

**THE IMPACTS OF ADULT HIV/AIDS MORTALITY ON
ELDERLY WOMEN AND THEIR HOUSEHOLDS IN RURAL
SOUTH AFRICA**

Catherine Ajibola Ogunmefun

**A thesis submitted to the Faculty of Humanities, University of the Witwatersrand,
Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy.**

Johannesburg, 2008.

ABSTRACT

This thesis examines the impacts of adult HIV/AIDS related mortality on elderly women and their households in Agincourt, a rural area in the north-eastern part of South Africa. It focuses specifically on demographic, socio-economic and socio-cultural impacts of adult AIDS and non-AIDS illness/death on near-old women aged 50-59 and older women aged 60 and above.

The study uses the Agincourt Health and Demographic Surveillance System (AHDSS) 2004 census data which contains some history about individuals and their households (e.g. household mortality experience between 1992 and 2004). The AHDSS dataset is used to examine elderly female household headship and its relationship with, firstly, pension status and secondly, adult AIDS/non-AIDS mortality, through statistical analyses. Also, the AHDSS census data is utilised as a sampling frame to select a random sample of 60 households in which 30 women aged 50-59 and 30 women aged 60-75 lived, for the qualitative part of this study. The sample was made up of 20 women who lived in households that had experienced an HIV/AIDS death between 2001 and 2003, 20 women that lived in households where another type of adult death had occurred, and 30 women in households with no adult death during the period.

The findings from the quantitative analyses of the AHDSS dataset reveal that there is no significant relationship between adult AIDS/non-AIDS death and elderly female household headship. Further findings, however, show that elderly female household headship is strongly associated with pension status, thereby suggesting that pension grant is a determining factor in the household headship status of elderly women. One implication of this is that elderly female household heads who are pensioners may be able to cope better with HIV/AIDS impacts as findings from the qualitative data demonstrate that pensioners (older women) are more likely, than non-pensioners (near-old women), to have access to coping strategies, which enable them to deal with the financial crises of adult illness/death in their households. There is, therefore, the need for programmes to target near-old women, who experience the financial impact of adult morbidity/mortality like their older peers.

Further findings from the qualitative data explicate secondary stigma as a socio-cultural impact of adult HIV/AIDS on elderly women who are caregivers to infected children. Findings also highlight different types of secondary stigma such as physical stigma in the form of separation from family members and social stigma in the form of social isolation. The study suggests that there is need for intervention programmes that address the issue of secondary stigma as it makes caregiving responsibilities more burdensome for elderly women.

Keywords: HIV impact, elderly, near-old women, older women, adult HIV/AIDS mortality, verbal autopsy data, demographic surveillance system, demographic impact, socio-economic impact, secondary stigma.

DECLARATION

I declare that this thesis is my own unaided work. It is submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination in any other University.

.....

Catherine Ajibola Ogunmefun

DEDICATION

To God the Father, the Son and the Holy Spirit who saw me through the physical, emotional, financial, and spiritual challenges I faced during the journey of attaining a PhD. Take all the glory in this work.

To all women around the globe, who through the challenges they face, have developed strength of character to overcome the adversities of life in this era of HIV/AIDS.

ACKNOWLEDGEMENTS

My sincere appreciation goes to my supervisor, Prof. Leah Gilbert, for all the intellectual guidance, input, motivation, and constructive criticisms, you provided towards the attainment of this milestone. I am sincerely grateful for your support.

I am also grateful to my other supervisor, Dr. Enid Schatz, for your mentoring, assistance, guidance, and positive criticisms over the years. Thanks for giving me the opportunity to acquire qualitative research skills as the Project Manager of *Gogo* Project. I appreciate your input, support and encouragement, despite the fact that you are based in another continent.

I would like to thank the University of the Witwatersrand for granting me Post-Graduate Merit Award that allowed me to register for my PhD programme and other financial assistance I obtained during the journey. I am also grateful to William and Flora Hewlett Foundation who provided the funds for the Demography and Population Studies Fellowship I was granted during my programme. The journey would have been more challenging without your financial assistance.

I am deeply indebted to Mellon Foundation HIV/AIDS Node at the University of KwaZulu Natal, South Africa and the National Institute on Aging, Population Aging Centre at the University of Colorado, USA. You made the fieldwork for this project possible through the grants you provided. I also thank Prof. Jane Menken, Dr. Jill Williams and their other colleagues at the University of Colorado for supporting this project. I am sincerely grateful.

I extend my gratitude to the MRC/Wits Rural Public Health and Health Transitions Research Unit for providing access to the study site, integration into the Agincourt study site, support throughout the data collection as well as assistance with both the quantitative and qualitative data. In particular, I would like to thank Prof. Steve Tollman and Dr. Kathy Kahn for their support. In addition, I am grateful to Ben Clark and Mark Collinson for their assistance with the extraction of data for my quantitative study as well as assisting with sample selection for the qualitative research. My sincere gratitude goes to Mildred Shabangu, Rhian Twine, Obed Mokoena, Doreen Nkuna, Melta Buthelezi, Zubeda Bagus and other staff members at Agincourt who also supported me in one way or the other.

I owe special thanks to the three interviewers (in this project), Asnath Mdaka, Florence Mnisi and Joyce Nkuna, for providing insights to their culture as well as their quickness in gaining interviewing skills that made it possible for me to have a rich qualitative data. It was nice working with you. I am also grateful to Mr Khosa, our driver, for his contribution. I sincerely appreciate the elderly women in the study site who participated in this project. Without your narratives, my research would have been incomplete.

I would also like to thank the staff members of Wits Demography and Population Studies Programme, Prof. Clifford Odimegwu, Mrs Linda Oldert and Dr. Georges Reiners, and Dr. Olu Taiwo for their support and assistance. In addition, I need to thank Prof. David Sherwell and the Computational and Applied Mathematics (CAM) department for allowing me the use of their computer lab when I needed a space to work. I am sincerely grateful to you. Thank you, Dr. Maina Mutonya, for your assistance with the editing of my thesis.

I am deeply indebted to my family, especially my husband, Eniola, and my son, Joshua, for their love and support over the years. I really appreciate your financial support, Eniola. And, Joshua thanks for providing companionship as well as enduring the time I spent away from home during my PhD journey. I am blessed to have you in my life. I also need to thank my parents for their support and prayers over the years. Thanks also for your encouragement during the challenging times. In addition, I would like to thank my brother, Michael, for his love, support and prayers. It has been a blessing living with you in Johannesburg.

My sincere appreciation to friends that came into my life during my PhD journey; thanks for your friendship, prayers and support. In particular, I would like to thank Ore Labeodan who has been there for me during those difficult times. It has been nice having you as a friend. I am also grateful to Wumi Fareo; you are a wonderful friend. I also extend my gratitude to family friends who have been a blessing in one way or the other, namely the Essiens, Folarins, Alades, Akindeles, Govenders and Taiwos. Lastly, I want to thank Juliet Edayi for her love and friendship.

Finally, I express my gratitude to every other person that I encountered on my journey, who was a blessing to me in one way or the other. Thanks a lot.

TABLE OF CONTENTS

CHAPTER ONE: GENERAL INTRODUCTION	1
1.1 Introduction	1
1.2 Problem Statement	3
1.3 Aims	4
1.3.1 Overall aim	4
1.3.2 Specific aims	4
1.3.3 Research questions	5
1.4 Rationale of the study	5
1.5 Structure of the Thesis	8
CHAPTER TWO: LITERATURE REVIEW	10
2.1 Introduction: Direct and indirect impacts of HIV/AIDS	10
2.2 Demographic impact of adult HIV/AIDS morbidity and mortality	14
2.2.1 Elderly female headed households	18
2.3 Socio-economic impact of adult HIV/AIDS morbidity and mortality	20
2.3.1 Social capital	23
2.3.2 Old age pension grant in South Africa	25
2.4 Socio-cultural impact of adult HIV/AIDS morbidity and mortality	29
2.4.1 Primary Stigma	29
2.4.2 Secondary stigma	32
2.4.3 Managing HIV/AIDS-related stigma	34
2.4.4 Causes and beliefs surrounding HIV/AIDS and its stigma	36
CHAPTER THREE: CONCEPTUAL FRAMEWORK	39
3.1 Psycho-socio-environmental Model	39
3.2 Family Stress Theory	42
3.2.1 Applying family stress theory to HIV/AIDS impacts study	44
3.3 Outline of the application of the PSE and ABC-X models in this study	45
CHAPTER FOUR: METHODOLOGY	48
4.1 Research Design	48
4.2 The Study Site	50
4.3 Agincourt Health and Demographic Surveillance System (AHDSS)	54
4.3.1 Verbal autopsy data	55
4.3.2 Quality control and data entry	57

4.4	Quantitative Research: Data and Methods	58
4.4.1	Logistic regression analysis model (statistical analyses)	61
4.4.2	Limitations of the quantitative data	64
4.5	Qualitative Research: Data and Methods	65
4.5.1	Building on the <i>Gogo</i> Project	65
4.5.2	Data collection	67
4.5.3	Data analysis	70
4.5.4	Limitations of the qualitative research	71
4.6	Ethical issues	72

CHAPTER FIVE: BACKGROUND: SOCIAL, CULTURAL AND HISTORICAL CONTEXTS 74

5.1	Geography	74
5.2	History	76
5.3	Population	80
5.4	Cultural Context	82
5.5	Social Context	83
5.5	South Africa's Social Security System	86

CHAPTER SIX: DESCRIPTION OF THE AGINCOURT POPULATION 90

6.1	Age Structure of the Population	90
6.2	Socio-demographic Characteristics of the Agincourt Population	92
6.2.1	Socio-demographic characteristics of near-old and older people	94
6.2.2	Socio-demographic characteristics of near-old and older women	96
6.3	The Verbal Autopsy Data	99
6.3.1	AIDS and non-AIDS mortality	101
6.3.2	Adult AIDS mortality	103
6.3.3	Non-AIDS mortality	104
6.4	Summary	105

CHAPTER SEVEN: DEMOGRAPHIC IMPACT OF ADULT HIV/AIDS MORTALITY 107

7.1	Introduction: Elderly Female Headship	107
7.2	The Concept of Household	109
7.3	Descriptive Analyses	111
7.3.1	Household headship in Agincourt	111
7.3.2	Relationship of household members to the head	112
7.3.3	Socio-demographic characteristics of household heads	114

7.3.4	Socio-demographic characteristics of elderly female household heads	117
7.3.5	Living arrangements of elderly women	120
7.3.6	Mother's residence status	121
7.3.7	Household headship and adult mortality experience of elderly women	124
7.4	Statistical Analyses of the AHDSS data	125
7.4.1	Household headship and socio-demographic characteristics (Agincourt)	125
7.4.2	Elderly female household headship and socio-demographic characteristics	130
7.4.3	Elderly female household headship and household mortality experience	135
7.5	Discussion and conclusion	138

CHAPTER EIGHT: SOCIO-ECONOMIC IMPACT OF ADULT HIV/AIDS MORTALITY **141**

8.1	Introduction	141
8.2	Older and Near-old Caregivers	143
8.2.1	Caregiving roles of near-old and older women	145
8.3	Socio-economic Status of Elderly Women	151
8.3.1	Socio-economic status of elderly women and pension grant	155
8.4	Coping with the Financial Costs of Adult Illness	156
8.5	Coping with the Financial Costs of Adult Death	162
8.5.1	Joining a burial society	164
8.5.2	Joining a church group and women's society	167
8.5.3	Depending on Social Capital	169
8.5.4	"A pension grant would have made a big difference"	171
8.6	Coping with the Financial costs of Caregiving for Foster Children and Orphans	173
8.7	Older Women's Coping Strategies	177
8.7.1	Living on credit	177
8.7.2	Joining a <i>stokvel</i> (rotating credit scheme)	179
8.8	Near-old Women's Coping Strategies	181
8.8.1	Engaging in economic activities	181
8.8.2	"No credits!"	183
8.9	Preliminary Findings	185
8.10	Recovery from Economic Shocks	188
8.11	Discussion and Conclusion	190

CHAPTER NINE: SOCIO-CULTURAL IMPACT OF ADULT HIV/AIDS MORTALITY **193**

9.1	Introduction: Secondary Stigma	193
9.2	Community, Family and Personal Responses to Secondary Stigma	195
9.2.1	Community Responses to HIV/AIDS	195
9.2.2	Experiences of stigma by caregivers	198
9.2.3	Managing secondary stigma	201

9.3	Causes, Beliefs and Consequences of Secondary Stigma	206
9.3.1	Causes of HIV/AIDS-related stigma	206
9.3.2	Beliefs behind HIV/AIDS and stigma	207
9.3.3	Consequences of Stigma	211
9.4	Discussion	214
 CHAPTER TEN: GENERAL DISCUSSION AND RECOMMENDATIONS		218
10.1	The Conceptual Framework(s) and Major Research Findings	218
10.2	Other Important Findings from the Study	222
10.3	Recommendations	226
10.3.1	Informing Elderly Caregivers	227
10.3.2	Participating in income generating activities	228
10.3.3	Targeting near-old women	230
10.4	Conclusion	232
 BIBLIOGRAPHY		234
 APPENDIX A: The MRC/Wits Unit Study Site		251
APPENDIX B: Interview Guide for Older (aged 60+) Respondents		252
APPENDIX C: Interview Guide for Near-old (aged 50-59) Respondents		256
APPENDIX D: Socio-economic profile of older respondents in the qualitative study		262
APPENDIX E: Socio-economic profile of near-old respondents in the qualitative study		263

LIST OF FIGURES

Figure 3.1	The application of the psycho-socio-environmental model to the HIV/AIDS impacts study	41
Figure 3.2	The application of the ABC-X model to the HIV/AIDS impacts study	45
Figure 3.3	The relationship between adult HIV/AIDS mortality and elderly female headship	47
Figure 6.1	Agincourt population pyramid (2004)	90
Figure 7.1	The connection between adult HIV/AIDS mortality and elderly female headship	136

LIST OF TABLES

Table 6.1	Agincourt population age structure (%) in 2004	91
Table 6.2	Socio-demographic characteristics of Agincourt population	93
Table 6.3	Socio-demographic characteristics of near-old and older people	95
Table 6.4	Socio-demographic characteristics of near-old and older women	97
Table 6.5	Number of deaths by age categories, 1993-2004	100
Table 6.6	Number of AIDS and non-AIDS deaths by age categories, 1993-2004	102
Table 6.7	Households with adult AIDS deaths by period	103
Table 6.8	Households with adult non-AIDS deaths by period	104
Table 7.1	Sex of household head by age categories	111
Table 7.2	Relationship of household members to the head by age categories	113
Table 7.3	Socio-demographic characteristics of household heads by sex	115
Table 7.4	Socio-demographic characteristics of elderly women by household headship (50+)	118
Table 7.5	The living arrangements of near-old and older women	120
Table 7.6	The residence status of mother of the children and adult population	122
Table 7.7	Elderly female headship status by household mortality experience	124
Table 7.8	Odds ratios for logistic regression of household headship on socio-demographic variables (Agincourt population aged 15 and above)	127
Table 7.9	Odds ratios for logistic regression of elderly female household headship on socio-demographic variables (elderly women aged 50 and above)	132
Table 7.10	Odds ratio for logistic regression of elderly female household headship on household mortality experience	137
Table 8.1	Caregiving for the sick	144

Table 8.2 Household mortality experience and socio-economic status of near-old and older women's households	152
Table 8.3 Household mortality experience and socio-economic status of all elderly women's households	154
Table 8.4 Household mortality experience and socio-economic status of pensioners and non-pensioners	155
Table 8.5 Household's wealth ranking by level of recovery from expenses related to caregiving	189

LIST OF ABBREVIATIONS

AHDSS	Agincourt Health and Demographic Surveillance System
DSA	Demographic surveillance area
FAO	Food and Agriculture Organisation
HAI	HelpAge International
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
LINC	Learning, Information dissemination, and Networking with Community
MRC/Wits Unit	Medical Research Council/Wits Rural Public Health and Health Transitions Research Unit (Agincourt)
PLWHA	People living with HIV/AIDS
SAinfo	South Africa. info
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
VA	Verbal autopsy
WHO	World Health Organization

Chapter One

GENERAL INTRODUCTION

1.1 Introduction

It is now nearly three decades since the emergence of the Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) and millions of people across the globe are still suffering from its impact. More than 22 million people had died of AIDS as of 2002 and about 32 million people are currently living with HIV/AIDS globally, while two thirds of these people live in sub-Saharan Africa (United Nations, 2004; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2007). HIV/AIDS impacts those that have it, their families, and their communities; this is especially true in developing countries. Families in developing regions of the world are normally left with, not only the burden of caring for the sick for a long period of time, but also the expenses incurred during the sickness and death of loved ones infected with HIV/AIDS. This is an acute strain especially on households with extremely scarce resources in rural areas of developing countries. In most cases, prime-aged adults are the ones dying, and their older (or younger) kin are the ones left with multiple burdens. These kin must give care to sick individuals and to orphaned children, and cover expenses incurred from the sickness and funeral (HelpAge International [HAI], 2003a).

In Africa, as elsewhere, gender plays an important role in determining duties assigned to family members. For instance, women are normally expected to give care to the sick and children in the family. The implication of this, in the era of HIV/AIDS, is that elderly women

will bear the brunt of the epidemic because of increased caregiving responsibilities caused by caring for the sick, dying children and grandchildren and by becoming surrogate parents to orphaned children (Ferreira, 2004a). Although some studies deal with the effects of HIV/AIDS on people in sub-Saharan Africa by highlighting the important role played by elderly people, especially elderly women, there is a great need for more knowledge and understanding about the roles elderly women are playing and the different impacts they are likely to experience as caregivers to adult children and grandchildren in South Africa, a country with one of the world's largest HIV epidemics (UNAIDS, 2007).

The history of HIV/AIDS epidemic in South Africa started in 1982 when a few AIDS cases were first reported among homosexual men in South Africa (Gilbert and Walker, 2002a). Since then, the number of people being infected yearly because of heterosexual transmission has grown geometrically and the social factors associated with apartheid have influenced the pattern and severity of the epidemic in South Africa (Gilbert and Walker, 2002a). In addition to the labour migration system and social inequality, a high unemployment rate, a well developed road network, rural-urban migration, and poverty have influenced the HIV/AIDS epidemic (Gilbert and Walker, 2002b). These factors, in one way or the other, may contribute to how the epidemic impacts on elderly women.

This thesis examines the experiences of elderly women aged 50 and above with regard to adult HIV/AIDS related mortality in a rural area in the northeast of South Africa. It focuses specifically on the multiple impacts of an adult illness and death on elderly women and their households. In order to have a comprehensive understanding of HIV/AIDS impacts on

elderly women, the coping strategies of near-old and older women¹ during crises such as adult illness and death are further investigated in this thesis.

1.2 Problem Statement

In Africa elderly people, particularly elderly women, are more likely to reside in rural areas. It is projected that by 2020, 64% of people over 60 years will reside in rural areas in Africa (HAI, 2004d). Rural dwellers in Africa are faced with numerous challenges such as inadequate infrastructures like water, electricity and health facilities. As more prime-aged adults continue to be infected with HIV, the question to ask is, how will these challenges in rural areas compound the impacts of HIV/AIDS on elderly women who are caregivers to adult children? And are there resources available for elderly caregivers in rural South Africa that help them to cope with the impacts of the epidemic?

South Africa is regarded as “a microcosm of global inequality” with a large percentage of its population suffering from the consequences of the policies made during the apartheid era (Makiwane, Schneider and Gopane, 2004). Some social factors, which are consequences of the apartheid era, include the labour migration system that has destabilized the family system, and social inequality, which contributed to a high poverty level among the African population and rural dwellers in particular (Barnett and Whiteside, 2002). How do these social factors, coupled with the HIV/AIDS epidemic, impact on elderly women in rural South Africa?

¹ In this thesis, ‘near-old’ or non-pensioners refers to women aged 50-59 while ‘older women’ or pensioners refers to women above 60. The term ‘elderly’ refers to all women in both of these two age groups or people above 50.

Research has shown how the HIV/AIDS epidemic is affecting older women in Africa (Ferreira, Keikelame and Mosaval, 2001; WHO, 2002a; Lindsey et al., 2003; Williams, 2003; HAI, 2004a; Ssengonzi, 2007; Ogunmefun and Schatz, 2007; Schatz, 2007). However, there is a paucity of knowledge about women aged 50-59 years, or the near-old, who traditionally in African culture are considered as elderly. This group is sometimes overlooked since they have not yet reached the pension age of 60 years (Hunter and May 2003). As a result of the need for more information, this thesis poses these questions: do near-old women in rural South Africa have similar experiences as their older peers with regard to the HIV/AIDS epidemic? How do they, as non-pensioners, cope with crises such as adult HIV illness and death? And, how do both near-old and older women experience secondary stigma, that is, the socio-cultural impact of HIV/AIDS? This study seeks to provide answers to these and other questions that have been raised in this section.

1.3 Aims

1.3.1 Overall aim

To examine the demographic, economic, and socio-cultural impacts of adult HIV/AIDS related morbidity and mortality on elderly women and their households in a rural area in South Africa.

1.3.2 Specific aims

- To examine elderly female household headship as a demographic impact of adult HIV/AIDS related mortality.

- To ascertain the contribution of the old-age pension grant to the economic well-being of elderly women's households with adult HIV/AIDS related morbidity and mortality.
- To explore secondary stigma as a socio-cultural impact of HIV/AIDS on elderly women.

1.3.3 Research questions

In order to achieve the aim of the study, the following questions are posed:

- Is there a relationship between elderly female household headship and adult HIV/AIDS related mortality?
- What are the socio-demographic characteristics of elderly female household heads?
- Are older women more likely, than near-old women, to cope better with adult HIV/AIDS related morbidity and mortality in their households as a result of their pension income?
- What are the experiences of elderly women who are caregivers with regard to secondary stigma?

1.4 Rationale of the Study

The literature on the HIV/AIDS epidemic highlights the impacts of HIV/AIDS on people, especially men and women in the productive and reproductive age groups, youth, children and babies. However, the impacts of HIV/AIDS on elderly people and those who depend on them are usually under-reported (Fouad, 2004). In addition, most HIV/AIDS policies and programmes do not target elderly people and families (or households) holistically (Ferreira, 2004a). Hence, there is need for more research to focus on elderly people and households

affected by the epidemic, so that their needs and problems can be highlighted and suitable recommendations will be made for policies and programmes that target them.

Some authors have particularly demonstrated the need for more research on the impact of HIV/AIDS on elderly women in the developing parts of the world, such as sub-Saharan Africa (Dayton and Ainsworth, 2002; Barnett and Whiteside, 2002; Zimmer and Dayton, 2003; HAI, 2003a). There is a consensus that elderly women are more likely, than elderly men, to bear the brunt of the impact of the HIV/AIDS epidemic in households in sub-Saharan Africa (HAI, 2003a; Barnett and Whiteside, 2002; Ferreira, 2004a). The reason for this may be due to issues of gendered relationships in the household and society, that is, certain roles associated with being a woman, and gendered power dynamics in the family/household. In order to understand the role of gender with regard to the HIV/AIDS epidemic, it is imperative to bring more attention to the gendered nature of the impacts of HIV/AIDS on elderly women, which is one of the intentions of this study.

Another reason why research on elderly women is important is because of a lifetime of disadvantages that women have endured. Women live longer than men; and, they are more likely to have had poor education and nutrition, lack of access to services, the labour market and property (HAI, 2002c). In sub-Saharan Africa, there are about 12 million, of the global total of 13.2 million AIDS orphans, and they are mostly cared for by elderly women (HAI, 2002c). There is also an increase in the number of chronically poor households that are headed by elderly women as a result of the HIV/AIDS epidemic (HAI, 2002a).

It is also imperative to focus on elderly women in the study of demographic and social impacts of HIV/AIDS, as they are mostly rural dwellers and therefore, likely to be vulnerable in times of crises. According to Barnett and Whiteside (2002), rural elderly women in sub-Saharan Africa are adversely affected by the epidemic. This phenomenon is because of inadequate infrastructures, such as water, health systems/facilities and electricity, which compound the burden of the role that elderly women are expected to play as caregivers of the sick and orphans left behind by dying adult children.

In South Africa, elderly women aged 60 years and above (and men over age 65), are eligible to receive a means-tested non-contributory pension. Even though this may help to reduce financial burdens associated with adult HIV/AIDS related mortality in their households, it may also increase dependency on elderly women as carers of the sick and orphans. Thus, there is a need for more empirical research that focuses on the contribution of pensions to elderly women's households (in rural South Africa), which is one of the objectives of this study.

In the literature on elderly women and HIV/AIDS, there is a paucity of information about women aged 50-59 years or the near-old, who traditionally in African culture are considered elderly, but are often overlooked since they have not yet reached the pension age of 60 years (Hunter and May 2003). As a result of the need to fill the gaps in literature on this group, and in order to get a better understanding of coping strategies in households without pensions, this study compares the experiences of HIV/AIDS on near-old women and older women.

1.5 Structure of the Thesis

This thesis comprises ten chapters; this chapter provides an introduction and a brief background of the study. The second chapter reviews the literature on the impacts of HIV/AIDS on elderly people, particularly elderly women in developing countries of the world. The review focuses specifically on the demographic, socio-economic and socio-cultural impacts of adult HIV/AIDS related mortality on elderly women and how this literature informs the present study.

In chapter three, a theoretical framework is developed for the study of the impacts of adult mortality on elderly women and their households. It explains how the psycho-social environmental (PSE) model provides an overall explanation of the multiple impacts of HIV/AIDS on elderly women. It also focuses on how the ABC-X model of the family stress theory explains the interaction between adult mortality (the A factor), pension-receipt (the B factor) and perception of caregiving role (the C factor), which results in crisis (the X factor).

The methodology of the study is presented in chapter four. It describes the quantitative and qualitative data (and methods) used in this thesis. In addition, it gives a description of the study site, the Agincourt Health and Demographic Surveillance System (AHDSS) census data, as well as the verbal autopsy data collected in the site. Chapter five presents the social, cultural and historical contexts of the South African population, while chapter six gives a description of the demographic characteristics of the Agincourt population, in order to provide a background picture of the study community.

Chapter seven provides an examination of elderly female headship as the demographic implication of adult HIV/AIDS related mortality and the relationship between pension status and elderly female headship. Chapter eight focuses on the socio-economic impact of adult HIV/AIDS morbidity and mortality on elderly women. This chapter is also a comparative study of the coping strategies adopted by near-old and older women in times of crises such as adult illness and death. Chapter nine features the socio-cultural impact of HIV/AIDS by recounting the experiences of elderly caregivers with regard to secondary stigma.

Lastly, chapter ten provides a general discussion of the major findings of the thesis. It also provides recommendations for intervention programmes and future research as well as the conclusion.

Chapter Two

LITERATURE REVIEW

2.1 Introduction: Direct and Indirect Impacts of HIV/AIDS

The HIV/AIDS epidemic has a multi-faceted impact on individuals, their households, families and communities. This multi-faceted impact of HIV/AIDS is felt, both by those that contract the disease directly and indirectly by those who are related to or associated with them. Some of its impacts, like the morbidity and mortality of children and prime-aged adults could be regarded as “direct impacts”, and focus has been on the consequences of these impacts on nations of the world, this is, at the macro-level. It is, however, important to understand that most of the devastating and immediate impacts are worst and first felt at the micro-level, that is, at the individual and household levels (Barnett Whiteside, 2002; Veenstra and Whiteside, 2005).

A number of studies have shown the “direct impacts” of HIV/AIDS at the individual and household levels (Steinberg et al., 2002; Ntozi, 1997; Donovan et al., 2003; Yamano and Jayne, 2004). One of these studies conducted a survey of 771 AIDS-affected households in South Africa and reported that there was an increase in expenditure on medicines and medical care due to HIV/AIDS (Steinberg et al., 2002). Since on average, the infected household member was chronically ill for a year before dying, this made HIV/AIDS “the tipping point from poverty into destitution” for already poor households (Steinberg et al., 2002). A study of six districts in Uganda also shows that the patients and caregivers were

unable to go out and earn a living for themselves and their households. As a result, previous investment and savings spent on treatment could not be replaced (Ntozi, 1997). Therefore, these households ended up with problems such as failure to pay school fees for children, and failure to purchase food for the household (Ntozi, 1997).

In Vietnam, a country with a low HIV/AIDS prevalence level, a study on the impact of HIV/AIDS on household vulnerability and poverty collected information from 125 households with 129 HIV/AIDS-infected individuals in four provinces (United Nations Development Programme [UNDP], 2005). Findings demonstrated that, in households with an HIV/AIDS-infected person, the total health care expenditure was 13 times higher than that of the average household. According to this study, coping strategies such as borrowing money and selling of assets, adopted by households, were more often “struggling strategies”(UNDP, 2005). Such strategies are likely to disadvantage the households into the future as they may find it difficult to recover (financially) because of lingering debts or failure to replace sold assets (Ogunmefun and Schatz, 2008).

Reductions in labour supply and household’s crop production are also some of the “direct impacts” of HIV/AIDS on households, as shown in studies conducted in Kenya and Rwanda. In order to cope with the financial impact of the disease (caused by reductions in labour supply that led to reduction in household expenditure), some of the households in these studies resorted to selling of household assets such as land and livestock, as in Vietnam (Donovan et al., 2003; Yamano and Jayne, 2004, UNDP, 2005). Such strategies may

increase the impact of HIV/AIDS on households as they may find it difficult to recover, as noted earlier.

Other studies conducted by the Food and Agriculture Organization of the United Nations (FAO) also show the impact of HIV/AIDS on food security in rural areas in Namibia and Uganda. In Namibia, findings show that 38% of the 513 households in the survey, affected by the epidemic, were unable to cope with shocks as nearly all the households own a lesser number of livestock than they did previously (FAO, 2003). In particular, the study reported that affected households sold more cattle in the past five years than households that had not been affected by the epidemic, in times of needs (FAO, 2003). Of the total 610 households sampled in the survey in Uganda, 31% were affected by HIV/AIDS. The study reveals that these AIDS-affected households in agriculture, fisheries and pastoralist communities had fewer resources and that they struggled to buy additional agricultural inputs such as fertilizers and pesticide. Thus, they were producing less (output) and becoming resource-poor (FAO, 2003).

One striking feature of the impact of HIV/AIDS is the number of orphans in households affected by HIV/AIDS, documented in some of these studies. In Zambia, FAO (2003) reports that, of 766 households sampled in a survey conducted in three rural districts, 31% were caring for AIDS orphans. The study further reports that there has been an increase in households fostering orphans because of adult HIV/AIDS related mortality, which places an additional burden on affected households (FAO, 2003). In a national household survey on HIV prevalence in South Africa, findings demonstrated that 13.0% of children aged 2-14

years had either lost a parent or both parents, probably due to the epidemic; in addition, 3.0% of households were headed by a child aged 12-18 years (Shisana and Simbayi, 2002). In Zimbabwe as well, where an orphan enumeration survey was conducted, it was found that of 570 households, 18.3% included children aged 0-14 years who had either lost one or both parents; 50% of these deaths could be attributed to HIV/AIDS (Foster et al., 1995). Some of these AIDS orphans ended up staying with other relatives such as grandparents that have to bear the “indirect impacts” of the epidemic (Foster and Williamson, 2000; Nyamukapa and Gregson, 2005; Atwine, Cantor-Graae and Bajunirwe, 2005).

Increasing attention has been given to the “indirect impacts” of HIV, such as the effects of the epidemic on elderly people who are parents to those who are HIV positive and caregivers to affected grandchildren. In the studies of the impacts of HIV/AIDS on elderly people, focus is mostly on their role as caregivers to the sick and orphans left by their adult children that died of AIDS (World Health Organization [WHO], 2002; Saengtienchai and Knodel, 2001; Lindsey et al., 2003). In particular, HelpAge International has conducted extensive studies on how elderly people are increasingly becoming “parents” to orphans and vulnerable children left behind in the wake of the epidemic (HAI, 2002a; HAI, 2002c; HAI, 2003a; HAI, 2004a; HAI, 2005a). However, HIV/AIDS is likely to affect elderly people, particularly elderly women, in other aspects of their lives apart from being left with the burden of caregiving. For instance, elderly caregivers may also experience emotional and socio-cultural impacts. These other impacts may have additional aspects or components that have not been previously focused on. It is, therefore, important to explore these other impacts of HIV/AIDS on elderly women in order to create a more holistic approach to understanding the

HIV/AIDS epidemic. This thesis takes such a holistic approach. The following sections focus specifically on the demographic, socio-economic and socio-cultural impacts of adult HIV/AIDS related mortality by reviewing studies that have examined the various impacts of the disease on elderly people, particularly elderly women, in sub-Saharan Africa.

2.2 Demographic Impact of Adult HIV/AIDS Morbidity and Mortality

One of the ways in which the epidemic impacts on elderly people, especially elderly women, is through its demographic impact on their households. The demographic impact of HIV/AIDS has long been a cause for concern among researchers and policy makers. However, the focus has been at the national and regional levels. According to Barnett and Whiteside (2002), even though demographic indicators focus only on nations, provinces or areas, the impact of HIV/AIDS may be concentrated in households and among specific groups. Small scale impacts, such as those on individuals, households or families, are overlooked in most of the discussions of the demographic impact of HIV/AIDS (Barnett and Whiteside, 2002).

Demography is mostly concerned with fertility, mortality and migration, which means that the demographic impact of HIV/AIDS, occurs because of any demographic events such as a death or movement caused by the epidemic, or births that do not occur because of the epidemic (Barnett and Whiteside, 2002). These demographic events are likely to cause a change in the type and structure of households in which elderly women reside, as there may be a drastic alteration in household composition and capacity when dealing with the disease (Madhavan and Schatz, 2007).

A change in household structure can occur if an adult who is infected with HIV/AIDS returns home to his elderly parents and later dies. In their work in Thailand, Knodel and Saengtienchai (2002) found that 40% of adult children, cared for by their parents, returned home from elsewhere and sometimes, this happened when the sickness had reached an advanced stage. In another study in the Kagera region of Tanzania, about 37% of people who died of HIV/AIDS had moved to their parents' households a few months before their deaths (Dayton and Ainsworth, 2002). This must have changed the household structure even if temporarily.

A study conducted in the United States of America (USA) also confirms that people infected with HIV/AIDS are likely to return home. In this study, Ellis and Muschkin (1996) found that over 19% of interstate AIDS-infected migrants moved to small cities and rural counties where there were inadequate medical and social service facilities, but a high percentage of elderly people. These authors concluded that the motivation for this phenomenon was because of those who sought assistance from their elderly parents when they became ill (Ellis and Muschkin, 1996). It is also found in the Agincourt study site (rural South Africa) that increasing numbers of migrants who become ill in urban areas are returning home to convalesce and eventually die (Clark et al., 2007). According to Clark et al. (2007), the "returning home to die phenomenon" is likely to lead to an increase in household health expenditure and loss of income because of cessation of remittances. This phenomenon may also lead to a change in structure of the households to which these migrants returned, especially if there were previously no young adults or middle generation in the households.

A change in household structure can also occur when the sick adult child returns to his elderly parents' household with his children (or was already living with them or dies and then sends his/her children to his/her elderly parents for care). When the sick person dies, these parents usually take over the responsibility of taking care of the orphans (WHO, 2002a). Knodel and Saengtienchai (2002) show that at the time of their study in Thailand, about 50% of the AIDS parents (people with adult children that died of AIDS), had AIDS orphans (children whose parents died of AIDS) living with them. In another study conducted in Kikole in rural Uganda, Williams (2003) also found that the largest group of children under 15, that were living with their grandparents, had lost a parent to AIDS in that (same) household.

The WHO (2002) research conducted on elderly people in Zimbabwe demonstrated that, in most cases, the elderly people turned out to be the only available and willing people to take care of AIDS orphans. As a result of the movement into the households of elderly people in this study, there was an increase in the number of children in such households. In Uganda, Ssengonzi (2007) also found there was a sudden increase in the household size of elderly caregivers because of HIV/AIDS patients moving into their parents' households with their dependants.

One implication of the movement of children into elderly people's households, after the death of their parents, is the creation of "skipped generation households"² (Ferreira, 2004a; Makiwane, Schneider and Gopane, 2004). The literature suggests that there is likely to be an

² Households made up of grandparents and grandchildren with no middle generation.

increase in number of skipped generation households in sub-Saharan Africa is because of the HIV/AIDS epidemic (HAI, 2003a; Barnett and Whiteside, 2002; Ferreira, 2004a). However, Madhavan and Schatz (2007), in an analysis of three cross-sections of the Agincourt Health and Demographic Surveillance System (AHDSS) data (1992, 1997, 2003), have found very little increase in either child-headed or skipped generation households in the Agincourt study site. In another research that examined the impact of adult mortality on the living arrangements of older people in a demographic surveillance area (DSA) in northern KwaZulu-Natal Province (South Africa), skipped generation households were also found to be rare in spite of high levels of adult mortality (Hosegood and Timæus, 2005). These two studies suggest that skipped generation households are short-lived because of other adults joining the household, children moving out to join other households, or dissolving the households (Hosegood and Timæus, 2005; Madhavan and Schatz, 2007).

Even though there is no empirical evidence of an increase in skipped generation households resulting from the prevalence of adult HIV/AIDS related mortality, especially in sub-Saharan Africa, the literature suggests that the HIV/AIDS epidemic could cause an increase in female-headed households (Monasch and Boerma, 2004; Ferreira, 2004b). This could be regarded as a change in household structure as a household is more likely to be headed by a male, especially in sub-Saharan Africa. In the MRC/Wits Unit (Agincourt) field site, there has been an increase in the proportion of *de jure* female-headed households from 29% in 1992 to 33% in 2000 and the *de facto* from 39.6% in 1992 to 41.6% in 2000 (Townsend et al., 2004). According to Townsend et al. (2004), the difference in the proportion of *de jure* and *de facto* female-headed households could be as a result of the migrant labour system,

which led to the absence of adult men. There is, however, the need for studies to further examine whether the increase in female-headed households could be attributed to the occurrence of adult HIV/AIDS related mortality in these households.

2.2.1 Elderly female-headed households

Another type of household, which may emerge because of adult HIV/AIDS related mortality, is elderly women-headed household. Even though studies on the living arrangements of elderly people have shown that elderly women are likely to live in multi-generational households headed by an adult male child, a growing number of elderly women are household heads in the (multi-generational) households in which they live, especially in rural Southern Africa (Bongaarts and Zimmer, 2001; Zimmer and Dayton, 2003; Ferreira, 2004b).

A study conducted in South Africa shows that elderly women are likely to live in households headed either by their spouses or adult children (Noumbissi and Zuberi, 2001). However, when their spouses and these children die (presumably of HIV/AIDS), these elderly women are likely to become household heads, thereby creating elderly women headed households. In their study, Noumbissi and Zuberi (2001) reported that 51% of elderly women are household heads. There was, however, no empirical evidence whether this was as a result of adult HIV/AIDS related death in their households. This study, therefore, explores the prevalence of elderly women-headed households as well as the relationship between adult HIV/AIDS related mortality and elderly women-headed households in the MRC/Wits Unit (Agincourt) study site.

Studies around the globe have shown that female-headed households are more likely than male-headed households to be vulnerable, especially when affected by HIV/AIDS, therefore, members of such households are likely to live in poverty (Tienda and Angel, 1982; McLanahan, 1988; Lloyd and Gage-Brandon, 1993; Kimenyi and Mbaku, 1995; Barros, Fox and Mendonça, 1997; Moralda et al., 2001; FAO, 2003; Williams, 2003; May, 2003; Chant, 2007). In particular, work from sub-Saharan Africa has shown that female-headed households are more likely to be impacted by the epidemic following the depletion of households' asset-base caused by sale and repossession of assets (by in-laws) following a spouse's death (Ntozi and Mukiza-Gapere, 1995; FAO, 2003; Williams, 2003; Oleke, Blystad and Rekdal, 2005). Furthermore, findings from Uganda and Zambia show that households headed by widows and grandmothers are more likely to care for AIDS orphans (FAO, 2003; Williams, 2003). The implication of this is that the epidemic will increase the burdens of caregiving on female household heads, especially if some of the orphans in their households have been infected with the virus.

Some of the aforementioned studies suggest that, in addition to living in poverty, female elderly households are likely to rely on social welfare in order to meet essential needs in the households (Tienda and Angel, 1982; McLanahan, 1988; Kimenyi and Mbaku, 1995; Chant, 2007). In South Africa, eligible elderly women start receiving a non-contributory pension from age 60. Thus, households headed by elderly women are likely to depend on this social grant. The implication is that pensions may make elderly women-headed households less vulnerable to financial hardship than other households in a rural area, or at least compared to elderly female-headed households in regions without such pensions.

Studies have shown that many pensioners play a vital role in their households as their pension money is used to alleviate poverty and mediate crises such as adult HIV/AIDS related illness and death (Sagner and Mtati, 1999; Ferreira, Keikelame and Mosaval, 2001; Bachmann and Booysen, 2003; Moller and Ferreira, 2003; May, 2003; Booysen, 2004). According to Sagner and Mtati (1999), pension sharing enables the elderly to earn respect and obedience from their children and other household members, thereby enhancing their status. Pension status is, therefore, likely to contribute to the headship status of elderly women, that is, enhance their position as a household head. In order to further examine how a pension grant can enhance the status of the elderly, this study explores the relationship between pension status and headship status among elderly women, especially with regard to adult HIV/AIDS impact.

The following section focuses on another way in which elderly women could be impacted by adult HIV/AIDS related mortality, that is, the socio-economic impact of HIV/AIDS.

2.3 Socio-economic Impact of Adult HIV/AIDS Morbidity and Mortality

Although illness occurs in individuals, coping with its costs usually occur at the level of the household (Sauerborn, Adams and Hien, 1996). In addition, the socio-economic status of the household may be affected especially if it is a long-term illness or a terminal disease like HIV/AIDS. The reason for this is that a long term illness increases the expenditure on medical care (medicines, transportation to services, as well as allopathic and traditional medical treatment) and food. Thus, an adult HIV-related illness and death is likely to reduce the household savings drastically (Barnett and Whiteside, 2002). The time and energy spent

on caregiving reduces those hours spent on economic activities and household chores as well. If the patient was an income-earner for the household, their income is lost during sickness and after death, funeral-related expenses are incurred by the household.

Studies have shown that HIV/AIDS has a great impact on the economic well-being of elderly people, particularly elderly women, and their households (Knodel, Watkins and Vanlandingham, 2002; WHO, 2002a; Lindsey et al., 2003). Not only do these elderly people lose a potential source of income when their HIV-positive children become too sick to work, but they also have to spend the little they have on taking care of them, as well as paying for their funerals. In the study conducted in Zimbabwe, WHO (2002) found that some of the elderly people's households lost the savings that they have accrued over a long period due to the long-term illness of their adult children and the cost of taking care of their children's health care needs before their children eventually died. In addition, the elderly people's limited resources were used to pay for funerals and care for orphans left behind. In Botswana, Lindsey et al. (2003) also found the cost of funerals to be a compounding problem for elderly caregivers, especially when three or four family members died within a short period of time. As a result of this, there is a curtailment of elaborate and costly funeral rituals (Lindsey et al., 2003).

Knodel and his colleagues, who did extensive research on the impacts of HIV/AIDS on elderly people in Thailand, also reported similar findings. In their studies, they found that elderly people in Thailand are playing an important role as caregivers to infected adult children (Knodel et al., 2002; Knodel, Watkins and VanLandingham, 2002; Knodel and

Saengtienchai, 2002; Knodel and Im-em, 2003). In one survey, findings show that, in half of the cases where parents took care of their ill children, one or both parents either stopped or reduced their economic activities. And, some parents that were involved in agricultural pursuits had to enlist the assistance of other people during the periods that work was unavoidable; this was likely to cost them some money (Knodel and Im-em, 2003). This means caregiving entails some opportunity costs which may be detrimental to the economic well-being of elderly caregivers (Ogunmefun and Schatz, 2008).

Furthermore, HIV/AIDS had a huge impact on the economic well-being of AIDS parents in Thailand, despite there being a government intervention policy in place to help alleviate this impact on them. This intervention is a basic government health insurance, which covers the costs of available treatment and thereby reduces the economic impact of an illness on a family (Knodel, Watkins and VanLandingham, 2002; Knodel et al., 2002; Knodel and Im-em, 2003). Knodel et al. (2002) show that 60% of the adult children who died of AIDS were covered by this health insurance and that this helped to reduce the economic impact of AIDS on their parents. This type of intervention by the government that helps reduce the economic impact of HIV/AIDS was not reported in other studies (WHO, 2002a; Lindsey et al., 2003). The implication of this is that, in countries where this kind of policy is not in place, the elderly are likely to experience the economic of HIV/AIDS on a greater dimension.

In South Africa and many other sub-Saharan African countries, where government health insurance or universal health-care system is not in place, the cost of medical care may be affordable, but other factors such as transport cost and use of traditional healers may increase

the economic impact of HIV/AIDS on elderly people with sick children. As a result of a lifetime of low wages and poor access to medical aid schemes, many elderly people in South Africa have no health insurance coverage (Ferreira, 2000). The implication of this is that elderly people, particularly elderly women who are caregivers, are likely to seek health care from traditional practitioners, such as herbalists, diviners and witchdoctors, as well as western medical practitioners (Ferreira, 2000). Expenses incurred from accessing these different practitioners will likely increase the financial burden of elderly women as caregivers to sick adult children. In order to cope with this burden, they may sometimes depend on their social capital³ for financial assistance as explored in the following subsection.

2.3.1 Social capital

Although the concept “social capital” is sometimes not directly mentioned, studies have shown how individuals and households rely on assistance from their kin and friends in times of crises such as illness and death (FAO, 2003; UNDP, 2005; Wood, Chase and Aggleton, 2006; Thomas, 2006; Gerdner, Tripp-Reimer and Simpson, 2007). According to (Muriisa, 2006), social capital can help to alleviate the impact of HIV/AIDS on affected people. The implication of this is that elderly caregivers who are affected by adult HIV/AIDS related illness and death may be relieved of some of the financial expenses related to caregiving through assistance from their kin, friends, and members of their community. In addition, reliance on social capital or social network can serve as a coping strategy in times of adult HIV/AIDS related illness and death in elderly women’s households.

³ Social capital refers to benefits that accrue to individuals by virtue of their membership in social networks or structures (Cattell, 2001; Wakefield and Poland, 2005)

In a Thailand study involving parents who lost an adult child to AIDS, Saengtienchai and Knodel (2001) reported that, in addition to assistance with the physical aspect of caregiving, respondents reported obtaining financial assistance from family, former employers of the child with AIDS and community members to cover funeral related expenses and other significant aspect of the expenses. By relying on their social capital, these AIDS parents were able to cope better with the financial impact of adult HIV/AIDS related mortality in their household.

However, social capital may not be wholly reliable sometimes during crises, as assistance may eventually cease, especially if it is a long-term illness like HIV/AIDS. A study that collected data through solicited diaries from elderly caregivers in the Caprivi Region in Namibia showed that, household members and people outside the household provided assistance such as food and sodas for the patient during the early stages (Thomas, 2006). Eventually, when the patient failed to get better, assistance became less forthcoming. This left the caregiver to cope with little assistance at a time when household resources were already depleted through treatment expenses and time spent away from economic activities (Thomas, 2006). The cessation of support from their social networks when these caregivers needed it most was likely to have worsened their experience of the impact of HIV/AIDS.

In rural KwaZulu-Natal, a study conducted on HIV-affected households found that the little financial and material assistance from former partners or parents outside the household ceased when the person became ill or died (Hosegood et al., 2007). Since this support

stopped at the same time that the household was experiencing financial difficulties, it exacerbated household poverty (Hosegood et al., 2007) As a result of the unreliability of social capital in times of crises, there may be the need for elderly women who are caregivers to infected children to adopt other coping strategies such as relying on their pension grant; this is examined next.

2.3.2 Old-age pension grant in South Africa

An old-age pension program, like those available in a few developing countries, is an intervention scheme that may reduce the vulnerability of elderly people to poverty (HAI, 2003b; Case, 2001; May, 2003). Such programs have had a significant impact on poverty in developing countries such as Brazil, Namibia, Botswana, Lesotho and particularly in South Africa, where it has been used as a tool to re-distribute wealth among the population (Case and Deaton, 1998).

The South African pension grant programme was first introduced in 1928 for the White and Coloured populations and later extended to all South Africans in 1944 (Sagner, 2000; Legido-Quigley, 2003). In the early 1990s, after the abolition of apartheid, the programme was restructured in order to secure equal access and the same quality of service for all South Africans (Legido-Quigley, 2003). Even though the pension grant system is means-tested, it is almost universal for the black population as more than 90 percent of elderly blacks have access to it and only 16 percent of elderly whites receive a pension grant (Ferreira, 2000).

Despite the fact that the pension grant is meant for the elderly, it is usually shared between the recipient and members of his or her family/household (Ferreira, 2000; Sagner, 2000; HAI, 2003b). Considerable research has shown that pensions help alleviate poverty among the elderly and members of family/household (Moller and Sotshongaye, 1996; Case and Deaton, 1998; Sagner and Mtati, 1999; Ferreira, Keikelame and Mosaval, 2001; Duflo, 2003). Moller and Sotshongaye (1996) interviewed 50 grandmothers in urban, peri-urban and rural areas of KwaZulu-Natal in late 1995, and found that they regarded their pension as individual, rather family income; however, pension sharing was the norm. Although the amount of the pension was inadequate for family and personal needs, these grandmothers derived pleasure and self-esteem in pension sharing (Moller and Sotshongaye, 1996). The pension grant could, therefore, be considered as a morale booster for the elderly who would have been dependent on others for survival without it.

Pension sharing was also found to be common among elderly Africans in Khayelitsha in Cape Town. According to Sagner and Mtati (1999), even though pension sharing is partly triggered by poverty and unemployment, it is mostly a future-oriented security strategy. Many of the elderly pensioners in the study believe that they will not be helped in times of need if they do not share their pensions with their kin (Sagner and Mtati, 1999). The implication of this belief among pensioners is that elderly people, particular elderly women who are more likely to be vulnerable, will be compelled to share their pensions to their own detriment. There is, therefore, the need for studies to explore how elderly women can share their pensions with their household members without making their lives more difficult financially. However, this is beyond the scope of this present study.

Data from South Africa show that non-contributory pensioner households are more financially stable and also have “a lower probability of experiencing a decline in living standards” over time, than non-pensioner households (HAI, 2003b). In addition, May (2003) found pension payment to be an important safety net for the elderly and their household members in South Africa. In Agincourt, a rural area in South Africa, Schatz and Ogunmefun (2007) found that elderly women view the pension as a grant to the household, not just to themselves as individuals. Most women in their study, when asked “who is the pension for?” answered, “For me and my grandchildren”. Having access to a pension may, therefore, enable the elderly to share their resource(s) with household members, in particular, their grandchildren. It may, however, cause an increase in dependence on the elderly or an increase in household size because of a need to rely on pensions or other government grants, such as the child support grant and the disability grant. These grants are sometimes, the most reliable income a household has.

Elderly women, in particular those that have adult children that are dying or have died of HIV/AIDS, may use their pension in a way that reduces the economic impact of HIV/AIDS. In addition, their pension is used to deal with the economic burden of increased dependency of family members, e.g. orphaned and fostered grandchildren. The pension grant may also help them to recover from this financial strain and the impact of the epidemic. Despite the high prevalence rate of HIV/AIDS in South Africa, not much empirical work has been done to explore how old-age pension reduces the socio-economic impact of HIV/AIDS by helping elderly women to recover after they experience adult mortality in their households. This

study, therefore, examines not only how pensioners use their pensions to cope with the socio-economic impact of adult HIV/AIDS related illness and death in their households, but also how their pensions help them to recover afterward.

One shortcoming of much of the research on HIV/AIDS and the elderly, internationally and in South Africa, is the focus on those aged 60 years and above. This is because most studies focus on the elderly and their pension status and, since people become eligible for pensions as from ages 60/65 or 70 in most countries (HAI, 2004c), there is a tendency for studies to consider only those aged 60 years and above as elderly. In many African societies, however, the title “older person” (or elderly person) is dictated by one’s role in the community or family/household, for example, a person that has a grandchild is usually regarded as elderly regardless of chronological age (WHO, 2002a; Hunter and May, 2004). As women are more likely than men to attain parenthood at an early age, many are already grandmothers by age 50. Thus, women aged 50-59 years, who are also regarded as elderly in some societies, are likely to face the same challenges, such as caregiving to sick adult children and grandchildren, as their older peers, but they may be more vulnerable since they are non-pensioners. As a result of the limited research conducted on near-old women, this study attempts to fill this gap by focusing on elderly women aged 50-59 years and compares their experiences of adult HIV/AIDS related illness and death to those of their older counterparts who are above the age of 60 years.

Sometimes, the extent of the impact of the epidemic on elderly women may be as a result of the responses of people to the disease. The following section focuses on another impact of

HIV/AIDS which is mostly due to the responses of the people in a community towards those who are infected and affected, that is, HIV/AIDS related stigma.

2.4 Socio-cultural Impact of Adult HIV/AIDS Morbidity and Mortality

The HIV/AIDS epidemic not only impacts on people financially but also socially. One major way in which the disease impacts on people socially is through the experience of stigma. As documented in many studies, stigma or discrimination (felt stigma) has been associated with HIV/AIDS since the emergence of the disease (Alonzo and Reynolds, 1995; Green, 1995; Muyinda et al., 1997; UNAIDS, 2000; Parker and Aggleton, 2002; Madru, 2003; Posel, 2004; Patel and Carter, 2004; Duffy, 2005; Ogden and Nyblade, 2005). In most cases, stigma is targeted at the people infected with HIV/AIDS. According to Goffman's (1963) classic work, the term "stigma" denotes an attribute possessed by an individual that not only discredits but also differentiates him/her from others in the society. Thus, an individual with HIV/AIDS can be regarded as someone with "a spoiled identity," differentiating him/her from others in the community (Goffman, 1963).

2.4.1 Primary stigma

Even though there is recently a considerable research attention on HIV/AIDS related (primary) stigma in sub-Saharan Africa, previous studies conducted on the phenomenon were based in the developed countries, especially in the United States of America where gay men, African-Americans and Haitian communities were/are heavily stigmatised as potential carriers of the virus (Uys et al., 2005; Deacon, Stephney and Prosalendis, 2005). In a study of 23 gay and bisexual men conducted in the late 1980s in Arizona (USA), almost every

respondent reported that they experienced stigma from at least one member of their family who ceased contact with him (Weitz, 1990). According to this study, diagnosis with AIDS further reinforced the belief that homosexuality is immoral as some family members interpreted AIDS illness as divine punishment (Weitz, 1990). In addition, they reacted negatively towards those infected by “adopting extreme and medically unwarranted anti-contagion measures” such as bringing their own sheets when visiting, refusing to allow them to touch any food, share their bathrooms and come into close contact (Weitz, 1990). These manifestations of stigma are likely to prevent those who are infected with HIV/AIDS from disclosing their status as they do not want to experience additional social isolation.

Manifestations of stigma towards the HIV-infected were also reported in a study of the pervasiveness of stigma in the United States (US) conducted in the early 1990s. According to Herek and Capitanio (1993), African-American respondents in this survey were more likely to support policies such as quarantine and expressed a desire to avoid close contact with those who are infected with HIV/AIDS, while white respondents were more likely to blame them (HIV infected) for their illness and also expressed negative feelings towards them. Findings from a survey made up of 73% non-Hispanic White conducted in the late 1990s demonstrated that, even though overt expressions of stigma and support for punitive policies such as quarantine had declined throughout the 1990s and were at very low levels by 1999, inaccurate beliefs about transmission through casual contact had increased as well as the belief that people with HIV/AIDS deserve their illness (Herek, Capitanio and Widaman, 2002). Such beliefs do not only fuel stigma towards those who are infected with HIV/AIDS

in different societies in the US but also across the globe, as shown in other studies on HIV/AIDS related stigma.

In sub-Saharan Africa, studies show that negative labelling of HIV-infected people is one of the manifestations of stigma (Muyinda et al., 1997; WHO, 2002a; Uys et al., 2005). Particularly in Uganda, a study found that negative labelling for people living with HIV/AIDS (PLWHA) include *Kakokoolo*—scarecrow, *K'amuyoola*— was caught in a trap and *Yamira akaveera*— one who swallowed a piece of polythene bag (Muyinda et al., 1997). Other studies conducted in Lesotho, Malawi, South Africa, Swaziland and Tanzania, also found that derogatory words and phrases are used to described PLWHA, e.g. “stepped on cables”, “clothes hangers”, “the living dead”, “three letters”, three letters” (HIV), “house in Venda” (HIV), ACE (AIDS), and “joining the www” (Uys et al., 2005). Such negative labels are likely to distinguish those who are infected with HIV/AIDS as “abnormal” thereby contributing to stigma towards those who are infected with the virus in the community.

An investigation of the acceptance of people living with AIDS (PLWA) in communities in Southern Benue State in Nigeria showed that any individual labelled or identified as an “AIDS sufferer” is likely to start experiencing isolation and other indications of separation and rejection from community members as this indicates “a transition from the realm of the living to the dead” (Alubo et al., 2002). The normal practice of caregiving in the community, which involves visiting the sick, providing food, keeping his/her company, and tending the farm plots of the sick, is also only observed until the status of “AIDS sufferer” is revealed.

The study, therefore, concluded that level of stigmatisation is high and acceptance of PLWA is low in these communities.

2.4.2 Secondary stigma

Secondary stigma, also known as courtesy stigma, is another level of HIV/AIDS related stigma that is targeted at those who are in close proximity to people infected with HIV/AIDS, that is, people who are caregivers or family members who reside with those who are infected (Patel and Carter, 2004). According to Patel and Carter (2004), this kind of stigma can be experienced at the family, community and societal levels and it produces an isolating environment for the victim. Although it also creates great emotional pain, feelings of incapacitation and desperation, secondary stigma has not featured much in most studies on HIV/AIDS.

Work from Thailand shows that some older people who are caregivers to those sick with HIV/AIDS experienced secondary stigma or negative reaction from community members. According to these elderly caregivers, some people in the community gossiped about them, while others avoided talking to them and visiting during the period of the illness and (Knodel and Saengtienchai, 2002). In this same study, some caregivers, whose work involved selling food, experienced loss of livelihood as the number of their customers reduced and they eventually had to quit or change their type of work (Saengtienchai and Knodel, 2001).

A study conducted by the World Health Organisation (WHO) in Zimbabwe also reported that some older caregivers experienced stigma and rejection at the hands of members of the

community. Two of these caregivers said some people in their community no longer associate with them, while another caregiver reported that, after she lost several daughters to AIDS, her home earned the unflattering label of “heroes’ acre” because of the number of graves in her compound (WHO, 2002a). These types of incidences, therefore, made caregiving more difficult for these elderly people.

In another research project in the United States of America (USA) which included seventeen African-American, one Mexican and one Filipino caregivers aged 44 to 80, Poindexter and Linsk (1999) found there was lack of overt discrimination or stigma among some of these HIV-affected caregivers. This finding, however, is influenced by the fact that these participants had not disclosed the diagnosis of their patients. Although non-disclosure protected these caregivers from stigma, it was at the cost of being further isolated as the social and emotional support for their HIV caregiving was reduced (Poindexter and Linsk, 1999). This suggests that non-disclosure of the HIV status of patients could further isolate elderly caregivers even though it may also be risky to reveal their status. It is, therefore, necessary to examine whether elderly caregivers in a rural area like Agincourt also face this type of dilemma.

The International Center for Research on Women (ICRW) conducted studies in Ethiopia, Tanzania, Zambia and Vietnam, and found that the consequences of HIV/AIDS related stigma do not begin and end with infected people, but also extend to their kin, friends and caregivers (Ogden and Nyblade, 2005). Findings, from the studies, demonstrated that parents of the sick were held responsible for the “bad” behaviour that made children to be infected.

As a result, most of them experienced the same expressions of stigma as those who live with HIV/AIDS. Such expressions of stigma include loss of income, employment or housing, ostracism and isolation (Ogden and Nyblade, 2005). Although Ogden and Nyblade (2005) highlight different forms of stigma experienced by people infected with HIV/AIDS, for example, physical, social, verbal and institutional stigma, the authors give little attention to the different forms of stigma caregivers experience; these different forms of stigma shall be investigated in this study.

2.4.3 Managing HIV/AIDS related stigma

When stigma is anticipated because of a condition, individuals are likely to find means of dealing with it in order to reduce or manage the impact of negative attitudes on their well-being. With regard to the HIV/AIDS epidemic, some studies have shown how people, infected or affected, try to manage stigma in order to deal with the “abnormality” of the disease (Zhou, 2007; Muyinda et al., 1997; Powell-Cope and Brown, 1992). One of these studies was conducted in China where HIV/AIDS is sometimes regarded as an “indecent” disease because of its association with “promiscuous” or “deviant” sexual behaviours (Zhou, 2007). According to Zhou (2007), respondents were very discreet in their interpersonal and social interactions as protecting their status was regarded as an effective strategy for managing (anticipated) stigma as well as living a “normal” life. Zhou (2007) also found that respondents were reluctant to disclose their status to people outside families, such as friends, co-workers, neighbours, and health workers, but this, however, led to increased sense of isolation and exclusion.

In addition to non-disclosure of a condition, a stigmatized individual may make an attempt to conceal a physical defect in order to be accepted as “normal”, especially in public (Goffman, 1963). Muyinda et al. (1997) reported in their study in rural Uganda that PWAs sometimes conceal AIDS-related symptoms by keeping away from public places such as churches, mosques, and weddings; going out at night; wearing long sleeved shirts, trousers, long dresses, hats and big coats; and developing hostile responses in order to terminate unwanted encounters. Concealment of condition may, therefore, help people infected to deal with the problem of stigmatization outside their home.

The need to conceal the condition of those who are infected with HIV/AIDS is also crucial to close family members, especially caregivers, as they also want to appear “normal” and “untainted”. Muyinda et al.’s (1997) work found that family members of PWAs, in rural Uganda, manage stigma by denying the condition of the patient. In addition to this, family members also ensure that the face or body of the deceased is no longer shown to people before burial in order to avoid embarrassing comments in the community.

In the US, a study found that caregivers of PLWHAs managed HIV/AIDS related stigma by attempting to act as they were not associated with AIDS (Powell-Cope and Brown, 1992). In addition to using strategies such as making excuses, lying, withholding information, changing jobs or places of residence, caregivers also started avoiding certain social situations and family gatherings, in order to protect themselves and the PWAs from negative consequences (Powell-Cope and Brown, 1992). This study also demonstrated that acting “normal” often led to “a web of selective disclosure filled with lies, partial truths and

excuses” which eventually resulted in great emotional turmoil (Powell-Cope and Brown, 1992). This implies that managing stigma through these strategies may make caregivers’ experience of the epidemic more traumatic.

Caregivers’ obligation to protect themselves as well as PLWHA from stigma may sometimes be due to the beliefs surrounding HIV/AIDS and its causes in their community. According to Parker and Aggleton (2002), local cultural beliefs and explanations about a disease and its causes are likely to contribute to its stigmatization. There is, therefore, the need to understand the root causes of HIV/AIDS and its stigmatization, which sometimes are not well understood within the context of the traditions of a community.

2.4.4 Causes and beliefs surrounding HIV/AIDS and its stigma

African cultures usually attribute the causes of illnesses or diseases to two sources, that is, proximate cause, which provides biomedical explanation of disease causation and, ultimate cause, which provides spiritual or traditional explanation for why a person contracted a disease (Liddell, Barrett and Bydowell, 2005). Since the characteristics of HIV/AIDS include an epidemic, a sexually transmitted infection (STI) and a cause of premature death, which could be construed as mystical, biomedical views and traditional beliefs about the disease, are likely to co-exist in African communities (Liddell, Barrett and Bydowell, 2005). The implication of this is that traditional beliefs about disease causation may either promote or inhibit stigma in a community, hence, the need to understand the beliefs surrounding HIV/AIDS.

Some studies conducted in sub-Saharan Africa have shown that the signs and symptoms of HIV/AIDS disease are attributed to witchcraft and sorcery in some African communities (Yamba, 1997; Bond, Chase and Aggleton, 2002 and Kalichman and Simbayi, 2004; Lesko, 2005; Thomas, 2006). In rural Zambia, people believed that witches were responsible for the increase in the number of local deaths and disasters; as a result, there was a resurgence of witch-finders and witchcraft accusations (Yamba, 1997). This type of belief is likely to shift the “blame” of “improper behaviour” from PLWHA to the person accused of bewitchment, thereby reducing stigma towards them; however, it enables people not to accept responsibility for risky behaviours (Bond, Chase and Aggleton, 2002).

A study conducted in South Africa also suggests that the belief of witchcraft as a cause of the disease, may either reinforce stigmatizing attitudes and behaviour as people do not want to associate with the “cursed” person or make people to regard the infected person as an “innocent victim” thereby shifting the responsibility for his condition elsewhere (Lesko, 2005). Kalichman and Simbayi (2004), however, found that the belief of witchcraft may lead to HIV/AIDS related stigmatization in their work. In a survey of 487 men and women conducted in a black township in Cape Town, South Africa, they found that 11% of the respondents believed AIDS is caused by spirits and supernatural causes. Those with such beliefs were more likely to approve social sanction against PLWHA (Kalichman and Simbayi, 2004).

In addition to a belief in witchcraft, other cultural beliefs may also serve as an explanation of the cause of HIV/AIDS in a community. For instance, in Agincourt (rural South Africa),

Posel, Kahn and Walker (2007) found, through focus-group discussions (FGDs), that witchcraft was reported as one of the causes of HIV/AIDS in the community. However, the erosion of norms and traditions due to promiscuity, cited as the reason for the increase of prime-aged adult deaths, was more prominent in the discussions. Initial findings of this study demonstrated that HIV/AIDS related stigma is common among members of this rural community because of the belief that HIV/AIDS is transmitted by those who engage in “bad sex” (promiscuity) in the community (Posel, 2004). People in the community believe that those who engage in “bad sex” deserve to die from the disease (Posel, 2004). This is, therefore, a tendency for this type of belief to encourage stigma towards both infected and affected people, in particular, elderly women who are caregivers, as they may be held responsible for the “improper behaviour” of their sick children.

The study conducted by Posel and her colleagues included several key informants in the Agincourt community such as healers, prophets, village headmen, church ministers and home-based caregivers, however, the focus of the research was more on primary stigma, that is, the type of stigma experienced by PLWHA. Thus, there is still a need to understand the root causes and implications secondary stigma of HIV/AIDS, from the point of view of elderly women who are more likely to be closely involved in caregiving for adult children living with HIV/AIDS in Agincourt. Moreover, there is a need for a more nuanced understanding of the nature of HIV-related stigma and its practical manifestations as well as its impact on those concerned. Thus, this research is able to build on the work of Posel and her colleagues, by focusing on the experiences of elderly women who have lost adult children with regard to their experiences of secondary stigma.

Chapter Three

CONCEPTUAL FRAMEWORK

This research is informed by two models, the psycho-socio-environmental (PSE) model and the ABC-X model of the family stress model. The PSE model provides an overall explanation for the multiple impacts of HIV/AIDS on elderly women while the ABC-X model shows the connection between adult HIV/AIDS related illness/death, pension-receipt, perception of caregiving role and their impact on elderly women's well-being.

3.1 Psycho-socio-environmental Model

This research is informed by the psycho-socio-environmental (PSE) model which focuses on how health is promoted and maintained through socio-environmental and behavioural factors (Gilbert, Selikow and Walker, 2002). The PSE model puts health maintenance and disease causation in a broader context by focusing on other factors such as social and environmental factors, rather than biological (or medical) factor only, as their determinants. It is complementary to the bio-medical model which considers health and disease only within the biological (medical) context (Gilbert, Selikow and Walker, 2002; Taylor and Field, 2003). The PSE model provides an explanation for people's behaviour, the work they do, and the place they live as important determinants of their health status (Gilbert, Selikow and Walker, 2002; Gabe, Bury and Elston, 2004). In other words, other factors such as social and environmental factors and not only biological factors influence how healthy people are. The model, therefore, puts health and disease "in a social context which takes a macroscopic view and offers a broader perspective" (Gilbert and Walker, 2002a: 652).

The PSE model can also be used to explain the spread of a disease like HIV/AIDS. The HIV/AIDS epidemic shows that the biological (medical) factor is not the only factor that determines the spread of the disease (Gilbert and Walker, 2002a). Other factors such as social, economic and environmental factors are also important determinants of the HIV/AIDS epidemic, especially in developing countries. According to Gilbert and Walker (2002a: 652), HIV/AIDS is not only a medical problem but also a social one and this can be observed in “the inability and inadequacy of the medical establishment to control and curtail its expansion”. Therefore, the PSE model offers a useful framework for analysis of the spread of the HIV/AIDS epidemic and its consequences on social structures.

The HIV/AIDS epidemic has direct impacts on people infected and indirect impacts on people close or related to them, as noted in the literature review. As the PSE model provides an explanation of the way an infected person contracts the disease, it can also be used to analyse how an affected person (who is associated with someone infected) feels the impact of the disease. In other words, medical factor or impact is not the only consequence of being affected by the diseases but there are other factors or impacts such as economic and demographic impacts.

Applying the broad approach of the PSE model to the HIV/AIDS epidemic, this study utilizes the model to analyse the impacts of the epidemic on elderly women who are affected by it. Instead of focusing on only the health impact of the disease on elderly women, other impacts such as demographic and economic impacts are taken into consideration. Figure 3.1

explicates how the PSE model is applied to this study of HIV/AIDS impacts on elderly women who lost an adult in their household to the epidemic.

The diagram (figure 3.1) shows the connection between adult HIV/AIDS morbidity and mortality and five main impacts experienced by elderly women and their households. Emotional and physical impacts are both regarded as the health impact of HIV/AIDS. This research, however, focuses mainly on the demographic, socio-economic, and socio-cultural impacts of HIV/AIDS on elderly women and their households⁴.

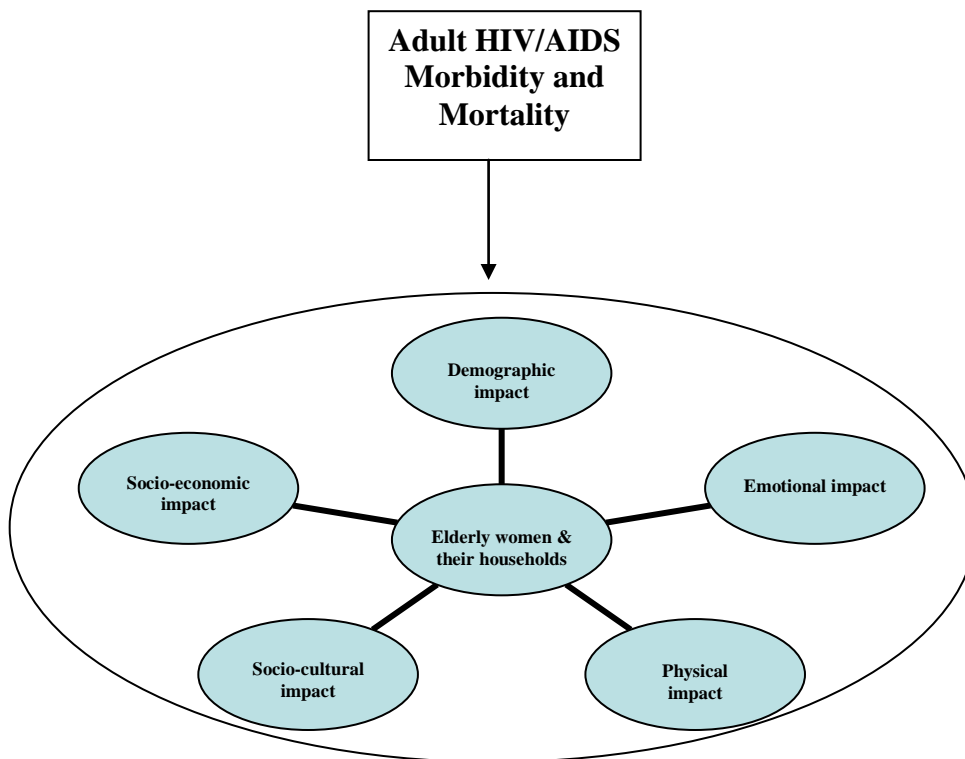


Figure 3.1: The application of the psycho-socio-environmental model to the HIV/AIDS impacts study

⁴ Due to time and resource constraints, this research focuses mainly on the demographic, economic and socio-cultural impacts of adult HIV/AIDS of older women. The author, however, acknowledges the fact that health impact is also as important as the other impacts, therefore this could be investigated in further research.

Using this adapted PSE model, the framework (figure 3.1) serves as the conceptual framework for this study. The link between adult HIV/AIDS related morbidity and mortality and the concepts of demographic, socio-economic and socio-cultural impacts experienced by elderly women and their households is explored in this thesis. As a result of the need to have a better understanding of these concepts, each concept and its link with adult HIV/AIDS related death is examined individually. For the purpose of this thesis, the concepts are defined as follows:

Demographic impact— is the occurrence of elderly female headship caused by the absence or death of an adult in elderly women’s households.

Socio-economic impact— refers to the financial crises experienced by elderly women who had an adult illness/death in their household as well as the effect of the incident on their socio-economic status.

Socio-cultural impact— refers to elderly women’s experience of secondary stigma, which may be rooted in some cultural beliefs in their community.

3.2 Family Stress Theory

In order to further explain the connection between adult HIV/AIDS morbidity and mortality and their impacts on elderly women and their households, with a particular focus on families adaptation to change, this research is also informed by the family stress theory. The theory was first developed by Reuben Hill to explain the response of families to stress and their adjustment to the crises of war separation and re-union (Hill, 1949; Waller, 1956). This theory also serves as an explanation for the changes that occur in

families/households because of life transitions and events such as migration, divorce, illness and death (Olson et al., 1983; Boss, 1988; Mckenry and Price, 1994).

The family stress theory has been used by authors in different fields, such as Sociology and Medicine, to explain how members of a family are affected when an event such as a chronic illness, disability or death befalls someone (Cox, 2002; Perry, 2004; Lim and Zebrack, 2004). The theory was also used by these authors to explain how family members, who are caregivers to the sick, experience difficulties or stressors which have impacts on their lives. This study, therefore, utilizes the family stress theory as one of the potential explanations for the crises that occur in an elderly woman's household when an adult (child) becomes ill or dies of HIV/AIDS.

As aforementioned, the family stress theory was first proposed by Reuben Hill in his research on families and stressors of war separation and reunion (Hill, 1949; Waller, 1956; Olson et al., 1983; Boss, 1987; Boss, 1988; Mckenry and Price, 1994). Using this theory, he formulated the ABC-X model, where:

A – The provoking event or stressor

B – The family's resources or strengths at the time of the event

C – The perception or the meaning attached to the event by the family

X – The outcome: the resulting degree of stress or crisis (Boss, 1988).

The A factor, or a stressor, is an occurrence that provokes a change in the family system as it affects the *status quo* (Boss, 1988; Mckenry and Price, 1994). Some examples of a stressor that could change a family system include divorce, loss of child, widowhood, unwanted

pregnancy, war separation, etc (Hill, 1949). The B factor is the family resources such as physical, psychological, economic and physical assets which members of the family can use to deal with the stressor event (Boss, 1987). The C factor is the family's perception of the situation which is critical as it will determine how they react to and cope with the event, while the X factor is the resulting degree of stress or crisis (Boss, 1988). The degree of stress is dependent on the family's definition of the stressor event as well as the adequacy of the family's resources to meet the demands of the changes caused by the stressor event (Mckenry and Price, 1994). This means that the degree of stress experienced may be less for those who have adequate resources to cope with the stressor event. The ABC-X model of family stress model states that, A (the event) interacting with B (the family's resources) interacting with C (the definition of the event by the family) produces X (the degree of stress or the crisis (Olson et al., 1983; Mckenry and Price, 1994).

3.2.1 Applying family stress theory to HIV/AIDS impacts study

The family stress theory, although developed in the late 1940s as part of the attempts to understand the psycho-biological paths related to stress as well as the adjustment to the crises of war separation and reunion by families (Hill 1949; Olson et al. 1983), offers an opportunity to focus on the particular impact of an event such as an adult death on a family/household. In this study, family stress theory, as a framework, offers the opportunity to examine the impact of adult HIV/AIDS related mortality on elderly women. The application of the ABC-X model of the family stress theory to this study is shown in the diagram below. A, B, and C factors are inter-connected and they are linked to the X factor. The A factor is an adult HIV/AIDS morbidity and mortality that occurred in an elderly

woman's household; the B factor is pension-receipt; the C factor is perception of caregiving role; the X factor is the degree of stress or crisis, i.e., HIV/AIDS impact. The A, B and C are factors that work together to produce X. This study examines how these factors interact and cause the impacts of HIV/AIDS on elderly women in their households. Figure 3.2 shows the inter-relation between the A, B, C, and X factors in this study of HIV/AIDS impacts.

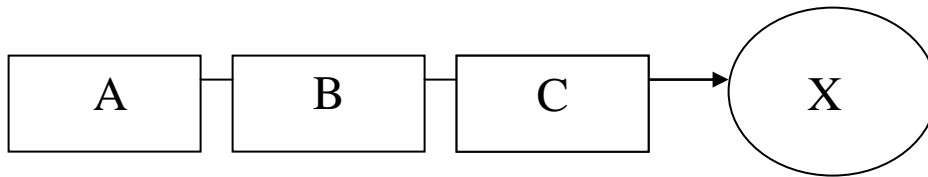


Figure 3.2: The application of the ABC-X model to the HIV/AIDS impacts study

Note: A= Adult HIV/AIDS morbidity and mortality; B= Pension-receipt; C=perception of caregiving role; X= HIV/AIDS impact

This adapted ABC-X model serves as the conceptual framework that further explains the connection between concepts such as adult HIV/AIDS related mortality, pension-receipt (or pension status), perception of caregiving role and the impact of HIV/AIDS on elderly women.

3.3 Outline of the application of the PSE and ABC-X models in this study

The psycho-socio-environmental (PSE) model provides an overall conceptual framework for this study as it provides an analysis and explanation for the multiple impacts of adult HIV/AIDS related illness/death on elderly women and their households, as shown in figure 3.1. It is used to explain the fact that when an adult HIV/AIDS related death occurs in an elderly woman's household, she is likely to experience multiple impacts. This conceptual framework does not only provide an explanation for the multiplicity of the impacts of

HIV/AIDS on elderly women, but also allows the use of both quantitative and qualitative methodologies, as shown in the following chapter. The concepts of demographic, socio-economic and socio-cultural impacts are examined with regard to their link with adult HIV/AIDS related morbidity and mortality through quantitative and qualitative analyses. The link between demographic impact of adult HIV/AIDS related death and elderly female household headship (demographic impact of HIV/AIDS) is first examined through quantitative analyses (chapter seven). Then, the connection between adult HIV/AIDS related illness/death and socio-economic and socio-cultural impacts of HIV/AIDS in elderly women's households is explored through qualitative analyses (chapters eight and nine).

In order to understand the socio-economic impact of HIV/AIDS, the conceptual framework of the ABC-X model is used to explain how the degree of the socio-economic impact (X factor), experienced by an elderly woman, is dependent on her perception of caregiving role (C factor), as well as the adequacy of the pension grant (B factor) to meet the demands of the crises caused by adult HIV/AIDS related morbidity and mortality (A factor) (chapter eight).

The ABC-X model is further adapted in this thesis to explicate the demographic impact of adult HIV/AIDS related mortality on elderly women by showing the connection between adult AIDS death, the A factor, and elderly female household headship, the X factor, as shown in figure 3.3 (see chapter seven).

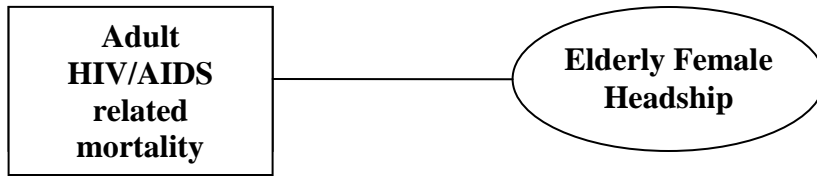


Figure 3.3: The relationship between adult HIV/AIDS related mortality and elderly female headship

This adapted model is used to explain the relationship between adult HIV/AIDS related mortality and elderly female headship (demographic impact). In addition, it is used to test whether the occurrence of elderly female headship is because of the experience of an adult HIV/AIDS in a household, through quantitative analyses. The following chapter presents the quantitative (and qualitative) data and methods used in analysing the concepts posited in the PSE and ABC-X frameworks.

Chapter Four

METHODOLOGY

4.1 Research Design

This thesis focuses on the impacts of adult morbidity and mortality on elderly women in the MRC/Wits Unit study site in rural Mpumalanga Province, South Africa. In order to have a comprehensive understanding of how the HIV/AIDS epidemic impacts on elderly women in a rural area, a triangulation of methods is used. A triangulation of methods, also known as mixed methods research, involves the mixing of quantitative and qualitative styles of research and data in the examination of a social phenomenon (Mathison, 1988; Neuman, 2003; Johnson and Onwuegbuzie, 2004). This approach is regarded as an effective research method as the weaknesses (or limitations) of using either method alone are compensated for by the counter-balancing strengths of both methods (Jick, 1979; Johnson and Onwuegbuzie, 2004). Triangulation not only provides an explanation for the same phenomenon from multiple perspectives, but also enriches one's understanding as it permits the emergence of new or deeper dimensions (Jick, 1979).

Although quantitative research has always been the domain of Demography, there is now a tendency towards mixed methods because of the fact that the use of survey measures to assess a social phenomenon is often not grounded in an understanding of social, cultural, and historical contexts (Schatz, 2002). The Measure Demographic and Health Surveys (DHS) project, one of the leading initiatives that provides data and analysis on the

population, health, nutrition of women and children in developing countries, now supports qualitative research because of the need “to produce informed answers that lie outside the purview of a standard survey approach”, as well as “to examine the social and cultural contexts of daily life” (Measure DHS, 2007).

As a result of the need to both measure and contextualize the impacts of adult HIV/AIDS morbidity and mortality on elderly women, in this thesis, the AHDSS (secondary) data is first used to give a background of the Agincourt population and also to examine the relationship between adult HIV/AIDS mortality and the demographic impact of HIV/AIDS. Then, the qualitative (primary) data, collected by the author, is used to contextualize the HIV/AIDS impact by exploring the socio-economic and socio-cultural impacts of the epidemic on elderly women.

The combination of quantitative and qualitative data and methods in this study compensates for the limitations of using either method. For instance, sole reliance on the AHDSS data would not have yielded enough information on elderly women at Agincourt as the yearly census conducted by the MRC/Wits Unit is targeted at households and focused information on older people is not necessarily collected. Likewise, the sole reliance on the qualitative data would have given information about the elderly women (and their households) in the study area without the benefit of background information at the aggregate level about the community.

As noted in the previous chapter, the conceptual framework (PSE and ABC-X models), employed in this study, allows the utilization of both quantitative and qualitative approaches. This integrated conceptual framework provides an explanation for the multiplicity of the impacts of HIV/AIDS on elderly women, hence the need for detailed investigation through triangulation of methods. Moreover, triangulating methods provide a more complete and holistic representation of the participants as well as their views of the social phenomenon under study (Jick, 1979; Johnson and Onwuegbuzie, 2004). The following sections first give descriptions of the study site, and then the quantitative and qualitative data and methods used in this thesis.

4.2 The Study Site

The quantitative section of this thesis analyses a dataset that comes from the Agincourt Health and Demographic Surveillance System (AHDSS), longitudinal data collected by the Medical Research Council/Wits Rural Public Health and Health Transitions Research Unit (MRC/Wits Unit)⁵. The MRC/Wits Unit study site is one of the sites for the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH). The vision of the INDEPTH Network is to “be an international platform of sentinel demographic sites that provides health and demographic data and research to enable developing countries to set health priorities and policies based on longitudinal evidence” (INDEPTH Network, 2007). With this vision and the mandate “to better understand the dynamics of health transition in rural South Africa in order to mount a more effective public health response” (Tollman, 2006), the MRC/Wits Unit set up a

⁵ The unit was formally known as the Agincourt Health and Population Unit (AHPU) but in 2003, it was awarded the MRC/Wits Unit status in recognition of the unit’s research endeavours (Tollman, 2006).

demographic and health surveillance system in the 21 villages of the Agincourt sub-district in the Mpumalanga Province⁶ of South Africa.

The Agincourt sub-district is situated in what was the Mhala District of Gazankulu, a former “homeland” which belonged to the Shangaan-speaking Tsonga ethnic group (Kahn, 2006). This sub-district, like other areas in former “homelands” in South Africa under apartheid, had no reliable source of vital statistics and continues to be characterized by social and health inequalities entrenched during the apartheid era. As a result of the need to redress the inequalities and lack of vital statistics, the MRC/Wits-Agincourt Unit has been collecting the AHDSS data through an annual census at the study site since 1992. The unit also collects the verbal autopsy data which yield information on the cause of each death at the site.

The study site, with a population that grew from 58,000 in 1992 to about 70,000 in 2006, is now situated in the Bushbuckridge district in South Africa’s rural north-east, which is adjacent to the country’s border with Mozambique (see maps in appendix A) (Collinson et al., 2003; Tollman, 2006). As a result, the study population is made up of about one-third Mozambican former refugees, many of whom fled their country during the mid- and late 19th century from war in the Gaza province and later, in the mid-1980s from the RENAMO-FRELIMO conflict (Kahn, 2006). These Mozambicans have now settled in the study area as immigrants. Even though the Mozambicans have strong language, cultural and kinship ties with the South African residents of Gazankulu and are now

⁶ The area was formerly in Limpopo Province.

legally eligible to have a South African ID and receive social pensions, they still remain a vulnerable group (Schatz and Ogunmefun, 2005; Kahn, 2006)

The geo-ecological zone of the study area is semi-arid with a population density of 148 persons per square kilometre (Collinson et al., 2002; Collinson et al., 2003). Although there have been substantial development initiatives recently, such as electrification and completion of the Inyaka dam, infrastructure is still limited (Kahn, 2006). There is water shortage in most villages as piped water flows erratically and mainly from communal standpipes, where it is collected manually by women or children, usually in 25-litre plastic drums and transported either by wheelbarrow or carried on the head (Collinson et al., 2002). Electricity is also a challenge for most villagers as it is too expensive for all but a minority of inhabitants (Kahn, 2006). Instead, most residents collect and use firewood as their primary fuel source. Most of the roads are not tarred, therefore, they are susceptible to floods and pot holes during rainy season in summer. These floods and pot holes make transportation more difficult between villages, especially since transport is mostly “public”, provided by privately owned *combis* or mini-bus taxis. Housing types range from traditional mud huts with thatched roofs to brick dwellings with tiled or tin roofs; levels of household sanitation are generally poor as pit toilets of varying effectiveness are the norm (Collinson et al., 2002; Kahn, 2006).

The Agincourt sub-district has an extremely modest economy (Kahn, 2006). Since the area is semi-arid, it is more suitable for game farming and low-density cattle farming than crop cultivation (Collinson et al., 2002). However, many villagers grow crops on small

household plots to supplement food bought from local shops and malls in nearby towns (Kahn, 2006). Unemployment is estimated at 40-50%, while many men and women migrate temporarily to work on nearby farms and timber plantations, game reserves and mines, and manufacturing and service industries in urban areas (Kahn, 2006). Most villagers usually engage in food and fruit vending (Collinson et al., 2002).

School enrolment occurs late in the Agincourt sub-district. Although 85% of children between 10 and 14 years enrol at primary school, less than 50% proceed to secondary school and only 3% continue studying after their secondary education (Collinson et al., 2003). Each village has at least one primary school only fourteen of the twenty-one villages have a secondary school (Collinson et al., 2002).

The study site has a health centre and five satellite clinics, all staffed by nurses; three district hospitals are situated 25-60 km from the site (Kahn, 2006). The health care has an ambulance and a small laboratory that performs a limited number of diagnostic tests, while a restricted number of drugs are dispensed from the primary health facilities in the clinics (Collinson et al., 2002). All services are free and these include family planning, ante-natal care, child health, delivery and postpartum care (Collinson et al., 2002). These services, however, are under-utilised due to poor drug supply; villagers also access traditional and faith healers to supplement or replace the care of allopathic practitioners (Collinson et al., 2002; The SASPI Team, 2004b; Kahn, 2006). The under-utilisation of public health facilities may contribute to the prevalent health problems revealed by the AHDSS verbal autopsy analysis such as diarrhoea, kwashiorkor, AIDS, tuberculosis,

cardiac, cerebrovascular, liver and malignant diseases (Kahn et al., 1999; Kahn, 2000; Collinson et al., 2002). In order to understand how this and how other information are collected, the following section focuses on the AHDSS.

4.3 Agincourt Health and Demographic Surveillance System (AHDSS)

The AHDSS is a multi-round, prospective community study that involves continuous demographic monitoring of the entire geographically defined Agincourt sub-district (Kahn, 2006). The baseline household census was first conducted in 1992 and since then, there has been a systematic recording of all birth, death and migration events in the populations, as well as recording and updating on household creation and dissolution (Kahn et al., 1999; Collinson et al., 2002). Between 1993 and 1999, the census was first updated at approximately 15-18 month intervals, since 1999, it has been conducted annually (Collinson et al., 2002; Kahn, 2006).

Hand-drawn maps were initially used during the census by fieldworkers. These maps included roads, dwellings other reference landmarks such as schools, churches, rivers, water reservoirs, soccer fields (Collinson et al., 2002). In order to link individual and household data to a village structure, each dwelling was allocated a unique identifying number (Kahn, 2006). Since 2004, a full geographic information system with geo-referencing of households has been introduced and fieldworkers now rely on digital maps (Kahn, 2006). These maps are updated annually as some new households are formed and some old ones are dissolved.

During the annual census, a fieldworker interviews the most competent respondent available and individual information is checked for every household member. Also, all events that occurred since the previous census are recorded and updated (Wittenberg and Collinson, 2006). Where possible, questions are directed to particular household members, for instance, a woman is directly asked about her maternity history and pregnancy outcomes (Collinson, 2002). Key variables related to an event are recorded, for example, in the case of a death, these would include place of death, name of hospitable, if applicable, and whether or not the death was registered (Kahn, 2006). In order to obtain information on education, labour force participation, socio-economic status and migration, occasional “modules” are also added to the annual census and repeated at intervals. In the initial phase of the AHDSS, there was a single data-collection team of ten field workers and a field supervisor; some these fieldworkers were trained to conduct verbal autopsies (VA) (Kahn, 2006). With the aim of increasing the speed of data collection, the field team was expanded to twenty fieldworkers, four supervisors, one VA supervisor and four VA fieldworkers (Collinson et al., 2002).

4.3.1 Verbal autopsy data

The AHDSS also includes the verbal autopsy data, which aims to identify the cause of death for each death in the study site. The verbal autopsy was introduced in 1993 (Collinson et al., 2002). The verbal autopsy (VA) is usually conducted by specially trained fieldworkers in a household where a death had been recorded. The caregiver or the person most closely associated with the deceased is usually selected as the respondent (Tollman et al., 1999; Kahn, 2000). Verbal autopsies are usually completed between one

month and one year of the deaths; in keeping with traditional mourning practices, no VA is conducted prior to at least a month after bereavement (Kahn, 2006). The VA interview schedule is an adaptation of the one previously used in Niakhar, Senegal (another INDEPTH site). The interview guide from Niakhar was translated into Shangaan and modified to include culturally appropriate terminology (Kahn et al., 1999). In the interview schedule, there is an open section or narrative which elicits the symptoms and signs preceding death in the respondent's own words. Also, fieldworkers probe for completeness of information, the sequence of signs and symptoms, and response to treatment (Kahn, 2006). Several filtering questions follow, such as; "Did the deceased cough?" and, the answer either leads to a detailed module on that symptom or the interview proceeds to the next filtering question (Kahn, 1999).

The verbal autopsies collected from respondents are later assessed by three medical officers to determine the cause of death (Kahn et al., 2000; Tollman et al., 1999). A probable cause of death is assigned by two doctors independently and the diagnosis is accepted when their reviews correspond. However, when they differ, the doctors discuss the case in an effort to reach consensus (Kahn, 2006). If no consensus is reached, a third practitioner is called in to make an independent and blind assessment. The case is reviewed if two out of three diagnoses correspond. The diagnosis is accepted as the "probable cause of death" when consensus is achieved, if not, the cause of death is described as "undetermined" (Kahn, 2000).

The Agincourt VA tool and assessment process was validated in the mid-1990s when final diagnoses were compared with the corresponding hospital diagnoses. The diagnoses were categorised as the same where the VA diagnosis and hospital record were in agreement, while diagnoses that were not the same were categorised as either “different” or “undetermined” (Kahn, 2000; Kahn, 2006). A validation of diagnoses between 2001 and 2005 against hospital records has also shown that HIV/AIDS diagnoses are reliable (Khan, 2006).

4.3.2 Quality control and data entry

In order to ensure data quality, quality control of the AHDSS data exists at five levels from field to data room. At the field level, data collection forms, including the VA questionnaires, are firstly checked by the fieldworkers themselves on a daily basis, secondly by fellow team members’ cross-checking on a weekly basis, and thirdly by supervisors making random checks (Kahn, 2006). Errors are either corrected in the field office or done after a household was revisited; random duplicate visits are also conducted by the supervisor on 2% of the population (Collinson et al., 2006). Fourthly, at the main Agincourt field office, a specialized “quality checker” carries out a final review of the interviews after which detected errors are recorded and forms returned back to the field for the fieldworkers to correct (Collinson et al., 2006). Lastly, at the data entry level, there are programmed computer checks for invalid codes, missing values, inconsistency of records and duplicated entries (Kahn, 2006). An error message is produced by the computer if there are any data items that do not pass the pre-determined validation rules;

the form is then re-checked manually and then sent back to the field, if necessary (Kahn, 2006). All these steps ensure the quality of the AHDSS census and verbal autopsy data.

After a data collection form has left the field and passed all quality checks, it proceeds to the level of data capturing (Collinson et al., 2002). In order to enhance data quality as well as facilitate working relationships between data and field teams, data is entered within the field site, in spite of infrastructural limitations (Collinson et al., 2002). The Agincourt database management system was first held in FoxPro, later re-written into Microsoft Access, but in 2001, it was converted into SQL Server which ensures a higher standard of data technology, data protection as well as improved means of querying the database (Kahn, 2006). The database is made up of related tables that store different aspects of the data, for instance, the “Individual” table stores key information on all individuals; the “Residence” table provides information on individual residence episodes, that is, the entry and exit of a person at a particular location at the field site; the “Memberships” table records information on how and when an individual entered and exited a particular household (Collinson et al., 2002). There is also a separate table for each vital event as well as special module tables, such as the asset survey, which are updated with varying frequency (Kahn, 2006).

4.4 Quantitative Research: Data and Methods

The quantitative data used in this thesis are a cross-section of the AHDSS census data collected in 2004, representing the individuals who were living in all current households in Agincourt in 2004. In order to obtain more information for the quantitative analyses,

some history about those individuals and households (e.g. mortality experience between 1992 and 2004) are also included in the dataset, using the verbal autopsy and longitudinal data on the households (see chapter six)⁷.

The Agincourt population is examined through univariate and bivariate analyses⁸ of the quantitative data, using STATA, a statistical package. From these analyses, detailed descriptions of the Agincourt population and elderly people, particularly elderly women, in the population are provided in chapter six. Variables in these analyses include socio-demographic variables such as age, gender, education, employment status, marital status and pension status. In chapter six, information on the occurrence of adult mortality in households is also provided through cross-tabulations of variables such as household, adult AIDS death and adult non-AIDS death (i.e. death from other causes).

The literature suggests that as males and females in the productive and reproductive age groups succumb to the HIV/AIDS epidemic, there is likely to be a change in household structure in many African communities, especially with regard to household headship (Ferreira, 2004b; Monasch and Boerma, 2004; HAI, 2004a). Studies have shown that elderly women are more likely live in households headed by either their spouses or children (Noumbissi and Zuberi, 2001; Dayton and Zimmer, 2003), therefore, when they become widows and their children die of HIV/AIDS, they may become household heads. This may lead to an increase in elderly female-headed households, a phenomenon that could be regarded as a demographic impact of adult HIV/AIDS on elderly women and

⁷ This data set was created with the assistance of Benjamin Clark, the database manager at the AHDSS.

⁸ Frequencies and cross-tabulations are employed in the univariate, and bivariate analyses.

their households. The PSE framework, employed in this study, also posits that there is a connection between adult HIV/AIDS related mortality and demographic impact, one of the impacts of adult HIV/AIDS on elderly women's households (see figure 3.1). As a result of the need for more empirical evidence of this phenomenon, bivariate analyses are used to examine household headship⁹ in Agincourt, in particular elderly female household heads, using variables such as "relationship to household head", "mother's residence status", "household headship" and "elderly female household headship" (chapter seven). In this thesis, household headship refers to the status of heading a household by an adult aged 15-49, while an elderly female household headship refers to the status of heading a household by a woman above age 50¹⁰.

In chapter seven, multivariate analyses (i.e. cross-tabulation of more than two variables) are used to provide a detailed description of elderly female household headship using socio-demographic, living arrangement, and household mortality experience variables. The variables utilized in the analyses include socio-demographic variables (e.g. age, marital status, pension status, etc), "relationship to household head", "mother's residence status", "adult AIDS death" and "adult non-AIDS death". There is, however, the need to further test, through statistical analyses, the relationship between elderly female household headship and socio-demographic variables (e.g. pension status) as well as between elderly female household headship and household mortality experience. The

⁹ Household headship, in this thesis, refers to all household heads in Agincourt including elderly household heads.

¹⁰ As mentioned in earlier chapters of this thesis, women as from age 50 are regarded as elderly in African communities.

following sub-section gives a description of the statistical method used in these statistical analyses.

4.4.1 Logistic regression analysis model (statistical analyses)

The logistic regression analysis model is used, in statistical analyses, to decide which characteristics (independent variables) are predictive or associated with an outcome (dependent) variable for instance, elderly female household headship (Afifi, Clark and May, 2004). The outcome variable is usually restricted to two values which represent the occurrence or non-occurrence of the outcome event (usually coded as 1 or 0, respectively) (Pezullo, 2006). The relationship of the outcome variable with the independent variables is determined by a variate¹¹ composed of the logistic coefficient(s) and the corresponding independent variable(s). The coefficients for the independent variables are estimated with the logit values or the odds value as the dependent measure (Hair et al. 2006). The model formulations are as follows:

$$\text{Logit}_i = \ln \left(\frac{\text{prob}_{\text{event}}}{1 - \text{prob}_{\text{event}}} \right) = b_0 + b_1X_1 + b_2X_2 + \dots + b_nX_n$$

Or

$$\text{Odds} = \left(\frac{\text{prob}_{\text{event}}}{1 - \text{prob}_{\text{event}}} \right) = e^{b_0 + b_1X_1 + b_2X_2 + \dots + b_nX_n}$$

¹¹ A variate is a linear combination that represents the weighted sum of two or more independent variables (Hair et al. 2006)

Where

X_1, X_2, \dots, X_n , are the independent variables

$b_0, b_1, b_2, \dots, b_n$ are the coefficients

e is the error term

\ln is logarithm

Both forms of the coefficients reflect direction and magnitude of the relationship between the dependent and independent variables (Hair et al., 2006). The interpretation of the coefficients for direction and magnitude can either be directly assessed in the original coefficients— positive or negative sign or indirectly in the exponentiated coefficients— less than 1 are negative, and greater than 1 are positive (Hair et al., 2006). When the coefficients are interpreted for direction, the direction of the relationship reflects the changes in the dependent variable associated with changes in the independent variable¹².

On the other hand, the exponentiated coefficients directly reflect the magnitude of the change in the odds value. The effect of the coefficient is not added to the dependent variable (the odds) but multiplied for each unit change in the independent variable. In order to determine the amount of change in probability, the following approach is used (Hair et al., 2006):

$$\text{Percentage change in odds} = (\text{Exponentiated coefficient} - 1.0) \times 100$$

When the odds ratio is greater than 1, this means the an independent variable has a positive effect on the dependent variable, while an odds ratio of less than 1 means an

¹² The relationship is positive when an increase in the independent variable is associated with an increase in the predicted probability, and vice versa for a negative relationship (Hair et al. 2006)

explanatory variable reduces the likelihood of the outcome under consideration (Kimuna, 2004). The Wald or Z statistic is used to assess the statistical significance of each coefficient by testing the null hypothesis that the coefficient is 0; coefficients with values less than alpha are statistically significant. If the coefficient is statistically significant, it is interpreted in terms of how it impacts the estimated probability (Hair et al., 2006; University of California [UCLA] Academic Technology Services [ATS] 2007).

The logistic regression analyses also involve the use of bivariate and multivariate models to test the relationship between the outcome and independent variables. Bivariate and multivariate logistic regression models are used, firstly, to examine the association between household headship¹³ (outcome variable) and socio-demographic characteristics (independent variables); secondly, to examine the relationship between elderly female headship (outcome variable) and socio-demographic variables (independent variables) (chapter seven). In order to address the issue of the relationship between adult HIV/AIDS related mortality and demographic impact, as provided in the conceptual framework (adapted ABC-X model), a bivariate logistic regression model is used to explore the association between elderly female headship (outcome variable) and household mortality experience variable (independent variable), controlling for socio-demographic variables (chapter seven).

¹³ In the statistical analyses, household headship is differentiated from elderly female headship as the headship status of the Agincourt population while the latter is the headship status of the elderly female population (in Agincourt).

4.4.2 Limitations of the quantitative data

One limitation of the quantitative (AHDSS) data used in this study is that it is not a representative sample of the South African population. Therefore, generalizations about the demographic impact of adult HIV/AIDS related death on elderly women cannot be made for the entire population of women above 50 in South Africa. However, since the study site is based in a rural area, findings could be used to make inferences about elderly female headship in rural areas especially since limited study has been done on its relationship with adult HIV/AIDS related death.

Another limitation is that since verbal autopsy data was used to identify households with adult HIV/AIDS related mortality, some AIDS-related deaths might not be detected. This is because information in the verbal autopsy questionnaire is collected from respondents who are caregivers of the deceased and some of them might give incorrect or incomplete information, especially if it was an HIV/AIDS related death. Some informants may purposefully give misinformation due to the stigmatization of HIV/AIDS illness and death in South Africa. In addition, due to ignorance or illiteracy, some respondents might not be able to give detailed information about the symptoms of the sickness. Sometimes, the causes or number of deaths reported by respondents might not correspond with hospital records (Kahn et al., 2000). Despite these possible problems, the verbal autopsy procedures in the Agincourt site have been validated as highly reliable (Kahn et al., 2000).

One other limitation of the quantitative data set is that it does not contain some information about the occurrence of adult AIDS death in elderly women headed

households, which would have yielded better results about the demographic impact of adult HIV/AIDS related mortality. Some of the “missing” information is available in the AHDSS, but was not included when the data set was created, e.g., who headed the household before the occurrence of adult AIDS mortality. Other information is not collected as part of the AHDSS, such as the role of elderly female household heads, especially with regard to caregiving for sick adult children, et cetera. However, the results could be used as preliminary findings for further investigation of the demographic impact of adult HIV/AIDS at the study site.

As a result of some of the limitations of the quantitative data, as well as the fact that the AHDSS data do not contain information on the socio-economic and socio-cultural impacts of adult HIV/AIDS morbidity and mortality on elderly women, primary qualitative data are also included in this study. The following section describes the qualitative data and method used in this thesis.

4.5 Qualitative Research: Data and Methods

4.5.1 Building on the Gogo¹⁴ project

The qualitative research of this thesis builds on the Gogo Project¹⁵, which focused on the HIV/AIDS related experiences of older women in the MRC/Wits Unit study site. One of the main aims of the Gogo Project, which was funded by the HIV/AIDS Node at University of Kwa-Zulu Natal, and through Mellon Foundation and National Institute of Aging grants held

¹⁴ Gogo is the word used to refer to elderly women or grandmothers among Africans in South Africa

¹⁵ The project started in 2004 when the Principal Investigator (PI), Dr. Enid Schatz, was a Wits University Research Council Post-Doctoral Fellow. As part of her PhD training, Catherine Ogunmefun was employed as the Programme Manager. Schatz is now currently an Assistant Professor at the University of Missouri and still affiliated to the Wits University as an Honorary Researcher and Visiting Lecturer.

at the University of Colorado, Boulder, was for Ogunmefun to train in qualitative fieldwork. The project gave her the opportunity to collect qualitative data and manage a team of fieldworkers. Using the AHDSS census data as a sampling frame, a random-stratified sample of 60 households in which 60 women aged 60-75 years lived was selected. The sample was also stratified by household mortality experience, using the verbal autopsy data from 2001 to 2003.

Half of the respondents in the Gogo Project were of Mozambican origin and half were born in South Africa. Given the importance of the pension to households in the study area, the 30 Mozambican respondents were added in a second phase of the project to capture households in which the older woman was not receiving a South African pension. Until March 2004, self-settled Mozambican refugees were not able to access social grants without a South African Identification Book. In drawing this sample, Schatz and Ogunmefun believed that the majority of Mozambicans in the field site held Permanent Resident Identification Books rather than South African Identification Books, and thus, would not be accessing social grants. However, a surprising two-thirds of the Mozambican respondents held South African Identification Books and were receiving pensions (Schatz and Ogunmefun, 2005).

Because of the inability of the Gogo Project to capture a significant number of elderly women who are pension non-recipients, this thesis now explores the experiences of the near-old, that is, women aged 50-59 years who are not yet age-eligible for the pension grant. The qualitative research of this thesis, not only focuses on the impacts of adult HIV/AIDS related mortality on near-old women, but also compares their experiences with those of their older

South African peers in the Gogo Project. These older South African women were also re-visited during the fieldwork for the near-old women in order to collect more information about their experiences of HIV/AIDS. The following sub-sections provide a description of the fieldwork and data used in this thesis, including the first phase of the Gogo Project.

4.5.2 Data collection

The data for the nested qualitative study analyzed in this thesis were collected in the MRC/Wits unit study site. Using the AHDSS census data as a sampling frame, a purposeful-random sample¹⁶ of 30 households in which, 30 women aged 60-75 years lived was selected. In order to compare the experiences of older women in different households, the sample was stratified by household mortality experience, using the AHDSS verbal autopsy data from 2001 to 2003. As a result, one-third of the women lived in households that had experienced an HIV/AIDS death between 2001 and 2003, one-third lived in households where a death due to another cause had occurred, and one-third in households with no adult death during the period.

Before the fieldwork commenced, ethical clearance was first obtained from the University of the Witwatersrand Ethics Committee. In June 2004, three local interviewers were selected from a pool of candidates after written and oral tests conducted by Schatz, Ogunmefun and the MRC/Wits Unit officials. As a result of the need to recruit mature interviewers, whose ages were close to those of the study participants, the recruited interviewers were aged 40 and above. These interviewers were trained in qualitative interviewing, to equip them well

¹⁶ This approach is used in this study because purposeful sampling enables the selection of “information-rich cases” for an in-depth study of a phenomenon while random sampling, even when the sample size is small, increases the credibility of the results from a qualitative research (Patton, 1990).

for the job. The duties assigned to each interviewer included interviewing 10 respondents thrice, recording, transcribing and translating interviews into English. Before an interview took place, verbal consent was obtained from the respondent by the interviewer¹⁷. The respondent was also permitted to withdraw at any point during the interview. The length of each interview was approximately one hour.

Between July and September 2004, three in-depth semi-structured interviews were conducted with each of the 30 South African respondents. In the first interview, respondents were asked about their childhood and family background, marriage and family life, as well as work and pension history. The second interview was about living arrangements in their household, caregiving for the sick and orphan/fostered children, perception of caregiving and, beliefs about and experiences of HIV/AIDS in their household and community. In the third interview, respondents were asked about pension consumption, socio-economic impact of HIV/AIDS, social and financial support from family and the government during crises such as adult morbidity and mortality (see appendix B). Out of 30 women aged 60-75 years, originally selected for this phase, six had either died, moved, refused or were too sick to be interviewed. However, alternates were selected to replace these respondents.

The sampling for the 30 additional near-old respondents for this thesis paralleled the original sampling strategy. Using the AHDSS census data, 30 households with 30 women (and 15 alternates) aged 50-59 years were selected for this phase of the fieldwork, which took place between November 2005 and February 2006. Using the AHDSS verbal autopsy data (2001-

¹⁷ Verbal consent was used instead of written consent in order to avoid embarrassing the respondents that are not literate.

2003), the sample was stratified by household mortality experience. There were, therefore, 10 women who lived in households with an adult HIV/AIDS related death, 10 women in households with a death due to another cause and 10 women in households with no adult death during the designated period. The three local interviewers recruited in the first phase of the project were re-hired and using in-depth semi-structured interviews, they interviewed each near-old respondent thrice.

Most of the topics in the interview guide for the first phase were retained and used in this second phase, however, some topics were adapted, while a few new topics were added (see appendix C). In addition, the concepts of socio-economic impact and socio-cultural impacts of HIV/AIDS on elderly women, as illustrated in the PSE framework, were explored. Some of the new topics or questions asked included the difference a pension grant would make during crises, expectation of getting a pension grant at age 60, stigmatization of HIV/AIDS in the community and household, personal experiences of HIV/AIDS related stigma as well as beliefs surrounding stigma. Before interviews were conducted, the interviewers obtained informed verbal consent from the respondents and also informed them that they were permitted to withdraw at any point during the interview. Out of the 30 respondents (in the original sample), three women were replaced by alternates because they were not available to be interviewed¹⁸.

In addition to the 30 respondents aged 50-59 years, the interviewers re-visited the South African respondents over age 60 that were initially interviewed in the first phase of this

¹⁸ Two of these three respondents went to visit relatives in Johannesburg at the time of the fieldwork while the third one is a migrant worker who comes home only at the end of the month.

project in 2004. Out of 30 respondents in the original sample, 27 were interviewed. One of the three respondents (that were not interviewed) passed away a few months before the fieldwork commenced; the second one refused to be interviewed and the third had a mental illness, so she could not be interviewed. These 27 respondents were asked questions relating to HIV/AIDS stigmatization as mentioned above. All interviews were taped, translated into English and fully transcribed, as in the first phase of the project. At the end of the last interview in each phase, respondents were given small food parcels to compensate for time spent for the interviews¹⁹.

4.5.3 Data analysis

The analysis of the data was based on the inductive approach, which depends on methods that allow an investigator to be close to the real world so that the theory or findings from the research are “grounded” in the empirical world (Patton, 1990: 67; Corbin and Strauss, 1990; Neuman, 2003). One important component of this approach is the notion of “constant comparison” which involves developing and refining the ideas that constitute a theory throughout the project (Oktay, 2004:24). Thus, during the fieldwork, each interview transcript was read, reviewed and used to explore emergent themes or concepts²⁰ that were further investigated in the second or third interview until “a point of saturation” was reached (Oktay, 2004: 24). This helped Ogunmefun not only to monitor the outcome of each interview but also make comparisons between data and concepts as well as refine the interview guide in line with emergent themes.

¹⁹ One of the MRC/Wits Unit policies is that study participants should be rewarded with small food parcels if a considerable length of time is spent in their households.

²⁰ Concepts are “conceptual labels placed on discrete happenings, events, and other instances of phenomena” (Strauss and Corbin 1990).

After the fieldwork, there were 261 interview transcripts. These were first typed with Microsoft Word and then imported into Nvivo (a qualitative software programme) for additional data analysis. In the coding stage of the analysis, a code-tree of categories²¹ was created from emergent themes. Other categories and sub-categories emerged as each sentence or paragraph was coded. About 288 categories and sub-categories emerged, while coding the interview transcripts. These categories and sub-categories were classified into 38 axial codes or categories. “Reports” were later retrieved from the axial categories related to the themes of caregiving, coping strategies, death, HIV stigma, etc.

4.5.4 Limitations of the qualitative research

One limitation of the qualitative research is that the sample size is small, although fairly large for a qualitative study, and therefore the findings cannot be generalized to a larger population. However, the participants were randomly selected. Thus, the findings are at least theoretically, if not statistically, generalisable to the Agincourt population. Another limitation is that accurate information about the financial costs of adult HIV/AIDS related death in a household could not be deduced as most of the participants could not recall how much they spent for funerals, probably because of their age and low level of literacy. However, most were able to give an estimation of the costs incurred.

The study is also limited as a result of the fact that it is restricted to only women. Involving other key informants such as elderly men, village heads and social works,

²¹ A category refers to a “grouping of concepts that seem to pertain to the same phenomena” (Strauss and Corbin, 1990).

would have yielded more information on HIV/AIDS and its impacts in the Agincourt community.

4.6 Ethical issues

The University of the Witwatersrand's Committee for Research on Human Subjects (Medical) had granted ethical clearance (No. M960720) for the AHDSS (Kahn et al., 2007). Nevertheless, add-on studies such as special census modules (e.g. asset survey), which require small adjustments to the AHDSS still have to be confirmed after an explanatory letter has been submitted to the Chair of the Committee (Tollman, 2006). When the AHDSS was initiated, community consent was obtained from both civic and traditional leadership. However, verbal informed consent continues to be obtained at individual and household level each time interviewers enter Agincourt households (Kahn, 2006). Fieldworkers are trained to fulfil informed consent procedures meticulously. They are also trained to recognise a study participant's right to withhold consent from all or part of a study (Tollman, 2006).

Community feedback and dialogue are integral to the Agincourt research process. Thus, information from the AHDSS and related research initiatives is communicated to members of the communities through printed "village fact sheets" and by *ad hoc* community meetings (Collinson et al., 2002). This, thereby, facilitates community involvement in local health action and related development activities (Collinson et al., 2002). Since 2002, the Agincourt unit's LINC (for Learning, Information dissemination, and Networking with Community) office has been compiling and updating information

on development and educational resources which is made available for leaders of the community and organisations (Kahn, 2006; Kahn et al., 2007). The LINC office is also committed to working with service providers such as health and welfare by providing policy-relevant research findings as well as participating in programme development (Kahn et al., 2007).

Chapter Five

BACKGROUND: SOCIAL, CULTURAL AND HISTORICAL CONTEXTS

In order to explicate HIV/AIDS impacts with regard to the situation of elderly women in South Africa, it is essential to understand the social, cultural and historical settings in which they live. This chapter, therefore, provides an overview of the geographical, social, cultural and historical contexts²².

5.1 Geography

The country of South Africa is located at the southernmost part of the African continent and it stretches latitudinally from 22° to 35° S and longitudinally from 17 ° to 33 ° E (Burger, 2005). Its total land area is 1, 219, 090 square kilometres and country measures about 1, 600 km from north to south as well as from east to west (South Africa. info (SAinfo), 2006).

Its long coastline (more than 2, 500 km) stretches from the eastern side of the country on the Atlantic Ocean, around the southern tip and then to the western side on the Indian Ocean (SAinfo, 2006). The country shares borders with Zimbabwe, Botswana, and Namibia, to the north. To the east, it has a longitudinal strip of border with Mozambique and curves in around Swaziland before rejoining Mozambique's southern border (SAinfo, 2006). While in the interior, the small mountainous country of Lesotho is nestled in the curve of the bean-

²² In order to give an accurate account, the sessions below were compiled from SouthAfrica.info (2006), South Africa Year Book 2005/2006 (Burger 2005), Barnett and Whiteside (2002), Department of Social Development (2004a and 2004b), Statistics South Africa (2007), Department of Health/MRC/MACRO International (1998), and Department of Social Development (2000), Overseas Development Institute (ODI) 2005, except where stated otherwise .

shaped Free State (one of the nine provinces of South Africa) and completely surrounded by South African territory (SAinfo, 2006).

There are seven ecological life zones, in South Africa, “with distinct environmental conditions and related sets of plant and animal life” (SAinfo, 2006). These ecological life zones are thicket, succulent *karoo*, savanna, *nama karoo*, grassland, *fynbos* and forest. The country is semi-arid with considerable variation in topography and climate (SAinfo, 2006). In summer, temperatures are above 32° C and sometimes exceed 38° C, especially in the Mpumalanga Lowveld and lower Orange River Valley (Burger, 2005). In the interior, where rocky hills and mountains rise from sparsely populated scrubland in the great Karoo plateau, the climate is extremely hot in summer and icy cold in winter (SAinfo, 2006). Whereas, the eastern coastline is well-watered and lush, the south-western corner of the country has wet winters and as hot and dry summers (SAinfo, 2006).

South Africa has two major rivers, that is, the Limpopo and the Orange. The latter runs from east to west and empties into the Atlantic Ocean at the Namibian border (SAinfo, 2006). Even though the country has an average annual rainfall of 450 mm, sixty-five percent of the country receives less than 500 mm year, while twenty-one percent of the country (the arid west) receives less than 200 mm per year (Burger, 2005). However, South Africa’s rainfall is unreliable and unpredictable as there are large fluctuations in the average annual rainfall in most areas of the country (Burger, 2005). The annual rainfall is more often recorded as below average than above average, while the country usually experiences drastic and prolonged droughts which sometimes end in severe floods (Burger, 2005).

The country is divided into nine provinces. Each province has its own legislature, premier and executive councils (Burger, 2005). The provinces are the Western Cape (south), Northern Cape (south west), Eastern Cape (south east), Limpopo (north), North West (north west), Free State (central region) KwaZulu-Natal (east), Gauteng (north east) and Mpumalanga (north east) (SAinfo, 2006). The administrative capital is Pretoria and the legislative capital is Cape Town (also known as the Mother City). The biggest city is Johannesburg, and it is situated in Gauteng province, which is regarded as “the powerhouse of South Africa and the heart of its commercial business and industrial sectors” (Burger, 2005).

5.2 History

Even though the history of South Africa is mostly associated with racial divisiveness, today, it is seen as the story of “a journey through massive obstacles towards the creation, from tremendous diversity, of a single nation whose dream of unity and common purpose is now capable of actualisation” (Sainfo, 2006). The San and Khoehkoe peoples (the “Bushmen” and “Hottentots” of early European terminology), although collectively known as the Khoisan, were the earliest representatives of that diversity of the nation of South Africa (Sainfo, 2006). For thousand of years, they were resident in the southern tip of the African continent for thousands of years, before the arrival of the European seafarers (SAinfo, 2006). The Bantu-speaking people, who moved into the north-eastern and eastern regions from the north, were also long-term inhabitants of the area for many years, before the arrival of the Europeans (SAinfo, 2006).

South Africa's written history begins with the Portuguese seafarers who pioneered the sea route to India in the late 15th century (Barnett and Whiteside, 2002; Burger, 2005). They were regular visitors to the South African coast during the early 1500s, while other Europeans followed from the late 16th century (Burger, 2005). In 1652, the Dutch East India Company established a settlement in Cape Town to supply provisions to ships on the Eastern trade route (Barnett and Whiteside, 2002; Burger, 2005). Trade between the Dutch and the Khoisan (for slaughter stock) later erupted into raiding and warfare (Burger, 2005). Eventually, the company imported slaves from East Africa, Madagascar and East Indies in order to meet the demand for labour by the colonists (Burger, 2005). The mixed-race group known as "coloured" are the descendants of these slaves, the Khoisan and white colonists (SAinfo, 2006).

In 1795, the Cape was occupied by the British as a strategic base against the French. The British also controlled the sea route to the East (Burger, 2005). In the course of the Napoleonic wars, it was retaken by the Dutch in 1806 but in 1814, Britain was confirmed as the new master of the colony (Barnett and Whiteside, 2002; Burger, 2005).

Initially, there was little attempt to expand beyond the settlement in Cape Town but as more colonists arrived by the early 1700s, they spread into the hinterland beyond the nearest mountain ranges (Burger, 2005). These colonists were mostly independent and mobile farmers (*trekboers*) who lived as pastoralist and hunters (Burger, 2005). The colonists encountered the Xhosa-speaking people as they moved into the hinterland, and a situation of uneasy trading and frequent warfare developed (SAinfo, 2006). By the second half of the 18th century, the colonists- mainly of Dutch, German and French

Huguenot stock- began to lose their sense of identification with Europe, while the Afrikaner nation was coming into existence (SAinfo, 2006). As the Afrikaners (also known as Boers) became to extend white occupation beyond the Cape' borders to the north (known as the Great Trek), they moved into the Highveld and Natal where they had conflicts with the Zulu people (Burger, 2005).

In the mid-1800s, South Africa was a farming/subsistence society with the British-controlled Cape Province and the Natal Colony as its cores (Barnett and Whiteside, 2002). In the interior were the Afrikaner or Boer republics of Orange Free State and Transvaal autonomous African states, e.g. the Zulu kingdom, were on the periphery (Barnett and Whiteside, 2002). Diamonds were later discovered on the borders of the Orange Free State in 1867 and this transformed the history of the country and sub-continent. In the 1870s, the town of Kimberly was established and the population of the area grew as more people flocked to the diamond fields (Barnett and Whiteside, 2002). By 1872, there were between 30, 000 and 50, 000 people (including 13, 000 Europeans) living and working in the diamond fields (Barnett and Whiteside, 2002). The people from the interior, such as the Pedi from Northern Transvaal, Tsonga from Mozambique and the Basutho from Lesotho provided labour. From 1872, all black employees were required to carry passes as an attempt to control black mine labour (Barnett and Whiteside, 2002). By 1885, black workers were living in compounds from the time of arrival to the time they finished their work at the mines. The conditions of the compounds were crowded and unsanitary (Barnett and Whiteside, 2002).

The year 1886 marked the discovery of the Witwatersrand goldfields in the Transvaal (Barnett and Whiteside, 2002). This was a turning point in the history of the country of South Africa as it presaged the emergence of the modern South African industrial state (Burger 2005). It also led to an increase in white immigration and the expansion of black labour. With these events, the racial divisiveness that dominated South African history for the next 100 years was set in motion (Barnett and Whiteside, 2002). Even though there were some conflicts between British and Afrikaners during this period, e.g. the Anglo-Boer/South African war (1899 -1902), both sides were in broad agreement about the position of black people in South Africa (Barnett and Whiteside, 2002). They had no political rights and few opportunities for economic advancement (Barnett and Whiteside, 2002). Legislation was geared towards stripping their rights and offering their labour in the white-dominated economy (Barnett and Whiteside, 2002). The black population was forced into crowded and impoverished homelands, while adults, mainly men, had to migrate to urban areas to work in white-owned factories and live in single-sex hostels (Barnett and Whiteside, 2002). This led to the breakdown of traditional, cultural structures and livelihoods (Barnett and Whiteside, 2002). Health services were limited and as a result, many diseases, such as Sexually Transmitted Infections (STIs) were untreated (Barnett and Whiteside, 2002).

Whether Afrikaner or British, white mastery was clear as the whites held economy and political power until the 1980s when internal opposition and international disapproval of the apartheid system expressed through boycotts and sanctions led to the watershed that put an end to segregationist ideologies and policies in South Africa (Barnett and

Whiteside, 2002; Burger, 2005). In February 1990, banned political parties were reinstated and political prisoners, including the African National Congress (ANC) leader, Nelson Mandela, were released (SAinfo, 2006). The white government began to negotiate itself out of power. In May 1994, the ANC won the first democratic election and Nelson Mandela became the first black president of South Africa²³ (Burger, 2005; SAinfo, 2006). This led to the integration of the country into a rapidly changing global economy as well as to reconciliation and the building of consensus founded on the commitment to improve the lives of all South Africans (Burger, 2005). In June 1999, Thabo Mbeki was elected as the president in the country's second democratic election (SAinfo, 2006). He was re-elected in 2004 and is the current president of South Africa.

5.3 Population

South Africa has a population of about 47 million people. More than three quarters (79%) are African, about 10% are white, 9% are coloured and 2.5% are Indian (Statistics South Africa, 2007). The estimated annual growth rate was about 1% between 2006 and 2007 (Statistics South Africa, 2007). According to the Department of Social Development (2004b), it was estimated in the 1980s, that the total population of South Africa would be between 70 and 80 million by 2020. However, decreasing fertility rates and increasing mortality rates have resulted in estimations that the population will decelerate in the current decade. It is now estimated that population will stabilize between 48 and 52 million people in the current decade (Department of Social Development, 2004b).

²³ For an in-depth discussion of South Africa's political history, see Burger, 2005.

Almost 51% of the population are women. Almost a third of the population is below age 15, while 8% are 60 years and above (Statistics South Africa, 2007). Statistics South Africa (2007) estimates that the infant mortality rate is currently 45.2 per 1000. They also estimate that total fertility rate has declined from 2.89 children per woman in 2001 to 2.69 children in 2007. Life expectancy is estimated at approximately 48.4 years for males and 51.6 years for females (Statistics South Africa, 2007). The number of years that men and women are expected to live (life expectancy) are likely to reduce because of increase in HIV/AIDS deaths, especially among adults. The estimated overall HIV-prevalence rate is approximately 11%, while the HIV positive population is estimated at approximately 5.3 million (Statistics South Africa, 2007).

In 2000, infant mortality was 55 per 1 000 live births, which was higher than the rate for 1995, while under-five mortality decreased from 93 to 70 per 1 000 children between 1990 and 2000 (Department of Social Development, 2004b). The leading causes of death from 1997 to 2001 were tuberculosis (9.1% of males and 6.7% of females), HIV (6.5% of males and 8.5% of females), and influenza and pneumonia (5.8% of males and 6.9% of females) (Department of Social Development, 2004b). Tuberculosis and HIV moved from their respective third and fourth positions as leading causes of death for both men and women in 1997 to the first and second positions in 2001 (Department of Social Development, 2004b). Underlying causes of death differed among the population groups of South Africa. The most common causes were tuberculosis and HIV/AIDS among the African group, while tuberculosis and cerebro-vascular diseases were common among the

Coloureds. For whites and Asian, the most common underlying reasons were ischemic heart and cerebro-vascular diseases (Department of Social Development, 2004b).

South Africa's basic literacy rate (the proportion of those who can read and write in at least one language) for 15-24 year olds is 95.8%, the adult literacy (the proportion of the population over 15 that can read and write in one language) is 85.3%. Net enrolment at primary level in South Africa is about 95% (Department of Social Development, 2004a; Department of Social Development, 2004b). Even though this figure is high and can be compared to the net enrolment (in primary) in countries like United States (95%), Switzerland (94%) and Austria (88%), the drop out rate is high as 80% of adult South Africans have not matriculated (Department of Social Development, 2004b). As a result, there is a shortage of high skilled workers in South Africa, especially among the black population, hence the need for the government to redress the apartheid legacy of inequality, as shown later in this chapter.

5.4 Cultural Context

The South African population is made up of the following groups: the Sotho-Tswana; the Tsonga; Venda; the Nguni (consisting of the Zulu, Xhosa, Ndebele and Swazi people); Afrikaners; English; coloureds; Indians; Khoisan; and those who have immigrated from the rest of Africa, Europe and Asia (Burger, 2005).

In terms of religious affiliation, about 76% of South Africans are Christians (Burger, 2005; SAinfo, 2006). Many, however, combine Christian and traditional African beliefs.

Other significant religious groups are the Hindus, Buddhists and Jews (SAinfo, 2006). A minority of the populations regard themselves as traditionalist or of no specific religious affiliation; therefore, they do not belong to any of the major religions (Burger, 2005).

South Africa is a multilingual country. The Constitution recognises 11 official languages— English, Afrikaans, isiZulu, isiNdebele, isiXhosa, Sesotho sa Leboa, Sesotho, Setswana, siSiwati, Tshivenda and Xitsonga (Burger, 2005). The English language is most widely understood and the second language of the majority of South Africans. However, the government is committed to promoting all the official languages (Burger, 2005).

5.5 Social Context of South Africa

As a result of the apartheid legacy of poverty and inequality, the country of South Africa is faced with the challenge of poverty and other social ills such as crime and violence. In most cases, “poverty is coupled with high levels of inequality in the conditions of living and access to resources on the one hand, and intense vulnerability within households and communities on the other hand” (Department of Social Development, 2004a). The inequalities are defined along race, gender, age and space dimensions; Africans, women and female-headed households, the young, older persons and rural people tend to live in poverty in South Africa (Department of Social Development, 2004a). Even though the post-apartheid government has started redressing the imbalance, high levels of poverty and inequality still remain a challenge for policy makers in South Africa (Department of Social Development, 2000).

In 2000, statistics show that, while about 25% of African men are unemployed, only 3.3% of white men are unemployed. Also, about 35% of African women are unemployed, while only 4.4% of white women are unemployed (Department of Social Development, 2000). Almost 27% of rural dwellers are unemployed, while about 22% of urban dwellers are unemployed. And of those aged 15-30 years, 36% are unemployed compared to 19% of those aged 31- 45 and only 10% of those aged 46-65 (Department of Social Development, 2000). Even though many jobs have been created (12% between 1995 and 2002), the unemployment rate has increased because the labour force increased at twice the rate of population growth as more young people enter the job market (Department of Social Development, 2004b). In addition, many older adults now seek employment (e.g. those from the rural areas) even though they were not part of the labour market in previous years (Department of Social Development, 2004b).

As a result of the need for an effective response to all infectious diseases as well as an effective impact on the general health of the nation, the South African government takes a comprehensive approach to all health challenges facing the country (Department of Social Development, 2004b). In 1994, free primary health care (PHC) to pregnant women and young children was introduced (Department of Social Development, 2004b). The development of clinics and basic health care programmes are the key elements of the PHC such as safe motherhood, child health and nutrition, expanded immunization, management of communicable disease and treatment of chronic ailments (Department of Social Development, 2004b). Approximately two-thirds of South Africans have good access to a health facility; however, the situation is better in the urban areas than in the

rural areas (Department of Social Development, 2004b). In 1998, only 17% of the adult population had access to medical aid. In addition, access to medical aid is highest among people aged 35-44 and lowest among the elderly and young adults (Department of Health/MRC/MACRO International, 1998). Twenty-four percent of urban dwellers had medical aid, while only 6% of rural dwellers had access to a medical aid. The disparities among the population groups were large as 75% of the White population had access to medical aid, compared with only 8% of the African population (Department of Health/MRC/MACRO International, 1998).

Food shortage is part of daily crises for many South Africans and this impacts on children in particular, as it leads to stunted growth and high levels of infant and child mortality (Department of Social Development, 2000). Crowded homes and dwellings are other major issues; these are compounded by high fertility rates that are still prevalent in rural areas (Department of Social Development, 2000). In addition, lack of access to efficient and safe sources of energy is a challenge for the poor (Department of Social Development, 2000). As a result, many lives and homes are lost to fire in squatting and informal settlements, especially during the winter season. Although many rural areas are electrified, purchasing electricity is beyond the financial capacity of many rural dwellers. In these areas, the burden of wood collection generally falls to women who may be vulnerable to physical and sexual assault when collecting wood (Department of Social Development, 2000).

As a survival strategy, many poor households are split over many sites and this, coupled with the migrant labour system, leads to fragmentation of the family. Moreover, many households, especially among the poor, are dependent on state transfers and remittances from family members employed away from home (Department of Social Development, 2000). All these existing patterns of poverty and social inequality tend to aggravate the impact of social problems such as crime, unemployment and HIV/AIDS on vulnerable groups such as rural dwellers, Africans, women and older people in South Africa (Department of Social Development, 2000). As mentioned earlier, the post-apartheid government has made some efforts towards redressing the balance and one of the initiatives towards tackling the challenge of poverty among vulnerable groups is discussed in the following section.

5.5. South Africa's Social Security System

South Africa's social security system, as a system of targeted social grants, was first initiated during the apartheid era to meet the need of the white minority in South Africa (Overseas Development Institute [ODI], 2005). It began with the Old Age Pensions Act of 1928 which explicitly excluded most black South Africans (ODI, 2005). In 1944, the old-age pension grant was extended to all South Africans, however the amount paid to each racial group was still racially and discriminately based (Legido-Quigley, 2003). Pensions were to be paid in the ratio of 4: 2: 1 to Whites, Coloureds and Indians, and Blacks respectively (Devereux, 2001). Other grants such as the disability and child support grants were also extended with the same racial basis.

The discrimination of the social security system continued until apartheid was abolished in the early 1990s. Since the incoming government inherited a fragmented social security system rooted in apartheid policies and ideologies, there was a need to restructure the system (ODI, 2005). Two main objectives of the reformed social security system are, firstly, to reduce poverty among vulnerable groups, e.g. the elderly and those with disabilities and children; secondly, to increase investment in health, education and nutrition, in order to increase economic growth and development (ODI, 2005).

There are five major social security grants in South Africa. The old-age pension targets men over age 65 and women over age 60; the disability grant provides support to adults with disabilities; the child support grant targets families with children under the age of fourteen; the foster child grant provides support to families with children, under age 18, in foster-care; and the care dependency grant provides additional support to families with children, below age 18, with disabilities (ODI, 2005). Even though eligibility for each grant is dependent on an income-based means test, the test is rarely administered to those who appear poor (Lam, Leibbrand and Ranchhod, 2005). However, the means testing is effective to the extent that it excludes almost all whites, those who receive private pensions and some upper-income Africans, and includes 80% of age-qualified Africans (Case and Deaton, 1998)²⁴.

The total number of grant beneficiaries increased from 2.8 to 5.8 million between 1998 and 2003 (Booyesen and Van der Berg, 2005). Between 2003 and 2006, it increased from 7 to 11 million grant beneficiaries (ODI, 2005; Department of Social Development,

²⁴ See Case and Deaton (1998) for a description of the means testing of the social grants.

2007). The payment of social grants has been the fastest-growing category of government expenditure since 2001 and now, it amounts to R70 billion a year, about 3.4% of gross domestic product (Department of Social Development, 2007). The amounts paid have increased significantly since 2001, especially the child support grant, which rose from R100 to R180 in 2005. As at 1st April 2006, the old-age, disability and foster care grants were R820 per month, while the care dependency grant and child support grants were R190 and R170 per month respectively (Department of Social Development, 2007).

The old-age pension grant is the second largest social grant (in terms of the number of people who access it), after child support grant, and many studies have shown how the grant has reduced the impact of poverty in many households, especially in the rural areas (Moller and. Sotshongaye, 1996; Case and Deaton, 1998; Sagner, 1999; Devereux, 2001; Ferreira, Keikelame and Mosaval, 2001; Duflo, 2003; May, 2003; Legido-Quigley, 2003; Moller and Ferreira, 2003; Booysen and Van der Berg, 2005; Department of Social Development, 2007; Schatz and Ogunmefun, 2007; Schatz, 2007). Findings from these studies show that the old-age pension grant is the main household income in some households (May, 2003); it takes care of the needs of grandchildren and other members of elderly people's households (Moller and Sotshongaye, 1996; Case and Deaton, 1998); gender sensitive towards women as their eligibility age is lower than that of men (Legido-Quigley, 2003) it delivers cash to remote rural areas where no institutions (e.g. banks) do (Devereux, 2001; Legido-Quigley, 2003) and provides access to credit for many elderly people in local markets (Devereux, 2001; Schatz and Ogunmefun, 2007).

In addition to poverty reduction, a few of these studies also show that pensions are being used to mitigate the impact of HIV/AIDS in pensioners' households (Booyesen and Van der Berg, 2005; Moller and Ferreira, 2003; Ferreira, Keikelame and Mosaval, 2001; Schatz and Ogunmefun, 2007; Schatz, 2007). However, there is limited evidence whether such households recover from the socio-economic impact of the disease. The capability of pensioners' households to recover from the socio-economic impact of HIV/AIDS is, therefore, examined in this thesis, in addition to in-depth investigation on how pensions are used by elderly women as a coping strategy during crises (chapter eight).

Chapter Six

DESCRIPTION OF THE AGINCOURT POPULATION

6.1 Age Structure of the Population

The dataset used in the quantitative section of this thesis is a cross-section of the AHDSS census data collected in 2004, representing those who were living in Agincourt in 2004, and some history about those individuals and their households (e.g. household mortality experience between 1992 and 2004) using the longitudinal data on that household. In July 2004, there were 69,897 people in 11,698 households and the average size of a household was approximately 6 persons. The Agincourt population is young as a greater proportion is below the age of 50 (figure 6.1). Despite being a young population, there is evidence that the older population is growing, as Madhavan and Schatz (2007) show that, while the percentage of children aged 0-14 decreased between 1992 and 2003, there was a slight increase in the percentage of the population over the age of 59.

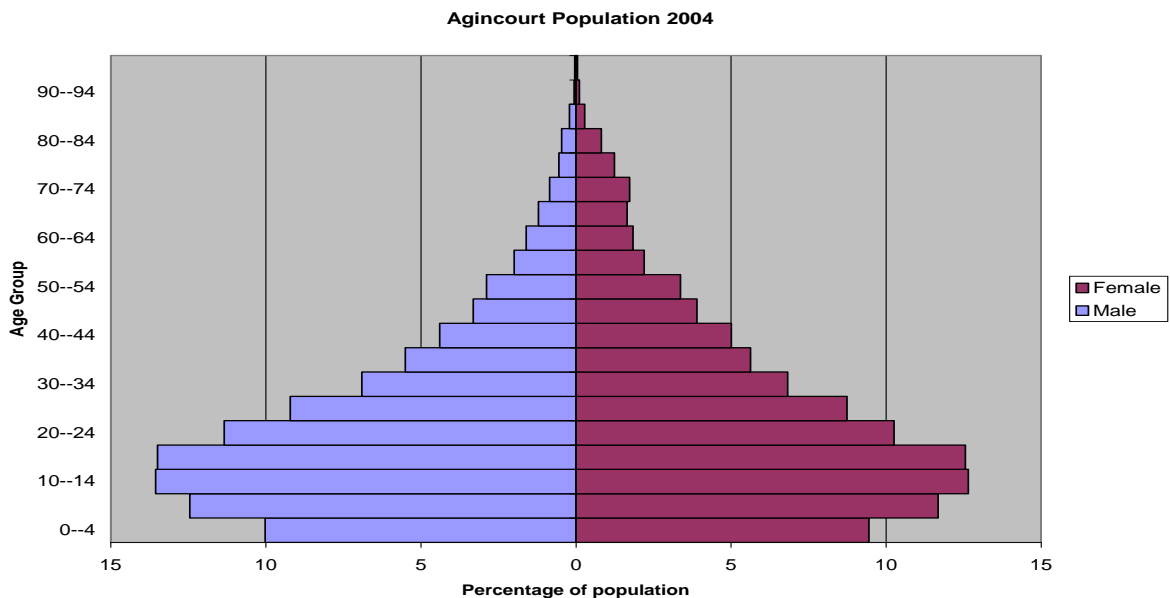


Figure 6.1: Agincourt population pyramid (2004)

The age distribution of the Agincourt population by sex is presented in table 6.1. Close to 40% are children (under age 15), while slightly over 10% are aged 50 and above. More than half of the population is female. There is, however, not much difference in the percentages of male and female in the older ages as from age 50, except for age group 65+ that has a difference of 2.5%. The literature suggests that women tend to outlive men, thus, resulting in a higher percentage of women at the oldest ages.

Table 6.1: Agincourt population age structure (%) in 2004

Age Distribution	Male	Female
0-4	10.0	9.5
5-9	12.4	11.7
10-14	13.6	12.6
15-19	13.4	12.6
20-24	11.4	10.3
25-29	9.2	8.7
30-34	6.9	6.8
35-39	5.5	5.6
40-44	4.4	5.0
45-49	3.3	3.9
50-54	2.9	3.4
55-59	2.0	2.2
60-64	1.6	1.8
65+	3.4	5.9
N	33,626	36,271

6.2 Socio-demographic Characteristics of the Agincourt Population

A more detailed description of the Agincourt population is provided in table 6.2 outlining the age, gender and the education, marital and employment status of members of the population. Here, age is re-categorized into 4 groups, i.e., 0-15 (child), 16-49 (adult), 50-59 years (near-old) and 60+ (older) age groups. In this thesis, focus is mostly on the near-old and older age groups.

Half of the population in the data are in the economically active age group of 16-49, 5.2% are in the less economically active age group of 50-59 years, while 37.9% and 6.4% are in the dependent age groups of 0-15 and 60+ respectively²⁵. About 70% of the population has had some education. There are, however, more people with primary (36.0%) and secondary education (21.6%) than those with matriculation (9.7 %) and higher education (3.3%). As a result of these low levels of education, only a few people in the population have access to high income jobs.

Almost 40% of the women at Agincourt are single, while 25.7% are married and 13.0% are widowed²⁶. Among individuals aged 15 and above, 32.8% are employed. However, unemployment could be regarded as high in the area as about 67% are not gainfully employed. This may have contributed to the increase in the rate of circular labour

²⁵ Although these are the 'traditional' dependent age groups, the older people may not be financially dependent on the 'economically active' age group. As unemployment rate is high at the study site and pensions are a significant source of household income, individuals in the 'economically active' age group may actually be dependent on pensioners. Studies have shown that pensions account for approximately 60% of total household income in pensioners' households in Agincourt as well as in South Africa as a whole (Case and Deaton, 1998; Case and Menendez, 2007)

²⁶ The marital status of men is not identifiable from the dataset being used in this thesis. Until 2006, the only information collected on marital status was from women. In 2006, a new variable on union status was introduced to capture information on marital status for both men and women.

migration at this study site, as many adults migrate to the cities and neighbouring areas to seek employment opportunities (Clark et al., 2007).

Table 6.2: Socio-demographic characteristics of Agincourt population

Socio-demographic Variables	%
Age Categories	
0-14	37.9
15-49	50.5
50-59 years	5.2
60+	6.4
N	69,897
Gender	
Male	48.1
Female	51.9
N	69,897
Education	
No education	27.6
Primary	36.0
Secondary	21.6
Matriculation	9.7
Higher Education	3.3
Unknown	1.8
N	63,101^a
Marital Status	
Divorced & Separated	10.5
Married	25.7
Single	39.8
Widowed	13.0
Unknown	11.0
N	22,963^b
Employment Status	
Employed	32.8
Job seeker	18.2
Non-job seeker	11.2
Occasional worker & Other	14.5
Student	23.3
N	45,530^c

^a Children under age 5 are excluded. ^b Only women are included, while men (and children below 15 years) are excluded due to the unavailability of information on their marital status. ^c Children below age 15 are excluded.

6.2.1 Socio-demographic characteristics of near-old and older people

About 12% of the total Agincourt population are aged 50 and above (table 6.2). Even though their percentage is small when compared to the percentage of those in the economically active age group of 16-49 (50.2%), findings from the initial stage of this research show that the elderly play an important role in their households (Ogunmefun and Schatz, 2008; Schatz and Ogunmefun, 2007; Schatz, 2007). Other studies have also shown that older people *can* and *do* make significant contributions to their households and community (Duflo, 2003; HAI, 2003; Lindsey et al., 2003; Ferreira, 2004). Therefore, in order to have a detailed description of the elderly population in Agincourt, this sub-section focuses on the socio-demographic characteristics of near-old, aged 50-59 years, and older people, aged 60 years and above, as presented in table 6.3. Age 60 is used as the cut-off age for older people as women become eligible for pension at that age in South Africa.

There are more elderly females in the Agincourt population as more than half of the near-old and nearly 63% of the older population are female. Older people are more likely than near-old to have no education (74% versus 49%), while there is more variation in the level of educational attainment among the near-old. Thus, the percentage of older people who are illiterate is higher than among the near-old. This is not surprising as older people in Africa were less likely to have had access to education when young. Unsurprisingly, as the level of education increases, the percentage of both near-old and older people who attained each level decreases.

Table 6.3 :Socio-demographic Characteristics of near-old and older people		
Socio-demographic Variables	Near-old people (50-59 years) %	Older people (60+) %
Gender		
Female	55.3	62.6
Male	44.7	37.4
Education		
No education	48.6	74.4
Primary	36.9	20.2
Secondary	8.5	2.9
Matriculation	1.3	0.5
Higher Education	2.2	0.5
Unknown	2.5	1.5
Employment Status		
Employed	48.3	15.4
Home worker	19.4	23.2
Job seeker	8.5	2.1
Non-job seeker	16.7	53.4
Occasional worker, Student & Other	7.0	5.9
Household Head		
Household Head	64.8	67.7
Pension Status		
Pensioner	13.7	68.8
N	3,657	4,472

Almost half of the near-old population are employed, while only about one sixth of the older population are employed. It is expected that fewer older people would be working as older men and women are more likely to retire and become pensioners at ages 65 and 60 respectively. More than half of the older population are non-job seekers, while about 23% older people and 19% near-old are home workers²⁷ respectively. This implies that more older people are less likely than near-old people to be engaged in economic activities. There is, however, not much difference between the percentage of near-old

²⁷ Home workers are those who work in their homes e.g. housewives.

people (64.8%) and older people (67.7%) who are household heads. This means that near-old people are also likely to head their household just as their older counterparts.

More than two thirds of the older people are pensioners. Although by definition, those who are near-old should not qualify for pensions because they officially are too young to qualify for the pension, 13.6% of the near-old people are pensioners²⁸. The reason for this may be due to “age-heaping” (in their identification document), which may make some near-old people “eligible” for a pension grant. This phenomenon was also observed in a study conducted by Case and Deaton (1998). According to their study, the timing of pension receipt may sometimes be arbitrary within age cohorts, especially because of “age-heaping”, that is, respondents rounding up their ages to the nearest multiple of five or ten in a survey or census. They also found that some people receive pensions even though they report their age to be less than the qualifying age and some who report that they have reached the qualifying ages of 60 (women) and 65 (men) have not started receiving their pensions. Findings from the qualitative part of this thesis also show that four (out of 30) near-old women had started receiving pensions, while one older woman was not a pension recipient at the time of the fieldwork (see appendices B and C).

6.2.2 Socio-demographic characteristics of near-old and older women

Studies have shown that elderly women, in different parts of South Africa, are more likely to make larger contributions in cash and in kind to their households than elderly men (Moller, 1993; Moller and Sotshongaye, 1996; Case and Deaton, 1998; Duflo, 2003;

²⁸ This does not affect the analyses in the quantitative section of this thesis as near-old and older women are combined in order to have enough cases for the statistical analyses in chapter seven.

Lindsey et al., 2003). Elderly women in Agincourt also play a very important role in their households by using their pensions to meet the needs of their families (Schatz and Ogunmefun, 2007; Schatz, 2007). Table 6.4 displays the socio-demographic characteristics of near-old and older women in the Agincourt population.

Table 6.4 :Socio-demographic characteristics of near-old and older women		
Socio-demographic Variables	Near-old women 50-59 years (%)	Older women 60+ (%)
Education		
No education	53.6	81.2
Primary	35.1	15.6
Secondary	6.3	1.5
Matriculation	0.7	0.2
Higher Education	2.4	0.3
Unknown	2.0	1.2
Marital Status		
Divorced	16.3	8.1
Married	43.7	20.9
Single	4.4	1.4
Separated	3.8	2.0
Widowed	25.1	64.2
Unknown	6.8	3.8
Employment Status		
Employed	34.5	7.5
Home worker	33.8	33.4
Job seeker	6.4	1.0
Non-job seeker	19.5	53.8
Occasional worker, Student & Other	6.0	4.5
Pension Status		
Pensioner	19.0	79.2
Household Head		
Household Head	43.4	53.2
N	2,021	2,801

Of the 4,543 women aged 50 and above, about 58% are older women above age 60. More of the older women are likely than their younger peers to have no education (81.1%), while near-old women are more likely than older women to have a primary

education (35.1%), secondary education (6.3%), or higher education (2.4%). There is, however, not much difference between the percentage of near-old women (0.7%) and older women (0.2%) that have matriculation. The reason for low levels of education in both groups may be due to the fact they had less access to schooling as girls due to strong preference for the schooling of boys.

Almost two thirds of the older women are widowed, while only 20.9% are married. This is expected as women, in Africa, are usually married to older men; therefore they are likely to outlive them. The implication is that older women who are widowed may become household heads, especially in the absence of an adult male child. On the other hand, the table reveals that near-old women are twice as likely to be married (43.7%) and more likely to be divorced (16.3% vs. 8.1%). Near-old women, also, are more likely to be single (4.4% vs. 1.4%) and separated (3.8% vs. 2.0%).

A larger percentage of near-old women are employed than older women (34.5% vs. 7.5%), while a higher percentage of older women are non-job seekers than near-old (53.8% vs. 19.5%). This is not surprising as women above 60 years are likely to retire from economic activities when they become pensioners. This is demonstrated in table 6.4 as nearly 80% of the older women are pensioners, while only 19% of the near-old women receive pensions. More than half of the older women are household heads, while only 43.4% of the near-old women are household heads. As noted earlier, women aged 60 years and above are more likely to have lost a spouse and therefore, become the household head. The implication of this is that they are likely to be responsible for

household expenditure, especially as pensioners, in the absence of adult or employed children.

6.3 The Verbal Autopsy Data

The AHDSS verbal autopsy data is used in the quantitative section of this thesis to examine the impact on elderly women of adult AIDS deaths in their households in Agincourt. This data identifies the cause of death for each death at the study site. The main causes of death in the site, as identified through the verbal autopsies, in children below age five include: kwashiorkor, diarrhoea; among those in the productive age group of 15-49 years main causes of death include: accidents, violence and AIDS; and, for those aged 50 and above they include: chronic degenerative diseases, mainly cardiac, cerebrovascular, liver and malignant diseases are common causes of death (Collinson et al., 2003; Kahn, 2006).

Mortality patterns, in Agincourt, have shifted over the last decade with a trend of increasing mortality among children under age 5 and adults aged 15-49, especially due to HIV/AIDS. Mortality, among women over age 50, has also started rising due to stroke and congestive cardiac failure (Collinson et al., 2003; The SASPI Team, 2004a). Despite this rise in mortality among elderly women and children, mortality is higher and still rising among adults aged 15-49 than among those in other age groups. Life expectancy was relatively stable for both males and females until the mid-1990s when male life expectancy dropped from 66 to 52 years, while female life expectancy dropped from 72 to 60 years, a loss of 14 and 12 years of life respectively (Kahn, 2006; Kahn et al., 2007).

This may be as a result of increase in mortality, especially due to HIV/AIDS, among those aged 15-49.

Table 6.5 provides the number of deaths that occurred between 1993 and 2004 by age categories. There were 5,235 deaths in Agincourt between 1993 and 2004. Within three periods— 1993-1997, 1997-2002, and 2002-2004²⁹, the largest number of deaths occurred in the adult age group of 15-49 (due to more person-years of exposure), followed by the age group of 0-14. In the mid-1990s, acute diarrhoea and malnutrition were responsible for 20% and 15% respectively of overall deaths in children under 5 years, while by 2000-2003, HIV/AIDS constituted 27% of all child deaths (Kahn et al. 1999; Kahn 2006).

Table 6.5 : Number of deaths in Agincourt by age categories, 1993-2004

Age Categories	1993-1997	1997-2002	2002-2004	Total
0 - 14	489	851	522	1862
15 - 49	710	1,284	832	2826
50 -59	63	119	76	258
60+	67	135	87	289
Total	1,329	2,389	1,517	5235

In the mid-1990s among adults 15-49, almost a third of all deaths were due to accidental and violent injuries, with a greater burden in males than females. However, by 2000-

²⁹ The data was set up in a way that the dates went from July 1(the previous year) to June 30 (the following year); hence there was no double counting of deaths in any year. The last period has a 2-year interval because the data for 2005 and 2006 were not available at the time the data was set up. The comparisons of the events that occurred over these three are therefore restricted.

2003, HIV/AIDS was the cause of 34% of male and a staggering 47% of female deaths (Kahn, 2006). The implication of this is that the burden of giving care to those infected with HIV/AIDS and taking care of funeral-related expenses incurred when they die will likely fall on older people, especially older women, in Agincourt. In older adults, aged 50 years and more, cardiovascular diseases (stroke and cardiac failure) were and still remain the leading causes of deaths, especially among females (The SASPI Team, 2004a; Kahn, 2006). The double burden of disease (communicable and non-communicable) is likely to compound the burden of caring on older adults as they deal with both their ill health and caring for others, especially as more young people die of HIV/AIDS.

6.3.1 AIDS and Non-AIDS mortality

For the purpose of this thesis, two types of death will be referred to: AIDS death— a death caused by HIV/AIDS related diseases³⁰ and non-AIDS death— a death from another cause. As mentioned earlier, AIDS is becoming the leading cause of death among children and adults in Agincourt. Table 6.6 presents the number of AIDS and non-AIDS death that occurred between 1993 and 2004. Of 5,235 deaths that occurred, 756 were caused by AIDS and related diseases such as tuberculosis and 4,479 were due to other causes such as cerebro-vascular accident (CVA), acute respiratory infection (ARI), congestive cardiac failure (CCF), genitor-urinary cancer, liver disease, kwashiorkor, motor vehicle accidents, assault and suicide.

³⁰HIV/AIDS related diseases include other diseases and conditions that are linked to HIV/AIDS such as pulmonary tuberculosis (PTB) and acute respiratory infection. Agincourt uses the International Classification of Disease to identify HIV-deaths.

Table 6.6 also reveals that AIDS and non-AIDS deaths are concentrated in the adult age group of 15-49. An AIDS illness and death, however, especially when the infected person is an adult, is likely to have a greater impact on a household than other illnesses and deaths (Barnett and Whiteside, 2002). One reason, for the greater impact of AIDS illness and death, is that, if the ill person is employed, the household will lose a source of income and at the same time, increase expenditures on medical care as they care for the sick. In addition, the length of illness and the need for care is likely to be longer, especially when compared to sudden deaths like those from car accidents.

Table 6.6 : Number of AIDS and non-AIDS deaths in Agincourt by age categories, 1993-2004

Age Categories	AIDS Death	Non-AIDS Death	All Deaths
0 - 14	254	1608	1862
15 - 49	430	2396	2826
50 - 59	32	226	258
60+	40	249	289
Total	756	4479	5235

In many households, especially in a rural area such as Agincourt, it is older women who take on the physical and financial responsibilities of caregiving. According to Schatz (2007), almost a quarter of households in Agincourt has an older woman living in it and many of these women play important roles in their household, especially with regard to caregiving to vulnerable household members such as ill adult children and fostered/orphaned grandchildren. As caregivers, these women are likely to be impacted by adult deaths in their households, but AIDS deaths may put particular strain on their

households. This thesis examines the impacts of adult AIDS and non-AIDS deaths on elderly women in households in Agincourt in the following three chapters.

6.3.2 Adult AIDS mortality³¹

This sub-section presents the number of households where an adult (either male or female) was living at the time he/she died as a result of HIV/AIDS related diseases at Agincourt over 3 periods – 1993-1997, 1997-2002, and 2002-2004 (table 6.7). Within these 3 periods, 468 households had 502³² adult AIDS deaths.

Table 6.7: Households with adult AIDS deaths by period

No. of AIDS death	No. of households			Total no. of households
	1993-1997	1997-2002	2002-2004	
1	46	265	126	437
2	0	24	5	29
3	0	0	1	1
4	0	1	0	1
Total	46	290	132	468

In the period 1993-1997, there was no household that experienced multiple adult AIDS deaths. However, 29 households had double adult AIDS deaths within each of the two latter periods of 1997-2002 and 2002-2004. One household experienced triple AIDS deaths within 2002-2004, while one household had 4 deaths within 1997-2002. This means households in Agincourt, even though few at present, have started experiencing

³¹ This includes AIDS deaths that occurred to all individuals aged 15 and above.

³² $437 + (2 \times 29) + (3 \times 1) + (4 \times 1) = 502$

multiple adult AIDS deaths. There may be additional households that had an adult AIDS death in more than one of the periods. The number of households with multiple adult AIDS death may increase later in this decade, especially if HIV/AIDS prevention and treatment programmes are not as effective as they ought to be and more prime-age adults continue to die because of contracting AIDS and its going untreated. This predicament is likely to escalate the impacts of adult AIDS death on household members, especially elderly women who are caregivers as they are the ones available, in most cases, to give care to dying adult children in a rural area such as Agincourt.

6.3.3 Non-AIDS mortality³³

The number of households that experienced another type of adult or adult non-AIDS death over the same periods is provided in table 6.8. Within the designated periods of 1993-1997, 1997-2002 and 2002-2004, 2,606 households had 2,871³⁴ adult non-AIDS deaths.

Table 6.8.: Households with adult non-AIDS deaths by period				
No. of non-AIDS death	No. of households			Total no. of Households
	1993-1997	1997-2002	2002-2004	
1	656	991	710	2357
2	62	104	70	236
3	2	6	2	10
4	2	1	0	3
Total	722	1102	782	2,606

³³ This includes non-AIDS deaths that occurred to all individuals aged 15 and above.

³⁴ $2357 + (2 \times 236) + (3 \times 10) + (4 \times 3) = 2,606$

Within the 3 periods, 2,357 households had one adult non-AIDS death, while 236 households had double adult non-AIDS deaths. Thirteen households, however, had more than two adult non-AIDS deaths within the same periods. Some of the households experienced both adult non-AIDS and AIDS deaths over these three periods. There were six households that had at least one non-AIDS death and one AIDS death within 1993-1997; 68 and 18 households also had the same experience within 1997-2002 and 2002-2004 respectively (not shown). Altogether, there were 92 households that experienced both adult non-AIDS and AIDS deaths within the designated periods. Since this number is negligible, the focus in this thesis is mainly on households that either had AIDS death or non-AIDS death in the three periods.

6.4 Summary

This chapter gives a description of the Agincourt population using the AHDSS 2004 census data. It primarily focuses on the socio-demographic characteristics of the Agincourt population as a whole and those of the elderly population, particularly elderly women. Findings from the descriptive analyses reveal that about 12% of the population are above 50 years and the level of literacy is low among the elderly, especially those aged 60 years and above. In addition, a greater percentage of the elderly above 60 is unemployed and on a pension grant. However, there is not much difference in the headship status of the near-old and older people. Findings also demonstrate that older women are more likely to be widowed and on a pension grant, while near-old women are more likely to be married and gainfully employed. Furthermore, a greater percentage of the older women are household heads.

The chapter also focuses on the mortality at the Agincourt field site. Findings show that the largest number of deaths occurred among adults aged 15-49 between 1993 and 2004. In the same periods, 502 adult AIDS and 2,871 adult non-AIDS deaths occurred in households. HIV/AIDS is regarded as the leading cause of death among adults (Kahn, 2006). In order to investigate the impact of adult mortality on households, the following chapter examines the demographic impact of adult AIDS and non-AIDS death on elderly women's households.

Chapter Seven

DEMOGRAPHIC IMPACT OF ADULT HIV/AIDS RELATED MORTALITY

7.1 Introduction: Elderly Female Headship

The growth of female-headed households, also called female headship in the literature, is not a recent phenomenon. Previous studies conducted in industrial and developing countries, show that women started becoming household heads in the latter part of the last century because of factors such as marital dissolution, increase in welfare benefits, increase in unpartnered adolescent fertility, erosion of extended family systems and traditional support networks, sex-specific migration and sex-ratio imbalances caused by war deaths and civil conflicts (Carliner, 1975; Bradbury et al., 1979; Danziger et al., 1982; Buvinić and Rao Gupta, 1997).

In recent times, the trend in increasing prevalence of female-headed households in sub-Saharan African has mostly been associated with increases in illnesses and deaths caused by the HIV/AIDS epidemic (Ferreira, 2004b; Monasch and Boerma, 2004). As a result of the fact that HIV/AIDS strikes mostly prime-aged men and women, the current trend is toward a surge in households headed by the elderly, particularly elderly women (HAI, 2004a; HAI, 2004b). As noted earlier in the thesis, Noubbissi and Zuberi's (2001) study showed that elderly women in South Africa reside in households headed by either their spouses or adult children. Since there is a tendency for women to outlive their spouses, these women will eventually become widows. If there were adult children in their households who become sick and later die of HIV/AIDS, there is likely to be an increase in elderly female-headed

households. Even though Noubissi and Zuberi (2001) report 51% elderly women as household heads in their study, there was no empirical evidence whether this phenomenon was due to the death of adult children that were infected with HIV/AIDS in these households. There is, therefore, the need to know whether the occurrence of elderly women headed households is as a result of adult HIV/AIDS death. This suggests that there is a relationship between elderly female headship (the X factor) and adult AIDS or non-AIDS death (the A factor) as shown in the adaptation of the ABC-X model (see chapter three).

There is also the need to know whether elderly female household headship is associated with their pension status, as studies have shown how elderly women use their pensions to support members of their households, in particular orphaned and fostered children (Sagner and Mtati, 1993; Moller and Sotshongaye, 1996; Duflo, 2003; HAI, 2004a; HAI, 2005b; Schatz and Ogunmefun, 2007). The study conducted by Sagner and Mtati (1999) on black South African (male and female) pensioners show that their headship status is due to their willingness to share their pensions with members of their household. Duflo (2003) in her study, conducted in South Africa, demonstrated that pensions received by women led to better health for girls who lived in their households; while Case and Menendez (2007) found that enrolment for girls is significantly associated with the presence of female pensioners in Agincourt. This finding implies that as household heads, pensioners may be more likely to make substantial contributions towards the needs of members of their household members. It is, therefore, imperative to test the relationship between elderly female headship and pension status, as demonstrated later in this chapter.

In Agincourt, there has been a steady increase over time of female-headed households, from 28% in 1992 to 36% in 2003 (Madhavan and Schatz, 2007). Madhavan and Schatz (2007) also found that the mean age of female household heads was older than among male household heads. There is, however, still the need to examine whether there is a trend towards elderly female-headed households, especially as more prime-age adults fall prey to the HIV/AIDS epidemic in Agincourt. This chapter examines household headship in Agincourt, particularly elderly female household headship, and the socio-demographic characteristics of household heads. It also explores the relationship between elderly female household headship and adult AIDS and non-AIDS deaths through descriptive and statistical analyses.

7.2 The Concept of Household

Households, in a community or society, are constantly undergoing transitions. For example, two people from different families may come together to become one family/household, give birth to children, the children become adults who may stay at, or leave home, the household may foster children from other households or become home to the child of an unwed parent, the parents retire from work and then die (Gordon et al., 1981; Barnett and Whiteside, 2002). As these transitions occur, the relationships of household members, their roles and responsibilities as well as the positions they occupy may change, especially with regard to the household head. For instance, in a multi-generational household, an adult child may be the household head even though his parents are still alive, especially if he is the breadwinner of the house. A change in the household headship may occur however, if the adult child dies leading to one of his

elderly parents becoming the household head. As more prime-aged adults fall victim to the epidemic, there is a need to consider household headship as an important demographic variable when examining changes in the household structure of a population (Kobrin, 1973; Merli and Palloni, 2004; Ferreira, 2004b).

Although a household is usually defined as those who reside or eat together, this definition is considered to be problematic as households (and families) are different from each other to some extent (Bender, 1967; Budlender, 2003). One problem associated with this definition is the possibility of an individual residing or “sharing the pot” in two households (Budlender, 2003). This situation may either occur in a polygamous household whereby, a man is regarded as the head of the different residences in which his wives live or a migrant worker who sends part of his income to his “rural family” and uses the rest to support his “urban family” (Budlender, 2003). Another problem is the use of decision-making or employment as the standard criteria for identifying or defining a household head, especially when the people in the household have other notions of what constitutes headship (Townsend et al., 2004). These problems may, therefore, make it difficult to identify the “real” household head in surveys and censuses.

In the Agincourt census, a household is defined as the social unit or people who eat from the same pot and the temporary migrants who are connected to the household (Collinson et al., 2003). It is difficult, however, for data collectors to define or distinguish whom the head of the household is due to some of the problems associated with the definition of a household head. As a result of this, in the Agincourt census, the interviewer usually asks

the older woman in the household to identify the household head (Townsend et al., 2004). This is likely to eliminate some of the problems with the definition of household head, since older women decide who the head is rather than the collectors imposing their own definition. Using the descriptive analyses of the AHDSS data, the following section examines households and household headship in Agincourt.

7.3 Descriptive Analyses

7.3.1 Household headship in Agincourt

As of July 2004, there were 11,698 households—each with a self-designated household head—in Agincourt: 63.5% of the households were male-headed, while 36.5% were female-headed. Table 7.1 provides the sex of household head by age categories.

Table 7.1 : Sex of household head by age categories

Sex of household head	Adult (%) (15-49)	Near-old (%) (50-59 years)	Older (%) (60+)	Total (%)
Female	29.5	37.0	49.2	36.5
Male	70.5	63.0	50.8	63.5
N	6303	2369	3026	11698

Nearly 56% of all the households are headed by adults in the productive age group of 15-49, while the rest of the households are headed by people above age 50 (not shown in table). About a quarter of households in Agincourt are headed by men and women over the age of 60 years, who are likely to be pensioners. These households may be economically less viable than those headed by adults in the productive age group of 15-49 if there are adults in the latter households that are gainfully employed. Elderly headed

households may be equally or more economically viable, however, if the elderly have access to a pension grant or two in their households.

There are more male-headed households among the adult and near-old household head age groups than among older household heads. Among the adult headed households, more than two-thirds are male, while nearly two-thirds of the near-old headed households are male. However, there is not much difference between the percentage of older male and female-headed households. The reason for this may be that women tend to outlive their spouses, thus, when they become widows, they also become household heads. Another reason may be that women start getting pension at age 60. There is, therefore, a greater likelihood of an older woman becoming a household head when household members depend on her pension income to sustain the household, especially in the absence of an adult or employed male.

7.3.2 Relationship of household members to the head

Another way to examine the household type of a population is by focusing on the relationship of household members to the head of their household, that is, the familial ties between household members and their household head. The data in table 7.2 presents the relationship of members of households to their household head in Agincourt. Of 24,367 children below age 15, 34% live in a household where a grandparent is household head, while 2.3% live in a household headed by a great-grandparent. Among adults aged 15-49, about 7% live in a household where a grandparent is household head, while only 0.2% live in a household headed by a great-grandparent. This finding suggests that one third of

the children and over 7% of adults live in a multi-generational household. In addition, about 48% of adults live with a parent who is a household head. This finding implies that nearly half of the adults live in a multi-generational household, especially if they have children in their households.

Table 7.2: Relationship of household members to the head by age categories

Relationship to household head	Children (%) (0-14)	Adults (%) (15-49)	Near-old (%) (50-59 years)	Older (%) (60+)	Total (%)
Household head	0.0	16.7	64.8	67.7	11,698 (16.7)
Sibling	0.7	4.8	2.3	1.1	2103(3.0)
Parent	0.0	0.1	2.6	13.7	744 (1.1)
Wife	0.0	11.5	22.7	12.0	5,615 (8.0)
Co-wife	0.0	1.4	2.7	1.4	677 (1.0)
Husband	0.0	0.2	0.5	0.9	98 (0.1)
Child	53.6	48.4	2.8	0.4	31,235 (44.7)
Grandchild	34.0	7.1	0.0	0.0	10,963 (15.7)
Great-grandchild	2.3	0.2	0.0	0.0	598 (0.8)
Sibling's child	4.9	2.7	0.0	0.0	2,163 (3.0)
Sibling's grandchild	0.8	0.2	0.0	0.0	261 (0.4)
Others ^a	3.7	6.8	1.1	3.0	3,742 (5.4)
N	24,367	37,401	3,657	4,472	69,897 (100)

^a Others include uncle, aunt, great-grandchild, unrelated member of the household, etc.

The table also shows the complexity of living arrangements in the Agincourt community as among children, 4.9% and 0.8% are the household head's sibling's children and grandchildren. Also among adults, 2.7% and 0.2% are the household head's sibling's children and grandchildren. According to Townsend et al. (2004), households are

containing more generations and becoming more complex. This phenomenon may make household headship more burdensome, especially for elderly household heads, as they may not have enough resources to meet the needs of the different generations who reside in their household. Studies have shown how elderly people are more likely to live below poverty line in many developing countries (HelpAge, 2004d; Kinsella and Philips, 2005); shouldering the responsibilities of different generations as household heads may therefore make them vulnerable to financial hardship.

Of 3,657 near-old and 4,472 older people, 64.8% and 67.7% are household heads respectively, while only one sixth of adults are household heads (N=37,401). This means a greater percentage of the near-old and older population are household heads. As household heads, many of these elderly people may be responsible for the financial well-being of their households. Other studies have shown that elderly people, in particular elderly women, take on the financial burdens of their households, especially as household heads and caregivers (WHO, 2002; Moller and Ferreira, 2003; HAI 2004a). Hence, there is the need to further examine the headship status of elderly women as well as their pension status later in this chapter.

7.3.3 Socio-demographic characteristics of household heads

As noted in a previous section, about two-thirds of the households in Agincourt are male-headed, while about one-third is female-headed. Also, more than half of the households are headed by adults aged 15-49, while the rest of the households are headed by people aged 50 and above. But what are the socio-demographic characteristics of these household heads? In order to understand the characteristics of a household head or who is

likely to be a household head, the socio-demographic characteristics of household heads in Agincourt by sex are examined in table 7.3.

Table 7.3: Socio-demographic characteristics of household heads by sex		
Socio-demographic Variables	Female household heads (%)	Male household heads (%)
Education		
No education	52.3	33.5
Primary	27.0	32.0
Secondary	11.1	16.9
Matriculation	4.9	9.9
Higher Education	3.1	4.7
Unknown	1.6	3.0
Marital Status		
Divorced	25.3	*
Married	6.6	*
Single	11.7	*
Separated	5.2	*
Widowed	50.2	*
Unknown	1.0	*
Employment Status		
Employed	37.3	64.9
Home worker	21.2	2.0
Job seeker	10.5	11.9
Non-job seeker	25.2	14.7
Occasional worker, Student & Other	5.8	6.5
Pension Status		
Pensioner	49.5	13.7
N	4,256	7,442

* Data is not available

More than half of female household heads have no education, while only one third of male household heads are not literate. About 67 % of male household heads has had some education, while only 47.7% of female household heads has had some education. The implication of this is that male-headed households may be more economically viable since the household head himself is more likely to be educated, and therefore, more likely to be employed and earn more income, whereas female-headed households may be less

economically viable because of the low level of literacy of their household heads, which makes the household head to earn less income (Barros, Fox and Mendonça, 1997). Studies from Botswana, Ghana, the Dominican Republic, Brazil and South Africa have demonstrated that female-headed households are poorer because their household heads either earn less income or have less access to the cash economy (Koussoudji and Mueller, 1983; Lloyd and Gage-Brandon, 1993; Rogers, 1995; Barros, Fox and Mendonça; Budlender, 2003). This, therefore, makes members of female-headed households, especially children, to be vulnerable to financial hardship.

The data presented in the table also shows that half of the women who are household heads are widowed, while a quarter of them are divorced³⁵. About 12% of female household heads are single, while only 6.6% are married. Thus, women without husbands are more likely to be household heads than those who have spouses. Data on male household head marital status are not available, but it is likely that male household heads are much more likely to be married than female household heads, as female household heads are more likely to be widows, divorcees and unmarried (Koussoudji and Mueller, 1983).

Almost two-thirds of male household heads are employed, while 35% are not gainfully employed. On the other hand, a higher percentage (62.8%) of female household heads is not gainfully employed, while only 37% are employed. This is not surprising since more men are educated and more likely to be of working age, so they are more likely to be

³⁵ Information on marital status was collected from women only, prior 2006, so the marital status for men is not identifiable from the dataset.

employed, as noted earlier. There are, however, more pensioners among female household heads as nearly half of them are pensioners, while only 13.7% of the male household heads are pensioners. This is another reason why female household heads are less likely to be working, that is, they receive a pension.

In sum, female household heads are more likely to be pensioners because they are older, while male household heads are more likely to be gainfully employed because they are more educated and more likely to be in an economically active age category. But does this mean households headed by female pensioners are vulnerable to financial hardship, even though they are likely to allocate resources in a way that will benefit household members, especially young children (Duflo, 2003)? In an attempt to answer this question, this thesis explores the role of pensioners, who are caregivers, to their household later in the following chapter.

7.3.4 Socio-demographic characteristics of elderly female household heads

Nearly half of all women aged 50 and above are heads of the households in which they live (49.7%). In order to further examine the characteristics of female household heads that are elderly, the socio-demographic characteristics of elderly female household heads and non-heads aged 50 and above are compared in this section.

Table 7.4 demonstrates that certain characteristics of elderly women household heads are not much different from those of elderly women non-household heads. For instance, there are no real differences in their education as about 70% of elderly female household heads

and non-household heads do not have any education. This finding is not surprising as elderly women in Africa are less likely to have access to education when young. This means that elderly women do take on the responsibilities of heading a household despite their lack of western education, and that education is not a predictor of elderly female headship.

Table 7.4 :Socio-demographic characteristics of elderly women by household headship (50+)

Socio-demographic Variables	Head (%)	Non-head (%)
Education		
No education	69.0	70.2
Primary	24.1	23.3
Secondary	4.1	3.0
Matriculation	0.5	0.4
Higher Education	0.9	1.6
Unknown	1.4	1.5
Marital Status		
Divorced	18.2	5.1
Married	5.5	54.6
Single	3.3	2.0
Separated	4.3	1.2
Widowed	67.9	28.2
Unknown	0.8	8.9
Employment Status		
Employed	21.6	16.2
Home worker	29.8	37.0
Job seeker	3.1	3.5
Non-job seeker	40.7	38.1
Occasional worker, Student & Other	4.8	5.2
Pension Status		
Pensioner	61.4	46.8
N	2,366	2,456

One of the primary differences between heads and non-heads is their marital status. Noticeably, household heads are more likely than non-household heads to be widows or

divorced. Eventually elderly women non-heads who are wives of household heads may also become household heads as the life expectancy of women is usually longer than that of men and widowhood does appear to be a predictor of household headship after a husband's death (Moralda et al., 2001; Kinsella and Philips, 2005). The data for this study also supports this fact as almost 68% of elderly female household heads are widowed, while only 5.5% are married (table 7.4); however, a greater percentage of non-heads are married, while only 28.2% are widowed.

As expected, only a few elderly female household heads are employed (21.6%), while nearly 41% are non-job seekers. This may be that many of these women are pensioners; therefore, they do not need to be employed or seek a job. Almost 30% of the household heads are home workers, while 37% of non-household heads are home workers. The reason for more home workers among non-household heads may be that they are more likely to have living spouses who are supporting them.

There are more pensioners among the household heads as the table reveals that 61.4% of the elderly female household heads are pensioners, while about 47% of those who are not household heads are pensioners. This finding suggests that pension receipt is an important issue to consider when focusing on elderly women, especially for those who are household heads, as it may be a determinant of household headship. Pension receipt may also play an important role in the lives of those with whom they live as it may be used to meet their needs (Schatz and Ogunmefun, 2007). In order to know who they live with, the

following sub-section focuses on the living arrangements of elderly women by examining their relationship to their household head³⁶.

7.3.5 Living arrangements of elderly women

According to Noubissi and Zuberi (2001), an examination of the relationship of the elderly to their household head gives insight into their residential and living arrangements, that is, whether the elderly live in a household headed by him/herself, his/her spouse, or his/her child, and who else resides in the household. In order to understand the living arrangements of elderly women in Agincourt, this sub-section focuses on their relationship to their household head. The relationship of near-old and older women to the household head is presented in table 7.5.

Table 7.5: The living arrangements of near-old and older women

Living arrangement/ Relation to head	Near-old women (%)	Older women (%)	Total (%)
Head (of household)	43.5	55.1	49.6
Spouse	45.6	21.2	31.6
Mother	5.0	20.7	14.2
Sister	2.1	0.7	1.4
Daughter	2.2	0.3	1.1
Others	1.6	3.6	2.8
N	2, 021	2, 801	4,822

³⁶ As a result of limited data on elderly people, especially in sub-Saharan Africa, ‘relationship to household head’ is sometimes used as a proxy for living arrangements in studies on elderly people (see Noubissi and Zuberi, 2001; Zimmer and Dayton, 2003; Merli and Palloni, 2004). Following these studies, the variable ‘relationship to household head’ is used in this chapter to explore the living arrangements of elderly women in Agincourt.

Older women are more likely to live in a household as the head (55.1%) than near-old women (43.5%). Whereas, near-old women are more likely to live with a spouse who is household head as the table reveals that 45.6% live with their spouse who is the household head. The reason for this difference is that older women are more likely to be widows, while near-old women are more likely to have a spouse that is still alive. This finding is consistent with the qualitative data of this study: in the older age group, the majority of our respondents were widowed, whereas among the near-old respondents, the majority has a spouse that is alive (see appendices D and E).

Older women (20.7%) are also more likely to live with a child that heads the household than near-old women (5.0%). The reason, especially for widows, may be that they need to rely on their children for physical support; in turn, pensioners are likely to financially support their children (and grandchildren). More near-old women, however, live in a household with a brother or parent who is the household head. This finding may be due to lesser likelihood of their being pensioners and having living older relatives; hence, they still rely on their parent or brother to sustain them financially, as well as physically.

7.3.6 Mother's residence status³⁷

In order to further explore living arrangements in the Agincourt community, this subsection focuses on the adult and children population and the residence status of their

³⁷ Due to the limitation of the quantitative data, which was not initially collected for analysis of elderly female headship, the variable 'mother's residence status' is used to here examine the presence of a mother in a household where a child and adult lives. This variable is also used in this chapter because information on the residence status of elderly women's children is not in the data set.

mother. It primarily focuses on whether those in the 0-14 and 15-49 age categories live with their mother in the same household or elsewhere (table 7.6).

Nearly 66% (N = 40, 523) of all individuals under the age of 50 live with their mother in the same household, while 8.4% (N= 5,156) and 4.8% (N= 2,904) have mothers who live in the same village and another village respectively. This finding suggests that a greater percentage of children and adults co-reside with their mothers in Agincourt than those whose mothers live elsewhere.

Table 7.6: The residence status of mother of the children and adult population

Residence Status	Children (%) (0-14)	Adults (%) (15-49)	Total (%)
Same household	86.5	51.9	65.6
Same village	1.9	12.6	8.4
Another village	2.2	6.4	4.8
Another place	4.5	13.6	10.2
Dead	4.9	15.5	11.2
N	24,367	37,401	61,768

Of 24, 367 children below age 15, 86.5% live in the same household with their mothers, while 9% do not live with their mothers. Of this percentage, about half have mothers who live in the same village or another village within the Agincourt area, while the other half have mothers who reside outside the Agincourt area. This finding suggests that 9% of the children under 15 in Agincourt may be fostered, which is not surprising as child fostering

is common in African society (Madhavan, 2004). Some of these fostered children may live in a household with a grandmother or an elderly female relative. According to Schatz (2007), over a quarter of the households in which an elderly woman resides in Agincourt have one or more fostered children. The implication is that elderly women, as pensioners or household heads, may be financially responsible for fostered or orphaned children. Table 7.6 further reveals that about 5% of the children are maternal orphans which may be due to maternal mortality, AIDS and other causes of adult death.

More than half of the adult population resides with their mother and as some of these adults are likely to live with their children; this means that the majority of adults live in households with two or more generations. Nineteen percent of the adults have mothers that do not live in their household, but do live in the same village or another village in the Agincourt area; these mothers may, however, still be connected to the households of their children, especially when there is a crisis such as an illness or death. Findings from previous studies show that elderly women take on the caregiving responsibilities of children and grandchildren in other households when there is an adult death (Ogunmefun and Schatz, 2008; Schatz and Ogunmefun, 2007). For adults who co-reside with their mother in the same households, they may either head the households or just be members of the households. In such households, mothers who are pensioners may be under an obligation to share their income with their adult children (or grandchildren) especially in times of crises such as adult mortality. However, elderly women who are household heads are likely to have more obligations since they will be responsible for the well-being of members of their household. In order to further explore adult mortality in elderly

female-headed households, elderly female headship and adult mortality in Agincourt are next examined.

7.3.7 Household headship and adult mortality experience of elderly women

As noted earlier in this chapter, almost 50% of the elderly women in Agincourt are household heads (see table 7.4). Since adult mortality has increased in most adult age groups since the mid-1990s in this rural area (Kahn et al., 2007), some elderly female-headed households must have experienced adult mortality. The data in table 7.7 present the elderly female headship status of some of the households that experienced, either adult AIDS or non-AIDS deaths between 1993 and 2004 in elderly women’s households (see chapter six for a full description of adult mortality in Agincourt).

Table 7.7: Elderly female household headship status by household mortality experience

No. of adult death (AIDS and non- AIDS)	Elderly female- headed households (%)	Non-elderly female- headed households (%)	Total (%)
1	86.5	89.4	87.5
>1	13.5	10.6	12.5
N	139	152	291

Of 291 households that experienced either an adult AIDS or non-AIDS death, 139 are headed by an elderly woman. Of these elderly female-headed households, about 87% had one adult death. Of 152 households that are not headed by an elderly woman, 89% also experienced an adult death once. This means a greater percentage of both elderly female-headed and non-headed households had experienced at least one adult death, at one point in time. Since previous findings reveal that elderly women do shoulder the burdens of

adult death in Agincourt households (Schatz, 2007; Schatz and Ogunmefun, 2007), these women might have been impacted by the occurrence of an adult death in their households. Those who are household heads may even be more impacted, than non-heads, as “breadwinners” of their families/households, as they take on the financial responsibilities of adult illness and death. Hence, it is imperative to first test the relationship between elderly female headship status and adult mortality through statistical analyses in the following section, before focusing on the financial impact of an adult death on elderly women in Agincourt in the following chapter.

7.4 Statistical Analyses of the AHDSS data

7.4.1 Household headship and socio-demographic characteristics (Agincourt population)

The socio-demographic characteristics of a household head are important variables to consider when focusing on household headship in a population as they are factors that may, directly or indirectly, influence who becomes a household head when a previous head has left or died, or impact the viability of a household. For instance, pension status may make an elderly person eligible for the position of household head. Pension may also make his/her household economically viable especially if the adult children in the household are unemployed. In order to examine the relationship between household headship (i.e. the headship status of the Agincourt population) and socio-demographic characteristics, logistic regression analyses are used to test the relationship between the dependent variable– household headship and independent variables– socio-demographic characteristics. (See the previous chapter for a full description of the socio-demographic characteristics of the Agincourt population).

The multivariate logistic models³⁸ of household headship on socio-demographic characteristics are presented in table 7.8. The dependent variable, household headship, is coded, such that a code of one is given to household head and a code of zero to non-household head. The independent variables are categorical; they are therefore run as dummy variables³⁹ such that each category of a variable is assigned the values of 1 or 0, indicating the presence or absence of a characteristic (Hair et al., 2006).

Model one is a baseline model of household headship and the variables for age categories; the variables for the other independent variables, except for marital status⁴⁰, are added in the progression of models two to five. The final model shows all the variables in one model. At the 0.05 level of significance, all the independent variables have a significant relationship with household headship. A bivariate model of household headship on each socio-demographic variable also reveals that each socio-demographic characteristic has a significant relationship with the dependent variable (not shown).

³⁸ Each model (in this chapter) displays the odds ratio, the coefficient in parentheses, and an asterisk which represents the level of significance in the model. In the text, the coefficients are used to interpret the direction of the relationship between the dependent variable and independent variables while the odds ratio are used to determine the magnitude of the relationship by reporting the odds ratio or the percentage change in the odds for a one unit change in the independent variable.

³⁹ For valid interpretation, a categorical variable is sometimes changed into a dummy variable. The first step is to decide the number of dummy variables, which is $k-1$, where k is the number of levels of the original variable (Princeton University DSS, 2007). When the dummy variables are created for all levels of the original variable, one level is not coded. Each level of the remaining variables will have a value of 1 or 0 while the level which is not coded will serve as the reference category for the other categories (Princeton University DSS, 2007).

⁴⁰ As mentioned in the previous chapter, information on marital status was collected from women only; it was therefore omitted in the models.

Table 7.8: Odds ratios for logistic regression of household headship on socio-demographic variables (Agincourt population aged 15 and above)

Variables ^a	Models				
	(1)	(2)	(3)	(4)	(5)
Age categories (Adult)					
Near-old	9.075 (2.205)*	11.963 (2.482)*	12.522 (2.527)*	8.136 (2.096)*	8.529 (2.143)*
Older	10.325 (2.335)*	15.205 (2.722)*	25.573 (3.242)*	13.558 (2.607)*	9.595 (2.261)*
Gender (Female)					
Male		3.877 (1.355)*	3.011 (1.102)*	3.374 (1.216)*	4.136 (1.420)*
Employment St. (Employed)					
Unemployed			0.198 (-1.616)*	0.192 (-1.650)*	0.1812 (-1.708)*
Education (No education)					
Primary				0.518 (-0.658)*	0.523 (-0.649)*
Secondary				0.291 (-1.234)*	0.292 (-1.233)*
Matriculation				0.265 (-1.328)*	0.263 (-1.336)*
Higher				0.338 (-1.085)*	0.352 (-1.045)*
Pension Status (Non-pensioner)					
Pensioner					2.124 (0.753)*
Observations	45530	45530	45530	45530	45530
Pseudo R2	0.146	0.201	0.270	0.290	0.296

^a The unknown categories for the variables are excluded as they neither contribute to the interpretation nor the discussion. The reference category for each variable is in parentheses. P<.05*.

In model 1, there is a positive relationship between household headship and the variables for age categories. Those who are in the near-old and older age categories have more chances of becoming a household head than those aged 15-49. The odds of becoming a household are greater for the near-old (than for adults) by a factor of 9.1, while for older people, the odds are greater by a factor of 10.3. Older people have 1.25 greater odds of

heading a household than near-old people. This means older people are more likely to be household heads. This finding is consistent with other studies that show that older people head households especially in rural areas (Noumbissi and Zuberi, 2001; Zimmer and Dayton, 2003). This suggests that ageing may be an important determinant of headship, especially in a rural area like Agincourt and that older individuals continue to occupy the position of household head despite the presence of an adult child.

In model two, gender variables are added and they increase the positive effect of the variables of age categories (near-old and older) on household headship. The variable, male, also has a positive relationship with household headship. The shows that being male increases the odds of household headship by 3.9 and a household head is more likely to be male even when controlling for age.

The two variables that relate to employment status are added in model three. The variable, unemployed, has a significant negative relationship with household headship. Not having gainful employment decreases the predicted odds of household headship by 80 percent. The negative relationship between unemployment and headship suggests that those who are not working have less likelihood of heading a household. This finding is not surprising as the employed may be in possession of resources that, as household heads, they can use to meet the needs of those who co-reside with them and as a result, their households are more likely to be economically viable.

In model four, the variables of education are added. They have a negative relationship with household headship, such that the more education one has, the less likely he/she is to

be a household head, while the education variable reduces the effect of the other variables, except male (gender). The significant negative effect of education on household headship is surprising, however, as it implies that education decreases the likelihood of headship. This may be that education is not a prerequisite for household headship in a rural area like Agincourt where a significant number of households (46%) are headed by the elderly who are less likely to have had access to schooling when young. Model four also demonstrates that the odds of household headship for those with primary education are 48 percent less than for those with no education. This means that those who have primary education have less probability of being a household head, while those with secondary and higher level of education also less likely to be a household head. The negative association of primary and higher levels of education with headship may also be due to the high level of illiteracy among elderly female household heads, as noted earlier.

In the last model, model five, the variables of pension status are added and as expected, being a pensioner has a significant positive relationship with household headship. This means being a pensioner increases the likelihood of being a household head and a pensioner is more likely to be a household head than a non-pensioner. The model shows that there is a 112 percent higher odds of being a head for pensioners than for those who are non-pensioners. Pension status is, therefore, an important predictor of household headship in Agincourt. This result is consistent with model one which shows that the probability of household headship is greater for near-old and older people, who are more likely to be pensioners. It is also consistent with other studies that have shown that African elderly people head their households and also make important contributions to

their households due to their pension status, especially in rural areas (Noumbissi and Zuberi, 2001; Van der Berg, 2002; HAI, 2005b). A study conducted in South Africa also shows that the status of headship is dependent on the willingness of pensioners to share their grants with members of their families/households (Sagner and Mtati, 1999). This means pension status is an important prerequisite for household headship in a rural area like Agincourt.

In sum, the models (in table 7.8) show that the variables of age categories, gender and pension status have a significant positive relationship with headship. This means that these three socio-demographic characteristics have a stronger association with household headship than education and employment status. Therefore, being elderly, male and a pensioner are more likely to characterize a household head, in the Agincourt population, than being educated or employed⁴¹. This implies that even though the elderly make up only 12% of the Agincourt population, they are likely to head their households, especially if they are also pensioners.

7.4.2 Elderly female household headship and socio-demographic characteristics

The results from the descriptive analyses suggest that there may be some factors or characteristics such as widowhood and pension receipt that are likely to define elderly female household heads. In order to further examine the relationship between these socio-demographic characteristics and elderly female household headship, logistic regression analyses are used to test the hypothesis that age, marital status and pension status are

⁴¹ Marital status is left out because it is excluded from most of the models since there is only data for women.

more likely than employment status and education to have a strong relationship with elderly female headship. Elderly female household headship is defined as the position of a household head occupied by an elderly woman aged 50 and above.

The multivariate logistic models of elderly female household headship on socio-demographic characteristics are presented in table 7.9. The dependent variable, elderly female household headship, is coded such that, a code of one is given to elderly female household head and a code of zero to elderly female non-household head. The socio-demographic variables are categorical; therefore they are run as dummy variables such that each category of a variable is assigned the values of 1 or 0.

Model one is a baseline model of elderly female household headship and variables for age categories. The variables for the other independent variables are added in the progression of models two to five. The final model shows all the variables in one model. All the variables of the socio-demographic characteristics have a significant relationship with household headship ($p < .05$), except one of the variables for education.

The baseline model, model one, shows that the variables for age categories have a significant positive relationship with elderly female household headship. Older women aged 60 years and above are more likely to be household heads than near-old women, while being an older woman increases the odds of elderly female headship by a factor of 1.5. This may be as a result of the fact that they are more likely to be widows and thus, become household heads than those aged 50-59 years. This finding is also consistent with

studies that have shown that older women head households, especially because of widowhood (Noumbissi and Zuberi, 2001; HAI, 2002a). It is also consistent with the qualitative data of this study which show that the majority of women in the older age group were widowed, whereas among the near-old respondents, the majority have a spouse that is alive (see appendices D and E).

Table 7.9: Odds ratios for logistic regression of elderly female household headship on socio-demographic variables (elderly women aged 50 and above)

Variables ^a	Models				
	(1)	(2)	(3)	(4)	(5)
Age categories (Near-old)					
Older	1.486 (0.396)*	0.644 (-0.440)*	0.750 (-0.288)	0.816 (-0.203)	0.537 (-0.622)*
Marital Status (Married)					
Divorced		37.023 (3.612)*	35.510 (3.570)*	36.312 (3.592)*	37.638 (3.628)*
Single		16.003 (2.772)*	15.008 (2.708)*	14.811 (2.695)*	15.776 (2.758)*
Separated		36.434 (3.596)*	34.945 (3.554)*	35.793 (3.578)*	36.979 (3.610)*
Widowed		29.270 (3.377)*	29.611 (3.388)*	31.497 (3.450)*	32.325 (3.476)*
Employment St. (Employed)					
Unemployed			0.563 (-0.574)*	0.598 (-0.514)*	0.509 (-0.674)*
Education (No education)					
Primary				1.543 (0.434)*	1.522 (0.420)*
Secondary & above				1.476 (0.389)	1.464 (0.381)
Pension Status (Non-pensioner)					
Pensioner					2.163 (0.772)*
Observations	4822	4822	4822	4822	4822
Pseudo R2	0.007	0.296	0.300	0.304	0.3140

^a The unknown categories for the variables are excluded as they neither contribute to the interpretation nor the discussion. The reference category for each variable is in parentheses.

In model two, the variables for marital status are added to the baseline model and the significant effect of the age category, older, still remains. All marital status variables have a significant positive relationship with elderly female headship as compared to the omitted category (married). Elderly women who are divorced/separated/widowed are more likely to be household head than those who are married. This finding is not surprising because a woman is likely to become a household head because of the death or absence of her spouse.

The variables related to employment status are added in model three and the variables for age categories became insignificant. The variable, unemployed, has a significant negative relationship with elderly female household headship in this model. It reveals that unemployment reduces the odds of elderly female headship by about 44 percent. This means those who are employed are more likely to head a household than the unemployed. This finding is surprising as there is a tendency for elderly women to retire from economic activities when they become pensioners. Findings from the qualitative data of this study demonstrated that majority of the elderly women stopped working when they became pensioners, whereas near-old women who are non-pensioners are actively involved in economic activities such as farming and selling grass mats (see the following chapter). The negative relationship between elderly female household headship and unemployment may, therefore, be due to near-old women who are still actively involved in income generating activities as household heads.

In model four, the variables for education were added; only primary school education has a significant relationship with elderly female household headship compared to no education. Adding education, however, increases the effect of nearly all the variables of marital status and employment status on elderly female headship, while those of age categories remain insignificant; probably due to the stronger effect of the other variables on elderly female headship. The model demonstrates that elderly women with primary education have 54% greater odds of heading their household than those with no education. The variable for secondary and higher education, however, has no significant relationship with elderly female headship. This suggests that beyond primary level, education has no effect on elderly female headship as illiteracy is high among elderly women in rural areas. It may also be that there are few elderly women with secondary and higher education who are also household heads.

In the last model, model five, there is a significant positive relationship between pension status and elderly female household headship. All the other variables also have a significant relationship with elderly female headship except the variable for secondary and higher education. As expected, pensioners are more likely to be a household head than non-pensioners, while being a pensioner increases the odds of headship by a factor of 2.2 among elderly women. The model also shows that pension status has a stronger effect on elderly female headship than the other significant variables except for marital status. This means pension receipt is more likely to characterize elderly female household heads than age, education and employment status. This finding is consistent with another study conducted in Eastern and Western Cape Provinces of South Africa, which show

that pensioners tended to be female, older and household heads (Moller and Ferreira, 2003).

In consideration of the models, as presented in table 7.9 marital status and pension status have the greatest influence on elderly female headship. This, therefore, supports the hypothesis that marital status and pension status have a strong association with elderly female headship. This means these two socio-demographic characteristics, marital status and pension status are more likely to characterize elderly female headship than age, education and employment status. The implication of this is that since the headship status of elderly women is strongly associated with their pension status, they may be under an obligation to use their resources to maintain their households as “breadwinners”. This, however, may have negative consequences for elderly women since the pension grant is primarily meant for them (Ogunmefun and Schatz, 2008). The following chapter further reveals the important role pensioners play in their household in times of crises such as adult mortality. This section (statistical analyses) next focuses on the association between elderly female headship and adult mortality.

7.4.3 Elderly female household headship and household mortality experience

A number of studies have shown that elderly female household headship in sub-Saharan Africa could be linked to early marriage and longer life expectancy of females as well as the absence of other adults in their households (Bongaarts and Zimmer, 2001; HAI, 2002b; De Vos, 2003; Zimmer and Dayton, 2003; HAI, 2004a; HAI, 2004b). Elderly female household headship could, however, be as a result of adult mortality, especially

caused by HIV/AIDS, hence the need to test the hypothesis that there is a relationship between elderly female headship and adult mortality, whether from AIDS or another cause. Using the adaptation of the ABC-X model, Figure 7.1 explicates the connection between elderly female headship and adult mortality. As noted in chapter three, adult mortality is the A factor that has a link with elderly female headship, the X factor. The association between these phenomena is thus examined through logistic regression analysis, as shown below.



Figure 7.1: The connection between adult HIV/AIDS related mortality and elderly female headship

Table 7.10 presents a logistic regression model of elderly female household headship and household adult mortality experience. The dependent variable, elderly female household headship, is coded such that, a code of one is given to elderly female household headship and a code of zero to elderly female non-household headship. The independent variable, adult mortality is coded such that a code of one represents both AIDS death and non-AIDS death⁴², while a code of zero represents no adult mortality.

⁴² For the purpose of statistical analyses which require variables with quantifiable values, AIDS and death from another cause (non-AIDS) were combined in the analyses. Adult mortality in table 7.10, thereby, consists of deaths that occurred to all adults (male and female) aged 15 and above.

Table 7.10: Odds ratio for logistic regression of elderly female household headship on household mortality experience

Variables	Model (1)
Household Mortality Experience	
Adult Mortality	0.946 (-0.055)
Observations	4822
Pseudo R2	0.0001

The model in table 7.10 shows that there is no significant relationship ($p < .05$) between elderly female household headship and the experience of adult mortality in a household, and therefore does not support the hypothesis that there is a relationship between elderly female headship and adult mortality (either AIDS or non-AIDS death). The reasons for this may be as follows:

- In order for the variables in the analyses to have quantifiable values, all the adult AIDS and non-AIDS deaths which occurred over a period of 11 years were combined; therefore, there may be no connection between a death that occurred prior to 2004 and headship status in 2004.
- A study conducted in Agincourt shows that increasing numbers of migrant workers from the study site return home when they become ill so they could be cared for and buried by their families (Clark et al., 2005). This means, in elderly women headed households, adult children who died of AIDS or non-AIDS death might have returned home from the city to be cared for by their mothers. This implies that for those mothers who were already household heads, their headship

was not determined by adult mortality in their homes as it happened prior to the death of their adult children.

- The non-significant relation between elderly female headship and adult mortality could also be as a result of the limitation of the dataset, which was not primarily collected for the study of elderly women and their experience of adult AIDS and non-AIDS death in their households.

Notwithstanding these results, the connection between elderly female headship and adult mortality is a phenomenon that is worth further investigation, especially through qualitative research. The number of elderly women's households affected by adult HIV/AIDS related deaths is increasing in the Agincourt community. Future research in Agincourt could further examine the relationship between adult mortality and changes in headship, as households headed by male adults in the 15-49 age group are likely to experience a change in household headship if the head passes away—and currently, this is a age/sex group that is highly affected by HIV/AIDS.

7.5 Discussion and conclusion

This chapter examines elderly female household headship as a demographic impact of adult HIV/AIDS related mortality in the Agincourt study site. It primarily focuses on the connection between elderly female headship and adult mortality. In addition, it explores the relationship between elderly female headship and pension status.

The descriptive analyses of the quantitative data reveal that even though only 12% of the Agincourt population is elderly, 44% of them are household heads. Of these elderly headed households, 43% are headed by women aged 50 and above. Older women are, however, more likely than their younger peers, to be household heads as they are more likely to be widows. They are also more likely to be pensioners: one of the findings from the logistic regression analyses in this chapter demonstrates that female household headship is strongly associated with pension status. This concurs with findings from other studies in South Africa which shows that pensions are a very important source of income for elderly people, particularly those who are household heads (Moller and Ferreira, 2003; Makiwane, Schneider and Gopane, 2004). Thus, as household heads, elderly female pensioners may use their grant to make important contributions to their households, especially during times of crises such as adult illness and death. In order to shed some light on the contributions of pensions to elderly women's households in times of adult morbidity and mortality, this issue is further investigated through the utilization of qualitative data in the following chapter.

Another major finding from the logistic regression analyses of the quantitative data, however, shows that there is no significant relationship between elderly female headship and adult mortality (AIDS or non-AIDS mortality). This, therefore, does not support the adapted ABC-X model outlining a relationship between the A factor (adult mortality) and X factor (elderly female headship). In other words, the A factor, adult (AIDS and non-AIDS) deaths have no association with the X factor, elderly female headship. The reason for this may be that there are other factors, such as pension status and marital status,

which are strongly associated with headship status of elderly women and therefore determine their status as household heads regardless of the mortality profile of the household. Nevertheless, there is need for future research to examine the relationship between these phenomena especially through collection of primary data rather than relying on secondary data which may limit the investigations, as in this present study. As a result of one of the limitations of the secondary (quantitative) data used in this thesis, that is, it does not contain information on other impacts of adult mortality on elderly women, such as socio-economic and socio-cultural impacts, the following two chapters focus on the analyses of the qualitative data that are primarily collected for this study.

Chapter Eight

SOCIO-ECONOMIC IMPACT OF ADULT HIV/AIDS RELATED MORTALITY

8.1 Introduction

The socio-economic status of a household is usually impacted as a result of a long term illness that is likely to cause an increase in the expenditure on medical care (medicines, transportation to services, as well as allopathic and traditional medical treatment) and food. Additional costs will also be incurred such as mourning and funeral expenses, as well as loss of income/remittance, especially if it is a chronic/terminal disease like HIV/AIDS. The reason for this is that an adult HIV/AIDS related illness and death is likely to reduce the income of a household more drastically than other causes of adult death because the duration of HIV/AIDS illness is longer, and it mostly affects prime-age men and women, that is, those in the productive and reproductive age groups (World Bank, 1993; Barnett and Whiteside, 2002).

As prime-age men and women become infected and ill with HIV/AIDS, elderly women are becoming caregivers to adult children in their households (Ferreira, 2004a; Ferreira, 2004b; HAI, 2004a; HAI, 2004b). These elderly women, with adult AIDS illness and death in their households, not only bear the physical burden of caregiving, but also take on the financial responsibilities related to it; this could have numerous economic repercussions for them. For instance, they may sell their property or go into debt in order to cover the costs of treatment (Knodel and Saengtienchai, 2002), thereby negatively affecting their standard of living or socio-economic status.

In South Africa, where older people receive a non-contributory pension grant, studies have shown how pensioners use this grant to alleviate both poverty (Case and Deaton, 1998; Sagner and Mtati, 1999; Barrientos, 2005) and the socio-economic impact of HIV/AIDS (HAI, 2005b; Booysen and Van der Berg, 2005). According to the ABC-X model (conceptual framework), the degree of the socio-economic impact experienced by an elderly woman is dependent on her perception of caregiving role as well as the adequacy of the pension grant to meet the demands of the crises caused by adult HIV/AIDS related mortality. This thesis, therefore, explores how adult HIV/AIDS related morbidity and mortality as well as perception of caregiving role work together with pension-receipt to lessen or reduce the socio-economic impact of the epidemic in elderly women's households.

One shortcoming of much of the literature on HIV/AIDS and the elderly in South Africa is the focus on those aged 60 years and above, as they are likely to be pensioners, while a large segment of potential caregivers, that is those aged 50-59 years, are left out in the literature. In many African societies, however, people are regarded as elderly when they start having grandchildren. As a result of the attainment of motherhood at an early age, many women are already grandmothers by the age of 50. As elderly people, they face the same challenges as those over age 60. For instance, near-old women, like those aged 60 years and above, are likely to be involved in giving care to adult children infected with AIDS and orphaned and fostered grandchildren.

There is little empirical evidence of how HIV/AIDS impacts near-old people aged 50-59 years, who are, for the most part, not yet pensioners. In order to begin to fill this gap, this study focuses on the socio-economic impact of adult HIV/AIDS related mortality on both near-old and older women. This chapter explores the contribution of pension grant to the economic well-being of elderly women's households that experienced adult morbidity and mortality. In particular, it focuses on whether older women are more likely than near-old women, to have access to a broader range of coping strategies when there is an adult AIDS or non-AIDS death in their households. In the sections below, qualitative data are used to examine the caregiving roles of near-old and older women, their socio-economic status, their coping strategies at the time of adult illness and death in their households, and lastly, their levels of recovery after the crises.

8.2 Older and Near-old Caregivers

As demonstrated in the methodology chapter, 30 near-old women (aged 50-59 years) and 30 older women (aged 60-75 years) were interviewed about caregiving of the sick and orphan/fostered children, pension usage, beliefs about and experiences with HIV/AIDS, and the socio-economic impact of the epidemic on their lives as elderly women. Despite stratifying the sample by household mortality experience, such that there were 20 households with no adult death between 2001 and 2003, nearly all the respondents had experienced adult mortality or morbidity in their households or extended kin networks. Some of them experienced deaths prior to 2001 and some after 2003, which were the sampling cut-offs set for mortality experience in the households sampled in this study⁴³. One of the respondents lost her husband a few months before the interview took place. A few of the respondents'

⁴³ See chapter four for a full description of the sample and fieldwork.

experiences of adult illness and death, especially when due to HIV/AIDS, was because of a kin living in another household. The data in table 8.1 reveal the kin the respondents gave care to by household mortality experience.

Regardless of age, almost all the respondents had been involved in giving care to kin (table 8.1). Out of 60, 58 respondents said they had or are currently taking care of at least one loved one⁴⁴. More than half of the respondents had given care to an adult child; however, older women were more likely to report giving care to an adult child, while near-old women were more likely to report giving care to a spouse. The reason for this may be a result of older women having matured adult children, who could have gone out to work in the city and then come back home for caregiving when ill. According to Clark et al. (2005), many prime-age migrant workers do return home to Agincourt when ill (with AIDS) to be cared for and buried by loved ones. Another reason may be that spousal illness was more recent and prominent in the lives of the near-old women since they are less likely to be widows (see appendix E).

Table 8.1 : Caregiving for the sick

Household Mortality Experience	Near-old (N=30)			Older (N=30)		
	Adult Child	Spouse	Other Kin	Adult Child	Spouse	Other Kin
AIDS Household	8	1	1	9	1	0
Non-AIDS Household	2	5	2	6	3	1
No Death	3	3	4	6	1	2
Total (N=58)	13	9	7	21	5	3

⁴⁴ Some of the respondents reported that they also took care of another kin, besides their child. Since this study focuses on the effect of adult illness and death, the table only takes account of caregiving for at least one adult child except in cases where a respondent reported giving care to either a spouse or another kin only.

There is not much difference in the number of near-old and older women in AIDS households who reported that they took care of an adult child. Whereas, older women in non-AIDS and no death households are more likely than near-old women in non-AIDS and no death households to have taken care of an adult child. This may be that older women experience more adult deaths in their house since, as noted earlier, they have more adult children that are either at risk of becoming infected with HIV/AIDS or getting involved in violence or motor vehicle accident (other leading causes of adult death in Agincourt).

In sum, nearly all the elderly women in this study, whether above or below age 60, have experienced adult morbidity in their households. The sub-sections below further shed light on their personal experiences with adult illness in their household.

8.2.1 Caregiving roles of near-old and older women

As summarized in table 7.1, almost all the near-old and older women had taken care of a loved one at one point or another. Findings from prior research show that most of the older women found caregiving overwhelming, as it includes a diverse array of activities and financial responsibilities (Ogunmefun and Schatz, 2008; Schatz, 2007). These respondents reported that their caregiving activities include bathing, fetching and preparing treatments and helping their patient to the toilet (Schatz, 2007). The caregiving experience of near-old women does not differ from that of their older counterparts. Most of the near-old respondents also described their caregiving roles as very involving as they had to take care of their patient from morning to night and their caregiving activities include bathing, cooking, feeding, carrying or escorting to the toilet (which is usually outside the house), washing soiled clothes

and blankets, escorting to the doctor or traditional healer, helping with treatments, and sleeping in the company of their patients at night in case they need attention.

In her narrative⁴⁵, Agnes, a 53 year old woman, shows how a caregiver is closely involved in the day-to-day life of a patient. She said:

In the morning, I washed him [her son], prepared his breakfast, cleaned his room, and washed his clothes. On some days, I took him to the hospitals and *sangomas* [traditional healers]. It was difficult to wash his faeces as an adult and to carry him to the hospital on my back... (Agnes, Near-old woman, AIDS household).

Like Agnes, Mumsy (aged 73 years) took care of an adult child. She described her caregiving tasks:

When [my daughter] became sick...it was painful for me. I was doing her washing, cooking... I even stayed with her during the night (Mumsy, Older woman, Non-AIDS death).

Both Agnes and Mumsy's descriptions of the arduous tasks of giving care to an adult is similar to what other near-old and older respondents reported in this study.

Respondents' perception of caregiving role is also reflected in their narratives as many felt obliged to care for a sick adult child. Both near-old and older respondents reported that they had to care for the sick, either because he/she was related to them or the person was resident in their household at the time of sickness. Melody, a 58 year old widow, recounted her caregiving experience:

⁴⁵ Quotes from the respondents are followed by a pseudonym, age category and household mortality experience.

Yes, I was looking after my daughter who passed away. She was ill for some months. She told me that she was not feeling well. All her body parts were painful. I tried traditional *muti* [medicine], it didn't work.... [I had to care for her] because she was staying with me in my house...She was unable to wash herself so I helped her by giving her a bath. I was cooking soft porridge, and cleaning her house (Melody, Near-old woman, Non-AIDS household).

Esther, one of the respondents who had no death in her household in 2001-2003, was also compelled to care for a household member, like Melody. In her case, it was a mother-in-law:

When I woke up in the morning, I would give her a bath, cook soft porridge and wash her clothes. In the afternoon, I would [also] cook for her... I was bound to look after her because she was my mother-in-law, and she gave birth to my husband (Esther, Near-old woman, No Death Household).

Notwithstanding the overwhelming roles described by these caregivers, both near-old and older respondents felt obliged to perform them, regardless of whom the patient was, as noted in their narratives. Suffice (it) to say, involvement in caregiving tasks is unavoidable for elderly women due to the gender roles they are expected to play in their household/family.

In addition to the fact that some elderly women, like Esther and Melody, feel they are obliged to take care of a sick relative, they may have no other choice but to do it as there is no one else willing to take care of an HIV infected person. When Khosi, a 52 year old

widow, who took care of her HIV positive daughter for two years, was asked about her she got her caregiving role, she said:

I am her mother [so] I have to take care of her. No one will volunteer to take care of someone who is seriously ill with AIDS because they are scared of being infected (Khosi, Near-old woman, AIDS household).

Whether due to compulsion by tradition or sense of duty among elderly women, it may be odd or rare for an elderly woman not to be involved in caregiving responsibilities, especially in a rural and close community such as Agincourt. As a result, most of the near-old and older respondents reported that they shouldered the responsibility of physical caregiving to their sick loved ones.

The caregiving role of elderly woman may also be shaped by their culture or social norms. A couple of the near-old and older respondents cited culture as the reason for their caregiving roles. When Agnes was asked why she took care of his son instead of his wife/partner, she replied:

Our culture doesn't allow someone whom you didn't pay *lobola* (bride price) on to take care of you when ill. That is why I had to take care of him for those six months he was seriously ill, while his wife moved back to her parent's place (Agnes, Near-old woman, AIDS household).

As a result, she bore the brunt of caregiving for her son without getting any support from her son's wife (or partner). According to Akinsola (2000), family members, especially elderly women, bear the burden of care because social norms in Africa do not permit people to reject kin who are experiencing a serious problem, particularly a serious illness.

An individual who rejects kin in such a situation is labelled a witch. It is even more risky for elderly women to show lack of concern for a relative who is seriously ill, especially in traditional African communities, where older women are sometimes unfairly suspected of practicing witchcraft (Akinsola, 2000). Therefore, another motivation potentially binding elderly women to caregiving for infected kin in a rural community like Agincourt is the desire not to be accused of witchcraft. Although this may be an underlying factor in this community, none of the elderly women in this study mentioned suspicion of witchcraft as the reason for their involvement in caregiving, but rather, they described being bound to do it due to the cultural or social norms surrounding caregiving in traditional societies. The sensitivity of the topic of witchcraft may also have impacted the respondents' unwillingness to disclose such motivations.

As a result of social norms in traditional societies, other household/family members are expected to assist the main caregiver with caregiving tasks. The onus of assisting with caregiving is also likely to fall on other female household members due to gender roles. When asked, the respondents who received some assistance reported that they were assisted by other kin such as their daughters-in-law, co-wives, children, aunts and (female) neighbours; thereby reinforcing the notion of the “gendered” nature of caregiving role. Pearl was assisted by her daughter-in-law when her (Pearl's) husband was sick. She said:

I was cooking for him, washing his clothes and taking him to the hospitals. I also went to collect *muti* [medicine] from the *sangoma* [traditional healer]. My daughter-in-law helped me to take care of him” (Pearl, Older woman, Non-AIDS household).

Pearl must have been relieved when her daughter-in-law assisted her with the caregiving tasks. A few of the respondents were not so fortunate. A couple of the respondents even complained bitterly about how a daughter-in-law did not care for their son (their daughter-in-law's partner) when he fell ill in the city before later returning home. One of them said:

He had diarrhoea and was thin. He was unable to get up to eat. He was just [like] an ordinary thing. He had been ill for long but his wife kept quiet. ...She [just] gave him cold drinks, locked the door and went off to work...I didn't see her since she left after the funeral. She didn't care ... because my son didn't pay *lobola*; they were just staying together (Zodwa, Older woman, AIDS household).

Zodwa's daughter-in-law must have felt she was under no obligation to care for her partner since they were not legally (or traditionally) married. This left Zodwa with no other option but to take over the responsibility of caring for her son. Notwithstanding the presence or absence of a daughter-in-law or other kin to assist them, elderly women are likely to be involved in caregiving responsibilities, whether the patient is a close relative like a child/spouse or an in-law.

Elderly women's caregiving responsibilities could sometimes be extended to grandchildren and great grandchildren who co-reside with them in their households. Nearly all the respondents live with their grandchildren and one sixth live with their great grandchildren. Some of these grandchildren and great grandchildren live in their households due to the death of their adult children. Other reasons for having fostered grandchildren and great grandchildren in a household include migration and non-marital

births⁴⁶. Co-residing with grandchildren could increase the caregiving burdens of elderly women because they may have to care for a sick adult child and their grandchild at the same time. For instance, Prudence had to care for her sick daughter and her daughter's child for one year. She recounted her caregiving experience:

It was not easy because she had a child who was very small. I had to look after the mother and child. I must always stay near her and whenever she needed water, I would go and give her (Prudence, Near-old Woman, AIDS household).

Most of the respondents who co-reside with their grandchildren and great grandchildren reported that their caregiving roles include bathing, cooking, washing for these children. Elderly women, therefore, do not only have caregiving roles as mothers but also as grandmothers.

8.3 Socio-economic Status of Elderly Women

When elderly women take over the physical responsibilities of caregiving, they take over many of the financial responsibilities of giving care to the sick and orphaned/fostered children as well. Elderly women may use the resources available to them to take care of the financial responsibilities of caregiving. The adequacy of these resources to meet the demands of the financial crises in their households will determine the degree of the socio-economic impact of adult illness they experience, thereby their socio-economic status. In order to explore how household mortality experience could affect the socio-economic status of the 60 elderly respondents in this study, a wealth index⁴⁷ was created during the

⁴⁶ Non-marital births are those that occurred to unmarried daughters of respondents.

⁴⁷ During the fieldwork, the interviewers were asked to create a wealth index for all the respondents based on household size and appearance of wealth. After assessing size and appearance of wealth, the

fieldwork to assess the socio-economic status of the respondents. The wealth index was based on each respondent's household size and appearance. After assessing size and appearance of wealth, an internal comparison was used to put each household into a below average, average, or above average category. The data presented in table 7.2 shows the socio-economic status of near-old and older women by household mortality experience.

Table 8.2: Household mortality experience and socio-economic status of near-old and older women's households

Household Mortality Experience	Near-old women (N=30)			Older women (N=30)		
	Below Average	Average	Above Average	Below Average	Average	Above Average
AIDS Household	5	5	0	7	1	2
Non-AIDS Household	2	4	4	4	2	4
No Death	3	6	1	4	3	3
Total (N=60)	10	15	5	15	6	9

It is surprising that (since their pension was supposed to be a booster for their socio-economic status), older women's households were more likely to be categorized as below average, while near-old women's households were more likely to be categorized as average. The reason the majority of the older women lived in a below average household is not certain, but adult illness/death may be a factor to be taken into consideration as they were more likely to have taken care of an adult child as demonstrated in table 8.1; this

interviewers used an internal comparison to put each household into a below, average or above average category. There was a focus on the well-being of the respondents within the households, as some respondents may not have had access to household-wide assets. In one particular case, one respondent lived in a compound that had a modern house, a small truck and a tractor (owned by her late son). This household could have been above average, but the interviewers categorised the respondent as poor because she stayed with 4 grandchildren in a small hut (in the same compound) with no bed to sleep on.

could have affected their socio-economic status because of resources used during caregiving and income/remittance lost if the adult child was contributing to their households.

The categorization of the majority of near-old women's households as average, may be due to the fact that they are less likely to be pensioners, so they are involved in economic activities that could help them to recover from the financial impact of adult death to an extent, but not to recover fully. In addition, near-old women are more likely to still have a spouse alive than older women, so their spouse could share the financial burdens of caregiving with them. Does this mean that near-old women would be able to cope better with the financial impact of adult mortality since such resources are available to them? Or would older women have a greater advantage due to their pension income? These issues are examined later in this chapter.

In order to further examine how adult mortality affects the socio-economic status of all the elderly women in this study, both near-old and elder women are combined in table 8.3. Of 25 elderly women's households categorized as below average, 12 had experienced an adult AIDS death, while only six had an adult non-AIDS death in their households, between 2001 and 2003. This may be due to the greater impact of AIDS illness and death in these households as the duration of AIDS illness is longer than most illnesses, therefore, it incurs more expenses. According to the World Bank (1993), the economic impact of AIDS is greater than other diseases for two reasons: it mainly affects adults in their productive years and people with AIDS are prone to infections such as pneumonia,

diarrhoea and tuberculosis, which lead to heavy demand for expensive health care. Thus, elderly women in these households with AIDS would have taken care of the expenses incurred during the illness and death of their patient, thereby affecting their socio-economic status.

Table 8.3: Household mortality experience and socio-economic status of all elderly women's households

Household Mortality Experience	Mortality		
	Below Average	Average	Above Average
AIDS Household	12	6	2
Non-AIDS Household	6	6	8
No Death	7	9	4
Total (N=60)	25	21	14

Of 21 elderly women's households categorized as average, nine did not experience an adult death, while the rest had an adult AIDS (6) and non-AIDS death (6) in the designated period. The households categorized as above average were more likely to have had an adult non-AIDS death than those categorized as either average or below average. This may be that it is easier for a household to recover from the economic impact of an adult non-AIDS illness and death than a long term illness such as AIDS, especially if there is a regular income like a pension grant in the household. This implies that pension-receipt reduces the degree of socio-economic impact of an adult death on elderly women. In order to explore the difference a pension grant could make with regard to the socio-economic status of elderly women's households with adult mortality, the following section focuses on pensioners and non-pensioners.

8.3.1 Socio-economic status of elderly women and pension grant

Studies have shown that elderly female pensioners usually use their grant to cope with the financial impact of adult mortality in their households (HAI, 2005b; Booysen and Van der Berg, 2005; Moller and Ferreira, 2003). This is likely to help them recover from an adult death and also improve their socio-economic status, unlike elderly women who are non-pensioners. The household mortality experience and the socio-economic status of pensioners and non-pensioners are examined in table 8.4. Out of 60 near-old and older women, 33 are pensioners, while 27 are non-pensioners⁴⁸.

Table 8.4: Household mortality experience and socio-economic status of pensioners and non-pensioners

Household Experience	Mortality	Pensioners (N=33)			Non-pensioners (N=27)		
		Below Average	Average	Above Average	Below Average	Average	Above Average
AIDS Household		7	2	2	5	4	0
Non-AIDS Household		4	3	5	2	3	3
No Death		5	3	2	2	6	2
Total (N=60)		16	8	9	9	13	5

Even though there is a notion that pensioners' households would have a better socio-economic status than non-pensioners, it is interesting to note that nearly half of pensioners' households were categorized as below average, while nearly half of non-pensioners' households were categorized as average. This may be that pensioners are more likely to be women above age 60, who are likely to experience the illness/death of an adult child. It may also be because many of the pensioners are widows (aged 60 and

⁴⁸ Despite ages registered in the Agincourt census as above/below age 60 respectively, only one of the older women had not started getting a pension grant while four of the near-old women were already pensioners at the time of the fieldwork.

above), therefore, they do not have spouses to share the financial responsibilities of caregiving with. This would make them to bear the brunt of the disease unlike most of the non-pensioners who are younger and more likely to have their spouses alive with whom they could share the financial responsibilities of caregiving⁴⁹. Nearly two thirds of the non-pensioners, who are near-old, have a spouse that is alive (two are divorced). For half of those with a living spouse, he is either working or receiving a pension grant. On the other hand, only five pensioners who are older women still have a spouse that is alive (and four are divorced) (see appendix D). The non-pensioners, who are near-old, are therefore likely to get financial support from their spouses during times of crises such as adult illness/death in their households.

There are, however, more pensioners (nine versus five) who are above average, probably because of their regular pension income. In order to closely examine the role of pensions in elderly women's households, especially in times of crises such as adult illness and death, the following section explores near-old (non-pensioners) and older women (pensioners) as well as the strategies they adopted in order to cope better with caregiving for adult children and grandchildren.

8.4 Coping with the Financial Costs of Adult Illness

As demonstrated in table 8.1, two thirds of the older women, who are more likely to be pensioners, had taken care of at least one adult child, while the rest had taken care of a

⁴⁹ Findings, later on in the chapter, show that non-pensioners are more likely than pensioners to report getting support from their spouse in times of crises.

spouse or a kin. Near-old women, who are less likely to be pensioners⁵⁰, had also taken care of the sick at one point in time. More than one third of these near-old women had taken care of an adult child, while nearly one third had taken care of a spouse. Regardless of whom the recipient is, caregiving demands a lot from caregivers, especially when they are elderly women. This is because, in addition to the physical and emotional strain caregiving may cause, it has financial demands attached to it. These demands may have a particularly dire economic impact on older women like those in this study, because they are likely to use the pensions that are meant for their own subsistence to meet caregiving demands (Schatz and Ogunmefun, 2007). The economic impact of caregiving may be even greater for near-old women who do not receive pensions. This is because sickness, especially a long term one like HIV/AIDS, increases the expenditure on medical care and food. Thus, adult illness, especially when caused by HIV/AIDS⁵¹, is likely to have financial impact on both near-old and older women and their households.

The older respondents were asked about their caregiving experience and nearly all of them reported that caregiving was difficult due to expenses incurred during sickness and death. They reported that they had to rely on their pension money. When Chelsie, a 71

⁵⁰Even though the sample of near-old women aged 50-59 was selected such that there would be no pensioners among them, surprisingly, four near-old respondents had already begun receiving a pension at the time of fieldwork. One of them said she has been on a disability grant for a long time but was recently changed to an old-age pension. The other three said they started getting pension grant recently so the pension income had not yet been accessed when they cared for a sick household member or when that household member died in the recent past.

⁵¹ Due to its long duration, an HIV/AIDS illness is likely to have more financial impact on a household than another adult illness; however, it is difficult to differentiate between the impact of adult AIDS and non-AIDS illness (and death) from the narratives in this study. The reason for this is because some respondents only had their HIV positive child with them for a few weeks while others refused to mention that they cared of an HIV infected patient due to the stigma surrounding the disease, as explicated later in this thesis.

year old widow, was asked how she used her pension money at the time of sickness, she reported:

I used it to take the sick person to clinics and hospitals. I also used it to pay them at the hospitals and buy food and other needs (Chelsie, Older woman, AIDS household).

Like Chelsie, most of the other older respondents used their pension money for taking their sick loved one to the hospitals or doctors. They reported that their pension money was also used for other caregiving needs such as payments for medical consultation, medicines from a pharmacy, traditional healers, traditional medicine, special food and fruits, prayers from pastors/prophets, and transport to take their patient for treatment. A few said they resorted to borrowing money, which they had to pay back with their pension money.

Most of these older respondents could not, however, recall the total amount they spent on sickness, as the money they spent varied from time to time and from day to day. Another reason for difficulty in recalling exact amounts spent was because the majority of them had opted for multiple means of treatment in desperation to get their kin cured. Thus, there were cases of respondents taking the same sick person to doctors/hospitals (for Western medicine), traditional healers (for traditional treatment) and pastors/prophets (for spiritual healing). Sometimes, there were multiple visits to these different places of treatment. So, it was difficult for most respondents to recall the total amount of money spent on all these various treatments. “Medical pluralism—the co-existence and availability of different ways of perceiving, explaining and treating illness”, is

widespread among the African population in South Africa because of the need to seek supernatural explanation for illness which, according to their thinking, is not in violation of scientific principles (Muller and Steyn, 1999). This phenomenon is likely to become more rampant in this era of HIV/AIDS, especially if efforts by Western medicine to find a cure for HIV/AIDS continue to be of no avail; and people continue to attribute the signs and symptoms of HIV/AIDS to witchcraft and sorcery, as demonstrated in some studies (Yamba, 1997; Bond, Chase and Aggleton, 2002 and Kalichman and Simbayi, 2004).

Among those who resorted to medical pluralism, a few older women were able to give an idea of how much it would cost to take a patient for different treatments. Auphrey, a 66 year old woman, was one of the respondents who used her pension money to pay for multiple treatments for her sick adult child. She said;

I paid the *sangoma* [traditional healer] R200. I hired a car twice which cost R400. The money I used to go and greet her in the hospital was R20 per day. She stayed [in the hospital] for two weeks. I spent [approximately] R200 (Auphrey, Older woman, AIDS household).

Altogether, Auphrey spent R800 for multiple treatments but she excluded other expenses from her calculations, such as buying food to take to the hospital for her daughter. The timeframe of her daughter's illness may also have been greater than what she reported given that HIV/AIDS has a longer duration than other diseases. It is likely she was taking care of her daughter for several months in addition to the crisis period she outlines. Due to these reasons, it is difficult to quantify the total amount of money the older respondents

spent when a loved one was ill. It is also difficult to differentiate the expenses of adult AIDS illness from adult non-AIDS illness.

Only a few respondents were able to give an estimate of how much they spent. Nomsa, a 67 year old woman, took care of her sick daughter for a long period. She recounted:

I used my [pension] money when I took my daughter to Link Pharmacy and they gave her medicine. I spent R200. I also took her to the hospital. I spent [in total] between R2000 and R3000 (Nomsa, Older woman, Non-AIDS household).

Since R2000 or R3000 is three to four times beyond Nomsa's monthly pension, this suggests that the expenses were incurred over a period of time or that she borrowed other money against her pension, if accrued over a shorter period. Notwithstanding, it was evident that Nomsa and the other older respondents had no choice but to rely on their pension grant, during an adult illness in their households.

The near-old women, like older women, also reported that it was difficult at the time of an adult illness in their household. They had to deal with the kind of adult illness expenses that older women dealt with as well. Even though most of them could not report how much they spent, a few, like Sylvia, gave an idea of how much it cost her;

I can't tell exactly but I remember that I paid R100 to a *sangoma* [traditional healer] and R150 to another *sangoma* in another village. I spent R35 for medicine at the pharmacy. I paid R100 for transport (Sylvia, Near-old woman, AIDS household).

However, there was no mention from Sylvia and the other non-pensioners, of a regular income to rely on at such a time, like the pensioners reported.

Melody was one of the near-old respondents that had no regular income to use when there was a death in her household. She said:

I didn't have enough money to look after the sick [her daughter]. And, no one helped me... It was not easy. Sometimes I had to borrow money to pay for a car to take her to the hospital (Melody, Near-old woman, Non-AIDS household).

Khosi also had to resort to borrowing, which could worsen the situation as she did not have access to a regular income such as a pension grant which could be used to pay back her debts. She reported:

Ha! It was very difficult. I can remember a day when I wanted to take her to the hospital and I didn't have any money so I had to walk to my relatives in [another village] to ask for the money. They gave [it to] me, and then I took her to the hospital (Khosi, Near-old woman, AIDS household).

Absence of pension may, therefore, make caregiving more difficult for near-old women, like Khosi, who had to trek to another village to borrow money to take her daughter to the hospital.

Even though a few non-pensioners and pensioners both reported that they borrowed money at the time of adult illness in their household, the pensioners were able to use their pension money to pay back their debts, while non-pensioners might have found it difficult to pay back such debts due to the absence of a regular income. As a result, near-old women are more likely to struggle to cope with adult illness in their household.

8.5 Coping with the Financial Costs of Adult Death

Even though the majority of the near-old and older respondents found it difficult to recall the exact amount they spent on a loved one when sick, some were able to estimate the amount spent when he/she died. The respondents reported that the expenses incurred at the death of a loved one include payment to transfer a corpse from hospital to mortuary, for coffin, burial, food and mourning period. Some respondents said they spent between R1, 300 – R1, 800, while some recalled they spent as much as between R3, 000 – R7, 000. No matter how much was spent, both the near-old and old respondents said it was difficult for them financially at the time of an adult death in their households.

Many of the non-pensioners, however, reported that they went through numerous difficulties at the time of death of their loved ones as they could not afford some of the expenses. Hence, they could not give their loved ones a “respectable” burial which, in this community, entails providing food and drinks for family and friends who came to mourn with the bereaved, as well as burying the departed in a decent wooden coffin⁵². Bulelwa, a 57 year old widow, was one of them. She took care of her husband who was ill for 10 years with a kidney problem and later died. She related her experience:

My husband’s corpse was never at the mortuary. He died here at home inside this house. We used planks to make a coffin, which we bought from someone in the village. I spent R200 to buy the planks to make a coffin [At his funeral], people never ate, they just came to bury my husband and they went back home

(Bulelwa, Near-old woman, No Death Household).

⁵² During the fieldwork, two of the interviewers lost a relative so the author had the opportunity to attend what could be regarded as ‘respectable’ funerals. She observed that many people from surrounding villages attended the funerals and some stayed with the bereaved for a few days, while they are catered for by them.

Like Bulelwa, Kgomotso could not afford a decent burial for her daughter. She said:

It was difficult... and my heart is sorrowful whenever I remember it. It was difficult because I didn't have money to buy food for the people who came to mourn so nothing was prepared for them. Also, I didn't have enough money to buy a coffin (Kgomotso, Near-old woman, No Death Household).

Since cultural and social obligations entail giving the departed a proper burial (HAI, 2003c), as noted earlier, failure to do so is likely to affect those left behind psychologically, as in the case of Kgomotso and other near-old women in this study who expressed their regrets, as shown later in this chapter.

The older women, however, were more capable than near-old women to deal effectively with the expenses because of their pension status. In their narratives, they mentioned some strategies that they adopted as pensioners to help them to deal with these expenses. Some of them adopted these strategies even before a death occurred in their households; these include membership of a burial society, church group, and women's group. These coping strategies were available to them because they were creditworthy as pensioners. These strategies were not available to most (elderly) non-pensioners, however, as they were not receiving a regular (pension) income. Studies conducted in South Africa have shown that pensioners are likely to be creditworthy because of their regular income and therefore, able to borrow money when in need of extra cash or join a burial society /church group (Moller and Sotshongaye, 1996; Ferreira, Keikelame and Mosaval, 2001). In rural Namibia, Devereux (2001) also found that pensioners are considered to be reliable customers by shop owners as they are more likely to pay off their accumulated

debts than even teachers. The sections below explore how elderly women who are pensioners adopted some strategies to deal with the financial expenses of an adult death in their households, while those who are non-pensioners found it more difficult to cope with the crises.

8.5.1 Joining a burial society

As elderly people near the end of their life, they are concerned with practical arrangements such as who will inherit what, and how they will be given a befitting funeral. Thus, in order to ensure there is enough money to meet social obligations around funerals, some people become members of a burial society/scheme (HelpAge, 2003c). A burial society/scheme could either be formal, that is, organized by registered organizations/companies/banks, or informal, that is, organized by members of a community. In some informal schemes, a collection is taken from members of a community when a person dies, while in formal schemes, members contribute money regularly and this fund is given to the family of a member when he/she dies or to a member who loses a loved one (HelpAge, 2003c).

All the pensioners, except seven, reported that they either joined a burial society or had been registered by their family member. The majority of the non-pensioners⁵³ said they had not joined because they could not afford the dues. For these elderly women, becoming a member of a burial society is a form of insurance against the financial shock of taking care of funeral-related expenses when a death occurs in their family, while most

⁵³ Only six near-old respondents have membership of a burial society, including two who had started receiving pensions. Thus, only four non-pensioners were members of a burial society.

non-pensioners have to rely on social networks or social capital, as shown later in this section.

Ferreira, Keikelame and Mosaval (2001) also found that membership of a burial society was widespread among pensioners in their study, therefore, making provision for a funeral through this insurance. In addition, burial society dues featured in two-thirds of household expenditure lists. Another research project found that the household expenditure of female pensioners in KwaZulu-Natal, South Africa, usually included burial society dues (Moller and Sotshongaye, 1996). The respondents in this present study also reported that the burial society dues are part of the household expenditure for which they use their pension money. Many of the women said that they did not only register themselves but also some members of their families such as their children or grandchildren. In many cases, an elderly woman gets the benefits if one of her registered family members dies, while they receive the benefits if she passes away. Registered family members who are covered by the insurance, therefore, benefit from the coping strategy adopted by these elder women as well.

The burial society monthly dues that the elderly women pay ranged from R20 to R70, which is less than ten percent of their pension income. Even though the amount spent by these pensioners on burial societies may be huge for them, the benefits are worthwhile. Maria, a 67 old divorcee, was one of the respondents who joined a burial society. She pays a monthly due of R30 to her burial society and registered three grandchildren in her

household whom she chose because two of them are orphans, while one is fostered. When asked about the benefits she would get if one of them dies, she replied;

The society will help me by giving me a coffin, a bag of *mielie-meal*, 12.5 kg of sugar and flour, R200 cash and ten chickens (Maria, Older woman, Non-AIDS household).

Many of the respondents reported similar benefits from their burial society. Tebogo, a 68 year old widow, who was assisted by her burial society when her husband died, said, “[During the death of my husband], the burial society gave me some money [R1, 500] and a coffin” (Tebogo, Older woman, Non-AIDS household). Tebogo confirmed that she received some from her husband’s burial society after his death. This must have relieved Tebogo’s financial burdens. This is because such benefits are more than likely to ease the financial impact of an adult AIDS death in elderly women’s households, especially if a coffin is included or if they are given enough money to buy one since the purchase of a coffin is a major funeral-related expense. One of the respondents also believes getting a coffin or being able to pay for one is the main benefit of joining a burial society. When asked whether the benefits from her burial society would be sufficient, she said, “It would be enough for me as long as I get a coffin” (Mumsy, Older woman, Non-AIDS death).

It is obvious from the narratives of the respondents that joining a burial society, made possible by their pension income, is an important strategy for pensioners, as this enables them to manage the financial shock of death in their households. Joining a burial society seems crucial for them, probably due to the high rate of adult deaths in their community

(Kahn et al., 2007). Having membership of a burial society is not, however, the only option available to them as pensioners in their community.

8.5.2 Joining a church group and women's society

As mentioned earlier, there are other means by which elderly women who are pensioners deal with the financial expenses of death in their household. Anna, a 60 year old divorcee explained another strategy in her narrative;

I joined the church group in 2001. We are many. It is mixed [i.e. male and female]. We pay R10 every month and when someone dies, we contribute R2 each on the day of mourning. We also give the bereaved R500 from the R10 we pay every month. And, my turn [will come] when someone in my house dies (Anna, Older woman, No death household).

Joining a church group is, therefore, another form of insurance against the financial shock of unexpected (or may be anticipated) death for elderly women. Only one non-pensioner reported that she joined a church group because most of them could not afford regular contribution of money, as shown later in this chapter. Whereas a few of the pensioners said they joined a church group in addition to a burial society. The dues for membership of a church is usually small, i.e. approximately R10, it would, therefore, be convenient for these respondents to be members of both a church group and a burial society, especially when there are likely to get more financial assistance when they lose a loved one.

Besides joining a church group, elderly women, especially those who are pensioners, could join a *makoti* society [women's society], which also provides financial assistance in the time of death in their household. Mumsy explained how she became a member of a *makoti* society;

I joined a *makoti* society. We had a meeting in our family before a death occurred and discussed [the need for] a *makoti* society. [We said] as long as someone bears our surname and is a relative, she could join the society [so that] we could help one another during the time of death. We donate R10 each and have a meeting after every two months. When someone loses a member of her family, she gets R800... During the death of my daughter, the money helped me to buy food to give people who came to visit us (Mumsy, Older woman, Non-AIDS household).

Taking the initiative to create and/or join a society like this, even before a death occurs, would, therefore, also help elderly women to cope better with the financial expenses of death when it eventually occurs in their households. Even though four non-pensioners were able to join a *makoti* society, only three of the pensioners reported that they joined one. This may be that most pensioners preferred to join a formal burial society, which does not involve regular meetings like a church group or women's society, whereas the few non-pensioners that joined had no other option.

Burial societies may have advantages that make them more appealing than church groups or women's societies. For example, many pensioners reported that they pay their burial society dues immediately they collect their pension at the pay point. This is because the burial societies usually send their representatives to pension pay points on pension day to

collect dues from their members. Collection of burial society dues at the pay point, therefore, makes it more convenient for elderly women to be members of burial societies rather than a *makoti* society, as some may find attending a meeting or gathering stressful. However, the choice of whether to join a formal burial society or church group is a luxury reserved for those who can afford it, namely pensioners, since the majority of the non-pensioners said they could not afford paying any dues. Without access to these various insurance schemes, non-pensioners primarily rely on their social capital in times of financial crisis.

8.5.3 Depending on Social Capital

Social capital refers to people's ability to secure benefits by virtue of membership of social networks or social structures that sometimes extend beyond their immediate family (Hawe and Shiell, 2000; Cattell, 2001; Wakefield and Poland, 2005). In other words, membership of a social group, e.g. in a community, confers obligations and benefits on individuals (Portes, 1998; Hawe and Shiell, 2000). Therefore, this enables people, especially in a close community, to support one another in times of crises.

Dependence on social capital is another way in which elderly women could take care of funeral-related expenses. As a result of the close community in which they live, most of the near-old and older women reported that they received financial assistance from their family and community members. Chelsie explained how the community supported her when her son died:

They came and supported me by giving me *mielie-meal* [maize meal]. Some came to cook at my home, while some slept and prayed with me. Some also donated some money to buy groceries which were needed for the funeral (Chelsie, Older woman, AIDS household).

Other respondents reported getting assistance from their spouse (mostly near-old women), children, siblings, and other kin. Khosi, another near-old respondent, talked about her experience:

...I didn't have money to transport the corpse from here to the mortuary so my cousin helped me by phoning his burial society to take the corpse to the funeral parlour. My relatives and one of my sons [also] helped me by contributing money to buy food, the coffin and other needs for the funeral (Khosi, Near-old woman, AIDS household).

This means that reliance on social capital can be used by elderly women to deal with some of the financial expenses incurred following an adult death in their household. This finding is consistent with those from another study, which shows how elderly caregivers were able to cope with funeral-related expenses through assistance from their social capital (Saengtienchai and Knodel, 2001).

Social capital can either occur at the micro-level, that is, through intra-community ties as noted earlier on or at the macro-level, that is, through state-society connections (e.g. social welfare) (Hawe and Shiell, 2000). For few of the respondents, dependence on social capital was through state-society connections as they reported that they obtained

assistance from social workers in their community. Sylvia, who lost a loved one to HIV/AIDS, was one of these respondents. She said:

It was more difficult [than when he was sick] because we didn't have money to buy a coffin. We were helped by social workers who gave us a coffin. ... [Also] we didn't have enough for the funeral [so] my husband borrowed money to buy food (Sylvia, Near-old woman, AIDS household).

The assistance Sylvia received must have relieved the burden of adult death on her, especially since her husband was able to share some of the burden and also took it upon himself to pay back the money owed. Makosi was also relieved of the burden of her brother's death through assistance from social workers, in addition to getting some support from relatives:

Our relatives that came contributed money like R10, R20, and R30... [This money] was used to buy food for them to eat. The social workers gave us a coffin to bury my brother (Makosi, Near-old woman, Non-AIDS household).

Even though dependence on social capital, whether at the micro-level or macro-level, can be considered as a coping mechanism for the financial burden of adult mortality in elderly women's households, this may not be sufficient for some caregivers especially those who do not have a regular income, like a pension grant, to depend on. In other words, sole reliance on social capital may not be enough for non-pensioners, as demonstrated in the following sub-section.

8.5.4 “A pension grant would have made a big difference”

Despite their dependence on social capital, many of the near-old women still thought it would have been much better if they had access to a pension grant when they experienced

an adult death in their household. When asked what difference a pension grant would make during crises such as adult illness and death in their households, many said it would have helped them to give their loved ones a befitting burial by buying a coffin/casket (instead of using planks), flowers to put on their grave, and food for those who came to mourn. Brenda was one of the respondents who thought a pension grant would have made a difference when her loved one passed away. She said “It would have made a big difference because I would have bought a casket for my daughter” (Brenda, Near-old woman, Other Death Household). As mentioned earlier, there are cultural and social obligations surrounding funerals in every society. Non-fulfilment of these obligations may, therefore, lead to feelings of regrets and remorse, which may compound the impacts of adult mortality on elderly women. These feelings may even lead to emotional trauma as they may continue to blame themselves for not fulfilling these obligations, long after their loved ones have passed away.

A few near-old women believed a pension grant would have kept their loved one from dying at the time he/she did. Winnie was one of the respondents who said a pension grant could have made a difference with regard to her daughter’s illness and death:

If I had been getting [my] pension I would have bought expensive tablets for AIDS and given them to my daughter, and even now she would still be alive (Winnie, Near-old woman, HIV/AIDS Household).

Like Winnie, Euginia believed a pension grant could make a difference when a loved one is seriously ill. She said:

It would have helped me to take my daughter to an expensive hospital where there is good care for patients. And, may be my daughter would not have died. But

because I didn't have enough money to take her to the hospital at Nelspruit [a nearby city], she died. [She died because] she didn't get strong tablets (Euginia, 57 years, HIV/AIDS Household).

The belief that a pension grant could help in saving the life of a loved one shows that a pension grant could bring a ray of hope to elderly people who are experiencing adult illness and death in their households. It could also lessen the emotional impact of losing a loved one by helping to fulfil the social and cultural around funerals. Even though it is unlikely that a pension grant could prevent the death of an adult infected with HIV/AIDS in elderly women's households, it is obvious, from this study, that it helped pensioners try their utmost best in giving care to their patient. Thus, the absence of a pension grant, not only affects near-old women, but also the loved ones in their care by preventing them from getting proper medical treatment when ill and a befitting burial when they pass away. As a result of this, many of the near-old respondents long for the day they will start receiving a pension grant because they believe it will help them to cope better with their caregiving responsibilities, as well as to fulfil social and cultural obligations around funerals.

8.6 Coping with the Financial Costs of Caregiving for Foster Children and Orphans

One consequence of adult morbidity and mortality in elderly women's household is an increase in the number of grandchildren with whom they co-reside⁵⁴. As mentioned earlier, most of the near-old and older women had to extend their caregiving

⁵⁴ Elderly women in Africa usually co-reside with grandchildren due to child fostering; however, there is likely to be an increase in the number of orphaned and fostered children as more adults fall prey to the AIDS pandemic.

responsibilities to orphaned children left behind by their adult children who died of AIDS and other causes of adult death or children fostered due to migration or non-marital births. Prudence, who stays with five grandchildren, said;

I take care of orphan children. Their father and mother died three years ago. I wash, feed and also send [them] to school. My daughter, the mother of these children, died so I have to take care of them. When they are sick, I take them to hospital. I also buy clothes for them (Prudence, Near-old woman, AIDS household).

This shows caregiving for grandchildren increases elderly women's financial burden as they have to take care of the expenses of their grandchildren, in addition to expenses incurred by their adult children during sickness and death.

Like caregiving for adult children, the respondents felt duty bound to take care of these grandchildren. Many of them, however, complained about how difficult it is to take care of young children. Maria co-resides with two orphans who lost their mother in 2003 and two fostered children (one from a non-marital birth). She narrated her caregiving experience:

I don't feel good. I'm suffering because I don't have enough money to support them. For instance, I do need to buy myself a dress but I can't because I don't have money. All of my [pension] money is used in supporting them... I don't know what to do with them, e.g. sometimes they need school fees but I don't have money to pay for them. They [and] I feel bad about it (Maria, Older woman, Non-AIDS Death).

Caregiving for grandchildren could, therefore, be overwhelming for elderly women, especially if they have schoolchildren in their care, who are frequently in need of school fees, uniforms, shoes, books, food, etc.

Lisbeth, a 70 year old widow, who co-resides with a grandchild who lost her mother in 2000, reported that that she is the sole provider for this child. She provides for her daughter's other child who resides outside her household as well. Her son-in-law who remarried, no longer takes care of the children left behind by his late wife. Lisbeth reported, like the other respondents, that she uses her pension money to take care of the grandchild in her home (and sometimes the one outside); she is, however, more worried about the future than the present situation of providing for her grandchild. She said:

Now I am old and taking care of my grandchild. What if I die now? I don't know who is going to take care of the child (Lisbeth, Older woman, AIDS household).

Elderly women, therefore, are not only saddled with the financial responsibility of taking care of children left by adult children who died in their households but also with the anxiety of what will happen to them, when they are no longer around to care for these young children.

Unlike older women who receive a pension, near-old women may find it more difficult to cope with caregiving responsibilities due to the absence of a regular income. As noted above, older women rely mostly on their pension grant to take care of orphaned and fostered children, but most of the near-old women did not have such an opportunity. Even though a few reported that they receive a child grant for one or more of the children in

their household, and some said they get financial assistance from their spouse and other relatives, it is often not sufficient to meet these children's needs. Edith is a 53 year old woman who lives with a grandchild that lost her mother in 2002. Even though Edith receives a child grant for her grandchild and financial support from her spouse and relatives, she complained:

Hi! It is a difficult thing because sometimes the child may need money to buy expensive clothes, nice food, etc and I don't have enough money to buy all these [things]. I am not getting a pension so I can't afford the money that the child needs. He gets R180 from the child grant but this is too small to meet his needs (Edith, Near-old woman, AIDS household).

This implies that the financial support from child grant may not be sufficient, sometimes for near-old women. Thus, non-pensioners still need a regular income, such as a pension grant, to help them cope. Even though access to a child grant may partially help these elderly women, the small size of the grant does not make it as attractive as a pension grant, which was R740 at the time of the fieldwork. In addition, factors such as lack of documentation and distance from service offices, which have been identified as barriers to accessing grants in Agincourt (Evans et al., 2007), may prevent some from making use of this coping strategy. For example, some respondents complained about these barriers especially with regard to missing birth certificates, which are needed for processing of child grants. Others reported that money from the child grant is being collected and spent by the mother of their grandchildren, while they are forced to solely bear the financial burdens of taking care of the child. Thus, finding ways to improve access to child grants

for elderly caregivers in rural areas may help in reducing the financial burdens of giving care for grandchildren.

As shown in the narratives, giving care to fostered and orphaned children increases household expenses of near-old and older women as they have to take care of others' basic needs such as food and clothing, in addition to their own needs. Since the expenses incurred by grandchildren could sometimes be huge, especially for those who are non-pensioners and sometimes may even exceed the regular income of pensioners, near-old and older women may need to find some other means to accommodate the daily demand of caregiving for grandchildren. The following section first focuses on the coping strategies adopted by older women and later on those used by near-old women.

8.7 Older Women's Coping Strategies

8.7.1 Living on credit

Sometimes, in order to cope with the day-to-day demands of caregiving for grandchildren, older women may need to buy basic necessities on credit, especially when they run out of cash. Pensioners are likely to have access to credit due to their regular income, which makes them fairly safe borrowers. When the older respondents were asked whether they buy essential items on credit, nearly all of them reported they use this coping strategy. A few said they have an account in a local shop or store where they buy food items on credit and later pay off the credit when they receive their pension money. This safeguards them from running out of food when they do not have enough cash. Nyeleti, a 61 year old widow, reported:

I send my children to go and pay for the *mielie-meal* I bought on credit because we do collect a bag of *mielie-meal* from the nearest store. We also tell them to give us another bag if money is not enough to buy another one on cash (Nyeleti, Older woman, Non-AIDS household).

This strategy helps Nyeleti to deal with the financial strain of taking care of nine grandchildren. However, this also means Nyeleti lives perpetually on credit because as she pays the debt for the foodstuff she bought the previous month, she buys another one on credit, in order not to run out of food in her household.

Rebecca is another older respondent who lives perpetually on credit; her account is at a local store as well. She said:

I have an account in the shop. I take what I want without paying and after receiving my pension. I go to the shop and pay (Rebecca, Older woman, Non-AIDS household).

Even though these respondents are able to handle the financial strain of living with grandchildren by living on credit, they may be left with no leftover cash after paying off the debt; therefore, they may resort to borrowing beyond their means if an emergency occurs. When Grace, a 62 year old widow, was asked what she would do if someone falls sick in her household, she replied, "I will borrow money from a neighbouring store" (Grace, Older woman, No Death household). If Grace did borrow money, she would have to pay back, probably with interest, from her next pension money. Thus, her pension money would be reduced, thereby recreating the need for her to buy some household items on credit, which she would then have to pay back in the following month, thereby creating a vicious cycle of credit.

Suffice (it) to say, Grace, like some of the older respondents who are pensioners, keep on depending and living on credit which sometimes make them vulnerable as they may have no cash leftover after paying for items bought on credit. Then, they have to resort to borrowing money at high interest rates when they need cash, since they already owe their pension cheque for the following month to the store from which they have received items on credit. The implication of this is that some coping strategies, such as living on credit and borrowing money, may provide a way out of crises but may have negative long term effects on elderly women. One such consequence is being perpetually in debt to creditors, who often charge high interest rates in addition to the monies owed for good. This may leave older women without sufficient funds for other purposes such as renovating their houses (Ogunmefun and Schatz, 2008).

8.7.2 Joining a stokvel (rotating credit scheme)

This is another strategy adopted by the respondents who are mostly pensioners. A *stokvel* is formed when individuals come together to form a savings group. Every month, the group meets to contribute a specific amount and each member receives the total amount collected in turn. The operations or activities of each *stokvel* vary from group to group. Eleanor, a 69 year old widow, explains how her *stokvel* operates:

We just meet in the afternoon at about 12 noon. We pray and dance before we start the *stokvel*. Then we collect R10 for food. After eating, we start to put our R100 on the grass mat, and then we tell the person who must receive it to take the money [that has been collected]. After that we pray and close the *stokvel* (Eleanor, Older

woman, Non-AIDS household).

The activities that Eleanor described show that being a member of a *stokvel* help elderly people to socialize with others; however, the main benefit is to sometimes have access to a sizeable sum of extra cash, which could be used to meet their needs. According to the respondents who are members of a *stokvel*, money received from their group has helped to meet essential, but expensive needs such as buying building materials, e.g. cement, door, windows; building a house; buying household items, e.g. wardrobe, hotplate, bed, blankets; paying off an instalment (for household items) or credit. Being a member of a *stokvel*, therefore, made a great difference in the lives of these elderly women as some of the needs they used *stokvel* money to meet would not have been possible if they had to rely on their monthly pension only. This is because the individual women would not be able to save this same amount of money over the four to five months that it takes for it to be her next turn due to the financial demands of caregiving for grandchildren. However, by contributing to the *stokvel* each month, it is as if she is setting that money aside for herself and when her turn comes, she has access to bulk money that she could not have saved on her own. A *stokvel* is, therefore, a form of group-enforced savings. Membership of these groups, however, is open to only those who have a regular income like pensioners. Thus, being a pensioner gives elderly women access to this strategy which appears to sometimes give them a lift from the financial constraint of caregiving.

A *stokvel* could also be regarded as a form of social capital that is available to elderly women. For instance, a *stokvel* could be used as a gathering for discussing issues that affect elderly women. According to Dorah, her group uses the avenue to discuss an issue

that affects everyone. She said:

I talk with my friend about AIDS at the *stokvel*. I tell them to warn their children about AIDS and to punish them when they go out during the night. [They agreed] and said we must try to arrange a sort of meeting where each comes with their children so we could advise them (Dorah, Older woman, No Death household).

This means a *stokvel* could be used as a means to reach out to other elderly women about important issues such as HIV/AIDS. In addition, it can serve as a support group for elderly women who are affected by HIV/AIDS, thereby helping them to deal with the trauma of losing a loved one.

8.8 Near-old women's Coping Strategies

8.8.1 Engaging in economic activities

Unlike elderly women over the age of 60, who are likely to retire from active work or economic activities when they start receiving a pension⁵⁵, most of the near-old women are still involved in one or more economic activity, in order to earn an income or provide food for their households. Nearly half of the near-old respondents sell items such as, traditional brooms, grass mats, tomatoes, ice blocks, ice cream, soup and bread, *niknaks*, scones, clothes or traditional beer. Four of the remaining respondents are kitchen helpers, three are workers (labourers) on a road/dam construction project, one is a volunteer at a local crèche and one used be a primary school teacher. Of seven respondents that are currently not working, four had never worked before. All the near-old respondents,

⁵⁵ Many of the older women (over age 60) said they stopped working when they started receiving a pension grant. Even though a few of them said they engaged in economic activities like farming, making grass mats and selling snacks, they did not rely on the small earnings obtained from these activities but rather on their pension money.

except two, said they engage in farming to produce food for household consumption. One respondent said she used to sell some of the maize she harvested as well. One of the two respondents that do not farm said it is because she has a small compound.

Even though being engaged in economic activities, such as selling and working as a labourer, may seem as a way to handle the financial responsibilities of caregiving, this is not sufficient for most of these women. The reason is because those that sell items such as scones, *niknaks* and ice blocks/cream barely make a profit. When Makosi, who supports 11 people in her household, was asked about the profit she makes from selling, she said:

I can't say exactly how much I get for profit because I sell *nik-naks* and ice block, what I do know is that I get R20 sometimes. Now that the schools are closed, I don't get enough money (Makosi, 55 years, No death Household).

Nearly all the respondents that sell said they make between R20 and R50 per day, which is likely gross and not net profit. Some sell at local schools, like Makosi, and therefore, they barely make any profit during school holidays.

Selling is profitable, however, for the respondents who are traditional beer sellers. Mpfuleni, a traditional beer seller, said, "It depends on that day; sometimes I make R80 or R100 in a day" (Mpfuleni, 58 years, Other Death Household). Mpfuleni supports 7 people, including her husband who is no longer working, but not yet a pensioner. She attested that since she started selling traditional beer, she has bought a stove, fridge, grocery cupboard, bed and built a house with two rooms, besides buying groceries for her household. When asked how life is since she is not getting a pension yet, she replied, "To me, life is good" (Mpfuleni, 58 years, Other Death Household).

Other respondents that work as kitchen helpers or construction workers do not think pre-pension life is good. These women earn between R400 and R700 per month and complained about how they struggle to support their households. Bulelwa supports 5 people including two children of her deceased brother and one grandchild. She works, on a contract basis, as a road construction worker and earns R700 per month. When asked about how she supports her family, she reported:

...We are suffering... It is difficult for me because even when I am sick I have to work in order to make money to support the family (Bulelwa, Near-old woman, No Death Household).

Considering the kind of work that Bulelwa and some of the respondents do, and the fact that the income they earn may not be enough to support their households, pre-pension life may truly be difficult for many elderly near-old women.

8.8.2 “No credits!”

As mentioned earlier, pensioners sometimes buy household needs on credit, in order to address the day-to-day demands of caregiving. They are, therefore, able to deal with financial crises in their households. In order to find out whether near-old women have the same coping strategies as pensioners, they were asked whether they buy goods on credit. Most of them reported they do not have access to such a coping strategy.

Fanie, a widow who used to sell grass mats, is one of those that does not buy on credit and she explained why, “No, I am afraid [to buy on credit] because I am not working” (Fanie,

Near-old woman, HIV Death Household). Fanie supports nine people including children and grandchildren and relying on just four child grants (a total of about SAR720/month). She said the money from the child grants is not enough to support her household. She is, therefore, vulnerable to financial hardship because she is no longer selling and therefore, cannot buy household needs on credit.

Seven of the of the respondents (including two recent pensioners) who sell are able to buy on credit, for example, Mpfuleni (quoted above) bought some of the household items on credit. However, it is not all sellers that are able to buy on credit. Brenda, who supports nine people and sells cold drinks and ice blocks, is reluctant to buy on credit. She said, “No, I am not able to buy on credit since I am neither working nor getting a pension” (Brenda, Near-old woman, Other Death Household).

Even though a few of the respondents who sell make enough profit and, therefore, are able to buy on credit, most of them barely make profit. Thus it is difficult for them to use credit as a coping strategy. It is unclear from the narratives of the near-old women whether their inability to use credit as a coping strategy is due to their own reluctance to be in debt, or if store keepers would not give them credit since they do not have a regular income. Their responses show that they have fear about the consequences of not being able to pay off a debt, so even if the option of credit is available, they may not make use of it. Thus, non-pensioners are less likely, than pensioners, to deal with financial hardship through the use of credit as a coping strategy, even when they are involved in economic activities such as selling.

Besides buying on credit, pensioners also join burial societies, which help when there is a death in their household, and *stokvels* (rotating savings schemes), which give them access to larger quantities of cash at fairly regular intervals. Joining a burial society or a *stokvel* is beyond the financial capacity of most of the near-old respondents. Only six near-old respondents, including two recent pensioners, reported having joined a burial society. When those who had not joined, like Euginia, were asked why, their responses commonly expressed a lack of funds, “I don’t have money to pay for it” (Euginia, Near-old woman, HIV/AIDS Death Household). The same reply was given when these near-old women were asked why they did not join a *stokvel*. The implication of this finding is that non-pensioners, unlike pensioners who use the *stokvel* and burial society as insurance against future household needs and crises, may be more vulnerable to future financial hardship, especially when there is an adult morbidity or mortality in their households that brings about expenses for which they are not prepared.

8.9 Preliminary Findings

The findings from previous sections of this chapter reveal that when elderly women experience a provoking event such as an adult illness and death and, their perception of caregiving is tied to the belief that they are bound to give care to their sick adult child (or relative) despite the financial expenses to be incurred. All elderly caregivers, both pensioners and non-pensioners, are likely to experience the socio-economic impact of adult AIDS or non-AIDS death; however, the degree of the impact is mediated by pension-receipt. The degree of the impact is lesser on pensioners who have access to more coping strategies following their pension-receipt. The interaction of adult AIDS or

non-AIDS morbidity/mortality with pension-receipt and perception of caregiving role, therefore, determines the degree of socio-economic impact experienced by elderly women, as noted in the conceptual framework (ABC-X model).

Furthermore, the findings demonstrate that pensioners have a variety of coping strategies, which help them to deal with the socio-economic impact of adult AIDS or non-AIDS death in their households. Their coping strategies include being a member of a burial society, church group, and women's society; these help them to get the financial assistance they need when there is an adult death in their household. Sometimes, when these means are not sufficient, they resort to borrowing or selling an asset. As grandmothers and caregivers for fostered and orphaned children, they also manage financial crises by living on credit and joining a *stokvel*. These enable them to handle better the daily demands of living with young children in their households. All these coping strategies are available to them, at least partially, due to their regular pension income. These findings are consistent with those from other studies which show that elderly women have means of dealing with crises such as adult HIV/AIDS related illness/death and caregiving for orphaned and fostered children, due to their pension status (Case and Deaton, 1998; Ferreira, Keikelame and Mosaval, 2001; Duflo, 2003; Moller and Ferreira, 2003; Legido-Quigley, 2003; HAI, 2005b; Booyesen and Van der Berg, 2005).

In addition, the findings from this chapter highlight the experiences of near-old women with regard to adult morbidity and mortality in their households. It was found that near-

old women, like women over 60, have caregiving responsibilities. Near-old women are different from older women, however, in their inability to access as broad a range of coping strategies such as a credit, *stokvels* and burial societies. Even though near-old women are more likely than their older peers to be involved in economic activities such as working or trading, and sometimes they get assistance from family members, they are still overwhelmed with financial responsibilities of giving care to sick adult kin and orphaned and fostered children. Many of the near-old respondents believed that a pension grant would make much difference in managing the costs associated with an adult illness and death in their households. Thus, they long for the day they will become pensioners and able to manage financial crises in their households.

A regular income such as a pension grant is likely to give near-old women a ray of hope in times of HIV/AIDS related crises as different options will be available to them. Suffice (it) to say, it is better than relying on small earnings from economic activities, and support from social network that even older women who are pensioners also found to be insufficient despite the fact they have other ways of dealing with these crises. Even though these other means of dealing with these financial crises may not make older women, who are pensioners, completely invulnerable to financial hardship, these strategies somehow help them to smooth out the hardship until they get back on their feet. In order to examine whether older women are more likely than near-old women to recover from financial crises, the following section focuses on the level of recovery (e.g. after the funeral of an adult child) of the respondents in this study.

8.10 Recovery from Economic Shocks

A pension grant offers the opportunity for coping mechanisms which enables poor households to withstand economic shocks. As a regular source of income, it can also help a household to recover from crises such as adult morbidity and mortality. In order to find out whether a pension grant could help elderly women and their households to recover, the elderly women in this study were asked if they were able to recover from the financial difficulties they experienced at the time of adult illness and death. That is, were they able to return to the same level of economic status they had prior to the occurrence of adult illness and death in their household? The recovery level of near-old and older women, as reported by the respondents, is provided in table 8.5. These results are presented by respondent's household's wealth ranking.

Of 58 near-old and older women who took care of a sick loved one, 36 reported that they had not recovered fully at the time of the interview. Even though near-old women (and non-pensioners) are more likely to live in an average household, they are less likely to recover. This may be due to the absence of a pension in their households. Of 30 near-old women, two thirds had not recovered, while over half of the older women had not recovered. As expected, there were more older women who recovered because of their pension grant, while more near-old women recovered because of assistance from their spouse or other relatives.

Table 8.5 : Household's wealth ranking by level of recovery from expenses related to caregiving

Household socio-economic status	Near-old women (N=30)			Older women (N=30)		
	Partial/ No Recovery	Recovered due to assistance	Recovered due to pension/ child grant	Partial/No Recovery	Recovered due to assistance	Recovery due to pension
Below average	9	1	0	8	0	7
Average	10	4	1	4	1	1
Above average	1	4	0	4	3	0
Total (N=58)	20	9	1	16	4	8

As demonstrated in table 8.5, almost all the near-old women whose households were categorised as below average had partial or no recovery, whereas, nearly half of older women's households that were categorised as below average were able to recover because of their pension status. This shows that a regular income, such as a pension grant, could help a household to recover. Even though the data in table 8.5 also reveal that fifteen of the older women's households were categorised as below average, despite the fact that nearly half recovered, these households may have been below average even before the crises.

The table also illustrates that 16 older women's households had no recovery despite the presence of a pension grant in these households. This may probably be as a result of having more recent occurrence of adult illness and death or due to the effect of lingering debts (Ogunmefun and Schatz, 2008); these households, however, are likely to recover with time due to regular pension income. The narratives of some of the women support this notion as well. When Pretty was asked whether the financial situation of her

household has improved, she said, “Yes, because the money from pension helps” (Pretty, Older woman, AIDS household). One of the near-old women who recently became a pensioner concurred with Pretty. She said, “We have recovered because I am now getting a pension and the children are getting child grants” (Prudence, Near-old woman, AIDS household).

The reverse is the case for some of the near-old women who are not pensioners. According to them, their financial situation has become worse. Zama, a 53 year old widow whose household was categorized as below average, said:

I haven’t recovered because [right now] I don’t have *mielie-meal* in my house. I am poor, more than the word poor, but God will help me to survive. I don’t have money to buy *mielie-meal* (Zama, Near-old woman, AIDS household).

The situation of Thembi, who lost a son to HIV/AIDS, is not much different from Zama’s:

I didn’t recover financially, instead it became worse. Even now as I am talking, I don’t have food in my house (Thembi, Near-old woman, No death household).

Zama and Thembi’s narratives show how vulnerable an elderly woman and her household that experience adult illness and death can be in the absence of a pension as well as the fact that recovery may be difficult to achieve.

8.11 Discussion and Conclusion

Using qualitative data, this chapter explores the socio-economic impact of adult AIDS and non-AIDS morbidity and mortality on near-old and older women. The experiences of

near-old and older women were compared with regard to the financial costs of caregiving for sick adult children and fostered and orphaned grandchildren. Even though there was not much difference between both near-old and older women in households with different mortality profiles, it was clear that older women are in a more advantageous position during crises such as an adult illness and death because of their monthly pension income which gives them access to a range of coping and insurance strategies.

Some findings from this study are consistent with findings from other studies, namely that elderly women who are pensioners are creditworthy and that they are able to use their pension income to cushion economic shocks (Moller and Sotshongaye, 1996; Devereux, 2001; Ferreira, Keikelame and Mosaval, 2001; Moller and Ferreira, 2003; HAI, 2005b). The findings also confirm that older women are more likely, than near-old women, to have access to a broader range of coping strategies and, therefore, able to deal with the socio-economic impact of adult AIDS (or non-AIDS) morbidity and mortality in their households because of their pension status.

In addition, findings from this study highlight that near-old women are more vulnerable as they do not have access to some of the coping strategies to which their counterparts have access. As a result, caregiving responsibilities weigh heavily on them. Their experiences are best compared with elderly people in other African countries where non-contributory pension grants are not available. Even though near-old women will eventually get a pension grant when they reach age 60, other women will become “near-old” and therefore “step into their shoes”. Thus, there is the need for programmes to

target elderly women in this age group, who feel the impact of adult morbidity and mortality like those over 60, but are being neglected. Lowering the cut-off age for getting a pension grant may not be a good option, as it may cause a financial constraint for the government. However, special programmes that target the near-old will not only lighten their burdens as elderly caregivers, but help them with the transition to old age as well.

Chapter Nine

SOCIO-CULTURAL IMPACT OF ADULT HIV/AIDS RELATED MORTALITY

9.1 Introduction: Secondary Stigma

The HIV/AIDS epidemic is a complex phenomenon mostly because the infected person, as well as those who are associated with him/her, are likely to experience the multi-faceted impacts of the disease, as demonstrated thus far in this thesis. In some cases, the impact experienced is because of society's explanations and attitudes towards the disease (Madru, 2003). These attitudes, usually negative, are sometimes fuelled by cultural or local beliefs about the disease and its cause (Parker and Aggleton, 2002; Liddell, Barrett and Bydawell, 2005). Thus, when people become infected, they often experience stigma from those with whom they come into contact. This makes them feel reduced from "normal" to "tainted" or "discounted" people (Goffman, 1963). This feeling is also often shared by those who are close to them such as their caregivers.

The literature suggests that as caregivers, elderly women may experience stigma from their kin, neighbours and community because they are in close (physical) contact with their patient because of their caregiving (VanLandingham, Im-en and Saengtienchai, 2005; Ogden and Nyblade, 2005; Deacon, Stephney and Prosalendis, 2005). Even though there is much focus on the ways that people living with HIV/AIDS experience stigma (primary stigma), there is still the need for more empirical work on the HIV/AIDS related secondary stigma, the type elderly caregivers are more likely to feel. Moreover, the PSE framework employed in this study, suggests that socio-cultural impact of HIV/AIDS,

denoted as secondary stigma, is one of the impacts that elderly women are likely to experience because of adult HIV/AIDS related death in their households. Hence, the need for this chapter that focuses on secondary stigma, as a socio-cultural impact of HIV/AIDS on elderly female caregivers.

Some studies conducted in Africa and Asia have shown how elderly people, who lost an adult child to HIV/AIDS, experience different manifestations of secondary stigma of HIV/AIDS, such as gossips from community members (Knodel and Saengtienchai, 2002); name calling and rejection at the hands of community members (WHO, 2002a); loss of livelihood (Saengtienchai and Knodel, 2001); and being held responsible for the “bad” behaviour of infected children (Ogden and Nyblade, 2005). There is, however, not much evidence in these studies about the root causes of HIV/AIDS related stigma in these settings. Thus, in order to understand secondary stigma, this chapter explores the causes and beliefs behind HIV/AIDS related stigma from the vantage point of elderly women. In addition, it focuses on the implications of HIV/AIDS related stigma for elderly women, particularly the potentially unique aspects of stigma related to caregiving. Elderly women’s gender roles are not limited to caregiving for the sick in their households; therefore, they may be impacted as grandmothers and wives as well. This chapter, therefore, focuses on the implications of secondary stigma for these women’s age and other gender roles. The sections below first explore the community, family and personal responses to secondary stigma and then, the causes and beliefs behind, and consequences of secondary stigma.

9.2 Community, Family and Personal Responses to Secondary Stigma

As documented in some studies on HIV/AIDS related stigma, infected and affected people often experience different forms of stigma from kin, friend and community members (UNAIDS, 2000; Ogden and Nyblade, 2005; Duffy, 2005). Some of the respondents in this present study also reported that they had similar experiences when a relative was sick or died of HIV/AIDS. For those who had no relative that died of HIV/AIDS, some were able to describe the experience of a family member, friend or neighbour that was infected or affected by the epidemic.

In most cases, the forms and expressions of HIV/AIDS related stigma experienced by HIV infected and affected individuals are usually because of the way a community views and responds to the epidemic (Ogden and Nyblade, 2005). Thus, in order to understand the experiences of the elderly respondents with regard to HIV/AIDS related stigma, they were asked about the attitude of people in the community towards an infected person; their responses are demonstrated in the following sub-section.

9.2.1 Community responses to HIV/AIDS

When asked about the general attitude of community members towards an HIV infected person, the responses were mixed. That is, the respondents reported both negative and positive attitudes towards PLWHA from members of the community. These findings are similar to those reported in Thailand as some participants reported some negative reactions towards PLWHA and their parents, while some reported sympathetic and

supportive reactions (Saengtienchai and Knodel, 2001; Knodel and Saengtienchai, 2002; VanLandingham, Im-en and Saengtienchai, 2005)

According to a third of the respondents in this study, people in the Agincourt community do not show love to PLWHA and they gossip about and laugh at them. Gloria explained the reason why:

They don't show love to them, and gossip about them. They don't like to talk to them and the reason for this is that they don't want to be infected (Gloria, Near-old woman, Non-AIDS Household).

Phumzile's response is similar to Gloria's but she gave another reason:

Community people will not show love to that person and they will gossip that the person is HIV positive because he/she is a prostitute (Phumzile, Near-old woman, No Death Household).

These responses reveal some of the stereotypes about HIV/AIDS and HIV infected people, namely fear of transmission and assumptions about the moral integrity of PLWHA, which were also reported in studies conducted in Ethiopia, Tanzania, Zambia and Vietnam (Ogden and Nyblade, 2005). These stereotypes, in most cases, lead to negative reactions towards people who are infected and affected by the epidemic.

On the other hand, thirteen of the respondents said the community show love and treat HIV infected people like others in the community. According to Dorries:

[The] community people show love to the person because he/she didn't like to be HIV positive, it happened by mistake (Dorries, Older woman, AIDS Household).

This kind of positive attitude towards PLWHA was reported by another study conducted in rural Malawi as community members generally provided moral and social support for those who infected and their caregivers. The study demonstrated that when questioned, the caregivers were reluctant to name AIDS, though they described its symptoms (Chimwaza and Watkins, 2004). The non-disclosure of the patient's status might, therefore, have contributed to the positive reaction from the community members.

Nearly one-third of the respondents said they do not know how the community responds to people who are infected. Some of them said they have no idea of what is happening in the community because they are old and some parts of their bodies are painful, making it difficult for them to move around. A few, however, said that it is hard to know how the community will react because people do not reveal their status. Margaret explained:

I don't know how [people react] because no one has exposed himself/herself by saying he/she is HIV positive so that we could see how the community reacts to him/her" (Margaret, Near-old woman, No Death Household).

Non-disclosure of status may, therefore, make it difficult to predict the reaction of people to HIV/AIDS as community members will not react either negatively or positively if they are ignorant of the status of PLWHA.

These narratives of the respondents show that the attitude of community members towards HIV infected people could either be negative or positive in the Agincourt community. These mixed results are likely to extend to their close family members, especially their caregivers. In order to further understand how elderly caregivers

experienced stigma, the following sub-section explores secondary stigma.

9.2.2 Experiences of stigma by caregivers

As shown in the previous chapter, nearly all the respondents in this study were/are caregivers to adult children, spouses and other kin, some of whom were/are HIV positive. Of 60 respondents, 58 had taken care of at least one sick adult relative and of these 58 caregivers, 19 knew or suspected that their patient was HIV positive. When those who took care of an HIV infected relative were asked about their experience of secondary stigma, some were able to relate their personal experiences, while a few said they never experienced stigma because they kept the status of their patient secret. The non-disclosure of the status of their patient, for these respondents, could be regarded as a symptom of “expected” or “anticipated” stigma, which was reported in a study conducted among African-American caregivers in the USA as well (Poindexter and Linsk, 1999). The respondents who reported that they did not take care of an HIV infected relative were also asked about secondary stigma and some were able to relate the story of a relative or “a certain *gogo* (grandmother)” in their village who experienced secondary stigma.

In their study of HIV-related stigma, Ogden and Nyblade (2005) cited four main forms of stigma that HIV-positive people experience, that is, physical stigma— physical isolation and violence; social stigma—social isolation, loss of identity and voyeurism; verbal stigma— pointing fingers, taunting and rumours; and, institutional stigma—loss or inability to secure livelihoods, housing, health care, and education. In order to find out whether elderly caregivers, who care for HIV positive people, also experience these main forms of

stigma, the respondents were asked questions relating to physical, social, verbal, and institutional stigma. Some of the respondents reported that they experienced different forms of stigma such as physical, social and verbal stigma from the community. Agnes, who lost a son to HIV/AIDS, was one of them. She described her experience:

...I will tell you about my experience with my son that died of AIDS. The community was gossiping and some were laughing at my family...Some of my friends were gossiping about me, that I would be infected because I was taking care of my son that died of AIDS. Some came to visit me in order to see what was happening in my house so that they could go around to gossip about me and my son... My husband is no longer sleeping with me. He said he doesn't want to be infected because I was the one taking care of my son who was HIV positive... I am sorrowful because I didn't choose to have a son who is HIV positive but I pray for them that God will open their eyes and make them to have feelings for those who are HIV positive (Agnes, Near-old woman, AIDS Household).

Not only did Agnes experience verbal stigma from the community members when they gossiped about her and her family, but also social stigma from friends who visited in order to report to others in the community. She expressed lack of trust in the 'people who come to visit' and probably felt as if she was isolated and rejected by friends and community members. In addition, Agnes experienced isolation (physical stigma) from her spouse who refused to sleep with her due to fear of infection. This means that the caregiving role of some elderly women may affect their other roles, e.g. being a wife. The loss of the role of wife likely affected Agnes emotionally and mentally.

Brenda is another respondent, like Agnes, who experienced verbal stigma from community members because of her brother-in-law's illness. She said:

I remember the time that my brother-in-law was sick with AIDS, people used to look at us in a bad way. Some said to me that they feel bad about my brother-in-law's condition meanwhile they only wanted to gossip about him. And, sometimes when I was passing by, they pointed fingers at me to laugh and gossip... I was very worried (Brenda, Near-old woman, Non-AIDS Household).

Brenda's lack of trust in people's concern for her show that experiences of stigma may lead caregivers (and PLWHA) to even doubt any gesture of social and moral support from friends and community members and, this is likely to lead to further isolation.

Although secondary stigma from community members and friends is very disturbing for these women, it can even be more painful when it comes from close relatives. Pearl, like Agnes, experienced stigma from her loved ones:

Because I was helping my sister to take care of her daughter who was HIV positive, my grandchildren keep on telling me that I must not cook anything for them because I may be HIV positive, because they don't want to be infected also...I am worried (Pearl, Older woman, Non-AIDS Household).

Pearl admitted that she has never been to the clinic for a test because she did not think she contracted the virus, but she was very worried about the isolation (physical stigma) she experiences from her grandchildren, who must have reacted that way through fear of transmission of the virus. Chelsie, like Pearl, experienced physical stigma from her grandchildren. She said:

I did experience [stigma] as I told you that my grandchildren are no more visiting me. They say that they are afraid to die because three people have died here in my house, may be I have something that kills people. May be they heard this from their parents (Chelsie, Older woman, AIDS Household).

Chelsie is a widow that lost a son and granddaughter that had some symptoms similar to those of HIV/AIDS. She must have felt bad about her grandchildren's attitude as, like Pearl, her caregiving role affected her other role as a grandmother. This implies that the caregiving role of elderly women does not only lead to stigma but negatively impact on their other gender roles as well.

9.2.3 Managing secondary stigma

Even though some respondents reported that they experienced secondary stigma⁵⁶ from community members, friends and relatives, a few said they had no such experience during or after caring for a loved one who died of HIV/AIDS. Edith reported the experience she had when her daughter died:

I was treated well, especially by people from the church. They used to come and pray for me and the sick person... And [my family members] were very supportive (Edith, Near-old woman, AIDS Household).

The reason why Edith and a few of the respondents said they never experienced secondary stigma may be that they kept the status of their loved one secret because of the anticipation of stigma. The literature suggests that when stigma is anticipated or expected (also known as felt stigma), people sometimes find ways to manage it, for instance, by

⁵⁶ There is no word for (secondary) stigma in the local language; therefore, respondents were asked whether they experienced negative reaction as a result of caregiving for a sick loved one.

concealing the status or condition (Goffman, 1963; Poindexter and Linsk, 1999; UNAIDS, 2000). Four of the respondents confessed that the reason that they did not experience stigma was because they did not disclose the HIV-status of their relative. In some cases, non-disclosure of status was easy as these caregivers' relative only came home shortly before passing away. Others must have passed the symptoms off as those of *tindzhaka*⁵⁷. This shows that when caregivers anticipate stigma, they may manage it through non-disclosure of their patient status. A study conducted in four townships in Western Cape, South Africa, also shows that due to stigma, some elderly caregivers concealed the disease, so that shame would not be brought on their household (Ferreira, Keikelame and Mosaval, 2001).

Zama, one of the respondents in this study, explained why she had to manage the stigma she anticipated:

People in the community were good to me. They came in large numbers to mourn. May be it is because my husband was a very kind man. Even during the funeral, people came in large numbers... I didn't experience any negative reaction because I didn't tell anyone that my husband was HIV positive. Even my parents and my husband's relatives did not know my secret... Dying of AIDS at that [time] was a secret. I think people would have gossiped about it and my husband's reputation would have been spoiled (Zama, Near-old woman, AIDS Household).

Zama's husband died in 2002 and she never told anyone (except her brother-in-law) since then, even though during the interview she said:

⁵⁷ The Agincourt community believes that *tindzhaka* is another disease that has symptoms that are similar to those of HIV/AIDS; however, *tindzhaka* is caused by the breaking of taboos surrounding death and sex. Some of the taboos of *tindzhaka* are explained in narratives later in this chapter.

Two years ago, people used to hate a person who is positive. They used to think that the person is infected because he/she is a prostitute. Nowadays, a person who is positive is loved by people. We feel sorry for him/her. We don't isolate him/her (Zama, Near-old woman, AIDS Household).

Although Zama believed that attitudes within the community may have changed such that people are more supportive of people with HIV and their families, she still kept her secret. This means she still she felt that disclosure of the status of a loved one, even years after his/her death, can ruin the person's reputation and also lead to stigmatization of those left behind. HIV/AIDS is a highly stigmatized disease especially where the major mode of transmission is through sexual intercourse. There is, therefore, the tendency for caregivers to manage stigma, especially by concealing the status of their patient. This is because keeping the status of a loved one secret may be a way to protect themselves from stigma and the shame of losing a relative to HIV/AIDS.

Another way for people to protect themselves from shame may be to live in denial or ignorance of the fact that the loved one died of HIV/AIDS, thereby managing stigma in this way. A study conducted in rural Uganda shows that denial of symptoms by a patient or family was common in the community (Muyinda et al., 1997). Family members of those who were infected kept repeating that they were alright or improving when the condition was actually deteriorating (Muyinda et al., 1997).

The responses of elderly caregivers, who are also family members to those who are infected with HIV/AIDS, may not be much different as they may also live in denial or ignorance of the fact that their patient is HIV positive. These elderly caregivers may find it easier to relate their experience by talking about a certain person that experienced it rather than referring to themselves. This may even make them feel safe as they do not want to be exposed to stigmatization. Such responses were heard from four of the respondents in this study, who lost a relative to HIV/AIDS. These respondents reported that they took care of a loved one that died of symptoms that are similar to those of HIV/AIDS. But, when asked about their experience of secondary stigma, their response was negative, that is, they did not have such experience; however, they were able to talk about “a certain *gogo* (grandmother)” that experienced secondary stigma.

Dorries took care of a daughter that had symptoms such as diarrhoea, sores and loss of weight and apparently died of HIV/AIDS. When asked whether she experienced secondary stigma because of taking care of her daughter, she replied that she did not experience stigma because her daughter died of headache. However, when asked whether she knew someone that experienced secondary stigma she said:

There was a certain *gogo* that was looking after her daughter who was HIV positive. She was treating her [daughter] well and they were sleeping together in the same room. She was cooking for her and also washing her. She was doing everything for her... People in the community were feeling sorry for the *gogo* and they visited the sick person. They also advised the *gogo* to take the sick person to the *sangoma* [traditional healer] to get *muthi* [traditional medicine]. Some gave

the *gogo muthi* to give to the sick person, so this shows that the community loved this *gogo* (Dorries, Older woman, AIDS Household).

Living in denial or talking about “a certain *gogo*” may make it easier for elderly women, like Dorries, to protect themselves from the shame or stigma associated with HIV/AIDS. Some may find it difficult to talk about their experience of stigma, particularly with the interviewers who were members of their larger community, although not from their own village. One of the respondents refused to talk about her experience of secondary stigma when asked. She said:

I have told you that I know nothing about AIDS, so if you keep on asking me about it, I will keep quiet (Auphrey, Near-old woman, AIDS Household).

The AHDSS verbal autopsy data revealed that someone had died from HIV/AIDS in Auphrey’s household in the period 2001-2003. Her complete denial of knowledge of the disease or stigma related to it could be as a result of fear of exposure to stigmatization.

In order to understand why some elderly caregivers may choose to conceal the disease and live in denial or ignorance of the disease, there is need to explore the causes and beliefs behind HIV/AIDS related stigma in the Agincourt community. The following section, therefore, focuses on the causes, beliefs behind HIV/AIDS and stigma as well as the consequences of primary and secondary stigma.

9.3 Causes, Beliefs and Consequences of Secondary Stigma

9.3.1 Causes of HIV/AIDS related stigma

As suggested in the literature on HIV/AIDS related stigma (Ogden and Nyblade, 2005; UNAIDS, 2000), fear of infection is the prevailing factor that causes negative reactions towards HIV infected and affected people. According to Ogden and Nyblade (2005), the knowledge about the three correct modes of HIV transmission (sex, blood, and mother-to-child) sometimes co-exist with erroneous beliefs such as transmission through ordinary daily interactions with PLWHA. This fear of transmission through contact, therefore, leads to stigma towards those who are infected and affected.

In order to have a better understanding of forms and expressions of secondary HIV/AIDS related stigma, the respondents were asked about the causes of stigma in their community. The respondents confirmed the presence of the fear of transmission in their community. According to Adele:

People are scared of HIV positive people because they think that they will be infected if they get close to the person, and others say that if you eat with them you may get infected (Adele, Near-old woman, No Death Household).

Such erroneous ideas about HIV transmission may result in stigma towards those who are infected and affected.

Maria has the same opinion as Adele and she gave an example, by way of illustration:

People are scared that they will be infected by this disease. For example, if I am HIV positive and I give you food to eat, you won't eat it... You will be scared by

the way I am looking because I will be thin with sores [on my body] and in the mouth. If I give food to you, you will refuse because you think that you will be infected (Maria, Older woman, Non-AIDS Household).

This picture demonstrates that people in this community perceive HIV like other communicable diseases that can be spread by contact with those who are infected. Regardless of the fact that some of the respondents are aware that the major mode of transmission of HIV (in the community) is through unprotected sex, transmission by contact still dominates their minds. This is demonstrated in Tumi's response:

Everyone is afraid of HIV/AIDS. People think if [an infected person] comes near you, you would be infected... We are told that it comes through sex but we don't [really] believe [it] (Tumi, Near-old, Non-AIDS Household).

This means that the fear of transmission may still persist in people's minds despite extensive information, education and communication (IEC) programmes about HIV/AIDS (McDonald and Schatz, 2006). This, according to Ogden and Nyblade (2005), may be due to the fact that HIV/AIDS messages rarely focus on explaining how HIV is *not* transmitted but on how HIV is transmitted and is incurable. This tends to fuel the stigmatization of HIV/AIDS in the society.

9.3.2 Beliefs behind HIV/AIDS and stigma

Assumptions about the moral integrity of people infected with HIV/AIDS, like fear of transmission, could also cause stigma towards the infected and affected people (Ogden and Nyblade, 2005). This is because venereal diseases (e.g. HIV) "carry a moralistic judgment of blame", supposedly due to the indecent or promiscuous behaviour of the

infected person (Madru, 2003; Zhou, 2007). As a result, the infected person is held responsible for contracting the illness and therefore stigmatized (Madru 2003). This could be extended to his/her caregivers as well. The link between HIV and morality could also be related to the fact that affliction is often discerned as a physical manifestation of a moral transgression or breaking of social prohibitions or taboos (Ogden and Nyblade 2005). The society therefore believes the culprit deserves the judgment of HIV disease.

In a rural setting, local cultural beliefs and explanations about disease and disease causation can contribute to HIV/AIDS related stigma (Parker and Aggleton, 2002). This stigma is likely to be transferred to elderly women who are caregivers to an infected child. Hence, they experience the socio-cultural impact of HIV/AIDS as demonstrated in the PSE framework. In order to explore this phenomenon, the respondents were asked about the traditional beliefs behind HIV/AIDS and stigma in the community. In their narratives, nearly all of the respondents said the prevalence of HIV/AIDS is because of young ones who are no longer obeying the norms and traditions of their society. This belief is in some way beneath the erroneous explanation of how HIV is transmitted in the community. Agnes said:

The belief is that the young ones, mostly under the age of 18, should not have sex but because this belief is not respected by them, they are affected by AIDS. The youth are not obeying the norms and values of the society, so many different diseases like AIDS and TB are at a high [prevalence] level (Agnes, Near-old woman, AIDS Household).

The perception that HIV infection is the product of personal choice, which makes a person choose to engage in bad behaviours, may impact on the community's assumption that the person ought to carry the blame if HIV infection ensues (Ogden and Nyblade, 2005). In addition, it creates stigma from the community towards PLWHA if long-standing cultural traditions are broken in the process of making the personal choice that caused HIV infection; this stigma is latter extended to affected kin. Phumzile believes this (perception) to be true in the community. She said:

Community people will not show love to that person and they will gossip that the person is HIV positive because he/she is promiscuous (Phumzile, Near-old woman, No Death Household).

Another study conducted in Agincourt also showed that stigma is as a result of the belief that HIV/AIDS is transmitted by those who engage in “bad sex” (promiscuity) in the community and therefore, death from the disease is a just reward for their behaviour (Posel, 2004). This shows that if a community believes that traditions are being broken because of people's sexual behaviour, they are not likely to show empathy towards the infected person, and this could result in stigma towards the “offender”.

Nyeleti also believed the high rate of death is because of the disobedience of youth but cited a taboo as an example of the tradition that is being broken:

AIDS is caused by the young ones who never listen to their parents when they tell them about the norms and values of our culture. For example, if there is a death in our family and we eat food, we are not allowed to have sex until 7 days [pass]. But you will discover that they eat food in the afternoon and have sex with their

partners at night, so this causes *tindzhaka* disease that is similar to AIDS (Nyeleti, Older woman, Non-Aids Household).

Like Nyeleti, many of the respondents, believed the breaking of the “taboo of *tindzhaka*” is the reason why many are dying of HIV/AIDS in the community. Taboos reflect attempts to maintain order and protect against disaster in traditional societies (Madru, 2003). Thus, local beliefs about the cause of HIV, such as youth disobeying the norms and traditions of the society and people breaking taboos, are likely to underpin stigmatization towards the infected and affected people in the community.

Stigmatization may also be due to the fact that people (in many societies) tend to believe in *karma*, the law of cause and effect, which is expressed in the Bible as “What a man sows so shall he reap” (Ogden and Nyblade, 2005). This, therefore, makes community members react negatively towards PLWHA and sometimes, the affected. When Gloria was asked whether she knew an elderly woman who experienced stigma as a result of taking care of an infected person, she said:

My neighbour died last month, towards the end of December, and people gossiped that she was HIV positive. Her mother [who cared for her] also became ill and now she has died. She will be buried on the 7th January 2006. People said that the mother was also HIV positive. As you can see that there is nobody going to mourn in their house. May be they are scared that the person was HIV positive. Since morning, no one has gone to their house, even the pastor did not come to do the devotion. After her husband died some years ago, she started running around with men, telling people that she is not old. Today, she has died of AIDS and people

didn't come to her house, and the few others that went there to mourn were grumbling that she became a prostitute when her husband died (Gloria, Near-old woman, Non-AIDS).

Although it is not clear from Gloria's narrative whether it was the daughter or mother that was promiscuous, it does show that stigma could be extended from the infected person to the caregiver, even after the person dies. This is because people think that the infected person deserved the punishment due to his/her actions. However, stigmatizing the people who are infected and affected does have dire consequences for the people involved. The following sub-section focuses on the consequences of stigma on infected and affected people.

9.3.3 Consequences of Stigma

In order to have an insight into the consequences of secondary HIV/AIDS related stigma in the community, the respondents were asked about the effects of stigma on people infected and affected by HIV/AIDS.

Emily was asked about the effects of stigma on PLWHA and she said:

HIV positive people won't say that they are sick and, they [will] always sleep around with people. When the health workers tell someone that he/she is HIV positive, that person starts to think that he/she is useless. Some drink poison to commit suicide... [because] they know that they will die because AIDS has no cure (Emily, Older woman, No Death Household).

A few of the respondents attested, like Emily, that due to stigma, HIV infected people do not disclose their status and therefore, continue to have sex with other people. Dorries further explained the reason for this:

Some of them will not reveal their status because they are HIV positive and they will go around spreading this disease...They say that they don't want to die alone so it is better to die with others (Dorries, Older woman, AIDS households).

Ogden and Nyblade (2005) also found in their study in Ethiopia, Tanzania, Zambia and Vietnam that people living with HIV struggled with the issue of disclosure due to stigma so some continue to have sexual relations. Stigma also hindered these people from availing themselves of services that prevent further spread of the disease such as HIV testing, counselling, etc. This means stigmatization of HIV/AIDS may inhibit efforts to curb the spread of disease in a community, especially since some of the infected (and affected) people tend to conceal their status.

Some respondents in this study believed stigma could make PLWHA suffer loneliness as they isolate themselves or feel isolated:

They don't enjoy life anymore, and they feel that they are not welcomed in the community. They isolate themselves and think that it is better to die (Thembi, Near-old woman, No death household).

As Thembi and Emily above explained, the loneliness and depression related to an AIDS diagnosis and resulting stigma may even lead some to commit suicide. In order to elaborate on this, Goodness recalled a story about a suicide in her response:

They are not happy about it because they could see that people don't show love

towards them, so some shoot themselves to death to commit suicide. I remember one boy committed suicide because nurses told him that he was HIV positive. He excused [himself] at night by telling his wife that he was going to the toilet, and [because] he was naked, his wife thought that he was really going to the toilet. Later they found him dead on the veld the following day (Goodness, Older woman, Non-AIDS Household).

This narrative shows that stigma towards PLWHA may make them contemplate suicide as a way out of their problem, especially if they feel they have been rejected due to loneliness and depression by their community. This may also make others conceal their status as they may not want to be rejected because of lack of empathy from other people in the community.

Like those who are infected with HIV/AIDS, affected people can suffer loneliness, feel or be isolated by friends and the community because;

People don't want to visit the family as they are afraid of the disease, and they think that they will be infected if they visit the family (Bulelwa, Near-old woman, No Death Household).

The reluctance of community of members to visit the family of an infected person is also due to the erroneous knowledge about the mode of transmission of the disease that is prevalent in this community, as demonstrated earlier in this chapter.

In addition to loneliness and isolation, some of the affected, especially caregivers, may lose their source of livelihood. Khensani explained, “[The] family will have a problem if

they have a business as people will no longer buy from them” (Khensani, Near-old woman, Non-AIDS Household). One of the respondents who lost a child to HIV/AIDS had this experience:

Like me, I sell traditional beer, so three months after the death of my daughter, the number of people who came to buy traditional beer decreased. But it is okay now and they are coming in large numbers like before (Nyeleti, Older woman, Non-AIDS Household).

Even though Nyeleti was fortunate to have her customers return, some affected people may be less fortunate. In the study conducted in Thailand, Saengtienchai and Knodel (2001) found that some caregivers had to quit or change to other types of work because of stigma. Thus, secondary stigma can have dire consequences for those who are affected, like some of the elderly women in this study. The implication of this is that HIV/AIDS related stigma may have long term effect on caregivers, especially in relation to their livelihood which is affected because of stigma.

9.4 Discussion

This chapter explores secondary stigma, as a socio-cultural impact of HIV/AIDS on elderly women. Narratives from respondents reveal that people believe that the high rate of adult death in their community is because young ones no longer respect the norms and traditions of their society, e.g. they no longer obey the “taboo of *tindzhaka*”. Such belief, therefore, fuels HIV/AIDS stigma towards PLWHA and also elderly women who are their caregivers, thereby suggesting that secondary stigma could be rooted in cultural

beliefs. Hence, secondary stigma can be regarded as a socio-cultural impact of HIV/AIDS, as suggested in the conceptual framework (PSE model).

Furthermore, findings demonstrate the forms and expressions of secondary HIV/AIDS related stigma in Agincourt rural community. The narratives show how secondary stigma impacts the affected and how closely it mirrors primary stigma experienced by PLWHA. Even though the respondents reported that community responses towards infected and affected people vary from hatred to love, HIV/AIDS related stigma is still a cause for concern, especially when it is experienced by elderly caregivers, like those in this study. They not only experience stigma from the community and family members, but sometimes from their own spouses, as in the case of Agnes quoted above. In other words, they may both be affected as elderly caregivers and as married women, mothers and grandmothers. Some of the forms of secondary stigma experienced by the respondents include physical stigma in the form of isolation and separation from family members; social stigma in the form of voyeurism, social isolation, and verbal stigma in the form of being gossiped about, finger-pointing and jeering at them.

Although some of the respondents said they had never experienced secondary stigma, findings demonstrated that their lack of such events was at least in part due to non-disclosure of the status of infected family member. In other words, some managed “anticipated” stigma through non-disclosure of their patient’s status. As a result, some women were able to protect themselves from stigma and the shame of losing a loved one to HIV/AIDS. A few of the respondents also managed stigma by living in denial or

ignorance of the status of their loved one. These respondents found it easier to talk hypothetically about “a certain *gogo*”, while they might have talked about themselves. The implication of denial/non-disclosure is that the prevalence of secondary HIV/AIDS related stigma, as HIV/AIDS infection, will be under-reported.

This study demonstrates that the caregiving role of elderly women may have negative effects on other gender roles such as being a wife and a grandmother. Since these other roles are as important as their caregiving role, this is likely to compound the impact of HIV/AIDS on elderly women. However, not much has been documented about this phenomenon, hence the need for further research on this issue. The issue of loss of livelihood, following secondary stigma, is another issue that is worth further investigation in future research, as it can also compound the impact of HIV/AIDS by resulting in financial crisis, which could be regarded as a socio-economic impact of HIV/AIDS. That is, when elderly women experience loss of livelihood (socio-cultural impact), they may be affected financially (socio-economic impact) as well. However, the inter-relation between these phenomena is beyond the scope of this thesis, hence the need for future research.

The findings from this study are consistent with results from other studies (UNAIDS, 2000; Posel, 2004; Ogden and Nyblade, 2005), as narratives show that fear of infection is one of the causes of HIV/AIDS related stigma in the Agincourt community. Regardless of knowledge about unprotected sex as the major mode of transmission in the

community, many still perceive HIV as a communicable disease that can be contracted through casual contact, e.g. eating with and staying near PLWHA.

As the epidemic progresses and more elderly women become caregivers to sick adult children sick, there is need to address the issue of secondary stigma, just as primary stigma has come under spotlight in many HIV/AIDS intervention programmes. This is because stigma can make their caregiving responsibilities more burdensome as they try to cope with the stigma and shame of losing a loved to HIV/AIDS.

Chapter Ten

GENERAL DISCUSSION AND RECOMMENDATIONS

The purpose of this study was to examine the multiple impacts of adult HIV/AIDS related mortality on elderly women in Agincourt, a rural area in the north-eastern part of South Africa. Using quantitative and qualitative data, this thesis shows the various impacts experienced by near-old and older women, as well as the coping strategies adopted to deal with these impacts. This final chapter presents the major findings of this study and recommendations on how to address the challenges facing elderly women.

10.1 The Conceptual Framework(s) and Major Research Findings

This present study is informed by the psycho-socio-environmental (PSE) model which puts health and disease causation in a social context (Gilbert and Walker, 2002a). This model posits that other factors such as social and environmental factors, besides medical factor, are important determinants of the spread of a disease like HIV/AIDS (Gilbert and Walker, 2002a; Gilbert, Selikow and Walker, 2002). As noted in chapter 3, the PSE model does not only explain how an infected person contracts HIV/AIDS, but also serves as an explanation of how someone that is associated with him/her (the affected) experiences the impacts of the disease. Hence, the adapted PSE model for this study, posits that the impact of adult HIV/AIDS related mortality on elderly women is multifaceted (see figure 3.1). In other words, when an adult HIV/AIDS related death occurs in an elderly woman's household, she is likely to experience demographic, socio-economic, health and socio-cultural impacts of the disease.

The findings from this study are consistent with the adapted PSE model, which provides the overall (theoretical) framework for this study. The examination of elderly women above 50 in Agincourt shows that they experience multiple impacts of adult AIDS and non-AIDS morbidity in their households. The study reveals specifically that elderly women experience demographic, socio-economic and socio-cultural impacts⁵⁸ of adult AIDS and non-AIDS in their households. Some of the findings even suggest that the impacts experienced by elderly women could sometimes be inter-related. For instance, the narratives from respondents suggest that an elderly woman who is experiencing secondary stigma (socio-cultural impact) may lose her source of livelihood (socio-economic impact). This implies that the impacts experienced by elderly women do not necessarily occur in isolation, as one impact may be connected to another. The interconnectedness between the impacts experienced by elderly women is an issue that can further be investigated in future research, as it is beyond the scope of this thesis, as noted in the previous chapter.

In the literature on elderly people in South Africa, there is not much focus on near-old women aged 50-59 years as they are less likely to be pensioners. This study, therefore, attempts to fill the gap in the literature by revealing how near-old women also experience multiple impacts of adult HIV/AIDS related mortality like older women above age 60. Findings reveal that, as non-pensioners, they are more likely than older women to be impacted by HIV/AIDS as they are less likely to have access to the coping strategies that are available to their older counterparts. This implies that older women are more likely to

⁵⁸ As mentioned in chapter three, time and resource constraints did not permit the author to investigate the health impact of adult HIV/AIDS death.

cope with the socio-economic impact of adult AIDS/non-AIDS death than near-old women. These findings, therefore, exemplify socio-economic impact as one of the multiple impacts of HIV/AIDS on elderly women, as demonstrated in the PSE framework.

In line with the PSE framework, findings from this study explicate secondary stigma as a socio-cultural impact of HIV/AIDS, as narratives reveal how HIV/AIDS related stigma is rooted in the cultural beliefs of the Agincourt community. Hence, elderly women who are caregivers to an infected adult child are prone to the experience of secondary stigma. Further more, findings highlight the different forms of secondary stigma experienced by elderly female caregivers such as physical stigma in the form of isolation and separation from family members; social stigma in the form of voyeurism, social isolation; and verbal stigma in the form of gossiping about them, finger-pointing and jeering at them. Narratives, however, reveal that some of the respondents were able to manage secondary stigma by living in denial or ignorance of the status of their loved one. Even though this may prevent the experience of stigma, it may lead to isolation as they would not be able to seek assistance from people with regard to their experience of adult HIV/AIDS related mortality.

In order to further explain the relationship between adult HIV/AIDS related death and impacts experienced by elderly women, the study is also informed by the ABC-X model of the family stress theory. The ABC-X model states that the A factor (the event) interacting with the B factor (the family's resources) interacting with the C factor (the

definition of the event by the family) produces the X factor (the resulting degree of stress or crisis) (Olson et al. 1983). In this study, the A factor is an adult HIV/AIDS related mortality; the B factor is pension-receipt; the C factor is perception of caregiving role; and the X factor is the impact of adult HIV/AIDS related death on elderly women. The concepts of adult morbidity and mortality (AIDS and non-AIDS), pension-receipt and perception of caregiving role with regard to socio-economic impact were, therefore, explored through qualitative analyses. Findings from the analyses reveal that the interaction of adult AIDS or non-AIDS illness/death with perception of caregiving role and pension-receipt, determines the extent of the socio-economic impact on elderly women. In other words, elderly women's experience of socio-economic impact is dependent on the provoking event (adult illness/death), the belief that they are bound to be involved in caregiving, and the availability of a pension grant to mediate the crisis. The study demonstrates that pensioners are more likely than non-pensioners to cope better with the impacts as they have an array of coping strategies, i.e. joining a burial society, *stokvel*, church group, and women's society due to their pensions. The degree of socio-economic impact is therefore lesser for pensioners.

The ABC-X model is further adapted to explain the relationship between adult HIV/AIDS related mortality (A factor) and elderly female headship (demographic impact) (X factor) (see figure 3.3). The results from the logistic regression analyses of the quantitative data, however, fail to establish a connection between adult AIDS/non-AIDS death and elderly female household headship. Thus, this study rejects the hypothesis that there is a relationship between elderly female household headship and adult AIDS/non-

AIDS mortality, as posited in the ABC-X framework. The study, however, points to another factor that could lead to elderly female headship, that is, pension status. The reason for this is that other findings from the quantitative analyses show that elderly female household headship is strongly associated with pension status. This suggests that pension status could be a determining factor of elderly female headship. One implication of this is that elderly female household heads who are pensioners are likely to cope better with HIV/AIDS impacts as shown in the qualitative data; however, there is need to investigate in other research whether elderly female-headed households cope better with the HIV/AIDS than other types of households such as elderly male-headed households.

10.2 Other Important Findings from the Study

Even though about 12% of the Agincourt population are aged 50 and above, the findings from this study show that as household heads and pensioners, elderly women are making important contributions to their household and community, especially in this era of HIV/AIDS, where adults in the productive and reproductive age groups are dying of the disease. The most important contribution is that, as caregivers, they bear most of the physical and financial responsibilities of adult AIDS and non-AIDS morbidity and mortality in their households and community.

This study focuses not only on the impact of adult mortality (both AIDS and non-AIDS) on elderly women but also, findings from the qualitative research provide insights into how adult morbidity financially impacts the lives of elderly caregivers. However, most of

the caregivers found it difficult to quantify the financial impact of caregiving to a sick adult because of the following reasons:

- Many elderly caregivers opted for multiple means of treatment such as private doctors/ hospitals/clinics, traditional and spiritual healers. This, therefore, made it difficult for them to estimate the total amount spent at these different places.
- The advanced ages of their respondents and their low level of literacy and numeracy also made it difficult for them to recall past events and keep track of monies spent. In order to get an accurate estimation of the financial costs of adult HIV/AIDS related illness in elderly people's households, future studies may need to involve younger members of their households.
- Some of the elderly women only became caregivers a few weeks/days before their patient died, so it was impractical to compare the expenses they incurred to those of others that took care of their patient for a longer period. Clark et al. (2005) show that many migrant workers in Agincourt do return home to die. The implication of this is that the financial impact of adult morbidity may be lesser for caregivers that had their patient with them for a shorter period; however, the impact may be greater if they had been relying on remittances from the patient and lose those remittances during the person's illness and subsequent death.
- It was difficult to distinguish between financial expenses incurred by elderly women in a household that had an adult AIDS and those in non-AIDS households. This may also be due to some children, sick with HIV/AIDS, returning home when they were about to die. If the elderly woman only had to care for the AIDS patient for a short period of time, the expenses incurred may not differ extensively

from the expenses associated with illnesses from other causes. However, some of the respondents, in their narratives, agreed that an HIV/AIDS illness is likely to cost more due to its long duration.

The findings from this study are consistent with other studies (Ferreira, Keikelame and Mosaval, 2001, Barnett and Whiteside, 2002; Knodel and Saengtienchai, 2002; WHO, 2002a; Lindsey et al., 2003; Moller and Ferreira, 2003; HAI, 2004a; HAI, 2004b) that have shown how elderly women are becoming caregivers to adult children and both orphaned and fostered grandchildren. The thesis goes further to compare the experiences of near-old women, who have so far been neglected in studies that focus on elderly people, and their older counterparts above age 60. Thus, this research fills an important gap in the limited literature on near-old women, who due to their social status as grandmothers are considered elderly in many African societies. Some comparisons of near-old and older women experiences of adult morbidity and mortality (whether AIDS or non-AIDS death) are as follows:

- Near-old and older women are both likely to become caregivers to a sick adult child; however, older women are more likely to give care to an adult child, while near-old women are more likely to be caregivers to a spouse. It is important to point out the fact that as the HIV/AIDS epidemic progresses, near-old women may end up giving care to a spouse and adult child sick with the disease⁵⁹.
- Both near-old and older women have to bear the brunt of physical and financial responsibilities of caregiving, but near-old women are less likely to have as

⁵⁹ One of the near-old respondents reported that she took care of a son that died of HIV/AIDS about two years before the fieldwork commenced; at the time she was interviewed, her spouse was sick, supposedly with HIV/AIDS.

regular financial resources to cope with the crisis, especially due to the absence of pensions.

- Even though the majority of the near-old reported that they are involved in economic activities such as selling snacks and traditional beer, and the majority of the older women retired from active work when they reached pension age, near-old women are more likely to experience financial constraint.
- As non-pensioners, near-old women have less access to coping strategies that are available to their older counterparts. These coping strategies include joining a burial society, *stokvel*, church group, and women's society. If available, these strategies would have helped the near-old women in this study to deal better with the socio-economic impact of an adult death.
- The absence of pension grants also makes it more difficult for near-old women to recover from the socio-economic impact of the epidemic. Findings show that some of the older women were able to recover from the financial impact of an adult death in their household due to their pensions. This study does not, in any way, suggest that a pension grant is a panacea for the financial impact of HIV/AIDS on elderly women, but that it does make it less overwhelming for those affected.

In sum, this study provides evidence that near-old women are affected by the epidemic in a similar way as older women who are affected; thus, there is the need for studies and programmes on HIV/AIDS to start focusing on this age group, especially as more young

people continue to succumb to the epidemic, instead of focusing mainly on people above age 60.

10.3 Recommendations

Traditionally, elderly people are regarded as important members of their families, households, and communities. Although, due to urbanization and modernization, false assumptions and myths about how the elderly “have nothing to contribute” to their communities and “are an economic burden” have emerged (Kalache, 1999). The spotlight on the HIV/AIDS epidemic, however, has started to shed light on how elderly people, in particular elderly women, are still making important contributions in their households and communities, especially in relation to bearing the burden of the impacts of the epidemic.

This study, in particular, has shown how both near-old and older caregivers are impacted by adult AIDS and non-AIDS morbidity and mortality in a rural community. Findings reveal, that as caregivers, elderly women are a resource to their families, communities and country, especially in relation to the fight against the HIV/AIDS epidemic and its impacts, though many of them may be ignorant of their resourcefulness. Firstly, whether due to compulsion or cultural belief, they are deeply involved in giving home-based care to infected individuals, thereby, reducing the strain on the health system. Secondly, they are the safety nets for many AIDS orphans, thereby reducing the strain on the social system (e.g. orphanages). Thirdly, their altruistic behaviour of putting the welfare of those in their care before their own shows that they can be trusted to use resources, if

available, to improve the lives of those infected and affected. In view of these premises and findings from this study, some recommendations are offered.

10.3.1 Informing Elderly Caregivers

There is the need for elderly women, as caregivers, to be well informed about the HIV/AIDS disease, especially with regard to HIV transmission and caregiving for PLWHA. Even though findings demonstrate that they have some ideas about how the disease is transmitted, they need to be aware of the necessary precautions to take with regard to daily caregiving for an infected person so that they will not be infected in the process. Some of the respondents in this study reported that they attended HIV/AIDS programmes at the community clinics organised by health workers. However, they need more detailed information as caregivers, rather than general information about HIV transmission.

One way of informing elderly caregivers is through community caregivers⁶⁰ who visit those who are giving care to infected relatives at home. This may expose them, however, to secondary stigma thereby, making it difficult for other caregivers to disclose the status of the patient in their care. The alternative is for community caregivers to use the *stokvel* gatherings of pensioners to reach out to these caregivers. This will serve as a forum for

⁶⁰ Community caregivers are volunteers in the community who are committed to providing care for infected individuals. These caregivers are trained by health workers to assist them in reducing the stain on nurses and doctors caused by the HIV epidemic. They are expected to give home based care to those who are bedridden as a result of HIV. In 2004, when the first phase of the project was conducted the activities of these community caregivers were non-existent. However, in 2006 when the last phase of the project was done, according to locals, there were a number of community caregivers in Agincourt. It was surprising to the author, though, that none of the respondents reported that were visited by a community caregivers. This shows that there is still the need for the services of community caregivers to be available to elderly caregivers in the Agincourt community.

them to be informed about caregiving for PLWHA and also a support group for elderly women who are experiencing adult HIV/AIDS morbidity and mortality in their households. However, the information passed out at *stokvel* gatherings will reach mostly older women as most near-old cannot afford to join a *stokvel*; there is, therefore, the need for special programmes that target near-old caregivers so that they could be well-informed as well.

10.3.2 Participating in income-generating activities

There is an assumption that most elderly people, especially women, are too frail to participate in economic or productive activities (Kalache, 1999). This assumption is false as findings show that elderly women are involved in physical caregiving duties which could sometimes be strenuous. This means that some elderly people, particularly women, could still have stamina to get involved in income-generating activities. This study shows that near-old women are more likely to be involved in economic activities, while those above 60 are less likely to do so, mostly due to their pension status. The fact that many of the pensioners reported that they stopped participating in economic activities when they became pensioners and, many near-old women are also likely to stop working when they attain pension age, show that there is need for elderly people in South Africa to be informed about “active ageing”.

According to the World Health Organisation (WHO, 2002b), “active ageing is the process of optimizing opportunities for health participation and security in order to enhance quality of life as people age”. This means elderly people can continue to

participate in economic activities as long as they have the physical capability and the means to do so. According to the Madrid International Plan of Action on Ageing, adopted at the Second World Assembly on Ageing in 2002, “older persons should be enabled to continue with income generating work as long as they want and for as long as they are able to do so productively” (WHO, 2002b). One advantage of continual participation in economic activities for women when they reach pension age is that they will have another source of income, even if small, instead of sole reliance on their pension grant, which can sometimes make them to live on credit. This will help them to cope better with the financial demands of caregiving as well.

In order for elderly people to continue participating in income generating activities, it is essential for the pension grant not to be regarded as a disincentive to involvement in economic activities, but as income that could be pooled with income from economic activities. According to HelpAge International (HelpAge, 2003d), an organisation that has done extensive work on the challenges facing elderly people in developing countries, participation of elderly people in income generating activities can provide the following:

- financial benefits
- regular amounts of cash to pay for emergency food, schooling, hospital fees and wedding or funeral costs
- leads to better nutrition and health
- brings satisfaction and improved self-esteem
- strengthens social networks
- improves older people’s social status in the family and community and

- increases respect for older people (HelpAge, 2003d).

HelpAge International (2003d) shows how the elderly have benefited from income-generating activities such as weaving baskets and mats, growing vegetables, livestock farming, trading, and food-processing in countries around the world. Most of these activities are successful because of support from non-governmental organisations which provide loans, training and advice for the elderly. As a result, there is need for NGOs and community based organisations (CBOs) to support income generating activities for the elderly especially in rural South Africa.

10.3.3 Targeting near-old women

In order for near-old women to have a “smooth” transition to old age, it is imperative to target them in programmes that focus on the elderly as well. As mentioned earlier, this age group has been neglected as a result of unclear definition of who an older person is. This study provides evidence that they face the same challenges as their older counterparts in rural South Africa. Even though lowering the age cut-off is not an option to consider as it may cause a financial constraint for the South African government, government institutions should work with NGOs and CBOs in order to involve near-old people in poverty reduction and HIV/AIDS programmes. These programmes should help them with productive income generating activities and also prepare them for pension life. They, however, need to be informed about the advantages of participating in economic activities, even if part-time, after they become pensioners. Continuing income activity is likely to reduce the financial burden of caregiving on them. In addition, special

programmes should target near-old women who are caregivers to infected children and other relatives as most do not have access to a regular income that can help them to cope with the impacts of HIV/AIDS in their household.

As non-pensioners, near-old women should be involved in entrepreneurial programmes that can help them to generate income for personal and household needs. These programmes should make loans available to those who are currently involved in economic activities. One way in which this could be done is to provide “revolving loans”. This entails lending someone a sum of money and when it is repaid, it is lent to another person. This phenomenon is likely to provide a longer-term source of capital for those involved, but it needs to be well managed (HelpAge, 2003d). Since many near-old women are already involved in economic activities, this kind of loan may help them to expand their current ventures.

Economic activities that near-old women could use the loans for include, making and selling traditional mats and baskets, garden farming and as well as livestock farming. Even though brewing traditional beer is another option, it may not be a viable alternative as some reports from the respondents show that there is a high level of consumption of alcohol in the community and this may be linked to social ills such as promiscuity and violence. Since a study that focuses on the association between consumption of alcohol and social ills is yet to be conducted at the study site, it is difficult to establish the link between these two phenomena. However, near-old woman can use *marula* fruits which are indigenous to the area, to make juice, instead of traditional beer. Through these

income-generating activities, near-old women would be in a better position to cope with crises such as adult illness and death in their households.

10.4 Conclusion

This thesis started with the premise that the impact of adult HIV/AIDS related mortality on elderly women is multi-faceted and that older women, due to their pension status, are likely to cope better than near-old women with the impacts. The findings from this thesis confirm that elderly women do experience multiple impacts of adult HIV/AIDS related mortality such as socio-economic and socio-cultural impacts. It specifically shows how near-old and older women are bearing some of the brunt of the HIV/AIDS epidemic because of their caregiving role in their households. However, older women are coping better than near-old women because of access to a variety of coping strategies due to their pension status. The study also reveals how older women are more likely to recover from crises because of their pension status. Thus, it confirms what has been documented in the literature, that non-contributory pension grants play a major role in the lives of elderly people, in particular elderly women, and their households. It also fills the gap in the literature about the experiences of near-old women with regard to the HIV/AIDS epidemic.

Findings show how overwhelming the experiences of adult morbidity and mortality are for elderly women in a rural area despite support (through social grants) from the government and the community. The study, therefore, suggests that as HIV/AIDS continues its foothold as one of the leading causes of adult mortality, there is the need to

support these elderly caregivers who are often left with no choice but to shoulder some, if not most, of the burdens of caring for infected and affected children and grandchildren in their communities.

BIBLIOGRAPHY

- Afifi A., V. Clark and S. May 2004. *Computer-Aided Multivariate Analysis*, 4th Edition. Chapman and Hall/CRC: New York.
- Akinsola H. 2000. "Effects of the AIDS epidemic and the Community Home-Based Care programme on the health of older persons in Botswana", *Southern African Journal of Gerontology*, Vol. 9, No. 1, Pp. 4-9.
- Alonzo A. and N. Reynolds 1995. "Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory", *Social Science and Medicine*, Vol. 41, No. 3, Pp. 303-315. Elsevier Science Ltd: Great Britain.
- Alubo O., A. Zwandor, T. Jolayemi and E. Omuodu 2002. "Acceptance and stigmatization of PLWA in Nigeria", *AIDS Care*, Vol. 14, No. 1, Pp. 117-126.
- Atwine B., E. Cantor-Graae and F. Bajunirwe 2005. "Psychological distress among AIDS orphans in rural Uganda", *Social Science and Medicine*, Vol.61, Pp. 555-564.
- Bachmann M. and F. Booyesen 2003. "Health and economic impact of HIV/AIDS on South African households: a cohort study", *BMC Public Health*, Vol. 3, No. 14, Pp 1-8.
- Barnett T. and A. Whiteside 2002. *AIDS in the Twenty-First Century: Disease and Globalization*. Palgrave Macmillan: New York.
- Barrientos A. 2005. "Non-contributory pensions and poverty reduction in Brazil and South Africa", Institute for Development Policy and Management, University of Manchester.
- Barros R., L. Fox and R. Mendonça 1997. "Female-headed households, poverty, and the welfare of children in urban Brazil", *Economic Development and Cultural Change*, Vol. 45, No. 2, Pp. 231-257.
- Bender D. 1967. "A refinement of the concept of household: Families, co-residence, and domestic functions", *American Anthropologist*, New Series, Vol. 69, No.5, Pp. 493-504.
- Bond V, E. Chase and P. Aggleton 2002. "Stigma, HIV/AIDS and prevention of mother-to-child transmission in Zambia", *Evaluation and Program Planning* 25, Pp. 347-356.
- Bongaarts J. and Z. Zimmer 2001. "Living arrangements of older adults in the developing world: An analysis of DHS household surveys", *Policy Research Division working papers* No. 148. Population Council: New York.
- Booyesen F. 2004. "The role of social grants in mitigating the socio-economic impact of HIV/AIDS", a paper presented at CSAE conference on Growth, poverty reduction and human development in Africa', 21-22 March 2004, St Catherine's College, Oxford, United Kingdom.

- Booyesen F. and S. Van der Berg 2005. "The role of social grants in mitigating the socio-economic impact of HIV/AIDS in two Free State communities", *Social African Journal of Economics*, Vol. 73, Special Edition on HIV/AIDS. Economic Society of South Africa: South Africa.
- Boss P. 1987. "Family Stress", in Sussman M. and S. Steinmetz (eds.), *Handbook on Marriage and the Family*. Plenum: New York.
- Boss P. 1988. *Family Stress Management*, Family Studies Text Series 8, Newbury Park. Sage: CA.
- Bradbury K., S. Danziger, E. Smolensky, and P. Smolensky 1979. "Public assistance, female headship and economic well-being, *Journal of Marriage and the Family*, Vol. 41, No. 3, Pp. 519-535.
- Budlender D. 2003. "The debate about household headship", *Social Dynamics*, Vol. 29, No. 2, Pp. 48-72.
- Burger, D. 2005. *South Africa Year Book 2005/2006*, Government Communication and Information System (GCIS); Pretoria: South Africa.
<http://www.gcis.gov.za/docs/publications/yearbook06.htm>. Accessed 18 August 2007
- Buvinić M. and G. Rao Gupta 1997. "Female-headed households and female-maintained families: Are they worth targeting to reduce poverty in developing countries?", *Economic Development and Cultural Change*, Vol. 45, No. 2, Pp. 259-280.
- Carliner G. 1975. "The determinants of household headship", *Journal of Marriage and the Family*, Vol. 37, No. 1, Pp. 28-38.
- Case A. 2001. "Does money protect health status? Evidence from South African pensions" *Princeton University and the NBER Report*. Princeton University: USA.
- Case A. and A. Menendez 2007. "Does money empower the elderly? Evidence from the Agincourt demographic surveillance site, South Africa", *Scandinavian Journal of Public Health*, 35 (Suppl 69), Pp.157-164.
- Case, A. and A. Deaton 1998. "Large cash transfers to the elderly in South Africa", *The Economic Journal*, Vol. 108, Pp. 1330-1361.
- Cattell V. 2001. "Poor people, poor places, and poor health: the mediating role of social networks and social capital", *Social Science and Medicine*, Vol. 52, Pp. 1501-1516.
- Chant S. 2007. "Children in female-headed households: Interrogating the concept of an 'Inter-generational transmission of disadvantage' with particular reference to the Gambia,

Philippines and Costa Rica”, London School of Economics, Gender Institute, New Working Paper Series, Issue 19, February 2007. ISSN No: 1470-8511.

Chimwaza A. and S. Watkins 2004. “Giving care to people with symptoms of AIDS in rural sub-Saharan Africa”, *AIDS Care*, Vol. 16, No. 7, Pp. 795-805.

Clark J., M. Collinson, K. Kahn, K. Drullinger and S. Tollman 2007. Returning home to die: Circular labor migration and mortality in South Africa. *Scandinavian Journal of Public Health*, 35(Suppl 69), Pp. 35-44.

Collinson M., SM. Tollman, K. Kahn and S. Clark 2003. “High prevalent circular migration: Households, mobility and economic status in rural South Africa”, a paper prepared for the Conference on African Migration in Comparative Perspective, Johannesburg, South Africa, June 4-7, 2003.

Collinson MA, O. Mokoena, N. Mgiba, K. Kahn, S. Tollman, M. Garenne, S. Shackleton, and E. Malomane 2002. “Agincourt Demographic Surveillance System (Agincourt DSS)”, in Sankoh et al. (eds.), *Population, Health and Survival in INDEPTH sites*. INDEPTH Series Volume 1, Part C. IDRC. Ottawa, Canada.

Corbin J. and A. Strauss 1990. “Grounded theory research: Procedures, canons and evaluative criteria”, *Qualitative Sociology*, Vol. 13, No. 1, Pp. 3-21.

Cox R., 2002. “Theory-based family problem-solving interventions”, *Clinical Excellence for Nurse Practitioners*, Vol. 5, No. 6, Pp. 3-12

Danziger S., G. Jakubson, S. Schwartz and E. Smolensky 1982. ”Work and welfare as determinants of female poverty and household headship”, *The Quarterly Journal of Economics*, Vol. 39, No. 3, Pp. 519-534.

Dayton J. and M. Ainsworth 2002. “The elderly and AIDS: Coping strategies and health consequences in rural Tanzania”, *Policy Research Division working papers*, No. 160. Population Council: New York.

De Vos S. 2003. “Research note: Revisiting the classification of household composition among elderly people”, *Journal of Cross-Cultural Gerontology*, Vol. 18, Pp. 229-245, 2003, Kluwer Academic Publishers:USA.

Deacon H., I. Stephney and S. Prosalendis 2005. “Understanding HIV/AIDS stigma: A theoretical and methodological analysis”, Human Sciences Research Council Research Monograph, Pretoria, South Africa.

<http://www.hsresearch.ac.za>. Accessed 06 December 2007

Department of Health; Medical Research Council (MRC) and MACRO International INC 1998. "South Africa Demographic and Health Survey 1998, Full report. Department of Health/MRC/MACRO International INC: Pretoria

Department of Social Development 2000. "The state of South Africa's population report (2000): Population, poverty and vulnerability". Pretoria, South Africa.

Department of Social Development 2004a. "Country report on the International Conference on Population Development +10, Country Report, Republic of South Africa. Pretoria, South Africa.

Department of Social Development 2004b. "Population policy for South Africa: Policy implementation evaluation report, 1998-2004". Pretoria, South Africa.

Department of Social Development 2007. "Social Development", in Burger D. (Ed.), *South Africa Year Book 2006/2007*. Pretoria: South Africa. <http://www.gcis.gov.za/docs/publications/yearbook.htm>. Accessed 23 August 2007.

Devereux S. 2001. "Social pensions in Namibia and South Africa", Institute of Development Studies (IDS) Discussion Paper 379.

Donovan C., L. Bailey, E. Mpyisi and M. Weber 2003. "Prime-age adult morbidity and mortality in rural Rwanda: Effects on household income, agricultural production, and food security strategies", a research report, Food Security Research Project (FSRP) and Division of Agricultural Statistics (DSA), Ministry of Agriculture, Livestock and Forestry (MINAGRI), Rwanda.

Duffy L. 2005. "Suffering, shame and silence: The stigma of HIV/AIDS", *Journal of the Association of Nurses in AIDS Care*, Vol. 16, No. 1, Pp. 13-20.

Duflo E. 2003. "Grandmothers and granddaughters: Old age pension and intra-household allocation in South Africa", *World Bank Economic Review*, 17, No. 1, Pp. 1-25.

Ellis M. and C. Muschkin 1996. "Migration of persons with AIDS— a search for support from elderly parents?", *Social Science and Medicine* 43, No. 7, Pp 1109-1118.

Evans R., M. Collinson, T. Polzer and K. Kahn 2007. "Evaluating access to a child-oriented poverty alleviation intervention in rural South Africa", *Scandinavian Journal of Public Health*, 35(Suppl 69), Pp. 118-127.

Ferreira M. 2000. "Growing old in the new South Africa", *Ageing International*, Spring 2000, Pp. 32-46.

Ferreira M. 2004a. "Older caregivers in African households affected by HIV/AIDS: supporting the caregivers and promoting family well-being", a paper presented at the

Union for African Population Studies/ Human Sciences Research Council (UAPS/HSRC) Ageing Conference 2004, Johannesburg.

Ferreira M., 2004b. "HIV/AIDS and family well-being in Southern Africa: Towards an analysis of policies and responsiveness", a paper prepared for a United Nations Department of Economic and Social Affairs Division for Social Policy and Development Policy Workshop, held in Windhoek, Namibia on 28–30 January 2004.

Ferreira M., M. Keikelame and Y. Mosaval 2001. "Older women as carers to children and grandchildren affected by AIDS: A study towards supporting the carers". Institute of Ageing in Africa, Faculty of Health Sciences, University of Cape Town, Observatory, Cape Town.

Food and Agriculture Organisation (FAO) 2003. "HIV/AIDS and Agriculture: Impacts and responses— Case studies from Namibia, Uganda and Zambia", Food and Agriculture Organization of the United Nations.

ftp://ftp.fao.org/sd/SDW/SDWW/ip_summary_2003-webversion.pdf. Accessed 12 November 2007.

Foster G. and J. Williamson 2000. "A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa", *AIDS*, 14 (suppl. 3), pp. S275-S284.

Foster G., R. Shakespeare, F. Chinemana, H. Jackson, S. Gregson, C. Marange and S. Mashumba 1995. "Orphan prevalence and extended family care in a peri-urban community in Zimbabwe", *AIDS Care*, Vol. 7, No. 1, Pp. 3-17.

Fouad D. 2004. "Role of elderly people in the era of HIV/AIDS in Africa", a paper presented at the Union for African Population Studies/ Human Sciences Research Council (UAPS/HSRC) Ageing Conference 2004, Johannesburg.

Gabe J., M. Bury and A. Elston 2004. *Key Concepts in Medical Sociology*. Sage: Thousand Oaks, CA.

Gerdner L., T. Tripp-Reimer, H. Simpson 2007. "Hard lives, God's help, and struggling through: Caregiving in Arkansas Delta", *Journal of Cross Cultural Gerontology*, Vol. 22, Pp. 355-374.

Gilbert L. and L. Walker 2002a. "HIV/AIDS in South Africa: An overview", *Cadernos De Saúde Pública/Reports in Public Health, Brazil*, Vol. 18, Pp. 109-118.

Gilbert L. and L. Walker, 2002b. "Treading the path of least resistance: HIV/AIDS and social inequalities, a South African case study" *Social Science and Medicine* Vol. 54, Pp. 1093-1110.

Gilbert L., T. Selikow and L. Walker 2002. *Society, Health and Disease: An Introductory Reader for Health Professionals*. Ravan Press: South Africa.

Goffman E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster: New York.

Gordon M., B. Whelan and R. Vaughan 1981. "Old age and loss of household headship", *Journal of Marriage and the Family*, Vol. 43, No. 3, Pp. 741-747.

Green G. 1995. "Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be?", *Social Science and Medicine*, Vol. 41, Pp. 557-569.

Hair J Jr., W. Black, B. Babin, R. Anderson, and R. Tatham, 2006, *Multivariate Data Analysis*, 6th Edition. Pearson/Prentice Hall: New Jersey.

Hawe P. and A. Shield 2000. "Social capital and health promotion: A review", *Social Science and Medicine*, Vol. 51, Pp. 871-885.

HelpAge International (HAI) 2002a. *Gender and Ageing Briefs*, HelpAge International, United Kingdom.

HelpAge International (HAI) 2002b. *State of the World's older people 2002*, HelpAge International, United Kingdom.

HelpAge International (HAI) 2002c. *HIV/AIDS and older people: the African situation*, a leaflet by HelpAge International African Regional Development Centre. Nairobi: Kenya.

HelpAge International (HAI) 2003a. *HIV/AIDS and ageing: a briefing paper*, HelpAge International. London: United Kingdom.

HelpAge International (HAI) 2003b. *Non-contributory pensions and poverty prevention: A comparative study of Brazil and South Africa*, HelpAge International. London: United Kingdom.

HelpAge International 2003c. "End of life", *Ageways: Practical Issues in Ageing and Development*, Issue 63, August 2003. HelpAge International. London: United Kingdom.

HelpAge International 2003d. "Income-generating activities", *Ageways: Practical issues in ageing and development*, Issue 63, May 2003. HelpAge International. London: United Kingdom.

HelpAge International 2003e. *Forgotten Families: Older people as carers of orphans and vulnerable children*. HelpAge International/ HIV/AIDS Alliance. London: United Kingdom.

HelpAge International 2004a. *The cost of love: Older people in the fight against AIDS in Tanzania*, HelpAge International, Tanzania.

HelpAge International 2004b. *The impact of HIV/AIDS on older people in Cambodia*, HelpAge International, United Kingdom.

HelpAge International 2004c. *Age and Security: How social pensions can deliver effective aid to poor older people and their families*, HelpAge International, United Kingdom.

HelpAge International 2004d. *Ageing issues in Africa: A summary*, HelpAge International. London: United Kingdom.

HelpAge International 2005a. *Coping with Love: Older people and HIV/AIDS in Thailand*, HelpAge International. London: United Kingdom

HelpAge International 2005b. *Making Cash Count: Lessons from cash transfer schemes in east and southern Africa for supporting the most vulnerable children and households*, Save the Children UK, HelpAge International and Institute of Development Studies. London: United Kingdom

Herek, G. and J. Capitanio 1993. "Public reactions to AIDS in the United States: A second decade of stigma", *American Journal of Public Health*, Vol. 83, Pp. 574-577.

Herek, G., J. Capitanio and K. Widaman 2002. "HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999", *American Journal of Public Health*, Vol. 92, Pp. 371-378.

Hill R. 1949. *Families under Stress: Adjustment to the Crises of War Separation and Reunion*. Harper and Brothers Publishers: New York.

Hosegood V. and I. Timæus 2005. "The impact of adult mortality on the living arrangements of older people in rural South Africa", *Ageing and Society*, Vol. 25, No. 3. Pp. 431-444.

Hosegood V., E. Preston-Whyte, J. Busza, S. Moitse and I. Timaeus 2007. "Revealing the full extent of households' experiences of HIV and AIDS in rural South Africa", *Social Science and Medicine*, Vol. 65, Pp. 1249-1259.

Hunter N. and J. May 2003. "Growing old gracefully?": Ageing in post-apartheid South Africa", Paper prepared for the Fourth African Population Conference "Population and Poverty in Africa: Facing the 21st Century Challenges", Tunis, 8-12 December 2003.

INDEPTH Network 2007. "An international Network of field sites with continuous Demographic Evaluation of Populations and their Health in Developing Countries", INDEPTH Network.

http://www.indepth-network.org/core_documents/vision.htm. Accessed 03 August 2006

Jick T. 1979, "Mixing qualitative and quantitative methods: Triangulation in action", *Administrative Science Quarterly*, Qualitative Methodology, Vol. 24, No. 4, Pp. 602-611.

Johnson R. and A. Onwuegbuzie 2004, "Mixed methods research: A research paradigm whose time has come", *Educational Researcher*, Vol. 33, No. 7, Pp. 14-26.

Kahn K, Tollman S., Garenne M. and J. Gear 1999. "Who dies from what? Determining cause of death in South Africa's rural northeast", *Tropical Medicine and International Health*, Vol. 4, Pp. 433-441.

Kahn K. 2006. "Dying to make a fresh start: Mortality and health transition in a new South Africa", Umeå University Medical Dissertations, New Series No. 1056 ISSN 0346-6612 ISBN 91-7264-173-8, Epidemiology and Public Health Sciences, Department of Public Health and Clinical Medicine, Umeå University, SE-901 87 Umeå, Sweden.

Kahn K., M. Garenne, M. Collinson, and S. Tollman 2007. "Mortality trends in a new South Africa: Hard to make a fresh start", *Scandinavian Journal of Public Health*, 35 (Suppl 69), Pp. 26-34.

Kahn K., S. Tollman, M. Collinson, S. Clark, R. Twine, B. Clark, M. Shabangu, X. Gómez-Olivé, O. Mokoena and M. Garenne 2007. "Research into health, population and social transitions in rural South Africa: Data and methods of the Agincourt Health and Demographic Surveillance System", *Scandinavian Journal of Public Health*, 35(Suppl 69), Pp. 8-20.

Kahn K., S. Tollman, M. Garenne and J. Gear 2000. "Validation and application of verbal autopsies in a rural area of South Africa", *Tropical Medicine and International Health*, Vol. 5, No. 11, Pp. 824-831.

Kalache A. 1999. "Active ageing makes the difference", *Bulletin of the World Health Organization*, Editorials, Vol. 77, No. 4, Pg. 299. World Health Organization, Geneva: Switzerland.

Kalichman S. and L. Simbayi 2004. "Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa", *AIDS Care*, 16, Vol. 5, Pp. 572-580.

Kimenyi M. and J. Mbaku 1995. "Female headship, feminization of poverty and welfare", *Southern Economic Journal*, Vol. 62, No. 1, Pg. 44.

Kimuna S. 2004. "Living arrangements of older adults in Zimbabwe: Their socio-economic and socio-demographic conditions", a paper presented at the Union for African Population Studies/ Human Sciences Research Council (UAPS/HSRC) Ageing Conference 2004, Johannesburg.

Kinsella K. and D. Philips 2005. "Global Aging: The Challenge of Success", *Population Bulletin*, Vol. 60, No. 1, Pp 3-43. Population Reference Bureau: Washington, DC.

Knodel J. and C. Saengtienchai 2002. "AIDS and older persons: The view from Thailand", *Population Studies Center Research Report*, No. 02-497. Ann Arbor: Michigan.

Knodel J. and W. Im-em 2003. "The economic consequences for parents of losing an adult child to AIDS: Evidence from Thailand (revised)", *Population Studies Center Research Report*, No. 02-504. Ann Arbor: Michigan.

Knodel J., S. Watkins, and M. VanLandingham 2002. "AIDS and older persons: An international perspective", *Population Studies Center Research Report*, No. 02-495. Ann Arbor: Michigan.

Knodel J., W. Im-em, C. Saengtienchai, M. VanLandingham, and J. Kespichayawattana, 2002. "The impact of an adult child's death due to AIDS on older-aged parents: Results from a direct interview survey", *Population Studies Center Research Report*, No. 02-497. Ann Arbor: Michigan.

Kobrin F. 1973. "Household headship and its changes in the United States, 1940-1960, 1970", *Journal of the American Statistical Association*, Vol. 68, No. 344, Pp. 793-800.

Kossoudji S. and E. Mueller 1983. "The economic and demographic status of female-headed households in rural Botswana", *Economic Development and Cultural Change*, Vol. 31, No. 4, Pp. 831-859.

Lam D., M. Leibbrand and V. Ranchhod 2005. "Labour force withdrawal of the elderly in South Africa", a paper presented at the International Union for the Scientific Study of Population (IUSSP), 18-23 July, Tours, France.

Legido-Quigley H. 2003. "The South African old age pension: Exploring the role on poverty alleviation in households affected by HIV/AIDS", a paper for the 4th International Research Conference on Social Security, "Social Security in a Long-Life Society", Antwerp, Belgium, 5-7 May 2003.

Lesko I. 2005. "Attitudes and beliefs around HIV and AIDS stigma: The impact of the film- The sky in her eyes", Unpublished Masters thesis, Institute for Social Development, University of the Western Cape, South Africa.

Liddell C., L. Barrett and M. Bydowell 2005. "Indigenous representations of illness and AIDS in sub-Saharan Africa", *Social Science and Medicine*, Vol. 60, Pp. 691-700

Lim J. and B. Zebrack 2004. "Caring for family members with chronic physical illness: a critical review of caregiver literature", *Health and Quality of life Outcomes* Vol. 2, No. 50, Pp. 1-9

Lindsey E., M. Hirschfeld, S. Tlou and E. Ncube 2003. "Home-based care in Botswana: Experiences of older women and young girls", *Health Care for Women International*, Vol. 24, No. 6, Pp. 486-501.

- Lloyd C. and A. Gage-Brandon 1993. "Women's role in maintaining households: Family welfare and sexual inequality in Ghana", *Population Studies*, Vol. 47, No. 1, Pp. 115-131.
- Madhavan S. 2004. "Fosterage pattern in the age of AIDS: Continuity and change", *Social Science and Medicine*, Vol. 58, No. 7, Pp.1443-1454.
- Madhavan S. and E. Schatz 2007. "Coping with change: household structure and composition in rural South Africa, 1992 – 2003", *Scandinavian Journal of Public Health*, 35(Suppl. 69), Pp. 85-93.
- Madru N. 2003. "Stigma and HIV: Does the social response affect the natural course of the epidemic", *Journal of the Association of Nurse in AIDS Care*, Vol. 14, No. 5, Pp. 39-48.
- Makiwane M., M. Schneider and M. Gopane 2004. "Experiences and needs of older persons in Mpumalanga", a report by Human Sciences Research Council, Mpumalanga Provincial Government and Department of Health and Social Sciences, South Africa.
- Mathison S. 1988. "Why triangulate?", *Educational Researcher*, Vol. 17, No. 2, Pp. 13-17.
- May J. 2003. "Chronic poverty and older people in South Africa", *Chronic Poverty Research Centre (CPRC) Working Paper 25*. CPRC and HelpAge International.
- McDonald C. and E. Schatz 2006. "Competing discourses: How older women in rural South Africa make sense of the HIV/AIDS epidemic", University of Colorado Population Program Working Paper, POP 2006-09.
- McKenry P. and S. Price (eds.) 1994. *Families and Change: Coping with Stressful Events*. Sage: Thousand Oaks, CA.
- McLanahan S. 1988. "Family structure and dependency: Early transitions to female household headship", *Demography*, Vol. 25, No. 1, Pp. 1-16.
- Measure Demographic and Health Surveys (DHS) 2007. Demographic and Health Surveys: Qualitative Research. <http://www.measuredhs.com/aboutsurveys/qr/start.cfm>. Accessed 06 December 2007.
- Merli G. and A. Palloni 2004. "The HIV/AIDS epidemic, kin relations, living arrangements and the elderly in South Africa", Centre for Demography and Ecology (CDE) working paper, No 2004-23.
- Moller V. and M. Ferreira 2003. *Getting by...: Benefits of Non-Contributory Pension Income for Older South African Households*. Non-contributory Pensions and Poverty Study (NCPSS) report, Institute of Ageing in Africa, University of Cape Town.

Moller V. and A. Sotshongaye 1996. "My family eat this money too": Pension sharing and self-respect among Zulu grandmothers", *Southern African Journal of Gerontology*, Vol. 5, No. 2, Pp. 9-18.

Moller V. 1993. "Living with adult children: A benefit assessment of co-resident living arrangements among black and white older South Africans", *Southern African Journal of Gerontology*, Vol. 2, No. 1, Pp. 10-16.

Monasch R. and J. Boerma 2004. "Orphanhood and childcare patterns in sub-Saharan Africa: An analysis of national surveys from 40 countries, *AIDS*, Vol. 18, (suppl 2), Pp. S55-S65

Moralda H., M. Llaneta, T. Panga and C. Pomentil 2001. "Female-headed households in the Philippines," a paper presented at the Department of Labour and Employment (DOLE) First Research Conference held on the Occupation Safety and Health Center on 5 December 2001, Quezon City.

Muller A. and M. Steyn 1999. "Culture and the feasibility of a partnership between westernised medical practitioners and traditional healers" in Gilbert L., T. Selikow and L.

Muriisa R. 2006. "The AIDS pandemic in Uganda: Social Capital and the role of NGOs in alleviating the impact of HIV/AIDS", an unpublished PhD thesis, Department of Administration and Organisation Theory, University of Bergen.

Muyinda H., J. Seeley, H. Pickering and T. Barton 1997. "Social aspects of AIDS-related stigma in rural Uganda", *Health and Place*, Vol. 3, No. 3: 143-147.

Neuman L. 2003. *Social Research Methods: Qualitative and Quantitative Approaches*, Pearson Education, Inc: USA.

Nhongo T. 2004. "The changing role of older people in African households and the impact of aging on African family structures", a paper presented at the Union for African Population Studies/ Human Sciences Research Council (UAPS/HSRC) Ageing Conference 2004 in Johannesburg.

Noumbissi A. and T. Zuberi 2001. "Household structure and aging in South Africa: A research note", prepared for the Virtual Conference on African Households: An exploration of Census Data, organized by the African Census Analysis Project, Population Studies Center, University of Pennsylvania, November 21-23, 2001.

Ntozi J. 1997. "AIDS morbidity and the role of the family in patient care in Uganda", *Health Transition Review*, Supplement to Vol. 7, Pp. 1-22.

Ntozi J. and J. Mukiza-Gapere 1995. "Care for AIDS orphans in Uganda: findings from focus group discussions", *Health Transition Review*, Supplement to Vol. 5, Pp. 245-252.

- Nyamukapa C. and S. Gregson 2005. "Extended family's and women's roles in safeguarding orphans' education in AIDS-afflicted rural Zimbabwe", *Social Science and Medicine*, Vol. 60, Pp. 2155-2167.
- Ogden J. and L. Nyblade 2005. "Common at its core: HIV-related stigma across contexts", International Center for Research on Women (ICRW).
- Ogunmefun C. 2007. "Hidden impacts: Near-old women's experiences of adult mortality and morbidity in the era of HIV/AIDS in rural South Africa", a paper presented at the 5th African Population Conference, 10-14 December 2007, Arusha, Tanzania.
- Ogunmefun C. and E. Schatz 2008. "Caregivers' sacrifices: The opportunity costs of adult morbidity and mortality on female pensioners in rural South Africa, *Development Southern Africa*, accepted for publication.
- Oktay J. 2004. "Grounded theory", in Padgett D. (ed.), *The Qualitative Research Experience*. Wadsworth/Thomson Learning: Belmont, USA.
- Oleke C., A. Blystad and O. Rekdal 2005. "When the obvious brother is not there": Political and cultural contexts of the orphan challenge in northern Uganda, *Social Science and Medicine* 61, Pp. 2628-2638.
- Olson D., H. McCubbin, H. Barnes, A. Larsen, M. Muxen, and M. Wilson 1983. *Families: What Makes Them Work?* Beverly Hills, CA: Sage.
- Overseas Development Institute (ODI) 2005, "Social grants, South Africa", Policy Brief 1, Inter-Regional Inequality Facility, sharing ideas and policies across Africa, Asia and Latin America, February 2006. London: UK.
www.odi.org.uk/inter-regional_inequality/papers/Policy%20Brief%201%20-%20South%20Africa.pdf. Accessed 21 August 2007.
- Parker R. and P. Aggleton 2002. "HIV/AIDS-related stigma and discrimination: A conceptual framework and an agenda for action", Horizons Program, Population Council.
- Patel R. and G. Carter 2004. "HIV/AIDS: Secondary stigma and secondary social death: the impact of HIV/AIDS on affected youth", (a case study: HIV/AIDS social workers/counsellors in Johannesburg, Gauteng), *Researching Social Life* 306Q.
- Patton M. 1990. *Qualitative Evaluation and Research Methods*, 2nd Edition. Sage Publications: Newbury Park, London, New Delhi.
- Perry A. 2004. "A model of stress in families of children with developmental disabilities: Clinical and research application, *Journal of Developmental Disabilities*, Vol. 11, no. 1, Pp.1-15.
- Pezullo J. 2006. "Logistic Regression".

<http://statpages.org/logistic.html>. Accessed 01 March 2007

Poindexter C. and L. Linsk, 1999. "HIV-related stigma in a sample of HIV-Affected Older female African American Caregivers", *Social Work*, Vol. 44, No. 1, Pp. 46-61.

Portes A. 1998. "Social capital: its origins and applications in modern Sociology", *Annual Review of Sociology*, Vol. 24, Pp. 1-24.

Posel D. 2004. "Sex, death and embodiment: reflections on the stigma of AIDS in Agincourt, South Africa", a paper for symposium on Life and Death in a time of AIDS: the Southern African experience, Wits Institute for Social and Economic Research (WISER), 14th – 16th October, 2004.

Posel D., K. Kahn and L. Walker 2007. "Living with death in a time of AIDS: A rural South African case study", *Scandinavian Journal of Public Health*, 35 (Suppl 69), Pp 138-146.

Powell-Cope G. and M. Brown 1992. "Going public as an AIDS family caregivers", *Social Science and Medicine*, Vol. 34, No. 5, Pp. 571-580.

Princeton University Data and Statistical Services (DSS) 2007. "Working with dummy variables", Princeton University Library.
http://www.dss.princeton.edu/online_help/analysis/dummy_variables.htm. Accessed 21 June 2007

Rogers B. 1995. "Alternative definitions of female headship in the Dominican Republic", *World Development*, Vol. 23, No.12, Pp. 2033-2039,

Saengtienchai C. and J. Knodel 2001. "Parental caregiving to adult children with AIDS: A qualitative analysis of circumstances and consequences in Thailand", *Population Studies Center Research Report*, No. 01-481. Ann Arbor: Michigan.

Sagner A. and R. Mtati 1999. "Politics of pension sharing in urban South Africa", *Ageing and Society*, Vol. 19, Pp. 393-416.

Sagner, A. 2000. Ageing and social policy in South Africa: Historical perspectives with particular reference to the Eastern Cape, *Journal of Southern African Studies*, Vol. 26, No. 3, Pp. 523-553.

Sauerborn R., A. Adams and M. Hien 1996. "Household strategies to cope with the economic costs of illness", *Social Science and Medicine*, Vol. 43, No. 3, Pp. 291-301.

Schatz E. 2002. "Numbers and Narratives: Making sense of gender and context in rural Malawi". Unpublished PhD Dissertation, University of Pennsylvania, Graduate Groups of Sociology and Demography.

- Schatz E. 2007. "Taking care of my own blood": Older women's relationships to their households in rural South Africa, *Scandinavian Journal of Public Health*, Vol. 35 (Supplement 69), Pp.147-154.
- Schatz E. and C. Ogunmefun 2005. "Caring and Contributing: The role of older women in multi-generational households in the HIV/AIDS era", University of Colorado, Institute of Behavioral Science Population Program/Aging Center Working Paper. POP 2005-06.
- Schatz E. and C. Ogunmefun 2007. "Caring and contributing: The role of older women in multi-generational households in the HIV/AIDS era", *World Development*, Vol. 35, No. 8, Pp. 1390-1403.
- Shisana O. and L. Simbayi 2002. Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media, Household Survey 2002, Executive Summary. Human Sciences Research Council, South Africa.
- SouthAfrica.info (SAinfo) 2006. "The quick guide to South Africa". http://www.southafrica.info/ess_info/sa_glance/quickguide.htm. Accessed on August 16, 2007
- Ssengonzi R. 2007. "The plight of older persons as caregivers to people infected/affected by HIV/AIDS: Evidence from Uganda", *Journal of Cross Cultural Gerontology*, 22: 339-353.
- Statistics South Africa 2007. "Mid-year population estimates", a report by Statistics South Africa. Pretoria: South Africa.
- Steinberg, M., S. Johnson, G. Schierhout, D. Ndegwa, K. Hall, B. Russell, and J. Morgan, 2002. *Hitting Home: How Households Cope With the Impact of the HIV/AIDS Epidemic, A Survey of Households Affected by HIV/AIDS in South Africa*. The Henry J. Kaiser Family Foundation: Washington, DC.
- Strauss A. and J. Corbin 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Technique*. Sage Publications: Newbury Park, London, New Delhi.
- Taylor S. and D. Field (eds.) 2003. *Sociology of Health and Health Care*. Blackwell Publishing.
- The SASPI Team 2004a. "Prevalence of stroke survivors in rural South Africa: Results from the Southern Africa Stroke Prevention Initiative (SASPI) Agincourt Field Site", *Stroke*, 2004; 35; 627-632.
- The SASPI Team 2004b. "Secondary prevention of stroke— Results from the Southern Africa Stroke Prevention Initiative (SASPI), Agincourt field site", *Bulletin of the World Health Organisation* 2004; Vol. 82, No. 7, Pp. 503-508.

Thomas F. 2006. "Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia", *Social Science and Medicine*, Vol. 63, Pp. 3174-3187.

Tienda M. and R. Angel 1982. "Headship and household composition among Blacks, Hispanics, and other Whites", *Social Forces*, Vol. 61, No. 2, Pp.508-531.

Tollman S., K. Kahn, M. Garenne and J. Gear 1999. "Reversal in mortality trends: evidence from the Agincourt field site, South Africa, 1992-1995", *AIDS*, Vol. 13, Pp 1091-1097.

Tollman S. 2006. Medical Research Council/University of the Witwatersrand, Rural Public Health and Health Transitions Unit: Review 2006, Directors' Report.

Townsend N, S. Madhavan, M. Collinson, and M. Garenne 2004. "Collecting data on intra-household relationships in the Agincourt Health and Population Programme: benefits and limitations", in Van de Walle E. and Preston-Whyte E. (eds.) *African Households: an Exploration of Census Data*.

University of California (UCLA) Academic Technology Services (ATS) 2007. "Logistic Regression Analysis".

http://www.ats.ucla.edu/stat/stata/output/stata_logistic.htm. Accessed 21 June 2007.

UNAIDS 2000. "HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and determinants". Joint United Nations Programme on HIV/AIDS (UNAIDS). http://data.unaids.org/Publications/IRC-pub01/JC316-Uganda-India_en.pdf. Accessed 23 August 2007.

UNAIDS 2007. AIDS epidemic update: December 2007, Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO). http://data.unaids.org/pub/EpiReport/2006/2006_EpiUpdate_en.pdf. Accessed 10 January 2008.

United Nations 2004. *The impact of AIDS*, Department of Economic and Social Affairs/Population Division, United Nations Report. United Nations Publication, <http://www.un.org/esa/population/publications/AIDSimpact/AIDSWebAnnounce.htm>, Accessed 03 July 2005.

United Nations Development Programme (UNDP) 2005. "Impact of HIV/AIDS on household vulnerability and poverty in Vietnam", Report of UNDP-AusAID supported VIE98/006, Vietnam. http://www.undp.org.vn/undpLive/digitalAssets/2930_hiv.pdf. Accessed 15 November 2007

Uys L., M. Chirwa, P. Dlamini, M. Greeff, T. Kohi, W. Holzemer, L. Makoe, J. Naidoo, R. Phethu, 2005. "Eating Plastic," "Winning the Lotto," "Joining the WWW"...

Descriptions of HIV/AIDS in Africa, *Journal of the Association of Nurses in AIDS Care*, Vol. 16, No. 3, Pp. 11-21.

Van der Berg S. 2002. "Issues in South African social security", Stellenbosch Economic Working Papers: 1/2002, Bureau for Economic Research, Department of Economics, University of Stellenbosch.

VanLandingham M. W. Im-em and C. Saengtienchai 2005. "Community reaction to persons with HIV/AIDS and their parents in Thailand" *Population Studies Center Research Report*, No. 05-577. Ann Arbor: Michigan.

Veenstra N. and A. Whiteside 2005. "Economic impact of HIV", *Best Practice and Research Clinical Obstetrics and Gynaecology*, Vol. 20, No. 30, Pp.1-14.

Wakefield S. and B. Poland 2005. "Family, friend or foe? Critical reflections on the relevance and role of social capital in health promotion and community development, *Social Science and Medicine*, 60, Pp. 2819-2832.

Walker 2002, *Society, Health and Disease: An Introductory Reader For Health Professionals*. Ravan Press: South Africa.

Waller W. 1956. *The family: a dynamic interpretation*, revised by Reuben Hill, University of North Carolina. The Dryden Press: New York.

Weitz R. 1990. "Living with the Stigma of AIDS", *Qualitative Sociology*, Vol. 13, No. 1, Pp.23-38.

Williams A. 2003. *Ageing and Poverty in Africa: Ugandan Livelihoods in a Time of HIV/AIDS*. Ashgate, Hampshire: UK.

Wittenberg M. and M. Collinson 2006. "Restructuring of households in rural South Africa: Reflections on average size in the Agincourt sub-district 1992-2003", MRC/Wits Unit working paper.

Wood K., E. Chase and P. Aggleton 2006. "'Telling the truth is the best thing': Teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe", *Social Science and Medicine*, Vol. 63, Pp. 1923-1933.

World Bank 1993. *World Development Report 1993: Investing in Health*. World Bank. http://www.wds.worldbank.org/servlet/WDS_IBank_Servlet?pcont=details&eid=000009265_3970716142319. Accessed 21 June 2007.

World Health Organization (WHO) 2002a. "Impact of AIDS on older people in Africa: Zimbabwe case study", World Health Organisation Report. WHO, Switzerland.

World Health Organization (WHO) 2002b. "Active ageing: A policy framework", World Health Organisation, Non-communicable Disease Prevention and Health promotion, Ageing and Life Course. WHO/NMH/NPH/02.8. Geneva: Switzerland.

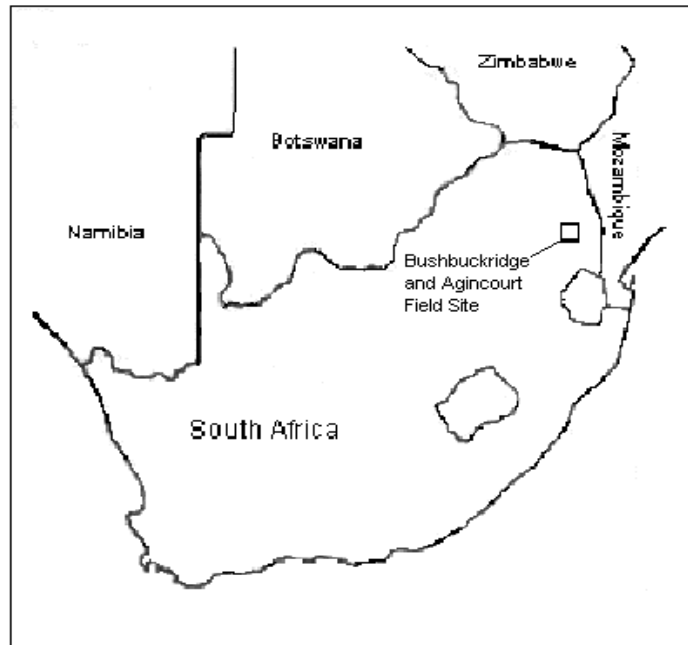
Yamano T. and T. Jayne 2004. "Measuring the impacts of working-age adult mortality on small-scale farm households in Kenya", *World Development*, Vol. 32, No. 1, Pp. 91-119.

Yamba C. 1997. "Cosmologies in turmoil: Witchfinding and AIDS in Chiawa, Zambia", *Africa: Journal of the International African Institute*, Vol. 67, No. 2, Pp. 200-223.

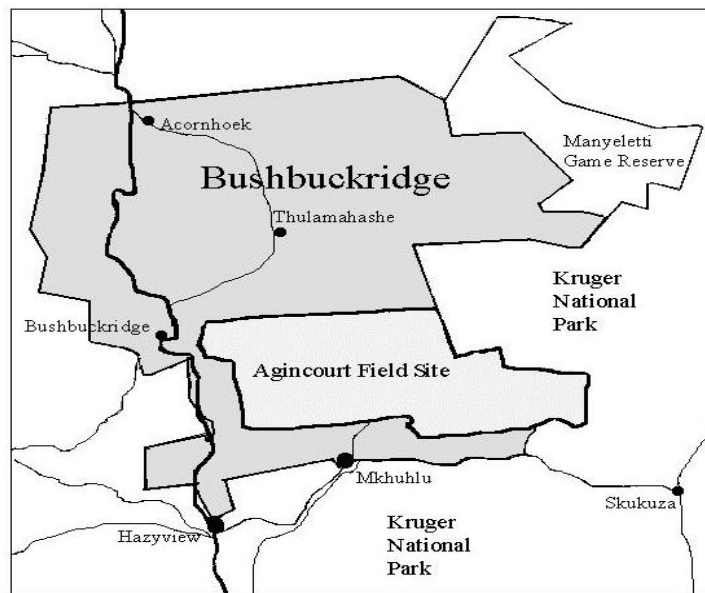
Zhou YR. 2007. "If you get AIDS... You have to endure it alone": Understanding the social constructions of HIV/AIDS in China", *Social Science and Medicine*, Vol.65, Pp. 284-295

Zimmer Z. and J. Dayton 2003. "The living arrangements of older adults in sub-Saharan Africa in a time of HIV/AIDS", *Policy Research Division Working Papers*, No.169. Population Council: New York.

APPENDIX A: The MRC/Wits Unit Study Site



Location of Agincourt study site within South Africa



Location of the Agincourt study site within Bushbuckridge District

APPENDIX B: Interview Guide for Older (aged 60+) Respondents

INTERVIEW 1

Childhood & Family Background

When/where born

Family composition (how many brothers/sisters, where was in line up, what's happened to siblings)

Youth (positive/negative memories, why)

Education (how far went, positive/negative memories, why)

Family Life

Courtship & marriage process (still same husband, if not what happened)

Family Composition (go thru each birth—father of child, year, currently alive, if not when died/how old when died, what died of)

Changes in Family Structure

Which if any children live with her now (always lived there, or moved out/in)

Where do the others live (when moved out, why)

What is the marital status of each?

How often does she see those who don't live in household?

What was occasion to see each last?

Where grandchildren live (any with her, if yes, why)

Other people who have moved in/out of household (circumstances)

Work & Pension History

Paid/unpaid jobs, one employer/different employers, odd jobs, work for self (even small business, helping family or farming no pay)

How often worked

How much earned

Still working?

If yes, same/different job? If yes or no, when/why changed?

Do you get a pension now (govt/private)? If not, why not?

How do you use it generally (self/hand over; on what goods)? This last month, what happened once got cheque? How was it spent? (chronology of first thing paid off, downwards) How much left for extras? Who/how keep left-over money? Who has say over how spent/kept?

How life pre/post-pension different? Amount of money, expenditures/luxuries, getting credit, better/worse

Family Circumstances—Social and Financial Assistance

Financial support networks (family, gov't grants, church, etc)

Emotional support networks (family, gov't grants, church, etc)

Financial stability of household

Mobility of household members—how affects household financially/emotionally

Respondent contributing to others

Conflicts over money?

Daily life & Health

What did yesterday? How same/diff from most days

How is health? if not well, describe & action taken/treatment sought

How does health affect what does on typical day?

How is mental health? (worry a lot, cry a lot, feel sad/depressed, not hungry, tired)

If not well, describe, why worried (about what & cause), etc & action taken/treatment sought

How does mental health affect what does on typical day?

Involved in social activities (church, women's group)

Respect from family/community; come for advice

Trust others? Jealousy

INTERVIEW 2

Household

Who exactly lives in house? (FOR EACH PERSON: age, relationship, when/why came to stay; anyone who used to stay, but don't anymore—USE LISTS, 2nd GUIDE, get reasons)

Which people in house AND outside of house does the gogo support with her pension/other work? What other work?

Who else provides support? What kind?

How does supporting other family members make you feel?

Applied for or thought of applying for child grants for any of the children?

Do grandchildren cause any trouble?

Caring for Foster/Orphaned children (skip if not relevant)

How long been fostered/orphaned

Experience of caregiving (how long taking care, why came/how got role)

What does

Average hours per week

Advantages/disadvantages (how helpful/problems)

Resources available (financial, and social)

Other people who help (who, how, enough?)

Advice/support sought (child grants)

What other people say about children, taking care of them

How do you feel about taking care of your grandchild/ren?

Caregiving for Sick (skip if not relevant)

How long ill (how knew when first ill)

Experience of caregiving (how long taking care, how got role)

What did/does

Average hours per week

Advantages/disadvantages

Resources available (financial, and social)

Other people who help (who, how, enough?)

Treatment/Advice sought (satisfied with treatment, assistance, advice?)

What illness (symptoms, why think that, how got it, worried about catching)

Other people (what say, fear catching, helpful/not)

HIV/AIDS & Community

Where HIV/AIDS comes from (causes, how understand, how explain in own ideas)

Why so much AIDS

Why people die from AIDS

Difference between AIDS and other deaths (own view, within community, ancestors)

Attitude toward HIV+ individuals, their families/caregivers, their children

Experience of HIV+ individuals, their families, families that take in their children

Impact on community

Most likely infected

Many of the gogos said that when they were young their parents thought if girls went to school they would become prostitutes. Did you agree? Do you think this is still true now?

How to treat it

Health and community services (what do they do, do enough?)

Getting information (where get it, sufficiently available, for whom?)

Community's efforts to address epidemic

How many funerals have you been to in the past month? What did the people die from?

HIV&AIDS & Household/family

HIV/AIDS affected their life

Worries about HIV/AIDS (people in family)

Discussions with family members about HIV/AIDS

Biggest worry (Probes: contracting it, already being infected, fear for family members, fear of being left with burden)

HIV/AIDS related tensions within family/household

Making a Difference in the HIV/AIDS epidemic

Efforts to address HIV/AIDS within family/household

What they want to tell younger generation about HIV/AIDS

How they could make a difference in terms of the HIV/AIDS epidemic (probe levels: household/family/community)

INTERVIEW 3

Pension

When started getting pension? How long ago? Had to wait a long time after thought should start? Etc.

Was your first pension payment a large one? How much? How did you spend it?

Who is pension for?

What should be used for?

Picking it up (how, who)? E.g. Tell me about what happens on Pension Day from when you get up in the morning.

Ideal/actual way spent (asked about how spent 1st interview)

Way used in health crisis/long term illness

What point in month used up (generally/last month)

Other grants (probe: knowledge, eligibility, tried to get one, difficulties)

More on child grants (if a kid is getting one, who gets the money, how is it used; if children aren't getting one, is there a reason)

Any conflicts in house around money? Requests/complaints from grandchildren?

What would people say if about a gogo who didn't use her pension money to help her grandchildren/children? Do you know anyone like this? What do people say about her?

Social and Financial Support

Respondent or family member belong to (why/why not):

Medical Aid

Burial Society/Funeral Policy (How much pay? Who is on list? Why? What returns will be?)

Stokvel/Women's group/Makoti Society/Church Group (How became a group? How many in group (ages/gender)? How much contribute? How often money comes to her? What she did with it the last time she got it?)

Family members who give support (Probes: kind, how often, discussions)

Community members/programmes that give support (Probes: kind, how often, discussions)

People in family/household/community who trust/don't trust (why)

Can you tell a story about a time when someone came and helped you when a family member was sick, or had died? (If can't think of one, a story about her helping someone else).

Economic Impact

1. Effect of sickness/death on household's finance.

2. Amount spent on the sick/death/funeral, e.g. on medicine, tablets, transport, hospital bills, etc.

3. Amount spent (generally/last month) on taking care on foster children/orphans, e.g. on school fees, clothes, books, food, etc.

4. Household assets like cattle, goats, and furniture, sold to take care of the sick/death/funeral/foster children/orphans.

5. What she thinks about the effect of sickness/death/burden of caregiving on finance

6. How did she recover (financially) after sickness/death?

APPENDIX C: Interview Guide for Near-old (aged 50-59 years) Respondents⁶¹

INTERVIEW 1

Childhood & Family Background

When/where born

Family composition (how many brothers/sisters, where was in line up-her position in the family, what's happened to siblings)

Youth (positive/negative memories, why)

Education (how far went, positive/negative memories, why)

Family Life

Courtship & marriage process (still same husband, if not what happened)

Family Composition (go thru each birth—father of child, year, currently alive, if not when died/how old when died, what died of)

Changes in Family Structure

Which if any children live with her now (always lived there, or moved out/in)

Where do the others live (when moved out, why)

What is the marital status of each

How often does she see those who don't live in household

What was occasion to see each last

Where grandchildren live (any with her, if yes, why)

Other people who have moved in/out of household (circumstances)

Work History & Social Grants

Paid/unpaid jobs, one employer/different employers, odd jobs, work for self (even small business, helping family or farming no pay) **If she farms, ask whether it is only for household consumption or she sells farm produce**

How often worked

How much earned

Still working?

If yes, same/different job? If yes or no, when/why changed?

How much does she earn now

How does she use income generally (self/hand over; on what goods)? This last month, what happened once got income? How was it spent? (chronology of first thing paid off, downwards)

Is income enough to take care of her household?

How much left for extras? Who/how keep left-over money? Who has say over how spent/kept?

How life pre-pension? Good?

What other things she spends her money on-expenditures/luxuries, getting credit

⁶¹ New questions are in bold.

Other sources of income

Remittances from children and other family members

Household members that get social grants (child grant, disability grant, pension, etc)

Contribution of social grants to household

What does she know about old age pension grant?

Expectation of receiving a pension grant at age 60

Is she looking forward to getting a pension or worried?

What difference will a pension grant make in her household?

Will gogo stop to work when she starts receiving pension?

Does husband get pension grant? (Ask if husband is alive, if dead was he getting one)

How does he spend his pension?

How do old men spend their pension generally? How different from the way gogos spend their pension?

Social and Financial Support

Emotional support networks (family, government, church, etc)

Financial support networks (family, government grants, church, etc)

Respondent or family member belong to (why/why not):

Medical Aid

Burial Society/Funeral Policy (How much pay? Who is on list? Why? What returns will be?)

Stokvel/Women's group/Makoti Society/Church Group (How became a group?

How many in group (ages/gender)? How much contribute? How often money comes to her? What she did with it the last time she got it?)

Financial stability of household (**Is there enough money to support the family?**)

Mobility of household members—how affects household financially/emotionally

Respondent contributing to others

Conflicts over money?

Family members who give support (Probes: kind, how often, discussions)

Community members/programmes that give support (Probes: kind, how often, discussions)

Can she tell a story about a time when someone came and helped you when a family member was sick, or had died? (If can't think of one, a story about her helping someone else).

INTERVIEW 2

Living Arrangement

Who exactly lives in house? (FOR EACH PERSON: age, relationship, when/why came to stay; anyone who used to stay, but don't anymore)

Which people in house AND outside of house does the gogo support with her income?

Who else provides support? What kind?

How does supporting other family members make you feel?

Applied for or thought of applying for child grants for any of the children?
Do grandchildren cause any trouble?

HIV/AIDS & Community

Where HIV/AIDS comes from (causes, how understand, how explain in own ideas)
Why so much AIDS
Why people die from AIDS
Difference between AIDS and other deaths (own view, within community, ancestors)
Impact on community
Most likely infected
How to treat it
Health and community services (what do they do, do enough?)
Getting information (where get it, sufficiently available, for whom?)
Why are more people dying of AIDS than other diseases?
Community view of AIDS; want to get community/general perceptions of AIDS.
Community's efforts to address epidemic
How many funerals have you been to in the past month? What did the people die from?
Would it be better if preachers/others talked about AIDS at funerals? Would it help as a warning if they did?

HIV&AIDS & Household/family

HIV/AIDS affected their life
Worries about HIV/AIDS (people in family)
Discussions with family members about HIV/AIDS
Tell me about a time that you advised your grandchildren or children about AIDS? What did you say? What did your child/grandchild say? GET DIALOGUE; What do you do to make sure that your children/grandchildren listen? GET EXAMPLES
Biggest worry (Probes: contracting it, already being infected, fear for family members, fear of being left with burden)
HIV/AIDS related tensions within family/household
Is there any relative who died of AIDS?

HIV/AIDS & Stigmatization

Experiences and forms of HIV/AIDS related stigma (HIV positive person)-in the community, in their household

What is the attitude of people in the community towards a person with HIV?

How do household/family members treat a person with HIV?

How does a person with HIV/AIDS experience physical isolation? (Probes: separate sleeping quarters, no longer allowed to participate in housework, abandonment by family, violence)

How does a person with HIV experience social isolation? (Probes: reduction of daily interactions with family, friends and the community, loss of social networks,

decreased/increased visits from neighbours, loss of power and respect, gossip, verbal abuse)

How is a person living with HIV/AIDS treated in the community? By their family?

Can she tell a story about someone that experienced HIV/AIDS related stigma?

Gogo's experience of secondary stigma- in the community, in the family

What is/was the attitude of people in the community towards gogo?

How do/did household/family members treat gogo?

How did she experience physical isolation? (Probes: abandonment by family and friends, public rejection, separate sleeping quarters, violence)

How did she experience social isolation? (Probes: reduction of daily interactions with family, friends and the community, loss of social networks, decreased/increased visits from neighbours, loss of power and respect, gossip, verbal abuse)

How was she treated in the community and among family members?

If she never experienced it, can she tell a story about a gogo (or someone) that experienced secondary stigma?

Causes of stigma in the community- fear of the disease, fear of contraction, etc

What are the beliefs behind stigma- cultural belief, moral judgment, taboos, etc

Consequences and impact of stigma- on people with HIV/AIDS, family members

Some gogos said that they knew someone who was "brave enough" to say that his sister/brother/child died of AIDS. Why does someone need to be "brave" to talk about a family member dying of AIDS? Why are people hesitant to talk about AIDS?

Making a Difference in the HIV/AIDS epidemic

Efforts to address HIV/AIDS within family/household

What they want to tell younger generation about HIV/AIDS

How they could make a difference in terms of the HIV/AIDS epidemic (probe levels: household/family/community)

What you think government/CDF should do to address HIV epidemic?

What you want government/CDF to do to help you?

INTERVIEW 3

Caring for Fostered/Orphaned children

Has she ever taken care of fostered/orphaned children?

How long been fostered/orphaned

Experience of caregiving (how long taking care, why came/how got role)

What does she do?

Average hours per week

Advantages/disadvantages (how helpful/problems)

Resources available (financial, and social)

Other people who help (who, how, enough?)

Advice/support sought (child grants)

What other people say about children, taking care of them

How do you feel about taking care of your grandchild/ren?

Amount spent on taking care of fostered/orphaned children (daily, monthly, and yearly), e.g. on food, school fees, clothes, books, etc.

Caregiving for Sick

Has she ever taken care of the sick?

How long ill (how knew when first ill)

Experience of caregiving (how long taking care, how got role)

What did/does

Average hours per week

Advantages/disadvantages

Resources available (financial, and social)

Other people who help (who, how, enough?)

Treatment/Advice sought (satisfied with treatment, assistance, advice?)

What illness (symptoms, why think that, how got it, worried about catching)

Other people (what say, fear catching, helpful/not)

Amount spent on taking care of the sick, e.g. on medicine/muti, tablets, transport, hospital bills, etc

Daily life & Health

What did yesterday? How same/diff from most days

How is physical health? If not well, describe & action taken/treatment sought

How does caregiving for sick and grandchildren affect physical health?

How does health affect what does on typical day?

How is mental health? (worry a lot, cry a lot, feel sad/depressed, not hungry, tired)

If not well, describe, why worried (about what & cause), etc & action taken/treatment sought

How does caregiving for sick and grandchildren affect mental health?

How does mental health affect what does on typical day?

Involved in social activities (church, women's group)

Respect from family/community; come for advice

Trust others? Jealousy

Economic Impact

Effect of sickness/death on household's finance- **how difficult was it during sickness, death, funeral, mourning**

Amount spent on the sick/death/funeral, e.g. on medicine, tablets, transport, hospital bills, etc.

Household assets like cattle, goats, and furniture, sold to take care of the sick/death/funeral/**mourning**/foster children/orphans

Where/How she got money to take care of the sick/death/funeral/mourning/foster children/orphans

What she thinks about the effect of sickness/death/burden of caregiving on finance

How did she recover (financially) after sickness/death?

How would a pension grant help during such crises? What difference would a pension grant make during sickness/death/funeral/mourning/caring for fostered/orphaned children?

APPENDIX D: Socio-economic profile of older respondents in the qualitative study
(N=30)

Pseudonyms	Relation to household head ⁶²	Strata ⁶³	Receives pension	Husband alive	Husband receives pension	Ranked/recorded by interviewers		
						wealth	household appearance	household size
Felicia	Z	1	yes	no	N/A	poor	poor	6
Auphrey	W	1	yes	yes	yes	rich	rich	7
Dorries	T	1	yes	no	N/A	poor	poor	8
Pretty	T	1	yes	no	N/A	poor	poor	11
Sinah	T	1	yes	no	N/A	rich	rich	11
Thandazile	W	1	yes	yes	yes	average	average	15
Zodwa	T	1	yes	no	N/A	poor	poor	7
Chelsie	T	1	yes	no	N/A	poor	poor	1
Lisbeth	T	1	yes	no	N/A	poor	poor	2
Sister	T	1	yes	no	N/A	poor	poor	14
Pearl	T	2	yes	no	N/A	rich	rich	6
Tebogo	T	2	yes	no	N/A	poor	poor	2
Maria	T	2	yes	divorced	N/A	rich	rich	4
Nomsa	W	2	yes	yes	yes	poor	poor	5
Rebecca	T	2	yes	no	N/A	poor	poor	7
Daphney	T	2	disability grant	no	N/A	rich	average	8
Nyeleti	T	2	yes	no	N/A	poor	poor	14
Eleanor	T	2	yes	no	N/A	average	average	6
Mumsy	T	2	yes	no	N/A	average	average	8
Goodness	T	2	yes	no	N/A	rich	rich	5
Cynthia	W	3	no	yes	yes	rich	rich	4
Dorah	W	3	yes	yes	yes	rich	rich	4
Ethel	T	3	yes	no	N/A	poor	poor	7
Grace	T	3	yes	no	N/A	average	average	6
Emily	T	3	yes	divorced	N/A	poor	poor	8
Anna	T	3	yes	divorced	N/A	poor	poor	13
Thandiwe	M	3	disability grant	no	N/A	poor	poor	13
Zanele	M	3	disability grant	1 divorced/2 died	N/A	average	average	12
Constance	T	3	yes	no	N/A	average	average	12
Themba	M	3	yes	no	N/A	rich	rich	2

⁶² Relationship to Household: T-household head; W-wife to household head; M- mother to household head; and Z-sister to household head

⁶³ Strata: 1-AIDS household; 2- Non-AIDS Household; 3- No Death Household.

APPENDIX E: Socio-economic profile of near-old respondents in the qualitative study (N=30)

Pseudonyms	Relation to household head ⁶⁴	Strata ⁶⁵	gets pension	husband alive	husband gets pension/works	Ranked/recorded by interviewers		
						wealth	hh appearance	hh size
Zama	T	1	no	no	N/A	poor	poor	9
Sylvia	W	1	no	yes	yes	average	average	18
Khosi	T	1	no	no	N/A	average	average	7
Fanie	W	1	no	no (recent)	N/A	average	average	11
Mimi	T	1	no	divorced	N/A	poor	poor	8
Agnes	W	1	no	yes	no	poor	average	10
Edith	T	1	no	yes	no	poor	average	4
Prudence	W	1	yes	yes	no	average	average	8
Winnie	W	1	no	yes	no	average	rich	9
Eugenia	T	1	no	divorced	N/A	poor	average	3
Gloria	W	2	no	yes	yes	rich	rich	5
Tumi	W	2	no	no	N/A	average	average	8
Mpfuleni	W	2	no	yes	no	rich	average	6
Mildred	T	2	no	no	N/A	poor	poor	5
Brenda	W	2	no	yes	yes	average	rich	9
Sibongile	M	2	no	no	N/A	rich	rich	13
Melody	T	2	no	no	N/A	average	average	8
Simanga	T	2	yes	no	N/A	average	average	2
Khensani	W	2	yes	yes	yes	rich	rich	4
Delight	T	2	no	no	N/A	poor	poor	2
Phumzile	W	3	no	yes	yes	rich	rich	7
Margaret	W	3	no	yes	yes	average	average	7
Thembi	W	3	no	yes	no	poor	poor	6
Bulelwa	T	3	no	no	N/A	poor	poor	5
Eliza	W	3	no	yes	no	average	rich	4
Esther	W	3	no	yes	no	average	average	4
Kgomotso	T	3	yes	no	N/A	poor	poor	13
Makosi	W	3	no	yes	yes	average	average	15
Yvonne	W	3	no	yes	yes	average	rich	3
Adele	W	3	no	yes	yes	average	average	7

⁶⁴ Relationship to Household: T-household head, W-wife to household head, M- mother to household head and Z-sister to household head

⁶⁵ Strata: 1-AIDS household; 2- Non-AIDS Household; 3- No Death Household.