridgeville:

- The sick adult children and grandchildren have to be involved in research to describe their experiences of the diseases and also to identify their needs as far as living in an HIV/AIDS affected household is concerned.
- The actual financial needs of HIV/AIDS affected households in Atteridgeville can be investigated

4.5 RECOMMENDATIONS FOR SOCIAL WORKERS IN ATTERIDGEVILLE

- Older women caring for HIV/AIDS affected households need emotional support to deal with their caring responsibilities. The social workers working with older people should establish support groups and conduct group work with these older women so that they can support each other emotionally.
- Social workers must explore additional resources of income to assist older women to care for their HIV/AIDS affected households.
- Support group interventions should address the material needs and emotional needs simultaneously
- Social workers working with older people in Atteridgeville should mobilise the available home-based care services to release some of the burden from older women.
- Social workers should initiate a multi-disciplinary forum including all health care categories as well as teachers working in the Atteridgeville area to ensure holistic, comprehensive assistance to all persons involved.
- Children with behavioural problems should be identified and referred to social workers for assessments and therapy. In Pretoria, there are schools like Jabulani, where children with special behavioural issues are admitted and they can get help to deal with their emotions and psychological problems.
- Social workers and health professionals should engage in workshops, training and awareness campaigns to educate communities on HIV/AIDS and they should include topics on specific problems and needs of the community.

4.6 PERSONAL REFLECTION

The researcher chose a topic on older women caring for HIV/AIDS affected household because the researcher is a social worker by profession working with these older women. The researcher therefore observed some of the problems the older women faced on a daily basis.

As the researcher, I come from an HIV/AIDS affected family. When I conducted this research, I had the older woman in my family in mind, who also has an HIV/AIDS infected adult child. It motivated me to conduct this study to explore the experiences of older women caring for their HIV/AIDS affected households in Atteridgeville.

As a professional social worker, the researcher decided to do a Master's degree in Public Health. This was a big step for me as I wish to be involved in decision and policy making in the healthcare system. I learnt that studying social work and public health were two different things. When I started my Masters' degree, some of the modules were challenging, especially the Analytic Health Measurement module, which involved statistics. I learnt that the vision of making policies comes with figures and statistics. I have also acquired a skill of doing chi-square tests amongst other tests.

When I started to draft my research proposal, I knew that I wanted to study the experiences of older women in HIV/AIDS households using qualitative research because I thought it is easier than quantitative research. As I started writing my proposal, I discovered that I had little knowledge about qualitative research so I had to spend a lot of time in the library reading about qualitative research.

As a researcher I can now conduct focus group interviews with ease. It was not easy conducting the focus group interviews because some older women did not want anyone in the community to know about the HIV/AIDS status of their families. They spoke about their hard emotional experiences; they were angry and emotional about it. As a researcher I could see that these older women were going through a lot of strain in their HIV/AIDS affected households.

Though I was the researcher, the situation of the older women touched me as they described their experiences as care-givers. Two participants were very quiet during

the focus group interview and they could not reveal a lot because they had so much anger. Most of these older women need to go for counselling because they have so much anger, they need to accept the existence of HIV/AIDS, get closure and move on with their lives.

Despite my five years of experience as a social worker, working with older women, I still did not know what these women were going through until they shared their different experiences. The loss of children to HIV/AIDS is quite a difficult issue to imagine. This study has taught me that it is not easy to identify, assess and resolve a problem without conducting a well-structured research. The experiences of older women in HIV/AIDS households have changed the way I perceive things as a person. I have learnt that the condition of HIV/AIDS is not the only problem that HIV/AIDS affected households are facing. There is a range of problems which older women face in their households.

It was a challenging task to analyse data for this study. Before analysing data, I had to transcribe data from the tape recorder. I had many pages of data which did not make sense to me. However, my supervisor guided me on how to analyse the data that I had gathered and I started to see relevant information related to the experiences of older women. It was a challenge for me putting the data in sub-categories and categories because the information seemed similar and overlapping. The process of data analysis was tiring and time consuming, but with the encouragement from family and my supervisor I managed to get through.

Regardless of the challenges I encountered during this research, I could not give up. I kept pushing towards achieving my goal, though many times there was a feeling that I might not complete the degree. I also faced problems in writing my ideas logically but I improved through reading and re-writing my chapters.

If I embark on another qualitative study I will probably do things differently to avoid the mistakes that I made in this study. It was an eye opener for me to do research on the experiences of older women caring for HIV/AIDS-affected households. Given an opportunity, I would want to do more research more on the same topic.

4.7 CONTRIBUTIONS OF THE STUDY

This study focused on exploring the experiences of older women caring for HIV/AIDS-affected households in Atteridgeville. The study has also identified important issues raised by the older women about their financial problems caused by HIV/AIDS. It became evident that the old-age pension and foster care grants for their grandchildren are not enough to sustain a HIV/AIDS-affected household and that other means of income must be explored.

The study raises awareness that older people are emotionally strongly affected by HIV/AIDS and they carry the physical burden of caring for their own adult children when they get sick and then later care for their grandchildren (with or without HIV/AIDS) when the sick adult children die.

In this study one older woman mentioned that she contracted HIV/AIDS through caring for an adult child with HIV/AIDS. This therefore means that care-givers have to be cautious when caring for a person with HIV/AIDS. Older women and other care-givers should get proper advice from health professionals on how to protect themselves when caring for someone with HIV/AIDS.

The importance of a multi-disciplinary team was identified and the social workers in Atteridgeville should be informed of the importance of such a forum.

4.8 LIMITATIONS OF THE STUDY

This study had a number of limitations, and they are as follows:

- The sample for older women caring for HIV/AIDS households was only selected from the three Elderly Centres in Atteridgeville. Women caring for HIV/AIDS households in Atteridgeville who do not attend these three centres were not considered. The findings cannot be generalized to all older women caring for HIV/AIDS affected households in Atteridgeville as the population of older women caring for HIV/AIDS affected households in Atteridgeville is unknown.
- Some older women care for both adult children and grandchildren with HIV/AIDS, and others care for adult children with HIV/AIDS and grandchildren

without HIV/AIDS, hence the difference in population composition of these households.

- As HIV/AIDS is a very sensitive topic, some participants in the study did not give as much information as others because of the way they feel about HIV/AIDS. As a result, some participants did not fully reveal their experiences of caring for HIV/AIDS affected households.

4.9 CONCLUSION

HIV/AIDS has affected older women negatively in this study. Many areas need improvement. With the assistance from social workers, older people can be educated about HIV/AIDS and family relations can be strengthened. There is a need to mobilize more resources and professional help. This will assist in the fight against HIV/AIDS and to decrease the number of HIV/AIDS related deaths and orphans who are normally left in the care of their grandparents.

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LIST OF ANNEXURES

ANNEXURE A: Ethical clearance certificate



UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE

HSHDC/131/2013

Date: 23 January 2013 Student No: 4709-117-7
Project Title: Experiences of older women caring for HIV/AIDS affected households in Atteridgeville.

Researcher: Kudzai Ottilla Zheve

Degree: Masters in Public Health

Code: DLMPH95

Supervisor: Mrs H du Toit

Qualification: M Cur

Joint Supervisor: -

DECISION OF COMMITTEE

Approved

Conditionally Approved

Prof L. Roets

CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE

Dr MM Molaki

ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

ANNEXURE B: Consent letter from Pretoria Care of the Aged

Permission letter

Pretoria Care for the Aged

Cnr Rachael de beer & Waterbok Street

Nina Park

Pretoria

Attention: Mr Attie De Jager (Programme Manager for Pretoria Care for the Aged)

Dear Sir

RE: PERMISSION TO CONDUCT RESEARCH - EXPERIENCES OF OLDER WOMEN CARING FOR HIV/AIDS HOUSEHOLDS IN ATTERIDGEVILLE

I am a social worker at Pretoria Care for the Aged in Atteridgeville. I am a registered Masters student with the Department of Health Studies at the University Of South Africa (UNISA). Find attached my ethical clearance certificate number HSHDC/131/2013 issued by the Department of Health Studies Higher Degrees Committee.

As part of the requirements for my Master's degree in Public Health, I wish to apply for permission to carry out a study to explore and describe the experiences of older women who care for their HIV/AIDS affected households in the Atteridgeville community. Interest in this field was sparked by interacting with older people and hearing that some of their problems emanate from the task of caring for HIV/AIDS patients in their homes.

Data for this qualitative study will be collected through focus group interviews with women of sixty years or older. One focus group interview with fifteen participants will be held at each of the three Elderly day Care Centres in Atteridgeville. This will provide evidence-based information that could be used to formulate operational guidelines that might assist social workers in Atteridgeville to support older women who care for their adult children or grandchildren with HIV/AIDS.

Thus the findings of this study have potential to influence program managers in the field of HIV/AIDS for more responsive programmes to assist older people on care-giving for HIV patients in their homes.

I would really appreciate if you can grant me permission to carry out the study. Should you have any queries, please do not hesitate to contact me on the details provided below.

Regards

Ms Kudzai Otilia Zheve

Phone: 012 320 3577

Cell: 071 253 2008

Email: kudziezet@gmail.com

ANNEXURE C: Informed consent letter for participants

I understand that I am being asked to participate in a research study here in Atteridgeville. This research will explore the experiences of older women who care for their HIV/AIDS positive infected children and orphaned grandchildren. I have been told about the nature and benefits of the study. If I agree to participate in the study, I will be involved in a focus group discussion at one of the three elderly day care centres, sharing my experiences on care-giving of my HIV/AIDS infected children and orphaned grandchildren. I am aware that the discussion will be recorded. I am aware that the results and personal details will be handled confidentially and my name will not be revealed to anyone.

I realise that my participation in this study is entirely voluntary. I understand that I can withdraw from the study at any time and that there is no penalty if I choose to discontinue. I also understand that the discussion may upset me and that counselling will be available afterwards, should I need it.

I can contact the researcher, Ms Kudzai Zheve from 0800hrs to 1600hrs on 071 253 2008 during the study.

I have read and understood this consent form, all of my questions have been answered and I agree to participate. I understand that I will be given a copy of this signed consent form.

.....
Signature of participant Date

.....
Signature of witness Date

.....
Signature of investigator Date

ANNEXURE D: Interview schedules

Schedule 1

Study title: Experiences of older women caring for HIV/AIDS affected households.

Interviewer/Researcher: K.O. Zheve

The focus group interview was held on 25/09/13. There were 12 older women involved with the researcher and the assistant. 3 older women could not attend due to personal reasons. Before the focus group participants arrived for the focus group interview the researcher and the research assistant checked if there were enough chairs in the boardroom, prepared the water and checked if the tape recorder was working.

The researcher welcomed all the participants, introductions and ground rules were spoken to the participants:

No one was allowed to just talk without permission from the researcher

No answer was incorrect , they were free to talk , and express themselves in any way

They were not allowed to laugh at other participants' responses

The participants had already signed consent forms, so the researcher reminded them about the objectives of the study.

In conclusion after the focus group discussions the researcher thanked the group for the information they provided and that they researcher would contact them if there is need for more information.

Interview schedule questions: Focus group 1

1. What are your experiences on caring for a household affected by HIV/AIDS
 - sick adult children
 - sick grandchildren
 - grandchildren without HIV/AIDS

2. How does this responsibility affect you as older women
 - physically
 - emotionally

- socially
 - financially
3. If children are living in a house with HIV/AIDS affected parents, how does this affect their lives and behaviour?
 - at home
 - at school
 - between friends

 4. If children are orphaned because of HIV/AIDS, how does it affect their lives :
 - interacting with friends
 - with relatives

Interview schedule questions: Focus group 2

1. What are the financial problems that you are going through caring for HIV/AIDS grandchildren?
2. How are the children performing at school?
3. What is the relationship between you and the teachers at school?
4. Do you get any emotional support from family, neighbours and community?
5. Last time when we were discussing about your experiences on caring for your adult children infected with HIV/AIDS some of you spoke about going to Sangomas for help. Did you receive any help from Sangomas?

ANNEXURE E: Example pages of data transcript

Researcher: stop crying ma, it hurts, but be strong

encouragement

Do you want to continue?

E: Yes ^{worried}

E: (things got really bad) I went back to the hospital her and now she could see that she was dying, she then told the doctor that me and my sister should resolve our differences so that when she dies we can stand together and take care of her children.

uniting the family professional help

L: awwww , but that was very good

E: I used to go to the hospital 3 times a day "this was very hard because I had to walk sometimes", I was very thin, and I was stressed. When I went back home one day to cook for her I then received a phone call from the hospital that she is dead. It hurt me even though I knew that in her condition she will not survive, but it was a relief in a way because I was suffering, taking care of her and she was also in pain.

burden
duty
worry

caring duty

caring worried

emotional
worried
acceptance

The group agreed: uuuuuuuuuuummmmmh

Researcher : are the children of your late daughter infected with HIV?

E : No my child

burden
widowed

more than 1 child sick

E : " my problems will not end". I am now caring for my other daughter who is also HIV positive, she was also secretive about the disease, she started taking her medication but it was late, now she is disabled because of that disease. When I discovered that my other daughter was also sick, I was devastated and even lost weight, but God keeps me going

compliance

duty
secretive

affected
of
the disease
worried

The group agreed:uuuummmmmh

Researcher : but how is she responding to treatment now?

compliance

E : She is responding well and recovering now because she is now serious about her medication, but if she had taken it earlier she could have not been disabled but they are our children they need support.

compliance
believer
better

AEUS

affected

F: you should have love for your sick children because with no love they feel it and they change their behaviour, they become angry, they need our support/

god nice
duty

caring
love
support

H - yaaaaaaa , and the whole group agreed.

K : can I talk

Researcher : yes go on

K : I had 2 daughters , twins. The other one passed away because of HIV, she left a child infected of HIV. I took my daughter to hospital when she was sick, and the

more than 1 child sick

grandchild
sic

duty



My daughter who was sick had no children. She went on treatment and now she has fully recovered, she even had 3 children and they are all healthy, they don't have HIV. But, my other daughter came from wherever she was, I don't even know, and she was very sick.

completely lost and not being a burden sense statements

H -: yhooh, (surprised)

↓ relation before care for her

D, A, G (sad faces)

disappointment
emotional
figure

L : My daughter came home pregnant , she was very very sick, I was very disappointed because I was resting from taking care of the first one then the other one comes sick with this disease) I took her to the hospital, but it was too late) She was about to deliver the baby, on delivery she passed away, she left a baby, without HIV, "you see how God works religious remark. (i)

burden worse and helpless

The group was in agreement: ummmmmh

L: the other one is drinking her medication and she is healthy and even working for her children.

ARVS work

compliance

coming for children

F: people should not underestimate the power of ARVS my daughter followed the doctor's instructions now she is "fresh"

professional intervention advice

E: can I talk

Researcher : you may go on

ser. motive

stigma fear

E - My child was very secretive, she could see that she was sick, but she did not say it. I went to check in her bedroom when she was out, and I found pills under her pillow, and when my daughter discovered that I was in her room she shouted at me and threatened to report me to the police because I was invading her privacy.

secretive
stigma
anxiety

Prophetic
secretary
anger of the sick child

E: (sobbing): she could have just told me the truth because she's my daughter) and I could have helped her go through all this.

poor relationship

regret (duty make)

ownership

Researcher: be strong and stop crying ma

encouragement encouragement

The group was very quiet, for a moment, people shaking their heads and some holding their chins

deep thoughts

emotions

E : I went to the hospital with my daughter and she did not even want me to know her status and she didn't even want the doctors to tell me (but as an older person I knew that it was HIV because she had all the symptoms) At home my daughter was refusing to drink her medication then she got very sick. I was always there helping her with everything, but she never stopped shouting at me.

wise
howled
to see
worried

secretary
professional
anger
burden
refusal worse off
med. help
emotions

(She was sick) but she abused me, with words which came out of her mouth, (crying)

poor relationship
poor relationships

B, J/L, D had their faces down

ANNEXURE F: Confidentiality agreement between the field worker and the researcher

I....., understand that I am being asked to assist as a field worker in a research study in Atteridgeville. This research will explore the experiences on older women who care for their HIV/AIDS positive infected children and orphaned grandchildren. I have been told about the nature of the study. The researcher explained my expected contribution during the focus group interview. I agree to keep all the information and personal details confidential to protect the rights of the participants of the study.

.....

Signature of field worker

.....

Date

.....

Signature of researcher

.....

Date