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# THE IMPACT OF HIV/AIDS ON ELDERLY PEOPLE IN THE THULAMELA MUNICIPALITY, VHEMBE DISTRICT, LIMPOPO PROVINCE

by

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Thesis Submitted in Fulfillment of the Requirements for the Degree

Masters in Public Health (MPH)

Department of Public Health

University of Venda

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Co-Supervisor: Professor Thelma Xabela Maluleke

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# DECLARATION

I, **Vhudivhusi Julia Singo**, declares that "**THE IMPACT OF HIV/AIDS ON ELDERLY PEOPLE IN THE THULAMELA MUNICIPALITY, VHEMBE DISTRICT, LIMPOPO PROVINCE**" is my own work, that all sources that I have used or cited have been indicated and acknowledged by means of complete references, and that this work has not been submitted by me for any other degree at this or any other institution.

**V.J. Singo** : .....

**Date Signed** : 13/08/2012

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# DEDICATION

This thesis is dedicated to:

- My late mother, Singo Masindi Selina, who has played a major role in my life and made me the person I am today.
- My husband, Muthala Mashudu Shadrack, whom I love very much, and who supported me during the study period.
- My two wonderful children, Mufunwa and Uatshila, the sources of my strength.

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- All my friends, sisters, brothers and their families, for their continuous support during my study.
- Professor D.C. Hiss, Department of Medical Biosciences at the University of the Western, for proofreading the thesis.


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# ABSTRACT

HIV/AIDS causes serious burdens on the lives of elderly people, and more particularly so because they are often expected to take care of their terminally ill children and assume the responsibility of looking after children orphaned by HIV/AIDS, in most cases with very little resources. The overall aim of this study was to explore and describe the impact of HIV/AIDS on elderly people infected with and/or affected by HIV/AIDS (EPLWHA) in the Thulamela municipality. The study sought to achieve the following objectives: describing the views of elderly people regarding the impact of HIV/AIDS on their lives, determining the challenges that EPLWHA face in their daily lives, and gaining a sense of the coping strategies they use to overcome the obstacles they face in relation to HIV/AIDS. Ethical issues such as permission to conduct the study, informed consent, confidentiality and anonymity, withdrawal of participation and measure to ensure trustworthiness were taken into consideration. A qualitative explorative descriptive study was conducted in two phases. During the first phase, key participants were interviewed using an interview guide. In the second phase, general participants were interviewed, also using an interview guide. Information provided by the participants was captured on a tape recorder. Data collected during interviews over a period of three weeks, with key participants and general participants, were collated into themes, categories and subcategories. The data were analyzed using an open coding method. The study findings revealed that HIV/AIDS has serious negative impacts on the lives of elderly people, particularly those living in poverty. The following key areas in relation to EPLWHA were established: psychological or emotional health, household and socioeconomic burdens. Considering the role that elderly people play in the community insofar as HIV/AIDS is concerned, primary health promotion and social welfare programmes should be directed at educating all elderly people and their service providers how to cope with the health and social problems related to HIV/AIDS.

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# ACRONYMS

- HIV: Human immunodeficiency virus
- AIDS: Acquired immunodeficiency syndrome
- People/persons living with HIV/AIDS (PLWHA)
- Elderly people/persons infected with and/or affected by HIV/AIDS (EPLWHA)
- HIV-infected orphans
- Key participants
- General participants
- Coping strategies
- Impact of HIV/AIDS
- Socioeconomic burden
- Psychological and emotional health
- Abuse and rejection of the elderly
- Support for the elderly
- Social grants
- Community-based foster care model
- Cultural traditions and myths
- Themes, categories and subcategories

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# TABLE OF CONTENTS


| | | |
|---|---|---|
| TITLE PAGE | | i |
| DECLARATION | | ii |
| DEDICATION | | iii |
| ACKNOWLEDGEMENTS | | iv |
| ABSTRACT | | v |
| ACRONYMS | | vi |
| TABLE OF CONTENTS | | vii |
| LIST OF ABBREVIATIONS | | x |
| LIST OF TABLES | | x |
| LIST OF ANNEXURES | | xi |
| CHAPTER 1: OVERVIEW OF THE STUDY | | 1 |
| 1.1 | Introduction and Background to the Study | 1 |
| 1.2 | Problem Statement | 3 |
| 1.3 | Purpose of the Study | 3 |
| 1.4 | Objectives of the Study | 4 |
| 1.5 | Major Research questions | 5 |
| 1.6 | Significance of the Study | 5 |
| 1.7 | Operational Definitions | 6 |
| 1.8 | Plans for Dissemination and Implementation of the Results | 7 |
| 1.9 | Outline of Chapters | 8 |
| 1.10 | Summary | 8 |
| CHAPTER 2: LITERATURE REVIEW | | 9 |
| 2.1 | Introduction | 9 |
| 2.2 | Literature Review | 9 |


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| | | |
|---|---|---|
| 2.2.1 | The Socioeconomic Impact of HIV/AIDS on EPLWHA | 10 |
| 2.2.2 | The Impact of HIV/AIDS on Households | 13 |
| 2.2.3 | The Socioeconomic Impact of HIV/AIDS | |
| 2.2.4 | Psychological and Emotional Health of the Elderly | 14 |
| 2.2.5 | Potential Danger of HIV Infection in the Elderly | 17 |
| 2.2.6 | Abuse and Rejection of the Elderly in Relation to Care | 17 |
| 2.2.7 | Cultural Traditions and Myths | 17 |
| 2.2.8 | Available Support for the Elderly | 19 |
| 2.2.9 | The Community-Based Foster Care Model | 21 |
| 2.3 | Summary | 22 |
| CHAPTER 3: RESEARCH METHODOLOGY | | 24 |
| 3.1 | Introduction | 24 |
| 3.2 | Study Design | 24 |
| 3.2.1 | Qualitative Research | 24 |
| 3.2.2 | Explorative Studies | 25 |
| 3.2.3 | Descriptive Research | 26 |
| 3.3 | Study Setting | 26 |
| 3.4 | Population and Sampling | 27 |
| 3.4.1 | Population | 27 |
| 3.4.2 | Sampling | 27 |
| 3.4.2.1 | Sampling of General Participants | 28 |
| 3.4.2.2 | Sampling of Key Participants | 29 |
| 3.5 | Data Collection | 29 |
| 3.5.1 | Interview Guide | 29 |
| 3.5.1.1 | Semi-Structured Interview | 30 |
| 3.5.1.2 | Key Participants | 30 |
| 3.5.1.3 | General Participants | 30 |


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| | | |
|---|---|---|
| 3.5.2 | Plan for Data Collection | 30 |
| 3.5.2.1 | Pre-Test of the Interview Schedule | 30 |
| 3.5.2.2 | Negotiating with the Participants | 31 |
| 3.5.2.2.1 | Departmental Approval | 31 |
| 3.5.2.2.2 | Interview Process | 32 |
| 3.6 | Data Analysis | 32 |
| 3.7 | Ethical Considerations | 34 |
| 3.7.1 | Permission to Conduct the Study | 34 |
| 3.7.2 | Informed Consent | 34 |
| 3.7.3 | Confidentiality and Anonymity | 35 |
| 3.7.4 | Withdrawal of Participation in the Study | 35 |
| 3.8 | Measures to Ensure Trustworthiness | 35 |
| 3.8.1 | Credibility | 36 |
| 3.8.2 | Transferability | 36 |
| 3.8.3 | Dependability | 37 |
| 3.8.4 | Conformability | 37 |
| 3.9 | Summary | 37 |
| CHAPTER 4: RESULTS AND DISCUSSION | | 38 |
| 4.1 | Introduction | 38 |
| 4.2 | Participants' Characteristics | 38 |
| 4.3 | Presentation and Discussion of the Findings from Key Participants | 39 |
| 4.3.1 | Theme 1: Key Participants' Description of the Impact of HIV/AIDS on the Elderly | 41 |
| 4.3.1.1 | Category 1: Difficulties Experienced by the Elderly | 41 |
| 4.3.1.1.1 | Subcategory 1: Burden of Taking Care of a Sick Adult Child | 41 |
| 4.3.1.1.2 | Subcategory 2: Lack of Knowledge About the Disease | 43 |
| 4.3.1.1.3 | Subcategory 3: Psychological Stress Related to Caring for HIV-Infected Orphans | 44 |


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4.3.1.1.4 Subcategory 4: Financial Burden Related to Caring for the Terminally Ill or Orphans 45

4.3.2 Theme 2: Key Participants' Description of Coping Strategies Used by Elderly People 47

4.3.2.1 Category 1: Experiences of Difficulties in Coping with the Diseases 47

4.3.2.1.1 Subcategory 1: Failure to Seek Support from Relatives or Friends, Due to Fear of Stigmatization 47

4.3.2.1.2 Subcategory 2: Pretending to be Coping as It is Expected by Culture 48

4.3.2.2 Category 2: Key Participants' Explanation of Coping Abilities Used by the Elderly 49

4.3.2.2.1 Subcategory 1: Using Governmental Institutions, Department of Health and Social Development 50

4.3.2.2.2 Subcategory 2: Depending on Social Grants (Foster Care, Child Support Grant) 51

4.3.3 Theme 3: Key Participants' Description of Challenges Faced by Elderly People 52

4.3.3.1 Category 1: Assuming a Parenting Role In Late Years of Life 52

4.3.3.1.1 Subcategory 1: Adopting a Role of Parenting Grandchildren 53

4.3.3.1.2 Subcategory 2: Being Stressed by Parenting Uncontrollable Grandchildren 54

4.3.3.1.3 Subcategory 3: Assuming the Role of Breadwinner with Little Income 55

4.3.4 Theme 4: Key Participants' Views About Services Rendered to EPLWHA 56

4.3.4.1 Category 1: Positive Responses Related to Services Received 56

4.3.4.1.1 Subcategory 1: Community Centres Established to Support the Elderly 56

4.3.4.1.2 Subcategory 2: Employment of More Social Workers 57

4.3.4.2 Category 2: Negative Responses Related to Services Received 58

4.3.4.2.1 Subcategory 1: They Get Short-Term Services Such as Food Parcels 58

4.3.4.2.2 Subcategory 2: More Information About HIV/AIDS Needs to be 59

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Disseminated to the General Public of Elderly People

4.4 Presentation and Discussion of the Findings from General Participants 60

4.4.1 Theme 1: The General Participants' Experiences Related to Finding Out About the HIV Status of Family Members or Self 60

4.4.1.1 Category 1: Difficulties in Relation to Finding Out About the HIV Status of Family Member or Self 61

4.4.1.1.1 Subcategory 1: Finding Out After the Death of Their Children or Grandchildren 61

4.4.1.1.2 Subcategory 2: Verbal and Physical Abuse of the Elderly by HIV-Positive Patients 64

4.4.1.2 Category 2: Positive Way of Finding Out About the HIV Status 64

4.4.1.2.1 Subcategory 1: Status Revealed to the Elderly by the Healthcare Worker 65

4.4.1.2.2 Subcategory 2: Finding Out About Own HIV Status After Voluntary Testing 66

4.2.2 Theme 2: The General participants' Experiences of Caring for An HIV/AIDS Patient 67

4.2.2.1 Category 1: Difficulties Related to Caring for HIV-Positive Patients 67

4.2.2.1.1 Subcategory 1: The Experience is Tough and Stressful 67

4.2.2.1.2 Subcategory 2: Poverty Worsens the Situation 69

4.2.2.2 Category 2: Positive Experiences Related to Caring for An Infected Family Member 70

4.2.2.2.1 Subcategory 1: Support from Infected to Affected Family Member 71

4.2.2.2.2 Subcategory 2: Understanding the Treatment of HIV-Positive Patients 72

4.4.3 Theme 3: Challenges Experienced When Looking After Persons Living with HIV/AIDS or Children Orphaned by HIV/AIDS 73

4.4.3.1 Category 1: Financial Challenges 73

4.4.3.1.1 Subcategory 1: Lack of Income 74

4.4.3.1.2 Subcategory 2: Cut Off from the Disability Grant 75

4.4.3.1.3 Subcategory 3: Fear that Funeral Policies Might not be Enough 75

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Disseminated to the General Population of Elderly People

4.4 Presentation and Discussion of the Findings from General Participants 60

4.4.1 Theme 1: The General Participants' Experiences Related to Finding Out About the HIV Status of Family Members or Self 60

4.4.1.1 Category 1: Difficulties in Relation to Finding Out About the HIV Status of Family Member or Self 61

4.4.1.1.1 Subcategory 1: Finding Out After the Death of Their Children or Grandchildren 61

4.4.1.1.2 Subcategory 2: Verbal and Physical Abuse of the Elderly by HIV-Positive Patients 64

4.4.1.2 Category 2: Positive Way of Finding Out About the HIV Status 64

4.4.1.2.1 Subcategory 1: Status Revealed to the Elderly by the Healthcare Worker 65

4.4.1.2.2 Subcategory 2: Finding Out About Own HIV Status After Voluntary Testing 66

4.2.2 Theme 2: The General participants' Experiences of Caring for An HIV/AIDS Patient 67

4.2.2.1 Category 1: Difficulties Related to Caring for HIV-Positive Patients 67

4.2.2.1.1 Subcategory 1: The Experience is Tough and Stressful 67

4.2.2.1.2 Subcategory 2: Poverty Worsens the Situation 69

4.2.2.2 Category 2: Positive Experiences Related to Caring for An Infected Family Member 70

4.2.2.2.1 Subcategory 1: Support from Infected to Affected Family Member 71

4.2.2.2.2 Subcategory 2: Understanding the Treatment of HIV-Positive Patients 72

4.4.3 Theme 3: Challenges Experienced When Looking After Persons Living with HIV/AIDS or Children Orphaned by HIV/AIDS 73

4.4.3.1 Category 1: Financial Challenges 73

4.4.3.1.1 Subcategory 1: Lack of Income 74

4.4.3.1.2 Subcategory 2: Cut Off from the Disability Grant 75

4.4.3.1.3 Subcategory 3: Fear that Funeral Policies Might not be Enough 75

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| | | |
|---|---|---|
| 4.4.3.2 | Category 2: Health Challenges | 76 |
| 4.4.3.2.1 | Subcategory 1: Due to Stress, Chronic Conditions are Worsened | 77 |
| 4.4.3.2.2 | Subcategory 2: Skipping of Meals Due to Stress | 77 |
| 4.4.3.3 | Category 3: Social Challenges | 78 |
| 4.4.3.3.1 | Subcategory 1: Verbal Abuse | 78 |
| 4.4.3.3.2 | Subcategory 2: Estate Disputes | 79 |
| 4.4.3.3.3 | Subcategory 3: Left with Uncontrollable Children and Their Elder Siblings | 79 |
| 4.4.4 | Theme 4: Impact of HIV/AIDS on the Family | 81 |
| 4.4.4.1 | Category 1: Disorganization of the Family | 81 |
| 4.4.4.1.1 | Subcategory 1: Elderly People Moving to the Houses of Their Late Children or Children Moving to Their Grandparents | 81 |
| 4.4.4.1.2 | Subcategory 2: Sibling Disputes | 82 |
| 4.4.5 | Theme 5: Coping Strategies Used by the Elderly | 83 |
| 4.4.5.1 | Category 1: Positive Coping Strategies Used by the Elderly | 83 |
| 4.4.5.1.1 | Subcategory 1: Department of Health and Social Development | 84 |
| 4.4.5.1.2 | Subcategory 2: Religion | 84 |
| 4.4.5.2 | Category 2: Negative Coping Strategies Used by the Elderly | 85 |
| 4.4.5.2.1 | Subcategory 1: Neither Friend Nor Relative Support | 85 |
| 4.5 | Summary | 86 |
| CHAPTER 5: RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS | | 87 |
| 5.1 | Introduction | 87 |
| 5.2 | Overview of the Study | 87 |
| 5.3 | Recommendations Based on the Themes, Categories and Subcategories | 89 |
| 5.4 | Recommendations Regarding Policy | 91 |
| 5.5 | Recommendations for Further Research | 91 |


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6. Limitations of The Study 92

7. Conclusions 92

7.1 Conclusions Regarding the Participant's Description of the Impact of HIV/AIDS on the Lives of Elderly People 93

7.2 Conclusions Regarding the Challenges Faced by elderly people infected and or affected by HIV/AIDS 93

7.3 Conclusions Regarding the Description of Coping Strategies Used by EPLWHA 93

8. Summary 94

REFERENCES 95

ANNEXURE A: RESEARCH INSTRUMENT 100

ANNEXURE B: INTERVIEW SCHEDULE OF THE KEY PARTICIPANTS 101

ANNEXURE C: INFORMATION SHEET 102

ANNEXURE D: CONSENT FORM 103

ANNEXURE E: REQUEST TO CONDUCT THE STUDY 104

ANNEXURE F: INTERVIEW TRANSCRIPT 105



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# LIST OF ABBREVIATIONS

| | |
|---|---|
| **HIV** | Human immunodeficiency virus |
| **AIDS** | Acquired immunodeficiency syndrome |
| **WHO** | World Health Organisation |
| **PLWHA** | People/persons living with HIV/AIDS |
| **EPLWHA** | Elderly people/persons infected with and/or affected by HIV/AIDS |
| **TB** | Tuberculosis |
| **ART** | Antiretroviral therapy |

## LIST OF TABLES


| | | |
|---|---|---|
| **Table 4.1** | Gender of Participants | 39 |
| **Table 4.2** | Themes, Categories and Subcategories of the Impact of HIV/AIDS on EPLWHA, According to Key Participants | 40 |
| **Table 4.3** | Themes, Categories and Subcategories of the Impact of HIV/AIDS on EPLWHA, According to General Participants | 62 |




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# LIST OF ANNEXURES


| | | |
|---|---|---|
| **ANNEXURE A** | RESEARCH INSTRUMENT | 99 |
| **ANNEXURE B** | INTERVIEW SCHEDULE OF THE KEY PARTICIPANTS | 100 |
| **ANNEXURE C** | INFORMATION SHEET | 101 |
| **ANNEXURE D** | CONSENT FORM | 102 |
| **ANNEXURE E** | REQUEST TO CONDUCT THE STUDY | 103 |
| **ANNEXURE F** | INTERVIEW TRANSCRIPT | 104 |


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# CHAPTER 1

# OVERVIEW OF THE STUDY

## 1.1 Introduction and Background to the Study

Infections with the human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) (hereinafter collectively referred to as HIV/AIDS) have a devastating impact on the lives of elderly people, but remain underreported (WHO, 2007). It has been identified that there is an urgent need to conduct research on the impact of HIV/AIDS on elderly people in many African countries because of their vulnerability resulting from lifetime hardships, susceptibility to malnutrition, poverty and chronic diseases. Thus, HIV/AIDS is now posing an additional burden to the aged. (Centre on Aging Studies, 2007).

Elderly people require support and expect to be looked after by their children and significant others. However, due to the HIV/AIDS pandemic, the opposite usually happens (WHO, 2007). Elderly people are often required to support and care for their sick and dying children and grandchildren. This poses a greater risk to them as they play the role of caregivers without much knowledge of the family member's disease. As a result, they are not familiar with the ways of protecting themselves from the disease, and in most instances, without even the basic resources to manage the sick person (WHO, 2007). In this era of HIV/AIDS, many elderly people are both affected by and infected with HIV/AIDS. Despite their poverty, they care for their dying children and/orphaned grandchildren (WHO, 2007).



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Informal caregivers of people living with HIV/AIDS (PLWHA), are mainly elderly family members. These caregivers usually display depressive symptoms, anger and anxiety. The symptoms are more pronounced amongst low-income families and these have detrimental effects on the physical health of the elderly caring for their sick family members (Noumbissi, 2003). Poor families have insufficient resources to care for PLWHA and hence there is high risk of elderly people being infected when caring for a sick family member. On other hand, the increasing numbers of orphans due to the high incidence of HIV/AIDS affect the living conditions and well-being of the elderly who have to care for their sick children and grandchildren (Noumbissi , 2003).

The Joint United Nations Programme on HIV/AIDS indicated that there are 2.8 million adults aged 50 years and older living with HIV, representing 7% of all cases. It was also indicated that by 2010, almost half of the people living with HIV will be older than 50 (Avert, 2008). There is increasing evidence that older women are particularly susceptible to HIV infection because they are mainly the caregivers in the families. Furthermore, some studies have shown that elderly people have less chances of survival after diagnosis of HIV (Today's Research on Aging, 2007). Moreover, there is a need for awareness programmes that will target doctors and healthcare professionals to try to move away from targeting young people only in HIV/AIDS prevention and education (UNAIDS, 2005). Many elderly people are being denied from accessing health education and early diagnosis. Elderly people need to be supported through community care and support programmes. The fact that HIV/AIDS programmes ignore them also exposes them to infection, both as caregivers as well as sexually active people (UNAIDS, 2005). According to Zimmer & Dayton, (2003), the elderly population falls into a special risk category, as both

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caregivers and as sexually active persons (they) need to be counted, supported and educated in the fight against HIV/AIDS. Their difficult roles and responsibilities need to be acknowledged. Hence, this study was aimed at exploring and describing the impact of HIV/AIDS on EPLWHA in Thulamela municipality, Vhembe District.

## 1.2 Problem Statement

HIV/AIDS places enormous stress on infected individuals and their families. In particular, family members are confronted with the demands of caring for the seriously ill and experience trauma of death. The impact of HIV/AIDS is worsened by the stigma associated with the condition, the material and psychological strain of coping with AIDS deaths and bringing up orphans (WHO, 2008). Elderly people affected and or infected by HIV and AIDS in the Vhembe District experience enormous stress. In many cases, elderly people are faced with the caring of the sick and looking after orphaned grandchildren. There are currently several programmes that address HIV infection in young people. However, very little is done for the elderly who are infected with and affected by HIV/AIDS, and very few services are available to assist and train them how to cope with the disease burden. Therefore, it was considered important to conduct this study to explore and describe the impact of HIV/AIDS on elderly people.

## 1.3 Purpose of the Study

The purpose of the study was to explore and describe the impact of HIV/AIDS on elderly people in the Thulamela municipality, Vhembe District, Limpopo Province.

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## 1.4 Objectives of the Study

This study sought to address the following objectives:

- Describe the views of social workers regarding the impact of HIV/AIDS on elderly people infected and or affected by HIV and AIDS;
- Describe the views of elderly people infected and or affected by HIV and AIDS regarding the impact of HIV/AIDS on their lives;
- Determine the challenges that elderly people infected and or affected by HIV and AIDS face in their daily lives;
- Describe the coping strategies used by elderly people infected and or affected by HIV/AIDS;
- Describe the coping strategies used by elderly people infectedd and or affected by HIV and AIDS;

## 1.5 Major Research Questions

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The study sought to answer the following questions:

- What are the views of social workers regarding the impact of HIV/AIDS on elderly people infected and or affected by HIV /AIDS?
- What are the views of elderly people infected and or affected by HIV and AIDS regarding the impact of HIV/AIDS on their lives?
- What are the challenges faced by elderly people regarding the impact of HIV/AIDS?
- What are the coping strategies used by elderly people infectedd and or affected by HIV and AIDs

## 1.6 Significance of the Study

The findings of the study highlight the plight of elderly people infected and or affected by HIV and AIDS. The results might contribute towards the restructuring of programmes for HIV/AIDS to include the needs of elderly people infected and or affected by HIV and AIDS. This might influence authorities to develop policies and programmes that support elderly people infected and or affected by HIV and AIDS. All these will alert responsible bodies to realise the importance of including elderly people infected and or affected by HIV and AIDS in policy development related to HIV/AIDS. It will also encourage the government to step up efforts and strategies to acknowledge the role elderly people play in the care of HIV/AIDS patients.

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## 1.7 Operational Definitions

**AIDS**

AIDS is a syndrome of opportunistic diseases, infections, and certain cancers, all of which have the ability to kill the infected person in the final stages of the disease (van Dyk, 2008). AIDS is also called an incurable decease caused by a germ (Paine, 1990). In this study, the term "AIDS" will be used according to accepted social and medical conventions.

**HIV**

HIV is a blood-borne virus. It is transmitted primarily through sexual contact, needle sharing, transfusion of tainted blood products, and perinatal transmission (i.e. through the birth canal and breastfeeding. It is a virus that knows no boundaries and can be found in persons of all ages, races, socioeconomic classes and sexual orientations (Centre on Aging Studies, 2007). In this study HIV will be used as described above.

**Elderly people**

The word "senior" is used to describe persons older than a certain age. The term "elderly" was and is still often used, but has been replaced by elderly people or elders because elderly is an adjective rather than a noun. Elderly people are normally individuals over the age of 60, characterised by vulnerabilities such as poor physical health, mental illness, poverty, insufficient education, lack of social support and dysfunctional family (Huber, Nelson, Netting & Borders, 2008). In this

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study "elderly people" is defined as people who are 50 years and above, infected with and/or affected by HIV/AIDS.

**Impact** Impact in this study will mean the consequences which could be challenges or benefits or gains or coping strategies that elderly people may experience as a result of HIV/AIDS.

## 1.8 Plans for Dissemination and Implementation of the Results

A copy of a research report describing this study will be submitted to directly to the coordinator of the elderly programme, provincial level Department of Health and Social Development. Presentations will be made to the elderly people on "elderly" days through the arrangement with the chairperson of elderly committee in the District of Vhembe.

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## 1.9 Outline of Chapters

| | |
|---|---|
| **Chapter 1** | Overview of the study |
| **Chapter 2** | Literature Review |
| **Chapter 3** | Research Methodology |
| **Chapter 4** | Results and Discussion |
| **Chapter 5** | Recommendations, Limitations and Conclusions |

## 1.10 Summary

This chapter provided an overview of the study, which included the introduction and background to the study, problem statement, purpose of the study, objectives of the study, major research questions, significance of the study, operational definitions and the chapter layout of the thesis. Chapter 2 is a literature review of the impact of HIV/AIDS on the elderly.

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# CHAPTER 2

# LITERATURE REVIEW

## 2.1 Introduction

An overview of the study was presented in Chapter 1. The objective of this chapter is to review the relevant literature. A literature review is a way of bringing readers up to date with previously published research in the area, pointing to general agreements and disagreements among researchers (Babbie & Mounton, 2008).

## 2.2 Literature Review

The South African National AIDS Council (2007) indicated that the government needs to make sure that the healthcare system is sound enough to support people who are living with HIV/AIDS. Government needs to work with civil society and business partners to ensure that there are enough programmes within South Africa to care for those living with HIV/AIDS. According to the South African National AIDS Council (2007), a Human Right is defined as the responsibility of everyone. It is within this context that the government needs promulgate laws to protect the rights of all people living with HIV/AIDS. Civil society is also accountable for educating communities on the realities of HIV/AIDS to reduce stigma and discrimination, and to make sure that all people infected with and affected by HIV/AIDS know their rights and act within their rights.

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Although HIV/AIDS is a source of concern in all age groups, to date little has been written about its impact on the older population. More recent examination of such issues has revealed that HIV/AIDS is increasingly affecting older persons, directly and indirectly. Over the last decade, the HIV/AIDS epidemic had devastating economic, social, health and psychological impacts on older men, especially in Sub-Saharan Africa (Humanitarian Practice Network, 2008).

About 60% of orphaned children in Namibia, South Africa and Zimbabwe are living with their grandparents. It has further been stated that an older person heads about 30% of all households in Sub-Saharan Africa. Fifty six percent of caregivers for orphans and vulnerable children in Namibia are more than 60 years old (WHO, 2008). Today's Research on Aging indicated that the majority of adults who die due to HIV/AIDS leave behind young children and elderly parents aged 50 and above (WHO, 2008). Those who succumb to the disease invariably leave elderly people with the responsibility of caring for their grandchildren, a situation that could have adverse effects on the well-being and life of elderly people (WHO, 2008).

### 2.2.1 The Socioeconomic Impact of HIV/AIDS on elderly people infected and or affected by HIV/AIDS.

Elderly people have been reported to take some time away from economic activities in order to care for their sick children and grandchildren, and this leads to temporary loss of income. Fear of contagion may lead customers to stop patronizing businesses run by the elderly person taking care of an HIV-infected person. Parents may also shoulder treatment and healthcare expenses as well as the daily living expenses of the ill son or the daughter. Parents may deplete their savings, sell possessions or

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property, and go into debt to cover such costs. When an adult child dies, funeral costs can be considerable with devastating consequences (Knoel & Wassana, 2004).

Elderly people are said to be providing care to patients with AIDS at the terminal stage of the illness when patients need constant care. In most cases, the challenges of caring for sick patients are compounded by the responsibility to care for children affected by HIV/AIDS, which also starts when their parents are still living, not when they become orphans. This demanding work was reported to negatively affect the elderly in various dimensions, including economic, emotional, physical and nutritional (Gerolntol & Cross, 2007). The impact on elderly persons is particularly enormous because of the central role they play in providing care for people living with HIV/AIDS and their families (Ssengozi, 2009). Elderly people, in particular, are vulnerable to poverty because when they retire, they find themselves unable to work or unable to find employment and regular income (WHO, 2008). When children with HIV/AIDS die, elderly people must find both the money for burials and to care for those left behind, many of whom they know may even themselves be sick and will die of the disease. During these extremely stressful times, the vast majority of elderly people are offered no financial, physical or emotional support (WHO, 2008). The economic burden on the parents also depends on how much other family members assist or depend on them financially. Contributions from community members or funeral society benefits can lessen the net cost of funerals (WHO, 2008).

Whether the parents foster orphaned grandchildren depends on several factors such as who else is available for the task, circumstances around an EPLWHA, and prior economic status of the parents and the adult child (Knoel & Wassana, 2004). Economically more affluent parents will be in a better position than poorer parents to

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endure expenses or loss of income associated with the illness and death of their child. Likewise, adult children who are better off financially can help defray some costs themselves (Knodel & Wassana, 2004). The poor appear to be the most adversely affected. Although they spent less on treatment, care and funeral plans, transportation to healthcare sites and the costs of some medications can create financial hardship for those without savings or assets, plunging them into debt (Knodel & Wassana, 2004). Such costs are also exacerbated by multiple episodes of illnesses and hospitalizations (Pallangyo & Mayers, 2009).

The economic pressures on the elderly are worsened by age, declining health status and caretaking responsibilities at home, and tend to further compromise their ability to earn an income. Thus, many elderly people resort to selling their assets to pay for expenses (Today's Research on Aging, 2007). This happens in countries with extensive poverty and lack of government social security mechanisms. However, in Thailand, the Government Health Insurance and Welfare programmes help to reduce a family's medical expenses (Today's Research on Aging, 2007). This is also the case in South Africa, older female persons who are 60 years and above and males who are 65 years and above are paid an old age grant on a monthly basis (Today's Research on Aging, 2007). The majority of them also receive foster care or care dependency grants on behalf of their grandchildren orphaned by HIV/AIDS (DSD, 2006).

Elderly people are often financially dependent on their children and when those children become sick, such assistance is no longer available. The sick family member gradually loses income and/or time to work, and eventually savings, if any, or even personal belongings. HIV/AIDS is reported to bring hunger and poverty to affected households. Some poorer communities are left with mainly old people who are weak.

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In addition, sick people die without having made proper plans for their families, and leave behind children with hardship and an insecure future (Gerontol & Cross, 2007).

### 2.2.2 The Impact of HIV/AIDS on Households

The impact of HIV/AIDS on households has also been described as very severe. Although no part of the population is unaffected by HIV/AIDS, it is often the poorest sector of society that is affected most gravely. HIV/AIDS causes households to dissolve as parents die and children are accepted by relatives for care and upbringing (WHO, 2008). According to Today's Research on Aging (2001) in Thailand, a large proportion of adults who died from AIDS had either lived with their parents by the time of their terminal stage of illness and their parents provided some type of care to them. In a study conducted by Pallangyo & Mayers (2009) it was observed that food security for families infected with and/or affected by HIV/AIDS was severely impinged upon. Meals were inadequate or missed and as a result family members would have no other choice but to beg for food. It became more difficult when infected individuals had to take antiretroviral therapy (ART) after a meal (Pallangyo & Mayers, 2009). Neighbours of EPLWHA are reported to be playing a greater role of sharing their own scarce food resources with affected households or with poverty-stricken grandmother–headed or child-headed households (Campabell, Naire, Maimane & Sibiya, 2007).

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### 2.2.3 Psychological and Emotional Health of the Elderly

Elderly people experience psychological and emotional strain associated with coping with HIV/AIDS deaths and bringing up orphans (UNAIDS 2005). Research in Africa and Asia points to a wide range of problems experienced by older caregivers (Humanitarian Practice Network, 2008). These problems include exhaustion, financial grief, emotional upheaval, lack of knowledge and resources for dealing with adult children infected with HIV/AIDS, conflict with grandchildren and stigma (Humanitarian Practice Network, 2008).

The maturing epidemic in Africa has certainly strained the extended family system, and the elderly population is one of the most affected groups. The loss of children or close relatives who would otherwise be expected to outlive their parents and care for them during illness, take emotional toll on the parents. HIV/AIDS is a disease with almost 100% case fatality, especially in settings with limited or no access to antiretroviral treatment, caregivers constantly live with the worry of losing their loved ones (Gerontol & Cult, 2007). In many instances, parents and close relatives of HIV-infected persons are depressed because of the looming death of a loved one in their midst and after the death they often miss the advice and company of their deceased relatives.

The level of care may affect the intensity of emotional distress, as was established among Kenyan grandmothers providing care to their grandchildren. In the case of older relatives, especially the parents, this emotional toll could influence their aging process, as it comes at a stage in their lives when they are frail or beginning to be frail (Gerontol & Cult, 2007). EPLWHA are reported to be undergoing frequent episodes of worry, crying, depression and a sense of hopelessness not only about the state of

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things presently, but also the future (Pallangyo & Mayers, 2009). The realization from caregivers that no matter how much they try, the sick relative would likely die, create a sense of futility and dilemma in their efforts (Pallangyo & Mayers, 2009). Elderly people in this situation view their efforts and resources spent to care for the HIV/AIDS patients as wasted, yet it is soothing as they felt they had to do it- not just out of responsibility, but out of love as well (Gerontol & Cult, 2007). Elderly people experience stress when watching loved ones suffer from HIV/AIDS, particularly caregivers who themselves are infected knowing that a similar fate awaits them (Pallangyo & Mayers, 2009).

EPLWHA are usually stigmatized which complicates the problem of care. They expect support from relatives, but failure to get it usually make them feel rejected (Pallangayo & Mayers,2009). Relatives normally blame the patient for bringing the sickness onto themselves. As a result, elderly caregivers and their patients avoid contact with the relatives as a way of coping which not only increases their stress level, but also negatively affects their physical and mental health (Pallangayo & Mayers, 2009).

Older caregivers experience physical tiredness caused by barriers such as lack of birth certificates for the children as some children are left by their deceased parents without the birth certificates. Children without such documents cannot access services provided by the state, and as a result, the primary caregiver become frustrated with the sense of helplessness to prove the nationality of their children. Sometimes, children are just brought to the elderly caregiver without these important documents (WHO, 2007). Exhaustion, loss of appetite, insufficient infection precautions, and lack of rest

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and sleep take their toll on the physical and mental health of the caregivers (Pallangyo & Mayers, 2009).

As elderly people focus on caring for their children and grandchildren they may neglect themselves and are at risk of becoming ill. They may go without food in order to provide for others. This may result in malnutrition and rapidly failing health. The physical demands and emotional strain of caring for the seriously ill can adversely affect the health of the elderly. Evidence from Thailand indicated that the increase in daily chores and activities related to care causes stress which has an effect on their physical health and well-being (Today's Research on Aging, 2007). Despite the challenges that elderly caregivers face, an analysis from ten countries shows that orphans living with grandparents are more likely to go to school than those living with other relatives or non-relatives (WHO, 2008).

Over time, caring is seen as a burden which could impact detrimentally not only upon the household asset base, but also on intra-household relations, thus leading to ill-feelings and tensions, particularly between caregiver and patient. A key cause of tension is the frequent mood changes of both patient and caregiver, based primarily upon the health status of the patient, with days of improvement in health reflected in optimism and increased psychological well-being, and days of worsening health and recognition of the patient's vulnerability and dependent condition as reflected in tension, sadness, frustration and anger between patient and caregiver. During times in which the patient was able to eat, or undertake livelihood activities, the caregiver showed optimism for the future and felt relieved hoping that the patient may recover. However, caregivers suffered from the physical strain of caring (Thomas, 2006).

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### 2.2.4 Potential Danger of HIV Infection in the Elderly

Some primary older caregivers are likely to place no physical barrier between themselves and the infected children in terms of care, some know of the potential of opportunistic infections, though others do it because of lack of knowledge. In some cultures, it is unacceptable to be seen as stigmatizing one's own child and this hinders the use of gloves as they believe they will be offending their children (WHO, 2007).

### 2.2.5 Abuse and Rejection of the Elderly in Relation to Care

Elderly people suffer some various forms of abuse from their terminally ill HIV-infected children, including discrimination, stigma, rejection, verbal and physical abuse. This kind of situation even causes them to develop some stress-related conditions (WHO, 2007). The effects of the disease on the patient's mental health, such as aggression and unpredictable moods swings, are exhausting and demoralizing. An argument over an unwanted kind of a meal can lead the patient to fill his/her mouth with food and blow it directly into the face of the elderly caregiver (Pallangyo & Mayers, 2009). There were reported stories of brutal gossip and rejection by neighbours to elderly infected people (Campbell, Nair, Maimane & Sibiya, 2007).

### 2.2.6 Cultural Traditions and Myths

Elderly people in any society are important bearers of tradition, including knowledge about illnesses and their causes. There is no concept of disease transmission through bacterial, viral or helminthic infections in Tswana folk medicine. Although it is recognised that 'dirty' food may cause illness, that some conditions such as epilepsy

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may run in families and that there are times of the year when many people are getting colds and flu, the only clearly defined concept of illness transmission is by breaking the sexual taboos. In most cases, the pollution that causes illness is seen as originating in the womb of the woman during certain critical periods as after an abortion, after an abnormal delivery, or while in confinement after birth. Defined periods of sexual abstinence should be observed, followed by purification rituals, before sexual activity is resumed. Violations of these taboos may render somebody polluted and consequently sick, and/or through sexual intercourse pass the pollution on to subsequent sexual partners and sometimes to their nursing children through mother's milk. Similarly, a woman who violates the rule of abstinence may bring illness upon herself or her child that she is caring for (Ssengonzi, 2009).

The majority of elderly people in the villages do not regard themselves as likely to get HIV/AIDS as they believe they can be affected by other types of sexually transmitted pollution. Actually, an important part of the aging process is seen to be caused by the blood gradually becoming 'dirty 'through the many sexual relationships of oneself or one's partners throughout life (Ssengozi, 2009). Invariably, some of these may involve taboos such as intercourse with a woman who had had an abortion without going through the proper rituals afterwards, or with her subsequent sexual partners. According to Tswana beliefs, one way of cleaning the blood and thus regaining some of the vitalities of youth is for an elderly person to have proof of its vitalising effect, they say, is that old men who marry young wives often seem younger than their actual age, many elderly people claim that such relationships actually exist secretly (Ssengozi, 2009).

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Cultural beliefs have a strong tendency of influencing the belief that people infected with HIV/AIDS had been bewitched. Very often, this tends to compound the already hard financial situation of the household as the family resorts to consulting traditional healers in efforts to reverse what is perceived as a curse, thereby draining a lot of financial and other resources. The patient often dies leaving a huge debt. It is in this kind of environment that the older person is expected to look after orphaned children (WHO, 2007).

Common American myth is that elderly people are neither interested in nor participate in sex. In reality, evidence suggests that American elders do engage in sexual activities and find sexual expression to be an important and satisfying part of living, and as a result, they, like others who have sex, are at risk for contracting sexually transmitted infections or diseases, including HIV/AIDS (Wooten, 1999). American society ignores and evenly actively discourages sex among older adults. Those elderly people who are sexually active may not feel comfortable discussing their sex lives with their healthcare providers. As a result of this cultural denial of elder sexual expression, the large population of older Americans is being excluded from HIV/AIDS education (Wooten, 1999).

### 2.2.7 Available Support for the Elderly

Despite their considerable caregiving role, the elderly remain largely hidden from the international HIV/AIDS agenda. Because it is assumed that they are not at risk of contracting HIV/AIDS, the elderly have received minimal programmatic and policy attention. However, elderly people are not only at risk of being infected, their income and health may also be adversely affected when they take on the role of caregiver.

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Furthermore, they may need support in their caregiving role. Recourses and information targeted at the elderly can enhance the efforts elderly of people to care for their loved ones and to protect themselves. Elderly people can also play a pivotal role in prevention by influencing their children to avoid risky behaviour (Today's Research on Aging, 2007).

Zelenetz et al (1998), in his recommendations, indicated that a primary healthcare effort should be directed at education, both of older individuals and the physicians who care for them. Given that 10% of elderly people have at least one risk factor for HIV/AIDS, physicians should have a higher index of suspicion for the disease. Risk factors for HIV/AIDS such as blood transfusion, either in the patient's history or their partner's, should ascertain. Thorough sexual histories should be obtained, including any record of homosexual sex and sexually transmitted diseases. Once assessed, the patient can be given information about their risk behaviours and strategies to prevent disease transmission, and they can also be offered HIV/AIDS testing. Physicians may feel that older patients are reluctant to discuss such subjects, that is they would be uncomfortable, but it had been noted that adults are willing to talk frankly about sexuality when the conversation is cached within the context of their health and the health of their loved ones (Zelenetz et al, 1998).

In South Africa, the government provides an old age grant to substitute and supplement income for elderly individuals. Older women mostly use their grant for much more than their own subsistence. In many households, the grant is the only income and, as a result, the needs of an elderly person are likely to be ignored while her grant has to maintain the whole family, while the grant is only intended for an elderly person's needs (Schatz & Ogunmefun, 2007). Not having children's birth

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certificates is a major obstacle in accessing child support grants and many elderly people mistakenly believe that their grandchildren are too old to receive the grant so they do not bother to apply. Since the child support grant is much less per month than the pension, elderly people do not view the child support grant as assisting as an old age grant (Schatz & Ogunmefun, 2007).

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### 2.2.8 The Community-Based Foster Care Model

Currently, the Thulamela municipality does not support EPLWHA. However, in Alexandra, Johannesburg, South Africa, there is a Community-Based foster Care Model. The same model also hosts the Go-Go Grannies. The Go-Go Grannies comprise a group of grandmothers who have lost their own children to AIDS/AIDS and who are now raising their orphaned grandchildren. They help and encourage each other to cope, both emotionally and physically with this daunting task (van Dyk, 2005). They are also supported by the Community-Based Foster Care Model. This provides psychological, financial and material support to the grandmothers. The project also assists them by providing once-off building grants to ensure adequate shelter for their growing families, as well as seeds and fertilizers so that grannies will be able to start their own gardens in order to provide food and income for their families (van Dyk, 2005).

Elderly people in Sub-Saharan African play a significant role in the care of children, including orphans, and this trend is increasing. Elderly people are often the first resort for children orphaned. Children come to their grandparents even before their parents die. Often their parents with HIV/AIDS return to the grandparent's home during the final stages of illness for care (Help Age International Material, 2004). The

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purpose of The Community-Based Foster Care Model is to ensure that community members access support nearest to home, which encourages participation by the people, responds to the needs of people, encourages traditional community life and creates responsibilities (Ncama, 2005). Community based structures protect the rights of individuals and facilitate access to health and welfare, and education - a number of HIV/AIDS activist groups are also involved in this function. These organizations are usually involved in initiating and running support groups for people infected and affected by HIV/AIDS. A well-known example is the Treatment Action Campaign in South Africa. This group has been successful in pressurizing the government to offer antiretroviral medications for people living with HIV/AIDS (PLWHA) in South Africa (Ncama, 2005). Community-based structures also provide support groups and income-generating activities. Other activities include voluntary counselling and testing (VCT) as well as education and information about HIV/AIDS (Ncama, 2005).

The services rendered by community-based structures include home visiting - volunteers visit patients in their homes and spend time talking and educating them and their families about basic care needs. Home visiting also provides support with cooking, cleaning and errands, including accompanying patients to health facilities. Home visitors may also arrange access to food parcels and other material support (Ncuma,2005).

## 2.3 Summary

This chapter reviewed the relevant literature in order to orientate the researcher to what is already known about the context of the study undertaken and described in this thesis. The issues discussed were socioeconomic impact of HIV/AIDS, psychological

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and emotional health, potential danger of HIV/AIDS infection by elderly people themselves, abuse and rejection relating to care, barriers affecting elderly people and the community-based foster care model. Chapter 3 outlines the methodology used in this study.

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# RESEARCH METHODOLOGY

## 3.1 Introduction

The previous chapter discussed the literature relevant to this study. This chapter describes the methodology and techniques that were used in the study.

## 3.2 Study Design

Research design is a logical strategy for gathering evidence about knowledge desired. It must be efficient, which means it must actually yield the knowledge desired (De Vos, Strydon, Fouche & Delport, 2005). The study design was qualitative explorative and descriptive in nature.

### 3.2.1 Qualitative Research

Qualitative research is an approach which does not usually provide the researcher with a step-by-step plan or a fixed recipe to follow (De Vos, 2005). Qualitative methods collect information in the form of words which gives an in-depth understanding of the nature of what people experience. In this study, the researchers were interested in the in-depth descriptions of the range of emotions, thoughts and coping strategies that people exhibit in particular situations. Qualitative methods

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allow participants to speak about their experiences in their own words (De Vos, 2007).

The focus of this qualitative study was to explore and describe the impact of HIV/AIDS on elderly people. The data were collected in the natural settings of the participants, which were their homes environments. The study also sought to understand the experiences of elderly people infected and or affected by HIV/AIDS. Social workers' views on the impact of HIV/AIDS on the elderly were explored and described. Data from social workers were collected in their respective offices.

### 3.2.2 Explorative Studies

Explorative studies are conducted to explore the topic in question or to provide a basic familiarity with that topic. This approach is typical when a researcher examines a new interest or when the subject of the study is relatively new. Such studies are also done to satisfy the researcher's curiosity and desire for a better understating and to determine the priorities of future research (Babbie & Mounton, 2001). The use of open–ended questions and the probing of participants' answers allowed for flexibility to further explore the study topic. The researcher was able to move beyond the limits of the present questions based on expected findings from the literature to explore the impact of HIV/AIDS on the elderly.

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### 3.2.3 Descriptive Research

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Descriptive research is more likely to refer to a more intensive examination of phenomena and their deeper meanings, thus leading to thicker description (De Vos, 2005). A major purpose of many social scientific studies is to describe situations and events (Babbie & Mounton, 2001). The data were used to produce a descriptive account, which was reviewed by an informant who confirmed its accuracy.

## 3.3 Study Setting

The study was conducted in Thulamela municipality, Vhembe District in the Limpopo Province. The majority of people living in this area are Vatsonga and Vhavenda speaking. Thulamela municipality has four main social work offices, viz., Thohoyandou, Malamulele, Makwarela and Tshilidzini, and under each main office there are several satellite offices depending on the number of villages it serves and accessibility to that particular sub-district. Social workers in this municipality render all three main models of social work, viz., community work, group work and case work. The small numbers of social workers provide probation services and the rest perform generic social work.

The Department of Health and Social Development is currently intensifying efforts to address HIV/AIDS-related issues. Currently, the Department has an HIV/AIDS programme. Services rendered are drop-in centres, home-based care, community-based centres, HIV/AIDS in the workplace, and family related services. Drop-in centres and home-based care focus mostly on children who are orphaned by HIV/AIDS. The programme on HIV/AIDS in workplace focuses mostly on

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employees working in children's homes. However the department extends its services to individuals infected with and/or affected by HIV/AIDS and other companies that might need their employees to be trained on HIV/AIDS.

## 3.4 Population and Sampling

### 3.4.1 Population

Population is a term that set boundaries on the study units (De Vos, Srydom, Fouche' & Delport, 2005). Population is also defined as the total set from which the individual or units of the study are chosen. On the other hand, population is also seen as the set of elements that the research focuses upon and to which the obtained results should be generalized (Bless & Smith, 2005). The study population comprised all elderly clients who were 50 years old and above, both males and females, receiving grants because they are either infected with and/or affected by HIV/AIDS. These were clients in the records of social workers within the Social Development Section of the Thulamela municipality. The study population was also composed of all social workers employed between 0- 10 years by the Department of Health and Social Development in Thulamela municipality.

### 3.4.2 Sampling

Sampling is the process of selecting a few examples from a bigger group. Probability sampling occurs when the probability of including each element of the population can be determined (De Vos et al., 2005). Non-probability sampling refers to the case where the probability of including each element of the population in a sample is

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unknown. It is not possible to determine the likelihood of the inclusion of all representative elements of the population into the sample (De Vos et al., 2005).

In this study, non-probability sampling was chosen and a subcategory of a purposive sampling method was used to select the participants. Purposive sample was elected because it illustrates some features or processes that are of particular interest to a study (De Vos et al., 2005). The sampling was two-folded: sampling of general participants and sampling of key participants.

### 3.4.2.1 Sampling of General Participants

The sampling was purposive because the researcher selected clients who have been in social work records. Those were elderly people 50 years and older, infected with and/or affected by HIV/AIDS, and residing in the villages and townships in Thulamela municipality. Participants were selected based on the following criteria:

- Receiving foster care grant for HIV/AIDS orphans
- Taking care of an adult who is receiving a grant because of HIV/AIDS
- Receiving a grant because of HIV/AIDS

Participants were selected from three social work sub-offices, viz., Thohoyandou, Makwarela and Tshilidzini. Clients who fulfilled the requisite criteria were identified and a total number of twelve were reached and the sample was determined by data saturation.

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### 3.4.2.2 Sampling of Key Participants

The key participants (social workers) were purposefully selected within the Thulamela municipality, from each main social work office (Thohoyandou, Makwarela and Tshilidzini), two social workers who were either coordinating or facilitating the HIV/AIDS programme were selected. A sample size of eight participants was achieved.

## 3.5 Data Collection

Data collection is a process in the research project that involves engaging with a target sample or population from whom data are collected (David & Sutton, 2004). Data collection is also defined as a series of interrelated activities aimed at gathering good information to answer emerging research questions (Creswell, 2007). The researcher used an interview guide to collect data.

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### 3.5.1 Interview Guide

An interview guide is a tool which provides the researcher with a set of predetermined questions that might be used as an appropriate instrument to engage the participant and designate the narrative terrain (De Vos, 2005). The researcher used an interview guide in order to produce a schedule and to think explicitly about what is to be achieved and what is to be covered in an interview. This helped the researcher to think about difficulties that may be encountered. The researcher used interview as a method of data collection and a subcategory of semi-structured items was utilised.

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### 3.5.1.1 Semi-Structured Interview

A semi-structured interview is a method of data collection that generally lasts for a considerable amount of time and can become intense and involved, depending on the particular topic (De Vos, 2007). In this study, semi-structured interviews were conducted in order to allow the researcher to explore the experiences of EPLWHA. Thus, participants were allowed to express themselves freely and the researcher could probe further into the situation.

### 3.5.1.2 Key Participants

The key informant (participant) utilizes questionnaires or interviews to obtain expert opinions from individuals who are presumed to have special knowledge about the target population's problems and needs, as well as current gaps in service delivery to that population (Rubin & Babbie, 1993). In this study, eight social workers were purposively interviewed utilizing an interview guide. This was done to obtain expert opinion (Annexure B). The data were collected using a tape recorder and notebook.

### 3.5.1.3 General Participants

The general participants were interviewed in their homes/natural environment using an interview guide. This gave the researcher an opportunity to gather non-verbal information. The researcher used an audio tape, notes were taken, and researcher probed and paraphrased questions in order to obtain responses.

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### 3.5.2 Plan for Data Collection

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Data were collected within a period of three weeks starting with the key participants (social workers) and then the general participants (elderly people 50 years and older, infected with and/or affected by HIV/AIDS). In this study, the schedule was first given to the supervisor for scrutinization. Secondly, two participants were interviewed from the Thohoyandou social work office. The results of the pre-test were incorporated into the main study as this was a qualitative study.

#### 3.5.2.1 Pre-Test of the Interview Schedule

After the researchers have developed the instrument and are satisfied with the general wording and sequencing of questions they must pre-test the schedule (Berg, 1989). Firstly, the schedule should be examined by other researchers or experts who are familiar with the subject matter. The second step is pre-testing the instrument before it can be used in a main study. In this study, after establishing satisfaction with the interview schedule, one key participant and one general participant were interviewed before the real data collection started and their information formed part of the data as this was a qualitative study.

#### 3.5.2.2 Negotiating with the Participants

##### 3.5.2.2.1 Departmental Approval

The researcher requested approval from the Provincial Department of Health and Social Development to interview key and the general participants. The researcher also requested approval from the District of Vhembe, same department (Annexure D).

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The approval letters from the provincial and district offices were submitted to the Municipal supervisor. Negotiations were done telephonically and face-to-face with clients themselves with the assistance of area social workers. The researcher negotiated directly with the key participants, also telephonically and face-to-face.

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#### 3.5.2.2.2 Interview Process

The researcher first interviewed on an individual basis 8 social workers in arranged venues, which were in their offices. After completing the key informant's part, the researcher started with the process of interviewing the general participants in their own homes and for those who were not found during the visit an arrangement was made to see them again. The participants were interviewed in their own homes, predominantly in the early hours of the morning. The visitation was conducted just like any social work home visit. The participants were aware of the visit, but not quite sure of the dates - this was done deliberately so that the natural environment was not altered or disturbed. During both interviews, the researcher used an interview guide. A tape recorder was utilised, after explaining the reasons for its use to the participants. Field notes were taken during the process of interviews. A total of 8 key participants was reached and a total of 12 general participants was attained. Observation, as a skill in interviews, was utilised in order to make sense of the non-verbal messages.

## 3.6 Data Analysis

The researcher analysed the data in a qualitative manner, using Tesch's method (cited in Creswell, 2003). According to this particular method, eight steps must be followed

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**Step 1** The researcher picked one document at a time, scanned through it carefully and wrote down ideas that came to mind.

**Step 2** One document was picked from the most interesting interview. The researchers went through it and the thoughts that came out were noted.

**Step 3** When the tasks of several participants were completed, a list of all topics was made. Similar topics were clustered into columns that were arrayed as major topics, and leftovers.

**Step 4** The list was taken back to the original data, the topics abbreviated as codes which were written next to the appropriate segments of the text.

**Step 5** The most descriptive wording for the topics was formulated and the topics were grouped into categories to reduce the list of categories. Topics related to each other were grouped.

**Step 6** A final decision on the abbreviation for each category was made and codes were arranged alphabetically.

**Step 7** The data belonging to each category were assembled in one place and a preliminary analysis performed.

**Step 8** The available data were recorded.

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## 3.7 Ethical Considerations

Research ethics are codes or sets of principles which place an emphasis on the human and sensitive treatment of research participants who may be placed at varying degrees of risk by researcher procedures (Bless, Smith, & Kagee, 2007).

### 3.7.1 Permission to Conduct the Study

Approval and permission to conduct the study was requested from the Higher Degrees Committee (HDC) of the School of Health Sciences, University of Venda. After the approval by the HDC was granted, the proposal was forwarded to the University Research and Ethics Committee for final approval. The proposal was also submitted to the Department of Health and Social Development, particularly the Social Development section, in order to obtain consent to conduct the study and to recruit their clients as participants (Annexure D).

### 3.7.2 Informed Consent

A basic ethical question when planning any research is whether the research might in any way cause harm to the research participants or society at large (Louw & Edwards, 2008). Participants have the right to know what the research is all about, how it will affect them, the risks and benefits of participation and the fact that they have the right to decline to participate if they choose to do so (Bless, Smith & Kagee, 2007). Permission was first obtained from the participants through informed consent (Annexure C). The purpose of the study and all procedures to be followed were

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explained to the participants. Possible pain, discomfort and stress that may accompany the research process were discussed with the participants.

### 3.7.3 Confidentiality and Anonymity

Information provided by participants, particularly sensitive and personal information, should be protected and made inaccessible to anyone other than the researcher (Bless, Smith & Kagee, 2007). Privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a private and trusted manner (De Vos, Strydom, Fouche & Delport, 2005). The participants were ensured that their privacy will be respected, and this was achieved by making sure that their personal details such as names and address will not appear in any public document.

### 3.7.4 Withdrawal of Participation in the Study

Participants were given every assurance that they were free to discontinue their participation at any time without being required to offer an explanation. Participants were also informed that stopping participation will not prejudice their receiving service if the project is conducted at a clinic or government institution (Bless, Smith & Kagee, 2007). The participants were ensured that their participation non-participation will not have any impact on the service they received, meaning the participants were told that they could refuse to participate in the study without any penalty. It was communicated clearly that they can withdraw during the process any time if they wished to do so. The participants were also alerted that the researcher will utilize a tape recorder for the purpose of preserving information. They were ensured that the information will be used only for the purposes of the study.

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Trustworthiness, another approach to clarify the notion of objectivity as it is manifested in qualitative research, is found in the highly influential work of Lincoln & Guba (1985). For them, the key criteria or principle of good qualitative research is found in the notion of trustworthiness: neutrality of its findings or decisions cited (Babbie & Mouton, 2008). The following four criteria were used to ensure trustworthiness as described by Lincoln & Guba (1985).

### 3.8.1 Credibility

Credibility is about compatibility between the constructed realities that exist in the minds of the respondents and those that are attributed to them (Babbie & Mounton, 2008). The researcher achieved this by making sure that the participants understood the questions, this was done by reframing the questions whenever the respondents showed misunderstanding. Reflexivity was ensured by interviewing participants in different venues and settings. Participants were given sufficient time to respond to questions and this ensured prolonged engagement. Key participants were interviewed to add more value to the responses.

### 3.8.2 Transferability

Transferability referrers to the extent to which the findings can be applied in other contexts or with other respondents (Babbie & Mounton, 2008). In this study, the researcher requested assistance from colleagues to purposefully select the participants, with the needed characteristics. This was done in order to ensure that the results

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suited other participants with the same characteristics. The characteristics and methods were also clearly described.

### 3.8.3 Dependability

Dependability involves providing the audience with evidence in order to ensure the same results in the case of repeating the study with similar respondents, and in the same context (Babbie & Mounton, 2008). The researcher made use of professionals and specialists to check the research plan and implementation.

### 3.8.4 Conformability

This is the degree to which findings are the product of the focus of the inquiry and not the bias of the researcher (Babbie & Mounton, 2008). Conformability was achieved by prolonged engagement with participants during in-depth individual interviews.

## 3.9 Summary

This chapter detailed the processes of how the study was conducted in order to achieve the research objectives. The study design was qualitative, explorative and descriptive in nature. Ethical consideration and trustworthiness were described. Chapter 5 provides an analysis and discussion of the data collected in this study.

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# CHAPTER 4

# RESULTS AND DISCUSSION

## 4.1 Introduction

A discussion of the research methodology was presented in the previous chapter. The objectives of this chapter were to analyse and develop the raw data into themes, categories and subcategories to reflect the participants' experiences, and to place the findings into proper perspective with the relevant literature. The results were obtained from the key participants, i.e., male and female social workers employed by the Department of Health and Social Development in the Thulamela municipality, and from the general participants (in social workers' records), i.e., male and female EPLWHA.

## 4.2 Participants' Characteristics

The findings were gathered from 8 social workers. Their ages ranged from 20 to 34 years. Their working experience ranged from 2 years to 6 years. These were social workers who rendered generic social work within the Thulamela municipality and social workers who provided services to the elderly infected with and/or affected by HIV/AIDS on daily basis. The general participants were 12 elderly people aged from 50 years to 83 years, in social workers' records infected with and/or affected by HIV/AIDS. The general participants were categorised as follows: taking care of infected adults, taking care of children orphaned by HIV/AIDS and EPLWHA. Key

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participant interviews took 40 to 45 minutes and the total interview time was 370 minutes. General participant interviews lasted 45 to 55 minutes and the total interviewing time was 600 minutes. Table 4.1 indicates the gender distribution of the participants.

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**Table 4.1**

**Gender of Participants**

| | Males | Females |
|---|---|---|
| Key participants | 4 | 4 |
| General participants | 1 | 9 |

## 4.3 Presentation and Discussion of the Findings from Key Participants

Table 4.2 show the themes, categories and subcategories that emerged from the analysis of raw data of the key participants. These are findings from social workers who are employed by the Department of Health and Social Development, participating in HIV/AIDS programme in the municipality. Key participants mentioned different view about the impact of HIV/AIDS on elderly people. Four major themes emerged from the data with categories and subcategories (Table 4.2). Appropriate quotes from raw data and literature to substantiate the theme are discussed.

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## Table 4.2

## Themes, Categories and Subcategories of the Impact of HIV/AIDS on EPLWHA, According to Key Participants

| Theme | | Category | | Subcategory | |
|---|---|---|---|---|---|
| 1. | Key participants' description of the impact of HIV/AIDS on the elderly | 1.1 | Difficulties experienced by the elderly | 1.1.1 | Burden of taking care of sick adult child |
| | | | | 1.1.2 | Lack of knowledge about the disease |
| | | | | 1.1.3 | Psychological stress related to caring for HIV-infected orphans |
| | | | | 1.1.4 | Financial burden related to caring for terminally ill or orphans |
| 2. | Key participants' description of coping strategies used by elderly people | 2.1 | Experiences of difficulties in coping with the disease | 2.1.1 | Failure to seek support from relatives or friends, due to fear of stigmatization |
| | | | | 2.1.2 | Pretending to be coping as it is expected by culture |
| | | 2.2 | Key participants' explanation of coping abilities used by the elderly | 2.2.1 | Using governmental institutions, Department of Health and Social Development |
| | | | | 2.2.2 | Depending on social grants (foster care, child support grant) |
| 3. | Key participants description of challenges faced by elderly people | 3.1 | Assuming a parenting role in late years of life | 3.1.1 | Adopting a role of parenting grandchildren |
| | | | | 3.1.2 | Being stressed by parenting uncontrollable grandchildren |
| | | | | 3.1.3 | Assuming the role of breadwinner with little income |
| 4. | Key participants' views about services rendered to EPLWHA | 4.1 | Positive responses related to services received | 4.1.1 | Community centres established to support the elderly |
| | | | | 4.1.2 | Employment of more social workers |
| | | 4.2 | Negative responses related to services received | 4.2.1 | They get short term services such as food parcels |
| | | | | 4.2.2 | More information about HIV/AIDS needs to be disseminated to the general population of elderly people |

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### 4.3.1 Theme 1: Key Participants' Description of the Impact of HIV/AIDS on the Elderly

Key participants expressed how the elderly are affected by HIV/AIDS. It was evident from the discussions that the elderly are experiencing challenges when infected with and/or affected by HIV/AIDS as described below.

#### 4.3.1.1 Category 1: Difficulties Experienced by the Elderly

All the participants described the difficulties experienced by elderly people as related to the burden of taking care of a sick adult child, lack of knowledge about the disease, psychological strain and financial burden. Difficulties experienced by elderly people involve different aspects as described by the key participants.

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##### 4.3.1.1.1 Subcategory 1: Burden of Taking Care of a Sick Adult Child

The results indicated the existence of the burden experienced by elderly people taking care of an adult child infected with HIV/AIDS. The burden, however, is worsened by a number of aspects that elderly people face, including low level of understanding of the causes of HIV/AIDS. This is mostly influenced by their beliefs which are culturally rooted, such as viewing an HIV/AIDS patient as someone who has to answer some calling or who is bewitched. This belief sways them to consult traditional healers first and then check in at the hospital in an advanced stage. EPLWHA also live in poverty and, as a result, do not even have adequate accommodation for their family members, this is worsened when they are expected to care for a sick child. The findings have also showed that elderly people normally



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takes care of more than one family member, which exacerbates the burden as they are expected to spend more money on care-related activities, an expense they can ill afford. This is supported by the following quotations.

One participant said: *'Our clients who are elderly people are left with the responsibility of looking after their sick children and unfortunately it is at the time when they are no longer strong to handle such responsibilities'.*

Another participant said: '*Our client's burden is even worsened by the fact that even if the treatment is explained to them, they start by trying other means such as consulting the traditional healers. All the time they will be focusing on traditional medicine, they ignore treatment from hospital. At the end they end up having to look after the terminally ill'.*

Elderly people are also said to require support and expect to be looked after by their children and significant others. However, due to the HIV/AIDS pandemic, the opposite usually happens (WHO, 2007). The literature indicates that elderly caregivers begin to care for HIV-infected relatives when they are bedridden, unable to walk on their own, and suffering from ailments such as diarrhoea, sores/wounds, and headaches (Cross & Gerontol, 2007). Although HIV-infected persons appeared to spend most of their illness time away from their elderly parents or other elderly relatives, they are said to seek care from the older persons during the terminal stages of their illness, a time when they need more day-to-day care (Cross & Gerontol, 2007). Chinwaza (2005) also reported that some caregivers receive support, some restricted support whilst others do not get it at all and Ehlers (2005) emphasized the

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need to support caregivers physically, socially and emotionally to reduce caregiver burnout.

#### 4.3.1.1.2 Subcategory 2: Lack of Knowledge About the Disease

The study has revealed that some elderly people have developed an understanding of HIV/AIDS while others suppressed their meagre knowledge of the disease by cultural beliefs, e.g., that disease is brought about by witchcraft. Data revealed that elderly people lack information about HIV/AIDS. This tends to expose them to infections as they do not practice safe protection measures. On the other hand, the HIV-infected people they care for are taken to traditional healers who advise them that if they stop treatment the condition will deteriorate naturally, which makes it more difficult to care for them. It was also implied that a lack of knowledge about HIV/AIDS and the beliefs of the elderly about the causes of illness contribute to late presentation for treatment or stopping the treatment.

One participant said: "*Most of my elderly clients are not even told about the status of their children. They are not even well informed about the disease; as a result they get infected while taking care of their infected children, and grandchildren, like when shaving their hair and handling of wounds*".

Another participant said: "*One of my clients did not believe that her daughter is infected; she used to believe that her daughter is a victim of witchcraft or at least has to answer to ancestral calling. This made her to take her daughter to the traditional healers and the antiretroviral treatment was stopped*".

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These findings are supported by literature which states that elderly people in any society are important bearers of tradition, including knowledge about illnesses and its cause. There is no concept of disease transmission through bacterial or viral infection in Tswana folk medicine (Ssengonzi, 2009). This shows it may be difficult for the elderly to understand disease transmission and apply preventive measures. Shiluvane, Risenga, Khoza & Lebese (2011) described how participants in their study had different perceptions about tuberculosis (TB) and HIV which influenced their health seeking behaviour. In the same study, younger people were said to have more knowledge about TB and HIV than elderly people. It has, however, been noted that elderly people are required to support and care for their sick and dying children. This poses a greater risk to them as they play the role of caregiver without the knowledge of the disease that their family member is having (WHO, 2007).

#### 4.3.1.1.3 Subcategory 3: Psychological Stress Related to Caring for HIV-Infected Orphans

Data from key participants has revealed that EPLWHA experience psychological stress during the caring process. EPLWHA are always afraid that they will lose a family member who can die anytime. They are always worried that they will not have enough money for funeral arrangements. It was also established that most of them have buried more than one family member and currently taking care of another terminally ill family member, and this frustrates them. Psychological stress was also said to be increased by the fact that HIV/AIDS has been stigmatized in their community and they are isolated in their communities, and even by relatives.

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Another participant said: *"The majority of our clients become psychologically stressed, due to pressure caused by HIV/AIDS, they even develop low self-esteem and blame themselves for not making their family members get better".*

Another participant said: *"Some of my infected elderly clients are neglected by their own children; infected elderly are often criticized on how did they become infected at their age, as a result, they end up stressed".*

Elderly caregivers usually show frequents episodes of worry, crying, depression, and a sense of hopelessness, not only about the state of things, but also about the future. The realization for caregivers that no matter how much they try, the sick relative will almost certainly die, is said to create a sense of futility and dilemma in their efforts. Elderly people in this situation often become worried when they think that they are taking care of orphans who will get married and get infected and leave more orphans for them (Cross & Gerontol, 2007). Psychological stress due to lack of knowledge and negative perceptions related to TB was identified (Shiluvane et al., 2011). Sukumani, Lebese, Khoza & Risenga (2011) identified feelings of isolation, stigmatization and fear of the disease as likely sources of psychological stress.

#### 4.3.1.1.4 Subcategory 4: Financial Burden Related to Caring for the Terminally Ill or Orphans

The study revealed that lack of finance is the most prevalent burden experienced by elderly caring for people infected with and/or affected by HIV/AIDS. Elderly people in this situation need sufficient income, in order to cope with the demands of the disease. It is just unfortunate that at this level they cannot be employed due to their

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health status or responsibilities. The elderly are also said to be faced with the responsibility of providing food and toiletries for the terminally ill which leaves them with a financial burden.

Another participant said: *"Clients are expected to provide good food for their sick family members so that they can be able to take treatment, unfortunately they do not have enough money to buy food which is also creating a lot of burden'.*

Another participant said: "*Most of my clients have been cut off from the disability grant, after it has been realized that they have shown some improvement health wise, this is causing a lot of problem as this was the only source of income in their families'.*

According to United Nations Population, the essential issue connected to aging populations in developing countries is lack of resources, i.e., poverty. The South African Human Development Report estimates that approximately 50% of South Africa's population falls below the national poverty line. Africans constitute the majority of poor in the country and are also the main beneficiary of current old age pension. It has been revealed that in certain cases many elderly people are the only ones with regular income, having to support the rest of the family on a monthly pension (Ssengozi, 2009). Family members of PLWHA are expected to provide special foods such as eggs, meat, milk, fruits and vegetables for patients, which the caregiver cannot afford (Rowe, Makhubele, Hargreaves Porter, Hausler & Pronyk, 2005). Constraints related to lack of financial resources in caring for patients at home was also described by Needham, Bowman, Foster, Tomlinson, & Godfrey–Faussett (2004), and Eastwood & Hill (2004).

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### 4.3.2 Theme 2: Key Participants' Description of Coping Strategies Used by Elderly People

All participants expressed in some way the strategies that are used by EPLWHA. Two categories were identified under this theme, viz., experience of difficulties in coping with the disease and key participants' explanation of coping abilities of the elderly.

#### 4.3.2.1 Category 1: Experiences of Difficulties in Coping with the Diseases

Data from the key participants revealed that EPLWHA experience difficulties in coping with the disease. Elderly people in this situation are discouraged from seeking support from relatives and close friends as they are likely to be blamed for their condition. It was further determined that EPLWHA always act as if they are coping with the disease whilst they are not. Two subcategories were identified, viz., failure to seek support from relatives or friends, due to fear of stigmatization and pretending to be coping as it is expected by culture.

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##### 4.3.2.1.1 Subcategory 1: Failure to Seek Support from Relatives or Friends, Due to Fear of Stigmatization

The findings revealed that EPLWHA do not want to be associated with the idea that they are either infected or affected. This reaction is caused by HIV/AIDS stigmatization which exists within communities. It was established that elderly people caring for HIV-infected people are always discriminated against and isolated as community members, including family members, do not want to be associated with them.

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One participant said: *"Our clients try by all means to ensure that their family's HIV/AIDS status remain private, because if not they will be stigmatised and will no longer be welcomed to participate in community activities".*

These findings are supported by Pallongayo & Mayers (2009) who described how EPLWHA are usually stigmatized, which complicates caregiving. The elderly were said to expect support from relatives and failure to get support usually makes them feel rejected. Relatives normally blame the patient for bringing the sickness on themselves. As a result, elderly caregivers and their patients avoid contact with the relatives as a way of coping. In this way their stress level is increased and the physical and mental health is negatively affected (Pallangayo & Mayers, 2009). Some caregivers get support from friends and relatives whereas others get limited support. Other caregivers experience no support at all. Visitors rarely come and pay a visit to the caregivers. Some caregivers are not visited at all. This affects the caregivers socially and psychologically (Chinwaza, 2005).

#### 4.3.2.1.2 Subcategory 2: Pretending to be Coping as It is Expected by Culture

The findings revealed that cultural beliefs and norms contribute negatively, when it comes to how elderly people cope with the disease. It is hard to determine if elderly people with strong cultural beliefs are coping or not as they do not believe in sharing deep secrets or verbalize that they cannot cope anymore. Cultural beliefs have taught them to behave as if they are they are fine even if they are not, which was said to be a problem.

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A participant said: *"The majority of my clients are not coping with the impact, however, they pretend to be fine, because according to most of African cultures an elderly people has to persevere anything".*

This is sustained by literature reports that elderly people in society are important bearers of tradition, including knowledge about illnesses and its cause (Ssengozi, 2009). This explains why they should pretend to be coping with the disease. It has been argued in the context of coping and lifestyle that coping refers to cognitive and behavioural styles or strategies, regardless of their success (Hopkinson, Hallett & Luker, 2004). In contrast to Radzilani-Makatu (2011), the following were said to be coping strategies used by siblings of mentally retarded children among Tshivenda speaking people: resignation and lowering expectations, learnt patience, belief in divine intervention, consciously making contact, self-negation and normalizing the condition.

#### 4.3.2.2 Category 2: Key Participants' Explanation of Coping Abilities Used by the Elderly

Data from key participants revealed that EPLWHA have positive ways of coping with the disease. This is borne out by two subcategories: participants use governmental institutions as a coping strategy and they depend on social grants (foster care and child support grants).

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#### 4.3.2.2.1 Subcategory 1: Using Governmental Institutions, Department of Health and Social Development

The results indicated that the Department of Health and Social Development is the only hope for EPLWHA. The Health section caters for the health needs by providing free treatment and Social Development makes provision for the basic and/or social needs in terms of food parcels and counselling. The findings further revealed that few EPLWHA benefit from home-based care services. These are services affiliated with the Department of Health and Social Development.

One participant said: "*They use social work services; because once they are diagnosed they are referred to our offices. We give counselling, impart knowledge, engage them in long term sessions, sometimes they are in denial, we give them hope*".

Another participant said: "*Orphaned children 0-18 years are regarded as vulnerable, the Department of Social Development tries by all means to meet their needs, such as educational and food*".

Another participant said: "*Community based structures that are handling health and welfare services are of greater importance in this regard, as the workers are from the same community with those who are to benefit from the service. Such structures can easily access elderly infected and/or infected by HIV/AIDS. Community-based structures also assist in the sense that they encourage elderly people infected with and/or infected to go to necessary place where they can get support, i.e., clinic or social worker's office*".

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Current planning for reducing the impact of HIV/AIDS and sexually transmitted infections (STI) in communities, affirmed the collaborative roles of the National Departments of Social Development and Health in taking the lead and responsibility. The two departments are responsible for food security, health security and educational support for children from affected families (National Norms and Minimum Standards, 2007). The support provided by home-based caregivers is corroborated by the literature that these services are rendered by volunteers from the same community, they visit patients in their homes and spend time talking and educating them and their families about basic care needs. Home visits also provide support with cooking and cleaning as well as accompanying patients to health facilities (Ncama, 2005).

#### 4.3.2.2.2 Subcategory 2: Depending on Social Grants (Foster Care, Child Support Grant)

Analysis of the data showed that the majority of EPLWHA depend on social grants, as their means of financial support. In all likelihood, there is no other family income, which makes the situation difficult, especially where the patient is the recipient of the disability grant which is effective only for a few months. In the case of foster care, elderly people also encounter problems when children reach the age of 21 and the grant has to be cut.

One participant said: "Our *clients are depending on social grants, old age grant, foster care grant, and disability grant. Majority of them depend on social grants as the only source of income in their families. The families are also big which make the money to be insufficient*".

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In South Africa, females who are 60 years and above and males who are 65 years and above are paid an old age grant on a monthly basis (Today's Research on Aging, 2007). The majority of them also receive foster care grants on behalf of their grandchildren orphaned by HIV/AIDS or a care dependency grant (Department of Social Development, 2006). All these confirm that social grants are the main source of income of elderly people in South Africa. In other countries like Tanzania, social grants are not a component of health and welfare policies (Pallangyo, 2009). Social grants as a source of income was also described by Sukumani et al. (2011) as a means through which caregivers of TB patients at home cope with the economic demands of care.

### 4.3.3 Theme 3: Key Participants' Description of Challenges Faced by Elderly People

#### 4.3.3.1 Category 1: Assuming a Parenting Role In Late Years of Life

All the participants described in some way the challenges faced by elderly people. It was revealed that elderly people are the population most affected by HIV/AIDS, considering the roles they must adopt when other family members are affected. It was discovered that while in the process of helping out, they put their own lives at risk as reflected in the following categories: adopting the role of parenting grandchildren, they are stressed out due to uncontrollable children and they are playing the role of breadwinners with little income.

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#### 4.3.3.1.1 Subcategory 1: Adopting a role of Parenting Grandchildren

The results confirmed that elderly people have a huge responsibility of taking care of grandchildren orphaned by HIV/AIDS. Some of the children are also infected. Due to the generation gap between the grandparents and grandchildren, and other pressures of life, their relationship is not always good. All key participants indicated that the majority of foster parents are grandparents and, in almost all cases, the relationship between the grandparents and grandchildren has some challenges, even to the extent that the grandparents wished they were dead, as they believe their grandchildren do not show them the respect they deserve.

One participant said: "*Elderly people are facing a great challenge, especially females who are in charge of taking care of the orphaned grandchildren, girls become pregnant and boys start drinking and using drugs*".

The role of parenting by elderly people is substantiated by the literature - about 60% of children orphaned by HIV/AIDS in Namibia, South Africa and Zimbabwe are living with their grandparents and this was said to be a problem (WHO, 2007). Travis, Bethea & Winn (2000) emphasised the need for continued support of family caregivers preparing them for the shared long-term responsibility and accountability to assume complex care such as medication administration. There is also a dire need for health education on recognizing adverse drug effects and understanding the myriad of atypical presentations that they may see in TB patients over the long term.

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#### 4.3.3.1.2 Subcategory 2: Being Stressed by Parenting Uncontrollable Grandchildren

The results showed that EPLWHA experience pressure looking after their grandchildren. Children who are in their teens seem to be causing a lot of stress to their grandparents, who are already tired of child rearing. It was uncovered that elderly people looking after children who are orphaned by HIV/AIDS blame their grandchildren for being uncontrollable as their parents were during their teen years. They believe that their grandchildren will die the same way their parents did. This was found to be causing a lot of pressure to elderly people.

One participant said: *"They are left with the burden of taking care of uncontrollable children'. Majority of my clients infected and/or infected by HIV/AIDS looking after their grandchildren, they are always in my office complaining that their grandchildren use vulgar words towards them, there are few cases where in grandparents were even abused physically. They normally complain about their grandchildren who spend nights with boys and drinking alcohol*".

Another participant said: "*Affected grannies are left with uncontrollable children, they bother grannies, demanding money especially if the child receives foster care grant. Some of my clients even decided to lie to the grandchildren about the foster grant being cut off*".

The literature suggests that youth whose family structures have changed experience behavioural problems. As families are the most important agent of socialization, a disorganized family cannot fulfil this function adequately. Family disorganization may prompt members to engage in deviant acts such as truancy, prostitution, drug

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abuse and suicide attempts (Bezeidenhout, 2008). This aspect was also emphasised by Ali, Ushijima & Muynck (2004), who identified that parental background of their respondents was an important contributory factor that drives street children away from home. This therefore means that children who are uncontrollable are a source of stress to the elderly.

#### 4.3.3.1.3 Subcategory 3: Assuming the Role of Breadwinner with Little Income

The study findings revealed that the majority of EPLWHA are the sole providers or breadwinners in their families, and they are normally taking such responsibility with the social grants, and more often than not the money is insufficient to maintain the whole family.

One participant said: "*Our client infected and/or affected are by HIV/AIDS, since their adult children died, they are left with the responsibility of maintaining their grandchildren and other family members with the social grants, as their likely to be unemployed due to their age or health factor. Even if they are employed they are mostly holding low earning jobs. This cause more pressure to the lives of elderly people infected with and/or infected by HIV/AIDS*".

The aforementioned was also supported by Today s' Research on Aging (2007), where majority of adults were said to be dying due to HIV/AIDS and leave behind young children under the care of their elderly parents aged 50 and above. They leave their elderly parents with the responsibility of caring for their children - a situation that has an impact on the individual, the family and community. In a study conducted

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on family home-based care of TB patients, caregivers were reported to experience financial strains associated with caring for the patient. Some of them did not have regular income or any source of income and had difficulties in prioritizing everyday necessities in the family, let alone caring for the patient as expected (Sukumani et al., 2011). This implies that by the time the elderly person starts to care for children left behind they would already have been experiencing financial burdens.

### 4.3.4 Theme 4: Key Participants' Views About Services Rendered to elderly people living with HIV/AIDS

Key participants described their views on the services rendered to EPLWHA. The results indicated the existence of two categories under this theme, viz., positive and negative responses related to services received.

#### 4.3.4.1 Category 1: Positive Responses Related to Services Received

The research conducted in this study showed that a number of services are emerging for EPLWHA, and as such they can benefit from these services. Two subcategories emerged, namely, community centres for elderly people and employment of more social workers.

##### 4.3.4.1.1 Subcategory 1: Community Centres Established to Support the Elderly

The studies revealed that, more community-based centres are being established, covering different population groups. Such centres are found within communities to

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enable them to be accessed by the elderly people. This is done in order for elderly people to have places where they can meet at particular times, and engage in different activities such as sports (active aging). Such centres are run by community members, but monitored by social workers to ensure better service for the elderly.

One participant said: "*Government is trying by all means to start establishment of elderly community based centres where they are able to share experiences. Home based caregivers visit them regularly, educating them about caring for an infected person*".

According to Guidelines for the Establishment of Community- Based Multi-Purpose Centres, a community-based centre is a physical structure where comprehensive services are focused on a targeted group within the community. It provides community-based care and support to enable the beneficiaries to have access nearest to home (within their community), which encourages participation by people, responsiveness to the needs of people and nurturing of traditional community life (Department of Social Development, 2007).

#### 4.3.4.1.2 Subcategory 2: Employment of More Social Workers

The study findings revealed that the government is employing and training more social workers as an initiative to ensure that everybody can access social work services, including EPLWHA.

One participant said: "*The government is training and employing more social workers. Social workers are being placed in different clinics, so that they will be accessible to all population*".

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The aspect of ensuring that services are accessible to the people who are supposed to receive such is one of service standards. The Department of Social Development is striving to achieve this goal of making its services accessible, even to elderly people (Batho Pele, White Paper, 1996).

### 4.3.4.2 Category 2: Negative Responses Related to Services Received

Some of key participants described their negative views concerning service delivery in relation to elderly people. Two subcategories were identified, viz., short-term services and more information about HIV/AIDS needs to be disseminated to the general population of elderly people.

#### 4.3.4.2.1 Subcategory 1: They Get Short-Term Services Such as Food Parcels

Analysis of the results revealed the various type of services that EPLWHA receive. The services are described as mostly short-term while long-term services are critically needed. EPLWHA normally experience periods in which no support is provided by the government and they are left without the basic needs. In some instances, they end up having problems when they want to take medication or give medication to the grandchildren.

One participant said: "*Most of my clients who are elderly persons living with HIV/AIDS mostly they get food parcels and food parcels are distributed due to availability. Our clients who qualify for disability grant they normally receive for the period of twelve months*".

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In a study done in Dar es Salaam, Tanzania, food security was found to be of great need when it became apparent that food security may affect adherence to ART and the ability to cope with the disease. Food and material support are required for low-income households affected by HIV/AIDS (Pallangyo, 2009).

#### 4.3.4.2.2 Subcategory 2: More Information About HIV/AIDS Needs to be Disseminated to the General Population of Elderly People

The findings revealed that elderly people, in general, need to be given more information concerning HIV/AIDS. It was also revealed that all elderly people, even those who are not affected and infected, need to be included in such health promotion and education programmes as this will be not only be of great assistance in caring for HIV-infected persons, but will as well promote social cohesion because those infected and/or affected will realize that they have the support of their peers. Moreover, those not yet infected and/or affected will know what to do when the same situation happens to them.

One participant said: "*There is needs to educate our EPLWHA, and also include the general population of elderly people. This will help in the sense that elderly infected or affected will feel supported, while those not infected or affected will be educated for encase they find themselves in the same situation*".

The issue of providing elderly people with more information is constantly raised, indicating that a primary effort should be directed at educating both the elderly and the physicians who care for them (WHO, 2008). In a study done in Dar es Salaam, Tanzania elderly people who were knowledgeable about HIV/AIDS were found to be

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encouraged by the improvement of their patients on ART. Those with knowledge were also ready to advise others in similar situations to go for medical attention on time, indicating that if they go earlier to the medical centre, they will not experience same problems (Pallangyo, 2009).

## 4.4 Presentation and Discussion of the Findings from General Participants

Table 4.3 summarizes the themes, categories and subcategories that emerged from the analysis of raw data of the general participants. Some information was extracted from the EPLWHA in social work records in Thulamela municipality. General participants expressed different experiences related to the impact of HIV/AIDS. Five major themes emerged from the data with categories and subcategories. Appropriate quotes from raw data and relevant literature were used to substantiate the themes. The themes that emerged are: the experience of general participants related to finding about the HIV status of family members or self, the general participants experience of caring for an HIV/AIDS patient, challenges experienced when looking after persons living with HIV/AIDS or children orphaned by HIV/AIDS, the impact of HIV/AIDS on the family, and coping strategies used by the elderly.

### 4.4.1 Theme 1: The General Participants' Experiences Related to Finding Out About the HIV Status of Family Members or Self

All participants expressed their experiences in finding out the HIV status of their family members or self. Two categories were identified from this theme, namely,

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difficulties in relation to finding out about the HIV status of family member or self, and positive ways of finding out about the HIV status.

#### 4.4.1.1 Category 1: Difficulties in Relation to Finding Out About the HIV Status of Family Member or Self

The majority of the participants expressed their views on how difficult it was when they found out about the HIV status of their family member or self. Two subcategories emerged from this theme, viz., finding out after the death of their children or grandchildren, and verbal and physical abuse of the elderly by HIV-positive patients.

##### 4.4.1.1.1 Subcategory 1: Finding Out After the Death of Their Children or Grandchildren

The results indicated that elderly people are not likely to know their children's status on time - usually they find out after the patient's death or when they are terminally ill. Most elderly people described how they come to know about the status of their relative from other members of the family or community members.

One participant said: "*I never knew about her status, but I think I now know. The other time I started to develop some sores, so I decided to be tested and I tested positive and I believe she infected me because I took care of her without protecting myself, because I did not know her problem. My husband died 31 years ago he cannot be the one, she is the one.*"

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## Table 4.3

## Themes, Categories and Subcategories of the Impact of HIV/AIDS on EPLWHA, According to General Participants

| Theme | | Category | | Subcategory | |
|---|---|---|---|---|---|
| 1. | The general participants' experiences related to finding out about the HIV status of family members or self | 1.1 | Difficulties in relation to finding out about the HIV status of family member or self | 1.1.1 | Finding out after the death of their children or grandchildren |
| | | | | 1.1.2 | Verbal and physical abuse of the elderly by HIV-positive patients |
| | | 1.2 | Positive ways of finding out about the HIV status | 1.2.1 | Status revealed to the elderly by the health care worker |
| | | | | 1.2.2 | Finding out about own HIV status after voluntary testing |
| 2. | The general participants' experiences of caring for an HIV/AIDS patient | 2.1 | Difficulties related to caring for HIV-positive patients | 2.1.1 | The experience is tough and stressful |
| | | | | 2.1.2 | Poverty worsens the situation |
| | | 2.2 | Positive experiences related to caring for an infected family member | 2.2.1 | Support from infected to affected family member |
| | | | | 2.2.2 | Understanding the treatment of HIV-positive patients |
| 3. | Challenges experienced when looking after persons living with HIV/AIDS or children orphaned by HIV/AIDS | 3.1 | Financial challenges | 3.1.1 | Lack of income |
| | | | | 3.1.2 | Cut off from the disability grant |
| | | | | 3.1.3 | Fear that funeral policies might not be enough |
| | | 3.2 | Health challenges | 3.2.1 | Due to stress, chronic conditions are worsened |
| | | | | 3.2.2 | Skipping of meals due to stress |
| | | 3.3 | Social challenges | 3.3.1 | Verbal abuse |
| | | | | 3.3.2 | Estate disputes |
| | | | | 3.3.3 | Uncontrollable children and their elder siblings |
| 4. | Impact of HIV/AIDS on the family | 4.1 | Disorganization of the family | 4.1.1 | Elderly people moving to the houses of their late children or children moving to their grandparents |
| | | 4.2 | Sibling disputes | | |
| 5. | Coping strategies used by the elderly | 5.1 | Positive coping strategies | 5.1.1 | Department of Health and Social Development |
| | | | | 5.1.2 | Religion |
| | | 5.2 | Negative coping strategies | 5.2.1 | Neither friend nor relative support |

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Another participant said: "*It all began when I was taking care of my late grandson. His mother was in Johannesburg, the grandson got sick; he developed some sores around the private part. I took him to the clinic; they referred us to the hospital. At the hospital they told me that I have to find my grandson's mother, when she arrived at the hospital she started assaulting me verbally saying that I have already told the doctors that she has many partners, that's when I realized that she already knew about her positive HIV status. That's how I found out. In fact I was never on good terms with my daughter. She is also dead.*"

Another participant said: "*I started to hear rumours that my son who stays in the same neighbourhood is very sick, when I asked him, he told me he is having flu, he died and after few months his ex-wife died, then followed the new wife. With my son I use to believe that he slept with a woman who was on menstrual period" One day community-based workers came looking for one of his children, I asked more question, the child himself confessed that he got infected because he was taking care of his mother. That's how I found out that they all died of AIDS.*"

The participant's experiences are also supported by literature. Elderly people are required to support and care for their sick and dying children and grandchildren. This poses a greater risk to them as they assume the role of caregivers without the knowledge of the disease that their family member is having (WHO, 2007). In the study by Shiluvane et al., (2011), TB was perceived as confirmation that the individual has HIV. This contributed to stigmatization of the disease and the people caring for patients infected with HIV. The stigmatization and discrimination attached to the disease could be the motivating factor for non-disclosure of the condition to the elderly as patients might fear neglect.



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#### 4.4.1.1.2 Subcategory 2: Verbal and Physical Abuse of the Elderly by HIV-Positive Patients

The results showed that even if the elderly person suspects that one of his/her family member is infected, they hesitate to confront them because of fear of abuse, either verbally or physically.

One participant said: "*The day that my daughter find me admitted with her son, she caused a scene, screaming at me indicating that I told the doctors that she has multiple sexual partners. As such I have told the medical staff about her HIV-positive status. Remember I was not even aware about her HIV status, but she was accusing me of gossiping about her HIV status. I do not know what was wrong with my daughter she used to assault me verbally.*"

These findings are also supported by literature. Elderly people indicated that they have experienced either verbal or physical abuse from HIV-infected persons. They even suffer both physical and verbal abuse from their terminal ill children (WHO, 2007). Intolerable patients can evoke a series of negative feelings in most caregivers. The patient may try to control the caregiver. Others use their symptoms as an admission ticket to a relationship that is controlled by presence of symptoms. All these behaviours affect the caregiver's emotional state of mind (Groves, 1978). Ehlers (2005) recommended that caregivers need physical, social and emotional support from the community and friends because without such support they can suffer physical and emotional fatigue, and even burnout.

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### 4.4.1.2 Category 2: Positive Way of Finding Out About the HIV Status

Some of the respondents expressed their views on how they have found out about the HIV status of a family member or themselves. Two categories were identified, viz.,

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status revealed to the elderly by the healthcare worker and finding out about HIV status after voluntary testing.

#### 4.4.1.2.1 Subcategory 1: Status Revealed to the Elderly by the Healthcare Worker

The study has revealed that some of the adults understood that they should tell their parents about their HIV status. Their concern was only how their parents are going to take it. As a result, they would rather send someone to disclose the status on their behalf and most of the time this particular person is a healthcare worker.

One participant said: "*The other day that I got a message that one lady who is my neighbour and health worker is calling me at her place and when I arrived she disclosed the status of my daughter. I took it well and knew that she needs my support.*"

Another participant said: "*When my daughter was pregnant, I was called to the clinic, they tried to tell me, but not with exact words. After she delivered the baby at the hospital they called me again, tried to tell me, I requested them to be clear which they did. I had to accept it for her sake, because I could see that she is troubled.*"

According to the literature, disclosure of HIV status to partners is associated with breakdown in social support, complicated by the unpredictable behavioural patterns, which poses a considerable dilemma for public health practitioners. Whether emphasis is on confidentiality or encouraging HIV disclosure, it has been suggested that emphasizing confidentiality may safeguard social support structures, but at the risk of discordant partners being infected under a professional's watch (Ateka, 2006).

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#### 4.4.1.2.2 Subcategory 2: Finding About Own HIV Status After Voluntary Testing

The findings support the notion that elderly people understand and know the symptoms of HIV/AIDS. They are using available services such as the media. The study revealed that some elderly people considered voluntary testing.

One participant said: "*I had flu for two weeks with a headache and diarrhoea and this are the all symptoms that I have heard on the radio, so I requested for a test.*"

*Another participant said: " I got sick and agreed to be tested.*"

The findings are in contradiction with the literature which indicates that the majority of elderly people lack knowledge about agencies and available services (U.S. National Institute of Health, 2003). There is therefore a need for awareness programmes that will target doctors and healthcare professionals to try to move away from targeting young people only in HIV/AIDS prevention and education programmes as this may be denying many elderly people from health education and early diagnosis (UNAIDS 2005). Thus, elderly people need to be supported through community care and support programmes. The fact that HIV/AIDS programmes ignore them also exposes them to infection, both as caregivers as well as sexually active people (UNAIDS, 2005). Including elderly people in HIV/AIDS prevention and education programmes will help with early diagnosis, as findings revealed that elderly people use available services concerning HIV/AIDS.

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### 4.4.2 Theme 2: The General participants' Experiences of Caring for An HIV/AIDS Patient

The results pointed out two categories in this theme, viz., difficulties related to caring for HIV-positive patients and positive experiences related to caring for infected family member.

#### 4.4.2.1 Category 1: Difficulties Related to Caring for HIV-Positive Patients

Several difficulties related to caring for HIV-positive patients were cited by the general participants. Two subcategories were identified, namely, they described the experience as tough and stressful and poverty worsened the situation.

##### 4.4.2.1.1 Subcategory 1: The Experience is Tough and Stressful

According to the results, EPLWHA are going through a lot of painful and stressful experiences. They are likely to witness their children and/or grandchildren being terminally ill and even die right in their presence. The findings have revealed that the majority of them took care of more than one patient, and some have already experienced more than one death of their loved ones. The majority of elderly caregivers were females, which presents a great challenge if the patient is an adult male. Elderly people do not feel comfortable to see their adult son's nakedness. This is a great challenge when the patients become terminally ill. Also, elderly people who are caregivers are at risk of becoming infected while caring for their grandchildren. Some who took care or are still caring have gone for an HIV test and tested positive, and they only did so when started to feel that they are no longer fine. Others took

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care of their children and/or grandchildren without the proper knowledge and they have not undergone HIV testing.

One participant said: "*It is tough because you don't even know what to do with a patient or what to give.*"

Another participant said: "*Keeping time for medicine is tough, remember it is not temporary, it is for the rest of her life. She needs to wake up very early so that she get breakfast, take medication and then go to school.*"

Another participant said: "*It is stressful, we spend sleeplessness nights, while am at work I am always thinking of going home. I even wish if I was dead.*"

One participant explained: "*I requested the hospital authorities to discharge him to me ,because I was hoping to take him in a certain place, unfortunately it was no longer possible to take him there as he was very sick, and it became very tough for me to fully take care of him while I am a woman, I had to do it until taken back to the hospital where he finally died, because there was nothing I could do.*"

One participant said: "*I had to move from my place to her place. My daughter did not tell me what her problem was. I had to do everything for her washing her, doing her washing, and accompanying her to the toilet. I had full contact with her. I believe she infected me because I was not protecting myself'. My husband died 32 years ago, it can't be him.*"

The literature supports the experiences of the participants, older caregivers are under serious financial, physical and emotional stress due to their caregiving

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responsibilities. Elderly people stated that their motivation for providing care to the people with HIV/AIDS and orphans was a demonstration of love and desire to keep those ill and children left behind as comfortable as possible (WHO, 2008). Some older caregivers are likely to place no physical barrier between themselves and the infected in terms of caregiving, some know of the potential of opportunistic infections, though some do it because of lack of knowledge. In some cultures, it is unacceptable to be seen as stigmatizing one's own child. Some do not use gloves, as they believe they will be offending their own children (WHO, 2007). In addition, Thomas (2002) also indicated how caregivers experience physical strain and emotional consequences when caring for patients and this leads to inability to provide adequately for the patient. The caregivers also become fatigued by caring for the patient for a long time and some caregivers do not eat or eat less when the patient is seriously ill (Thomas, 2002; Campbell et al., 2007).

#### 4.4.2.1.2 Subcategory 2: Poverty Worsens the Situation

The study reveals that poverty is making the already difficult situation even more demanding. In the poorest and weakest population, taking care of an HIV-infected person requires a lot of resources such as proper accommodation, nutritious food, and transportation - the majority of participants do not have any or all of these recourses.

One participant said: "*I receive the old age grant, being sick at the same time, my wife is not working due to health issues. As a result my grant is expected to cover for the needs for the whole family, remember my wife and I need food before we take medication. I do not believe that the grant money is to maintain the whole family but*

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*that's what happening in my own house'. On the other hand, I have to make sure that our funeral polices are in place, because we are the living dead."*

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Another participant said: "*With no one employed in the family, having to look after three orphans and with one of them being infected it is not easy. I remember when my grandson was still alive even with my old age grant and their foster care grant, I could still find myself going to the money lenders, because several times in a month I use to hire a car to take him to the hospital, that's why today am having debts. I had to bury my husband, my daughter, whom am still angry with for what she did to me, and lastly my grandson whom I love.*"

The difficulties experienced by elderly people are supported by literature. Most elderly people are particularly vulnerable to poverty when they retire. When children with HIV/AIDS die, elderly people must find both money for burials and the strength to care for those left behind (WHO, 2008). Poor health or ill health may cause a worker to be absent from work, which may reduce his/her level of income, especially if s/he is paid by the hour. Should the worker be the breadwinner and eventually lose the job, the family may find it hard to make ends meets (Bezuidenhout, 2008). Poverty also impacts negatively on patients taking TB and HIV medication because they do not have sufficient food to eat because drugs are known work optimally with ingested food. Medication taken on a full stomach minimizes side effects, thus when insufficient food is taken side effects may occur, this was also seen as a contributing factor for patients who default as a result of poverty (Rowe et al., 2005).

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#### 4.4.2.2 Category 2: Positive Experiences Related to Caring for An Infected Family Member

The study findings revealed that there are some positive experiences in relation to taking care of an infected family member. Positive experiences regarding several aspects related to caring for an infected family member were explained by the participants. Two subcategories were identified, viz., support from infected to affected family member and understanding the treatment of HIV-positive patients.

##### 4.4.2.2.1 Subcategory 1: Support from Infected to Affected Family Member

The study revealed that for those EPLWHA who also have another family member infected, be it a spouse or children, good support are from the infected to affected is given because they understand each other better as they have a mutual experience. They always have a zeal to continue with the treatment and life in general, particularly when the one party sees that the other party is doing well after complying with the treatment. In general, this kind of lifestyle becomes adopted as a family culture.

One participant said: "*Immediately when my wife and I found about our status, we went out for treatment, now we are each other's treatment supporter, we keep reminding each other about the time to take treatment. We also encourage each other not to default the treatment.*"

Another participant said: "*I started to get sick too often and my daughter advised me to be tested, she even accompanied me to the clinic, I tested positive, she supported*

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*me. We always encourage each other to respect the treatment because if we don't there is going to be negative results."*

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The findings are supported by studies conducted on HIV status disclosure. Mothers disclose more often to their daughters than to their sons (Ateka, 2006). The aspect of treatment support differed from the findings, the issue of giving other family members the responsibility and multiple prescriptions of the patient together with the caregiver's own medication is also a problem which affects compliance of the patient to treatment (Travis et al., 2000). This was also echoed by Chimwaza (2005) who described how participants displayed love for their patients, and felt that it was their duty to love them and care for them, even if they did not wish to do that.

#### 4.4.2.2.2 Subcategory 2: Understanding the Treatment of HIV-Positive Patients

Participants described how having an understanding on the treatment seemed to reduce their stress. It was also noted that understanding of the treatment goes hand in hand with getting used to the treatment and being at the level of understanding and/or accepting their situation.

One participant said: "*It is easy if one follows the treatment, in fact they let you choose your own time, if you choose 7 it must be it 7 am and 7 pm. Sometimes we fail to follow the time by few minutes, but we know that it should never be a tendency as it can be dangerous to us.*".

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One participant explained: *'I started with the treatment since 2007, previously I use to complain by losing weight, they changed my treatment now I am well taking my medications as told, I have no other problem with the treatment."*

According to the literature, the necessity of routinely taking medicines is one of the most common constraints faced by patients and treatment supporters. Due to the reason that the effectiveness of antiretroviral drugs is dependent on the regularity of the treatment, precise hours are specified to ensure a patient's adherence. A short delay in the prescribed time may eliminate the effectiveness of the treatment (Hejoaka, 2009). When family caregivers assist patients with medication administration there are difficulties with assisting the patient, such as scheduling logistics, whereby giving the medication on time is a problem (Travis, Bethea & Win, 2000).

### 4.4.3 Theme 3: Challenges Experienced When Looking After Persons Living with HIV/AIDS or Children Orphaned by HIV/AIDS

The participants explained the challenges that they were facing while taking care of people living with HIV/AIDS or those orphaned by the disease. Three categories were identified: financial-, health- and social-related challenges.

#### 4.4.3.1 Category 1: Financial Challenges

The study revealed that financial constraints are one of the major challenges faced by EPLWHA. As their caregiving role requires a lot of resources, it becomes a major

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problem for EPLWHA. Three subcategories were identified: lack of income, cut off from the disability grant and fear that their funeral policies might not be enough.

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#### 4.4.3.1.1 Subcategory 1: Lack of Income

The results showed that the majority of families headed by elderly people have no stable income as they depend mainly on social grants. Those with family members who are employed do not even know how much their family members receive and usually their family members are holding low paying jobs.

One participant explained her situation: *"I do not have an income, not even a grant for me to eat it means I must first do a piece job, mostly I depend on my unemployed daughter who is married. I do not even know how long she will be able to assist as she is depending on her husband."*

The findings are supported by literature that EPLWHA are deprived of support that the adult child, who is terminally ill or died, would have provided, they end up with no other source of income other than social grants (Knodel & Im-em, 2003). Rowe, Makhubele, Hargreaves, Porter, Hausler & Pronuk (2005) and Needham et al., (2004) also found in their studies that family members were expected to provide special food for patients, such as eggs, meat, milk, soft drinks, oranges and vegetables which the caregivers could not afford.

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#### 4.4.3.1.2 Subcategory 2: Cut Off from the Disability Grant

The study revealed that the majority of the participants depended on the temporary disability grant. The issue of cutting it off is causing a lot financial stress as the grant is usually the only source of income and, when cut, there is no other stable income. None of the participants was still receiving the disability grant at the time of the interview. The majority of them believed that the service providers did not clearly explain how and when the grant would be cut off.

One participant said: "*My wife seem to be more stressed by the fact that she only received the disability for only some few months, and then they cut it off'. Everyday she is complaining about why her grant has been cut off, at this time of financial needs and while she is still sick.*"

The Constitution of South Africa, Section 32(1), states that everyone has the right of access to any information held by state and any information that is held by another person and that is required for the exercise or protection of any rights (The Constitution of Republic of South Africa, 1996). Section 31 states that a person whose request for access to the records of public body has been granted must, if the record exists, be provided in the language of choice (The Promotion of Access to Information Act, 2007). This does not seem to be the case according to some participants.

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#### 4.4.3.1.3 Subcategory 3: Fear that Funeral Policies Might not be Enough

Most general participants expressed the fear that their funeral policies were not sufficient.

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#### 4.4.3.2 Category 2: Health Challenges

Study findings revealed that the health of EPLWHA is at risk as they focus on the health of an HIV/AIDS ill family member and forget about their own health or have little time for themselves. It becomes a great concern as it is at this age where they experience multiple chronic illnesses. Related challenges involve different aspects as explained by the participants. Two subcategories were identified: due to stress the blood pressure is always at high levels and skipping of meals due to stress.

##### 4.4.3.2.1 Subcategory 1: Due to Stress, Chronic Conditions are Worsened

The study findings revealed that the participants are afflicted with several chronic conditions, which were worsened by stress that they are experiencing due to HIV/AIDS.

One participant stated: "*Ever since I started feeling pressure for taking care of my daughter, am afraid I may even die due to high blood pressure.*"

Another participant explained: "*I can no longer do heavy duties as I use to do. I have asthma and sugar diabetes now that am HIV-positive the situation is worse.*"

Chanda & Gosnell (2006) indicated that family members sometimes lose interest in continued supervision and care for patients. Munthali's findings (cited in Chanda and Gosnell, 2006) correspond with those of Sagbakken, Frich, & Bjune (2008) that the chronic nature of the disease and prolonged treatment protocol can affect compliance to treatment, even with family support. Illnesses such as heart diseases, depression, high blood pressure, arthritis and Alzheimer's are more prevalent in older persons

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who are therefore more likely to be taking medicines for long-term illness or as a preventative measure for a pre-existing condition (WHO, 2008).

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#### 4.4.3.2.2 Subcategory 2: Skipping of Meals Due to Stress

The study findings revealed that the majority of EPLWHA skip meals for several reasons, including lack of food or loss of appetite because of HIV/AIDS-related stress.

One participant explained: "S*ome days I go to work with my lunch box, and during lunch I fail to eat my food due to pressure that am experiencing.*"

Another participant indicated: "*As I have no income, sometimes I did not get a piece job, I find myself having to take medication with insufficient food.*"

The responses of the participants are in agreement with the literature - as elderly people focus on caring for their children and grandchildren, they may neglect themselves and risk becoming ill, mostly going without food in order to provide for others. This may result in malnutrition and rapidly failing health (Today's Research on Aging, 2007). In addition, Thomas (2002) indicated how caregivers experienced physical strain and emotional consequences when caring for patients and this led to inability to provide adequately for the patient. The caregivers also become fatigued by caring for the patient for a long time, and some caregivers do not eat or eat less when the patient is seriously ill.

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#### 4.4.3.3 Category 3: Social Challenges

Social challenges faced by EPLWHA involved different aspects as explained by the participants. Three subcategories emerged: verbal abuse, estate disputes and being left with uncontrollable children and their elder siblings.

##### 4.4.3.3.1 Subcategory 1: Verbal Abuse

The study revealed that elderly people suffer verbal abuse, either from their terminally ill children or grandchildren. Usually they experience such behaviour in the process of assisting the abuser.

One participant said: "*My daughter always uses painful words on me, each time I fail to do something for her she tells me it is because I want her dead. What I know is that she does not like me, she thinks am bad. She believes people from outside love her most. She wants to go away from me, while I want her to be close because I know that if she goes she will not be able to take care of herself.*"

Another participant said: "*The day my daughter find me at the hospital with her son hospitalised, she seriously assaulted me blaming me for telling doctors that she is having multiple partners.*"

The literature supports these experience of the participants. EPLWHA suffer verbal and physical abuse from HIV-infected family members, including from their terminally ill children. This kind of situation causes them to develop stress-related conditions (WHO, 2007).

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#### 4.4.3.3.2 Subcategory 2: Estate Disputes

The findings revealed that EPLWHA also face disputes over the estates of their deceased children.

One participant said: "*I do not have a good relationship with my grandchildren's paternal uncles, after the deaths of my daughter and her husband. I decided to move to stay with the children. The uncles opposed the idea, they wanted the house to be left alone, so that it will be easy for them to occupy it illegally. I need it for my grandchildren when they grow up. I believe it is rightfully belonging to my grandchildren.*"

The above participant's experience relates to family and estate disputes - older caregivers experience physical tiredness caused by barriers, such as lack of birth certificates for the children. Some children are left by their deceased parents without such documents to access state provided services (WHO, 2007).

#### 4.4.3.3.3 Subcategory 3: Left with Uncontrollable Children and Their Elder Siblings

The study revealed that participants face another pressure in raising orphans. It also emerged that pressure was not only caused by orphans, but also by their elder siblings.

One participant said: "*I am now left with her children, they always fight, I cannot even send them to get something for me. When I receive their grant they want it, in order to spend the money on whatever they want. With my money, I have to cover all family needs, that's the reason am always on debts. The elder one is even worse she can even*

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*go without telling me and only come back after several days, when I ask her she assault me verbally, in fact this days I have decided just to keep quite and just look."*

Another participant said: "*This month I don't know what am going to do, because one of the elder siblings stole the bank card and took my grant and the foster grants for the younger siblings. She did it before we could even buy food.*"

Another participant said: "*I do not know what to do with the elder grandchild. She is no longer staying at home. She moves from one village to the next. If I follow her she runs away to the next village. I even hear that she has several boyfriends; she is using substances and stealing. It is just that I cannot shift this responsibility nowhere else I can take them.*"

There is an explanation for the abovementioned behaviours, especially for youth whose family structure has changed. Families are the most important agents of socialization - a disorganized family cannot fulfil this function adequately. It is the younger children, in particular, who may be deprived of developing important primary socialization skills. Family disorganization may prompt members to engage in deviant acts such as truancy, prostitution, drug abuse, suicide attempts and wife and children battering. Family members may experience fear, anxiety and feeling of guilt about their situation. This may escalate when the future of a family as a unit is at stake. Children may experience emotional stress and abuse and run away from home in search of stability and security (Bezuidenhout, 2008).

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### 4.4.4 Theme 4: Impact of HIV/AIDS on the Family

All the participants expressed the impact that HIV/AIDS have on the family. Two categories were identified, namely, disorganization of the family and sibling disputes.

#### 4.4.4.1 Category 1: Disorganization of the Family

The study findings revealed that HIV/AIDS has a serious impact on the family. All the participants described how their families were disorganised due to HIV/AIDS. One subcategory was identified, viz., elderly people moving to the houses of their late children or children moving to their grandparents.

##### 4.4.4.1.1 Subcategory 1: Elderly People Moving to the Houses of Their Late Children or Children Moving to Their Grandparents

Some of the participants have moved to their children's houses, while in some situations children have moved to stay with their grandparents, particularly the maternal grandmother. The results showed that both patterns of movement have negative impacts.

One participant said: "*When my daughter was very sick she came back home for me to take care of her, for only a week and died. After the death of the children's father the children were left under the care of their paternal grandmother. After her death the children had no other choice but to move to my place. I am not sure of what's happening to their parents' house.*"

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One participant stated: "*Now am neglecting other children's financial needs in order to cover all her expenses. I am taking other children's school fees money to assist on her needs, because her needs are too expensive, sometimes I buy her medication, I take her to doctors and she needs good food. I try by all means that she gets food she needs. My other children always complain that it seems as if she is my only child, and that's causing tension in my house. I even suspended other projects just to focus on her, because I can't afford all my family needs.*"

These findings are supported by literature. In families affected with HIV, particularly with little resources, social relationships are often strained as they are expected to share the little available resources particularly when this is combined with excessive and possibility increasing alcohol consumption, unemployment and other problems (Barnett, Whiteside, Khodakevich Kruglov & Steshenko, 2000).

### 4.4.5 Theme 5: Coping Strategies Used by the Elderly

All participants expressed their ways of coping with the challenges caused by HIV/AIDS. Two categories were identified, namely, positive coping and negative coping strategies.

#### 4.4.5.1 Category 1: Positive Coping Strategies Used by the Elderly

The study revealed that EPLWHA use some positive ways of coping with their situation. Two subcategories were identified: Department of Health and Social Development and religion.

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#### 4.4.5.1.1 Subcategory 1: Department of Health and Social Development

The results indicated that all of the participants do not turn to family for support, for one reason or the other, instead they go to external structures such as government and religious institutions.

One participant said: "*I have no other support, except that from social workers, clinic and hospital. Social workers give us food parcels, when get sick I go to the clinic or Hospital.*"

The pivotal roles that the National Departments of Social Development and Health have concerning HIV/AIDS were corroborated. The National Strategic Plan on HIV/AIDS and STI affirmed the roles of these lead departments that should jointly take responsibility for reducing the impact of HIV/AIDS in communities (National Norms and Minimum Standards, 2007).

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#### 4.4.5.1.2 Subcategory 2: Religion

Religion was also identified as another means of coping strategies used by participants.

One participant said: "*My grandchildren have a tendency of fighting, each time they start I begin to sing church songs and it's helping me a lot. Since am not able to guide the children. The pastor sometimes visits us and tries to guide them on sexual related issues and drinking alcohol. I really see it helping.*"

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Another participant said: "*My other children are so alcoholic, when drunk they cause a lot of trouble in the house, which is worsening my situation. I always read the bible because I know I always find solution in the bible.*"

The role that the church is playing in offering support is confirmed by the literature. Normally, church members visit families infected and/or affected by HIV/AIDS and pray for them. However, churches are viewed as not yet comings to term with the complex challenges of HIV/AIDS, e.g., churches do not have activities that openly address HIV/AIDS. It is clear that churches took a punitive approach to HIV/AIDS, regarding it as the result of bad sexual behaviour (Campbell, Nair, Maimane & Sibiya, 2007).

### 4.4.5.2 Category 2: Negative Coping Strategies Used by the Elderly

#### 4.4.5.2.1 Subcategory 1: Neither Friend Nor Relative Support

The study findings also revealed that none of the participants is receiving support from a close relative.

One participant said: "*My elder sister's daughter assisted me with the burial of my late daughter, but she told me to remember that she is not my relative, she told me she is only my sister's child, as a result I feel that am alone.*"

Another participant said: "*I am alone in this, I have no relatives all my relatives are deceased, only one is left and she is staying too far. As a result, I do not expect any support from relatives because I know am alone.*"

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Findings similar to these appeared in the study. Sometimes relatives avoid the role of assisting as they are afraid that they may end up taking up the entire responsibility and when the elderly caregiver fails to get support from those whom they believe they should, they feel rejected and isolated. They may even consider moving from one place to another (Pallangyo & Mayers, 2009).

## 4.5 Summary

This chapter analysed data collected from both the key and general participants. Discussions of findings were provided. Various themes, categories and subcategories were identified and correlated with the participants' responses recorded during semi-structured interviews. Participants' descriptions of the impact of HIV/AIDS on the elderly, coping strategies used by elderly people, challenges faced by elderly people, views about services rendered to the elderly, impact of HIV/AIDS, etc., were analysed and explained in the context of the literature in general. Chapter 5 deals with the recommendations, limitations and conclusions of the study.

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# CHAPTER 5

# RECOMMENDATIONS, LIMITATIONS AND CONCLUSIONS

## 5.1 Introduction

Chapter 4 discussed the data analysis performed in this study in relation to the relevant literature on the impact of HIV/AIDS on elderly people infected with and/or affected by HIV/AIDS (EPLWHA). This chapter will focus on the recommendations, limitations and conclusions of the study that closely align with the purpose and objectives set out in Chapter 1. Recommendations that might influence policy and service delivery, as well as suggestions for further research with respect to HIV/AIDS are also delineated in this chapter. Conclusions based on the principal findings of the study are also synthesized into a more general impression of how HIV/AIDS impinges on the lives and livelihood of elderly persons.

## 5.2 Overview of the Study

The purpose of the study was to explore and describe the impact that HIV/AIDS has on the elderly in the Thulamela municipality, Vhembe district, Limpopo Province, South Africa.

The objectives of the study were to:

- Describe the views of social workers regarding the impact of HIV/AIDS on

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elderly people.

- Describe the views of elderly people infected and or affected by HIV/AIDS regarding the impact of HIV/AIDS on their lives;
- Determine the challenges that elderly people infected and or infected by HIV/AIDS face in their daily lives; and
- Describe the coping strategies used by elderly people infected and or affected by HIV/AIDS.

All the objectives were met during data collection through the use of in-depth personal interviews and subsequent analysis. The research design for the study was qualitative, explorative and descriptive in nature. The research methods described were study setting, population and sampling and ethical adherence. The researcher chose the Thulamela municipality in the Vhembe district of the Limpopo Province. In this study, the population consisted of all elderly clients fifty years old and above, both males and females, who were receiving grants because they were either infected with and/or affected by HIV/AIDS (i.e., EPLWHA). EPLWHA were clients in social workers' records within the Social Development section of the Thulamela municipality. The study population also comprised all social workers in Thulamela municipality employed between 0–10 years by the Department of Health and Social Development.

In this study, participants who best suited the above criteria were chosen and the sampling was two-folded: sampling of general participants and sampling of key participants. Sample size was determined by data saturation. With the key participants, saturation occurred at the 8$^{th}$ participant and in the case of general

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participants, saturation was reached with the 12th participant. Verbal accounts of experiences were tape recorded and transcribed verbatim for analysis. Data were analysed qualitatively using Tesch's open coding method (cited in Creswell, 1990). The criteria of Lincoln & Guba (1985), i.e., applicability, conformity (neutrality), and dependability were used to ensure trustworthiness of the research.

Data analysis from the verbal descriptions of key and general participants during interviews revealed the following themes: *Key participants:* impact of HIV/AIDS on the elderly, coping strategies used by EPLWHA, challenges faced by EPLWHA, services rendered to the EPLWHA; *General participants:* finding about the HIV status of family member or self, experience of caring for an HIV/AIDS patient, challenges experienced when looking after a person living with HIV/AIDS or children orphaned by HIV/AIDS, impact of HIV/AIDS on the family and coping strategies used by the elderly.

Based on the abovementioned results, recommendations can be made because focal questions have been answered and the objectives and the purpose of the study have been achieved.

## 5.3 Recommendations Based on the Themes, Categories and Subcategories

The following recommendations were conceptualized to ensure that proper and sufficient services are rendered to EPLWHA and PLWHA.

- The role that elderly people play in this era of the HIV/AIDS pandemic should be recognized. They deserve to be acknowledged by the government and

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other sectors of society. A yearly event to recognize them for unfailingly taking care of HIV/AIDS infected/affected persons could include the handing out of gifts or vouchers. Department of Social Development should be responsible for funding such events.

- Social workers and psychologists should at least have monthly individual sessions with EPLWHA. Health promotion in relation to HIV/AIDS care to elderly people should be a priority for health professionals, as this will assist the elderly people to gather the required information they need to provide HIV/AIDS care.
- Group counselling with people who are experiencing similar problems will enable them to better assist each other as they share mutual feelings and objectives.
- Social workers should empower elderly people involved in HIV/AIDS care with contemporary parenting skills as there is a serious generational gap between them and their grandchildren, and this contributes to widespread misunderstanding and conflict in grandparent-headed households.
- Family- and community-based models which involve close friends and family members as well as religious structures should be developed, as this may reduce stigmatisation and elderly people will no longer be blamed for the situation and condition they and those close to them are currently in.
- Elderly people who qualify for the disability grant should be given the explanation and terminology they can understand, i.e., how are they going to receive the grant, and why and when it will be cut off. Before the grant is

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discontinued, a family assessment should be done on how the family is going to cope further.

## 5.4 Recommendations Regarding Policy

The study revealed a number of difficulties that necessitate policy makers to revisit current governmental HIV/AIDS policies, regulations and practices. Perhaps the most pressing is the financial difficulties faced by EPLWHA as participants indicated that they and/or those in their care sometimes take their medication with little or no food, particularly after the grants have been cut off. Hence, the following recommendations may alleviate financial burdens of PLWHA and EPLWHA:

- The policy should be reviewed to accommodate elderly people infected and or affected by HIV/AI to ensure that elderly people always have an income or receive food parcels regularly.
- Social workers should assess each family's needs as this will help to provide relevant and sufficient service to the elderly.

## 5.5 Recommendations for Further Research

The study findings revealed the impact that HIV/AIDS has on the lives of elderly people. This study also affirmed the significant role that elderly people play in this era of HIV/AIDS. Recommendations for future research include:

- Future researchers should be encouraged to explore other health and social ramifications of HIV/AIDS and how these impact elderly people.

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- Future researchers should study behaviour of the children orphaned by HIV/AIDS and how negative behavioural patterns can be overcome with appropriate care and intervention strategies.
- The Department of Health and Social Development should monitor and evaluate their services.

## 6. Limitations of The Study

As the study involved a condition that is stigmatized, some of the selected participants hesitated to be recruited. The problem of disclosure was evident as the researcher was regarded as a stranger to some of the participants. Interviewing colleagues was a challenge as some of them felt that the researcher was asking questions for which answers are known by the researcher. The researcher did not manage to obtain participants from Malamulele area, which is also part of Thulamela municipality.

## 7. Conclusions

Conclusions in this study are discussed in relation to the objectives of the study. The following conclusions were arrived at, based on the objectives of the study:

### 7.1 Conclusions Regarding the Participant's Description of the Impact of HIV/AIDS on the Lives of Elderly People

The findings in this study described the impact of HIV/AIDS on the lives of EPLWHA, the burden of taking care of sick adults, lack of knowledge of the disease, psychological stress related to caring for HIV-infected children, relatives and orphans,

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financial burden related to caring for terminally ill patients or orphans, and family disorganization. Therefore, it is essential for the Department of Health and Social Development to develop strict policies to offer support for EPLWHA, based on their unequivocal role in HIV/AIDS care.

## 7.2 Conclusions Regarding the Challenges Faced by elderly people infected and or affected by HIV/AIDS

Based on the findings of this study it has been concluded that EPLWHA are faced with the following challenges: adopting the role of parenting grandchildren, being stressed out because of parenting uncontrollable children, supporting their families with little income or lack of financial resources and material assets, cut-off of the disability grant, and the anxiety that their funeral policies are not sufficient. It is clear from the findings of the study that professionals such as social workers and psychologist need to involve EPLWHA in individual and group programmes that educate and promote them about HIV/AIDS - its causes, prevention and treatment. There is a need, however, to involve spiritual and traditional leaders as they have a huge influence on elderly people and receive a lot of respect from them. Elderly people who are not infected or affected need to be encouraged to form some sort of peer support groups.

## 7.3 Conclusions Regarding the Description of Coping Strategies Used by EPLWHA

The study findings have concluded that EPLWHA either use negative or positive approaches to coping with HIV/AIDS. The negative ways include failure to seek

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support from relatives or friends, fear of stigmatization, pretending to be coping as it is expected by culture, and dependency on government grants. The positive approaches to coping with HIV/AIDS include the use of governmental institutions, i.e., Department of Health and Social Development for social grants (foster care and child support grants), they benefit from community-based care and religion. The study concludes that officials concerned should strive working towards involving close relatives as this will curb stigmatization. Community members need to be involved as those infected and affected with HIV/AIDS are part of the community. It is also concluded that elderly people who qualify for disability grants should get a clear explanation on what the grant is for and how long they will receive it.

## 8. Summary

This chapter detailed the recommendations and conclusions of the study based on the objectives of the study. Recommendations such as social and psychological support by professionals were made, involving elderly people in their services. The help of community leaders, friends and close relatives, religious structures was also emphasized, and recommendations for policy makers and future research were made.

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# ANNEXURE A

## RESEARCH INSTRUMENT

## INTERVIEW GUIDE FOR GENERAL INFORMANT

**A. Demographic information**

1. Gender, Age and marital status information will be gathered from office documents.

2. Educational level

**B. Family composition**

Number of people staying in the household.

Adults: .....

Male: .....

Female: .....

Children: .....

Male: .....

Female: .....

**C. Family income**

Do you have any member of your family working?

No: .....

Yes: .....

What is your family income?

0------R250: .....

R251----R550: .....

R551------R800: .....

R801------R1050: .....

R1051 and above: .....: Specify: .....

Number of people receiving the grants and type.

Children: .....

Adults: .....

**D. How did you find out about the HIV status of your family member?**

**E. How is it to care for an HIV/AIDS infected family member?**

**F. What are challenges that you face when looking after the person/s living with HIV/AIDS or children orphaned by HIV/AIDS?**

**G. In your view how do HIV/AIDS affect the family?**

**H. What are your coping strategies with HIV/AIDS?**



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# ANNEXURE B

## INTERVIEW SCHEDULE OF THE KEY PARTICIPANTS

**A. Biographic Information**

Age: .....

Gender: .....

**B. Working experience in years: .....**

**C. What is the impact of HIV/AIDS on elderly people?**

**D. What are the coping strategies of elderly people infected with and/or affected by HIV/AIDS?**

**E. What are the challenges faced by elderly people infected with and/or affected by HIV/AIDS?**

**F. What are the coping strategies of elderly people infected with and/or affected by HIV/AIDS?**

**G. Do you think services rendered to elderly people infected with and/or affected by HIV/AIDS are enough? Explain.**

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# ANNEXURE C

# INFORMATION SHEET

**Introduction**

Good morning/afternoon. My name is Ms Julia Singo. I am a student at the University of Venda. I am gathering information about the impact of HIV/AIDS on elderly people in Thulamela municipality. I will be grateful if you would be willing to respond to the questions related to the subject matter. The interview will take approximately 60 minutes or more of your time.

The study is entitled: The impact of HIV/AIDS on the elderly people in Thulamela municipality.

**Purpose of the study**

The study aims to explore the impact of HIV/AIDS on elderly people. In this study, interviews will be used as a way of collecting data, related to the subject matter. The targeted population will be men and women, 50 years and older, whom are affected by HIV/AIDS. The questions will be about identifying different challenges they are facing, coping strategies, identifying available services and other related issues.

Your response to the questions will remain confidential; the information you will provide will not be linked to any identifying particulars (i.e., names and addresses). The University of Venda might also inspect information, Human Research Ethics Committee and other authorized persons.

Your taking part in the study may not benefit you directly, and it may also benefit others in the future. There will be no monetary benefits.

**Right to refuse or to withdraw**

Your participation is voluntary and you can also discontinue with an interview. You're taking part or not taking part won't have any impact concerning receiving any kind of service.

With this, I would like to invite you to participate in the interview of the study.

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# ANNEXURE D

## CONSENT FORM

**INFORMED CONSENT**

I am a Masters student at the University of Venda. I am presently engaged in a research study entitled "The impact of HIV/AIDS on the elderly people in Thulamela municipality, Vhembe District".

The study is conducted under the supervision of Dr R.T. Lebese and Professor T.X. Maluleke of the Department of Advanced Nursing Science.

The objectives of the study are to explore and describe the impact that HIV/AIDS has on the lives of elderly people and to develop recommendations that may improve services designed for the elderly people.

I need to conduct interviews with elderly people infected with and/or affected by HIV/AIDS. The interviews will be conducted within 40-55 minutes, and will be audiotaped for verification of the findings by my supervisors and an independent coder.

The name and dignity of each participant will be preserved by observing the following ethical standards throughout the research process:

- Voluntary participation and freedom to withdraw without a penalty
- Informed consent
- Names of the participants and their community will not be mentioned during discussions
- Raw material will be kept under lock and key to ensure confidentiality
- Information related to the interviews will only be accessible to my supervisors, Department of Social Development, Department of Health and the independent coder
- Field notes will be destroyed and audio tapes will be erased as soon as possible
- The summary of the research will be made available to the participant. if they wish

Your participation in this study will benefit other elderly people infected with and/or affected by HIV/AIDS.

I ..... hereby understand the content of this research after the researcher's explanations.

Thank you
SINGO VHUDIVHUSI JULIA
Researcher

Signature of the participant.....

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# ANNEXURE E

## REQUEST TO CONDUCT THE STUDY

P.O. Box 906
SIBASA
0970

**Department of Health and Social Development**

I am Vhudivhusi Julia Singo, a student at the University of Venda. I am currently doing a Masters degree in Public Health. In this level we are expected to complete a full dissertation.

The study title: The impact of HIV/AIDS on elderly people in Thulamela municipality, Vhembe District.

Objectives of the study are:

- Describe the view of elderly regarding the impact of HIV/AIDS
- To determine the challenges that elderly people affected and/or infected by HIV/AIDS face in their daily lives.
- To describe the coping strategies used by elderly people affected and/or infected by HIV/AIDS.

The study wants to determine the impact that HIV/AIDS have on the elderly in the Thulamela municipality.

The following issues are going to be considered in order to protect the participants, Informed concerned, Violation of Privacy, anonymity and confidentiality.

I therefore request for an approval to collect data from clients who will be identified through social worker's office. The offices included are within the

District of Vhembe, namely Thohoyandou, Malamulele, Tshilidzini and Makwarela

I hope that you will consider my request

Yours truly

Singo V.J. Signature----------

Date ----------

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# ANNEXURE F

# INTERVIEW TRANSCRIPT

**TRANSLETED FROM TSHIVENDA TO ENGLISH TO DEMONSTRATE THE IMPACT OF HIV/AIDS ON THE ELDERLY PEOPLE.**

**KEY: Researcher = R**

**: Key participants= KI**

**: General participant= GP**

**A. KEY INFORMANT**

**R**: Good morning

**KI**: Good morning

**R: What is the impact of HIV/AIDS on elderly people?**

KI: Mm mm: from what I have learnt during my years of working as a social worker I have realised that HIV/AIDS has a serious negative impact on the elderly people. It just unfortunate that not all of us are aware about what is really happening with elderly people affected and/or infected by HIV/AIDS.

**R: What is really happening?**

**KI**: This population is vulnerable to many things, when their sick children die they live behind their children who might be infected. It becomes a duty of an elderly person to look after the children left behind, they shave their hair, and some even get infected. Majority of them are facing financial challenges, which makes hard for them to go for medical assessment. This put them into a great risk.

**R: What are the coping strategies of elderly people who are infected and/or affected by HIV/AIDS?**

**KI**: You know what? With elderly people is sometimes tough to see to it clearly. Majority of my clients pretend to be coping even if they are not. They normally say culturally they are expected to be strong.

**R: Do they use your services?**

**KI:** Mm mm: they do but, sometimes, they normally come with excuses not to use our services, they are not always clear of what they want. When they come they come for counselling and food parcels.

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**R: what are the challenges faced by elderly people affected and/or infected by HIV/AIDS?**

**KI**: Many of our clients infected and/or affected by HIV/AIDS, face financial constraints, they are unemployed depend on social grants; it becomes a serious issue to those who are receiving disability grant, because it is temporary. In most instances they are left with no source of income. If they are employed, they normally earn too little to be able to maintain their families. Remember elderly people are always the breadwinners in their families.

**R: Tell me more.**

**KI**: One aspect that I have discovered to be challenging is communities. Our clients in this situation they are not always accepted, they are stigmatised, I have dealt with issues were in they were no longer accepted in participating in community activities such as cooking in funerals.

**R: Do you think services rendered to elderly people infected with and/or affected are enough? Explain.**

**KI**: No, services are not enough, they don't know much enough about HIV/AIDS, and I think giving then enough knowledge will solve a lot of problem.

R: Thank you very much for your time, have a good day.

**B. <u>GENERAL PARTICIPANT</u>**

**R: Good morning**

**GP: Good morning my child**

**R: How did you find out about the HIV status of your family member?**

**GP:** Mm mm, My son and her second wife use to stay in their own place, but is not far from her, even me I can walk to their place. I started to hear rumours that my son is very sick, I got angry with my daughter in-law because she never wanted me to find out that my son is sick. I confronted him he told me that it is just flu. Oh: my son he was very sick , and I knew that it can't be flu. I took him to my place . I organize a local pastor to pray for hi, (***uri vhamu phethele ndaela***). I believed that my daughter in law, slept with him during her periods (**odzhena *nae mabaini e madini***). I stayed with him for a month and he recovered. The wife took him back to their place. After a week or so a situation got worsened the wife took him to the hospital without notifying me. At hospital the situation was terrible for someone's mother (***Zwo Vha zwisa vhinwi nga mme mubebi.***), after 02 weeks I requested them to discharge him. I took care of him at home because it was no longer possible to take him to our at our church overseer in Polokwane.

**R: Hooo:**

I had to take him back to the hospital and he died the following day. My son spent 02 weeks in the morgue because myself and my daughter in-law we could not agree on anything and she ended up burying him in her own place of choice. Can you believe that my husband and I did not even attend his burial due to our differences. In a few month's time the wife died also. After few moths my son's first wife came back to me complaining about dizziness and headache.

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I had to take care of her, and my husband was also sick he was too old, they were both my responsibility as sick and old as I am. Due to pressure of taking care of two sick people my blood pressure raised, remember I have a heart condition. I use to fail to go to check-ups due to my responsibilities.

One day my daughter in law was very sick, I called for an ambulance, they took her to the /hospital. She got admitted and I fail her because I did not manage to visit her regularly. She died also. Latter on my husband died. Can you imagine o3 people die in front of you.

**R: Mmmm:, you can go on**

**GP:** Recently I discovered that my son 's son from the first wife who is 14 years old take some medication regularly , being assisted by other women who visit him regularly. I asked what is he suffering from? and he told me that he is HIV positive and he got infected while he was taking care of his mother before they came to stay with me. My child; that's when I found out about the reality of the whole situation.

**R: You mean that's how you found out?**

**GP:** Yes, My situation is just like a story.

**R: How is it to care for an HIV/AIDS infected family members?**

**GP:** It is very hard; you children of nowadays you do not tell us what is really eating you. Look now, the problem is that now am always having a sick per son in my house and am too old for that. With my son it was terrible I use to ask a male relative assist with changing him, as am a woman am not supposed to see my child's nakedness.

**R: You said a relative was assisting with the changing of your son, how was everything?**

**GP: It was not easy, as you know no one can do that task for a long time, I had to do it myself, changing nappies for my own son. It does not give me any peace even now. It is against our culture. During our days other males would have assisted. In my case the father was too ill to be able to assist.**

**R: What challenges are you facing when looking after the person/living with HIV/AIDS or children orphaned by HIV/AIDS?**

**GP:** The main challenge is money, by the time when I was looking after my son and his wife, we depended on old age grant (My husband's and mine). My son was no longer working due to illness. Presently we are depending on my old age grant and foster grant for my grandchildren. The money is still not enough. The other thing is that when you have a sick person in your house people no longer visit you.

**R: In your view how do HIV/AIDS affect the family?**

**GP:** I now blame HIV/AIDS for the divorce between my son and his first. Wife Look now am now a mother at my age, and as you can see I might die at any time who will look after these orphans.

**R. How do you cope with the challenges?**

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**GP:** I have no one all my relatives are dead, I put my trust to God, now that I have orphans in my house I regularly visit the social worker.

R. Thank you very much for your time, have a good day.

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**NAME OF RESEARCHER/INVESTIGATOR:**

**Mrs. Singo V.J (Student No. 9906768)**

**PROJECT TITLE:** The impact of HIV and AIDS on elderly people in Thulamela Municipality, Vhembe District

**PROJECT NO:** SHS/10/PH/004

**SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS**

| NAME | INSTITUTION & DEPARTMENT | ROLE |
|---|---|---|
| Mrs. V.J Singo | University of Venda. Dept. of Public Health | nvestigator |
| Dr. R.T Lebese | University of Venda. Dept. of Public Health | Supervisor |
| Prof. T.X Maluleke | University of Venda. Dept. of Public Health | Co-Supervisor |

**ISSUED BY:**

**UNIVERSITY OF VENDA, HEALTH, SAFETY AND RESEARCH ETHICS COMMITTEE**

**Date Considered:** 22 October 2010

**Decision by Ethical Clearance Committee** Granted

**Signature of Chairperson of the Committee:**

**Name of the Chairperson of the Committee:** Prof. X.G Mbhenyane

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LIMPOPO

PROVINCIAL GOVERNMENT

REPUBLIC OF SOUTH AFRICA

# DEPARTMENT OF HEALTH & SOCIAL DEVELOPMENT

Enquiries: Selamolela Donald

Ref: 4/2/2

07 February 2011
Singo V
University of Venda
Thohoyandou
0950

Dear Sir

**Re: Permission to conduct the study titled: The impact of HIV and Aids on elderly people in Thulamela Municipality, Vhembe District**

1. The above matter refers.
2. The permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
   - Further arrangement should be made with the targeted institutions.
   - In the course of your study there should not be any action that will disrupt the services
   - After completion of the study, a copy should be submitted to the Department to serves as a resource
   - The researcher should be prepared to assist in the interpretation and implementation of study recommendation where possible

Your cooperation will be highly appreciated

Head of Department
Health and Social Development
Limpopo Province

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18 College Str. Polokwane 0700 Tel.: (015) 293 6000 Fax: (015) 293 6211 Website: http/www.limpopo.gov.za

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**FACULTY OF NATURAL SCIENCES**
**DEPARTMENT OF MEDICAL BIOSCIENCES**

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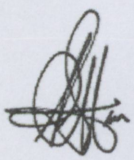
20 February 2012

To Whom it May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the MPH dissertation by **Singo Vhudivhusi Julia**: "**THE IMPACT OF HIV/AIDS ON ELDERLY PEOPLE IN THE THULAMELA MUNICIPALITY, VHEMBE DISTRICT, LIMPOPO PROVINCE**".

Sincerely Yours



Donavon C. Hiss
Ph.D. (Medicine), Dip. Freelance Journalism, Dip. Creative Writing

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