

**UNIVERSITY OF GHANA
COLLEGE OF HUMANITIES
DEPARTMENT OF SOCIAL WORK**

**EXPERIENCES OF ELDERLY WOMEN CARING FOR PEOPLE WITH HIV/AIDS IN
MASINDI DISTRICT, UGANDA**

**BY
KYOMUHENDO CLARE
(10553532)**

**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON
IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE
AWARD OF MPhil SOCIAL WORK DEGREE**

JULY, 2018

DECLARATION

This is to certify that this thesis is the result of research undertaken by Kyomuhendo Clare under supervision, towards the award of the Master of Philosophy degree in the Department of Social Work, University of Ghana. This research has not been submitted to any university for any award, and authors whose work has been cited have been duly acknowledged.

.....
KYOMUHENDO CLARE
STUDENT

.....
DATE

.....
DR. ALICE BOATENG
SUPERVISOR

.....
DATE

.....
DR. F. AKOSUA AGYEMANG
SUPERVISOR

.....
DATE

DEDICATION

I dedicate this study to my lovely mother Nyakato Judith, Uncle Atuhura Joseph and the family, Aunt Nyamahunge Jemimah, my father Mr. Mugalya Joseph and all my brothers and sisters for the support you provided me through thick and thin during the course of this study.

This study is also dedicated to the memories of my late aunt, Nyangoma Eunice, for the love and sweet memories we shared, the values you taught me, and enabling me to pursue the path of education in order to be successful in life.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank the Almighty God for seeing me through this programme successfully. I wish to express my gratitude and sincere appreciation to my sponsors Bugema University and the university administration board, for the study opportunity and the financial support that has enabled me to pursue my studies. I am most grateful to my two supervisors Dr. Alice Boateng and Dr. F. Akosua Agyemang, all at the Department of Social Work for their guidance, supervision, objective criticisms, suggestions and corrections, which contributed greatly to the completion of this work. Without you, this research would not have been possible.

I thank the two ethical bodies of the Ethics Committee for Humanities at the University of Ghana and TASO Research Ethics Committee in Uganda, for giving me an opportunity to carry out my study. I also remain indebted to TASO Masindi branch and Masindi Hospital Uganda, for allowing me to conduct my research with them and for being so accommodating with their resources. My acknowledgment extends to my participants, that is, the elderly women caregivers of people with HIV/AIDS and staff from TASO Masindi and Masindi Hospital for their time and contribution towards this study.

My deepest gratitude also goes to the family of Professor Patrick Manu, the Vice Chancellor, Bugema University and his dear wife, Mrs. Gracia Manu, for having embraced me as part of your family. I appreciate your tireless encouragements and all the support both spiritual and valuable resources you provided, and all I say is that God bless you abundantly. I cannot forget to extend my sincere gratitude to my loving family, my Mother Nyakato Judith, Uncle Atuhura Joseph, and Aunt Nyamahunge Jemimah, for standing with me throughout this study. Indeed you have been supportive and encouraging when I needed a shoulder to lean on. Thank you also for your patience and prayers you accorded to me. Finally, I would like to

appreciate all those who I did not mention by mistake, thank you all, I could not have made it without your support.

ABSTRACT

High HIV/AIDS prevalence rate among adults aged 15-49 is increasingly affecting elderly women, as caregivers of their sick family members and orphaned grandchildren, where they face various challenges and demands. These leave them poor, physically, and psychologically affected. Their vulnerability is compounded by the disintegration of the family support system and the inability of public and private sectors to adequately address their needs. This study explored the experiences of Elderly Women Caring for People with HIV/AIDS in Masindi District, Uganda. It sought to identify the caregiving roles of elderly women caring for HIV/AIDS people, explored the role reversal experienced by elderly women when caring for adult children with HIV/AIDS, identified the challenges elderly women face in caring for people with HIV/AIDS, ascertained the coping strategies adopted, and the support services available for them. A qualitative approach was adopted, 24 participants selected, including caregivers aged 60 years or more and key informants from The Aids Support Organization (TASO) and Masindi Hospital. In-depth face-to-face interviews were used to collect data. Data were analyzed using Creswell's (2009) concept of thematic analysis. Findings revealed that elderly women caring for HIV/AIDS people performed numerous roles, resulting in a role reversal when caring for dependent adult sick children, who are meant to care for these elderly parents. These posed economic, psychological, social, and physical challenges, thus adopting strategies to cope with the situation. Although family, friends, religious/community groups, government, and NGOs (TASO) provided support for the elderly caregivers, findings showed that efficient, optimal caregiving is lacking. The study recommends the Ugandan government to expand the Senior Citizens Grant (SCG) to include elderly caregivers for HIV/AIDS infected and affected people, to help meet their care needs. Also, there is the need to include the elderly caregivers in policy development and planning, on issues affecting them, to ensure that the policies/programs are working to meet their caregiving needs.

TABLE OF CONTENTS

| | |
|--|------------|
| DECLARATION..... | i |
| DEDICATION..... | ii |
| ACKNOWLEDGEMENTS | iii |
| ABSTRACT..... | v |
| TABLE OF CONTENTS | v |
| LIST OF ABBREVIATIONS | xi |
| CHAPTER ONE: INTRODUCTION..... | 1 |
| 1.1 Background of the Study..... | 1 |
| 1.2 Problem Statement | 1 |
| 1.3 Objectives of the Study | 3 |
| 1.3.1 General Objective | 4 |
| 1.3.2 Specific Objectives | 4 |
| 1.4 Research Questions | 5 |
| 1.5 Significance of the Study | 5 |
| 1.6 Defintion of Key Terms | 5 |
| 1.7 Organisation of the Study | 7 |
| CHAPTER TWO: LITERATURE REVIEW..... | 9 |
| 2.1 Introduction..... | 9 |
| 2.2 HIV Trend and Burden in Masindi District | 9 |
| 2.3 Caregiving Roles of Elderly Women Caring for HIV/AIDS People | 11 |
| 2.4 Elderly Caregivers and Role Reversal | 14 |
| 2.5 Challenges faced by Elderly Women Caregivers..... | 17 |
| 2.5.1 Economic Challenges | 17 |
| 2.5.2 Emotional/ Psychological Challenges | 19 |
| 2.5.3 Social Challenges | 21 |
| 2.5.4 Health, Physical, and Nutritional Challenges..... | 22 |

| | |
|--|-----------|
| 2.6 Coping Strategies Employed by Elderly Caregivers for People with HIV/AIDS | 25 |
| 2.7 Support Services Available for Elderly Caregivers Caring for HIV/AIDS People | 30 |
| 2.7.1 Informal Support Systems | 30 |
| 2.7.1.1 Support from Families | 30 |
| 2.7.1.2 Support from Friends and Neighbors..... | 31 |
| 2.7.1.3 Support from Religious and Community Groups | 32 |
| 2.7.2 Formal Support Systems..... | 32 |
| 2.8 Theoretical Framework | 34 |
| 2.8.1 Caregiver Identity Theory (Montgomery, Rowe & Koloski, 2007)..... | 34 |
| 2.8.1.1 Relevance of the Caregiver Identity Theory to the Study. | 37 |
| 2.8.2 Coping Theory by Lazarus & Folkman (1984) | 38 |
| 2.8.2.1 Relevance of the Coping Theory to the Study..... | 39 |
| CHAPTER THREE: RESEARCH METHODOLOGY | 41 |
| 3.1 Research Design..... | 41 |
| 3.2 Study Location | 42 |
| 3.2.1 Study Sites | 43 |
| 3.2.1.1 Background of Masindi Hospital | 43 |
| 3.2.1.2 Background of TASO- Masindi Branch | 44 |
| 3.2.1.3 Justification for selection of the sites..... | 45 |
| 3.3 Target Population..... | 46 |
| 3.4 The Study Population..... | 46 |
| 3.5 Sampling Techniques | 46 |
| 3.6 Inclusion and Exclusion Criteria..... | 47 |
| 3.6.1 Inclusion | Criteria |
| | 47 |
| 3.6.2 Exclusion Criteria..... | 48 |
| 3.7 Justification for Inclusion and Exclusion Criteria..... | 48 |

| | |
|---|-----------|
| 3.8 Sample Size..... | 49 |
| 3.9 Sources of Data | 49 |
| 3.10 Methods of Data Collection | 49 |
| 3.11 Data Handling and Analysis..... | 50 |
| 3.12 Trustworthiness and Credibility..... | 51 |
| 3.13 Ethical Considerations | 52 |
| 3.14 Limitation of the Study | 53 |
| 3.15 Dissemination of Findings | 54 |
| CHAPTER FOUR: PRESENTATION OF FINDINGS..... | 55 |
| 4.1 Introduction..... | 55 |
| 4.2 Demographic Characteristics of Participants | 55 |
| 4.3 The Caregiving Roles of Elderly Women Caring For HIV/AIDS People | 58 |
| 4.3.1 Physical Care Activities..... | 58 |
| 4.3.2 Nursing/ Health-Related Care | 59 |
| 4.3.3 Psychosocial Care..... | 61 |
| 4.3.4 Care and Support for Orphaned Children..... | 62 |
| 4.4 The Role Reversal Experienced by Elderly Women when Caring for Adult Children with HIV/AIDS | 63 |
| 4.5 Challenges Elderly Women Face in Caring for People with HIV/AIDS..... | 65 |
| 4.5.1 Economic Challenges | 65 |
| 4.5.2 Emotional/Psychological Challenges | 69 |
| 4.5.3 Social Challenges | 71 |
| 4.5.4 Health, Nutritional, and Physical Challenges..... | 74 |
| 4.5.4.1 Health Challenges | 74 |
| 4.5.4.2 Nutritional Challenges | 75 |
| 4.5.4.3 Physical Challenges | 76 |
| 4.6 Coping Strategies Adopted by Elderly Women in Caring for People with HIV/AIDS.. | 77 |

| | |
|---|------------|
| 4.6.1 Problem-focused coping strategies | 77 |
| 4.6.1.1 Seeking support from within the family and outside | 77 |
| 4.6.1.2 Adjustment in time..... | 79 |
| 4.6.1.3 Dealing with negative reactions (confrontation)..... | 80 |
| 4.6.1.4 Dealing with fears of infection. | 80 |
| 4.6.2 Emotion-focused coping strategies..... | 81 |
| 4.6.2.1 Acceptance of the caregiving role..... | 81 |
| 4.6.2.2 Positive reappraisal | 82 |
| 4.6.2.3 Spirituality as a coping mechanism | 82 |
| 4.6.2.4 Isolation and avoidance..... | 85 |
| 4.6.2.5 Negative emotion-focused coping strategies | 85 |
| 4.7 Support services available for elderly caregivers caring for HIV/AIDS people..... | 87 |
| 4.7.1 Informal support systems..... | 87 |
| 4.7.1.1 Support from family members | 87 |
| 4.7.1.2 Support from friends and neighbors | 88 |
| 4.7.1.3 Support from religious and community groups | 89 |
| 4.7.2 Formal support systems | 91 |
| 4.7.2.1 Support from Non-Governmental Organizations..... | 92 |
| 4.7.2.2 Support from the government | 96 |
| 4.8 DISCUSSION OF FINDINGS | 101 |
| CHAPTER FIVE: SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS..... | 110 |
| 5.1 Introduction | 110 |
| 5.2 Summary of findings..... | 110 |
| 5.3 Conclusions | 112 |
| 5.4 Recommendations | 113 |
| 5.5 Implication for social work practice | 117 |

| | |
|---|------------|
| REFERENCES..... | 119 |
| APPENDICES..... | 131 |
| APPENDIX A: TASO RESEARCH ETHICS COMMITTEE (REC) APPROVAL LETTER..... | 131 |
| APPENDIX B: UNIVERSITY OF GHANA ETHICS COMMITTEE FOR THE HUMANITIES (ECH) APPROVAL LETTER | 132 |
| APPENDIX C: INTERVIEW GUIDE FOR CAREGIVERS..... | 133 |
| APPENDIX D: TRANSLATED INTERVIEW GUIDE FOR CAREGIVERS | 139 |
| APPENDIX E: INTERVIEW GUIDE FOR KEY INFORMANTS..... | 145 |
| APPENDIX F: INFORMED CONSENT FOR CAREGIVERS | 148 |
| APPENDIX G: TRANSLATED INFORMED CONSENT FOR CAREGIVERS | 156 |
| APPENDIX H: INFORMED CONSENT FOR KEY INFORMANTS..... | 165 |

LIST OF ABBREVIATIONS

| | |
|---------------|---|
| ADL | Activities of Daily Living |
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-Retroviral Therapy |
| FBOs | Faith Based Organisations |
| HBHCT | Home Based HIV Counseling and Testing |
| HIV | Human Immunodeficiency Virus |
| IADL | Instrumental Activities of Daily Living |
| MDLG | Masindi District Local Government |
| MOH | Ministry of Health |
| NGO | Non-Governmental Organisation |
| OPD | Out Patient Department |
| PLHVS | People Living with HIV/AIDS |
| PMTCT | Prevention of Mother-To-Child Transmission |
| TASO | The AIDS Support Organization |
| TB | Tuberculosis |
| UN | United Nations |
| UNAIDS | Joint United Nations Programme on HIV/AIDS. |
| VCT | Voluntary Counselling and Testing |
| WHO | World Health Organization |

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

In recent decades, population ageing has become a global area of concern culminating in two World Assemblies on Ageing: the 1982 Vienna and 2002 Madrid Conventions (UN, 1982, 2002), due to the worldwide increase in the proportion of older people. Globally, there are about 901 million older people, which is 12.3% of the total population (Da Silva Francisco, 2017). This makes ageing a universal issue since the elderly population is projected to continue growing. For example, He, Goodkind, and Kowal (2016) revealed that in 2015, the elderly population was 617.1 million, which is projected to increase to about 1 billion in 2030. Da Silva (2017) adds that this elderly population is expected to exceed two billion in 2050. The author further states that in Africa, the elderly population is also expected to rise from 64 million in 2015 to 220 million in 2050. This continued growth is also confirmed by Mugisha et al. (2016). In Uganda in particular, the elderly population also increased from 1.1 million in 2002 to 1.3 million in 2010 (UBOS, 2010), and a further increase is expected from 1.6 million in 2014 to 5.5 million by 2050 (UN, 2013), presenting a great challenge and economic burden to an unprepared continent (Marešová, Mohelská, & Kuča, 2015).

According to Beales (2000) and Choudhary (2013), old age is a period where many experience poverty and powerlessness especially in developing countries, as most elderly lack savings or monthly pension to take care of their wellbeing, thus depending on children, who may not be alive or are equally poor. In recent times, however, the adequacy of help, support and care of older Africans from the younger kin has declined (Kautz, Bendavid, Bhattacharya, & Miller, 2010). Among other factors, Kyobutungi, Ezeh, Zulu, and Falkingham (2009) indicate that increased weakening of traditional social support structures

is also a consequence of the HIV/AIDS pandemic. Over the last decade, HIV/AIDS pandemic has caused an overwhelming effect on older women and men (Bejane, 2012) due to the increased care demands as well as support services by those infected and affected by the disease (Ssengonzi, 2009).

It is indicated that globally, 36.7 million people lived with HIV in 2016, with adults of 15–49 years accounting for 0.8% (UNAIDS, 2016). Even though across the globe the effect of HIV/AIDS varies, Sub-Saharan Africa is still more affected, with almost 1 in every 25 grown-ups (4.2%) being HIV infected (WHO, 2017). More so, 19.4 million people living with HIV were found in East and Southern Africa in 2016, with Uganda having the prevalence rate of 6.5% among adults aged 15-49 (UNAIDS, 2017). HIV/AIDS pandemic in Uganda, like in many countries in the sub-Saharan Africa is changing demographics and household structures (Kakooza & Kimuna, 2006). The disease has left many African family structures in a crisis, as it affects primarily working-age adults, hence posing an extra burden onto the elderly persons at a time they might need support as well as looked after (Kimuna, 2000). In many affected families, the elderly have been forced to become caregivers to sick family members and orphaned grandchildren, a role which younger relatives would have performed. This has generated a new focus on the changing of elderly roles, to being caregivers to younger generations (Kakooza & Kimuna, 2006; Kimuna & Makiwane 2007; Nala-Preusker, 2014; Seeley, Wolff, & Kabunga, 2009).

Moreover, this caregiving takes place in extremely limited conditions at home, where access to the formal health care system is very limited (Kipp, Tindyebwa, Karamagi, & Rubaale, 2006). Again, in sub-Saharan Africa, the primary caregivers of chronically ill family members are most often women, because caregiving is traditionally considered a role exclusively reserved for women, thus shouldering on them the burden of stressful tasks

(Bejane, 2012; Brannen & Petite, 2008; Hutchison, 2011). Depending on the intensity of caring for infected family members, caregivers often face unique challenges and demands (Nala-Preusker, 2014). Since the elderly are increasingly taking on the responsibility of being caregivers, it is vital to know the roles they perform, the role reversal and the issues that come with it, challenges, coping strategies, and support services available for them. Notwithstanding their key role in providing care, limited research has been conducted in Masindi District to investigate their lived experiences. In response to this gap, the study explores the experiences of elderly women caring for people with HIV/AIDS in Masindi District, Uganda.

1.2 Problem Statement

An increase in the number of people infected with HIV/AIDS means an increased demand for care and the needs that follow. This presents a challenge to the elderly persons, especially women at the frontline of meeting such demands, as they are often observed caring for the sick family members, including those infected and affected with HIV/AIDS. This is a problem because, in Masindi District, the January – March 2016 District HIV/AIDS bulletin indicates that 23,729 people were living with HIV, thus posing a great challenge to their families, due to the demand for care and support services. Unlike providing care for other diseases, elderly caregivers too could become more vulnerable when caring for people with HIV/AIDS, due to the prolonged care they provide. Despite being weak with deteriorating health due to aging, elderly caregivers have the added burden of taking care of other sick people at home, when they are neither emotionally, financially nor physically prepared to fully provide such care. This has been observed in the Masindi District by the researcher while she worked as an intern in one of the agencies in the District.

The elderly women's palliative care begins when their relatives are diagnosed with HIV and continues throughout the course of the illness, and eventually, helping the care recipient die with dignity and in peace (Corless & Nicholas, 2000). This long term care can come with a lot of financial challenges and depletion of the limited resources these elderly women may be having. Also, since HIV/AIDS is a life-threatening infectious disease, caregivers provide care in fear of contracting it, thus affecting their psychological well-being and emotions. Varying factors contribute to this fear, and these range from taboos (do's and don'ts) and myths associated with HIV/AIDS, coupled with the inability to obtain basic equipment, like gloves required when providing care.

Even though research has been conducted on HIV/AIDS and elderly caregiving in Uganda, not much is known about the experiences of elderly women caregivers for people with HIV/AIDS in Masindi District, despite their increased participation in informal caregiving. This motivated the researcher to carry out the study that sought to contribute to filling this research gap by exploring the experiences of elderly women caring for people with HIV/AIDS in Masindi District, Uganda.

1.3 Objectives of the Study

The research consists of general and specific objectives.

1.3.1 General Objective

The main objective of the study is to explore the experiences of elderly women caring for people with HIV/AIDS in Masindi District, Uganda.

1.3.2 Specific Objectives

- To identify the caregiving roles of elderly women caring for HIV/AIDS people in Masindi district.

- To explore the role reversal experienced by elderly women when caring for adult children with HIV/AIDS.
- To identify the challenges elderly women face in caring for people with HIV/AIDS in Masindi district.
- To ascertain the coping strategies adopted by elderly women in caring for people with HIV/AIDS.
- To find out the support services available for elderly women caring for people with HIV/AIDS in Masindi district.

1.4 Research Questions

- What caregiving roles do the elderly women perform when caring for HIV/AIDS people in Masindi district?
- What kind of role reversal do the elderly women experience, caring for adult children with HIV/AIDS in Masindi district?
- What challenges do elderly women face in caring for people with HIV/AIDS in Masindi district?
- What are the coping strategies adopted by elderly women in caring for people with HIV/AIDS?
- What support services are available for elderly women caring for people with HIV/AIDS in Masindi district?

1.5 Significance of the Study

This study is important because it will give insights into how HIV/AIDS pandemic influences the caregiving role experiences of elderly women caring for people with HIV/AIDS in Masindi district, and thus identify measures to help the vulnerable elderly in terms of economic, social- psychological support and care among other issues of concern. The study

will also provide knowledge and information on the challenges faced by the elderly caregivers in Masindi District and their coping mechanisms. Further, the study will add to knowledge in the field of social work and existing literature about HIV/AIDS and the caregiving role experiences of the elderly, which could also serve as reference point for future researchers.

Findings of this study may provide additional information to policymakers on the vulnerability of the elderly people. This will help draw attention to the government, together with various NGOs to design and implement policies that may address the issue. Also, the study could be beneficial to the Local Government, the Ministry of Gender, Labour and Social Affairs that deal with the elderly and the Ministry of Health, which is concerned with HIV/AIDS pandemic, to formulate policies that will effectively address the challenges confronting elderly women caring for people with HIV/AIDS across all the regions in the country.

Social workers could utilize the information generated from this study by collaborating with other agencies and practitioners to design appropriate interventions for the challenges faced by the elderly caregivers for people with HIV/AIDS. Social workers can advocate for formal welfare old age support system that will be helpful, amidst the dilemma of care and ageing in the face of the HIV/AIDS pandemic.

1.6 Definition of Key Terms

HIV/AIDS: Human Immunodeficiency Virus (HIV) is a virus/agent that causes the Acquired Immune Deficiency Syndrome (AIDS). People get infected with HIV through sexual contact, or by infected blood from infected needles and syringes, from infected mother to unborn child, or treatment with contaminated blood or blood products (Shannon & Ammann, 1985).

Elderly people: Hutchison (2011) in her definition of the elderly categorizes them into three major groups. That is, the young-old (65 to 74 years), the middle old (75 to 84 years and the oldest-old (85 and above). In this study, however, an elderly person is defined as one who is 60 years and above, giving care to people infected with HIV/ AIDS or infected with HIV. The age selection is as a result of the retirement age of Uganda being 60 years.

Caregiving: a process of providing care to a needy individual on a regular basis. The caregiver is related (family, friends, neighbor) to the person receiving care (Schoenmakers, Buntinx, & Delepeleire, 2010). In this study, caregiving will refer to caregiving activities frequently performed by the elderly caregivers for people infected with HIV/AIDS.

Caregiver burden: refers to the physical, emotional and financial hardships associated with providing care to a diseased individual (Chandran et al., 2016). In this study, caregiver burden will refer to the adverse effects of the emotional, social, financial, physical and spiritual functioning of caregivers to people with HIV/AIDS.

Role reversal: is when older people take on the role of sole caregivers to the younger generations, contrary to the tradition in the African society (Kimuna & Makiwane, 2007). In this study, role reversal refers to the caregiving roles elderly people perform for adult children with HIV/AIDS

1.7 Organisation of the Study

The research is organized into five main chapters. The first chapter is the introduction, which describes the background, problem statement, objectives, and research questions of the study. It also includes the significance of the study and definition of terms/concepts. The second chapter presents a review of relevant literature and a number of studies on HIV/AIDS and elderly caregiving. Chapter three provides the research methodology which comprises of the

research design, sources of data collection, the data collection tools employed, the sampling technique, sample size and the ethical considerations. Chapter four of the study involves data analysis, interpretation, and discussion of findings. This is a very important part of the research because it provides information to answer the research questions. Finally, the fifth chapter constitutes the summary, conclusions, and recommendations. This is also another relevant chapter because recommendations from the study help provide some solutions to the phenomenon.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In sub-Saharan Africa, the HIV/AIDS pandemic scale is greater than anywhere else. This is due to economic development differential levels, demographic conditions, inadequate state capacity to provide assistance, culture, and personal interactions (Knodel, Watkins, & VanLandingham, 2003). Thus, affecting a greater proportion of older persons indirectly as caregivers of both people infected with HIV/AIDS together with their children (Ssenigozi, 2007).

Focusing on the existing literature, a section of literature on the HIV trend, and burden in Masindi District is reviewed. This is followed by the review of literature that has established the relationship between HIV/AIDS pandemic and caregiving experiences of elderly persons. That is on the roles of elderly women caring for HIV/AIDS people, the role reversal experienced by elderly women when caring for adult children with HIV/AIDS, challenges faced by elderly women caregivers (social, economic, emotional/psychological, and health) and the coping strategies adopted. Literature is also reviewed on the support services available for elderly caregivers caring for people with HIV/AIDS.

2.2 HIV Trend and Burden in Masindi District

Statistics indicate that there has been an increase in HIV prevalence in Masindi district. For example, in 2006, the Uganda Health Report indicated that HIV/AIDS prevalence rate in Masindi district increased to 7.7 % (Uganda Health Report, 2006). In 2011, a report by the Ministry of Health revealed that districts that fall under mid-western and south-western Uganda, with Masindi inclusive, had the HIV rate ranging from 8% to 8.2%. However, a decline was recorded by UNAIDS in 2014, where the HIV prevalence rate in the district was

6.9 %, in people aged 15- 49 years old (UNAIDS, 2014). Unfortunately, in 2015, the Masindi District Local Government noted in its HIV/AIDS strategic plan, that the HIV prevalence was 8.2%; higher than the national prevalence, with an estimated 15,015 people living with HIV (14,285 adults aged 15-59 years and 757 children aged 0-15 years) (MDLG, 2015).

Even in the Mid-Western Region which comprises of seven districts (Buliisa, Hoima, Kibaale, Kiboga, Kiryandongo, Kyankwanzi and Masindi), Masindi still ranks high with the HIV prevalence rate of 10.6% (MDLG, 2015). Moreover, women and girls are more affected than the men as indicated in the country's 2010 Ministry of Health Epidemiological surveillance report, where the 2009 Antenatal HIV prevalence in Masindi hospital was 7.3 % (MOH, 2010).

In addition to the above, the Masindi district HIV/AIDS bulletin of January – March 2016 indicates that people living with HIV/AIDS (PLHVS) were 23,729. The indicated trend of HIV prevalence in the district is so alarming, despite efforts made by the Local Government together with various NGOs both Local and International in AIDS prevention and control. Some key factors identified to have contributed to the trend of the epidemic include; socio-cultural factors among the highly diverse ethnic groups with varied norms, beliefs, and cultures. These present a challenge in addressing the behavioural prevention strategies. For instance, the tendency of some men practicing polygamy (having more than one wife), contributes to the spread of HIV due to concurrent sexual network in case one of the partners is infected. Also, economic factors which include but not limited to: i) the influx of refugees due to the conflicts in the Democratic Republic of Congo (DRC) and South Sudan ii) the district being located on the high way as a trade route with a high number of key population reinforcing the risk of HIV transmission through transactional sex, and iii) neighbouring districts with fisher folks who interact within the district. Some other factors include; poverty, inequity and poor access to health care services, discordance, and non-disclosure, among

many others (MDLG, 2015). Therefore, the increasing number of young adults infected with HIV triggers the growing demand for care and support services, hence elderly persons especially women coming forward to help in meeting some of such demands. This inspired the researcher to carry out a study that explored the experiences of elderly women caring for people infected with HIV/AIDS in the district, which will be a stepping stone for the Local Government together with other stakeholders including local, international and faith-based NGOs to find better strategies of meeting the needs of the elderly caregivers and their families.

2.3 Caregiving Roles of Elderly Women Caring for HIV/AIDS People

The caregiving intensity needed by AIDS patients is determined by the phase of the illness. That is, the more imminent the terminal stage, the more intense the workload (Gordon-Garofalo & Lynch, 2000). Study findings by Waliser, Spriggs, and Feldman (2002) and Nygard (2003) revealed that female caregivers provided more hands-on care with activities of daily living (ADL), including basic activities, such as bathing, eating, transferring, etc. and instrumental activities of daily living (IADL), including more complex activities, such as home maintenance, dressing changes, assistance with medication, transportation, housework, among others. Ssengonzi (2007) also found that because few women are involved in work outside the home and in addition to being more tender, careful and loving than men, they were the primary caregivers of people infected with HIV/AIDS, performing activities like washing and changing clothes, providing food and drink, administering drugs, lifting the patient and being there for the patient. These findings are supported by Kosse (2012) who identified that in addition to making changes in dressings and giving medicine, caregivers were required to feed and bath their AIDS bed-ridden patients. These may need a caregiver's presence and support 24 hours a day.

Akintola (2006) and Chepngeno-Langat, Falkingham, Madise, and Evandrou (2010) categorize the above care activities into, Household work, like cooking and laundry; Nursing care, which includes assisting the ill person with bathing, feeding, dressing, toileting; Health-related care, which includes helping the sick person to bath, feed, dress, toilet; Health-related care, such as deciding where and when to seek medication, escorting the sick to the health facility, and consulting on their behalf with health experts, management, treating wounds, administering medications; and Psychosocial care, which includes providing counseling, encouraging, and spending time beside the sick individual.

In addition, Sefasi (2010) observes that elderly people have taken on new roles by providing care and support to orphaned children, playing the roles of rearing children in their extended families, and going forward with their traditional roles of advising their adult children and grandchildren. This supports the findings in a study conducted by Nhongo (2004) where older people were identified to be performing a significant role in the upbringing of children who are the world's future capital. Under this demanding role, these elderly persons find themselves providing physical, economic, and social support to their children infected with HIV/AIDS; thus finding little time to be involved in income generating opportunities to sustain their livelihoods. Also, Hawkins (2013) in her study on the impact of HIV and AIDS on Elderly Caregivers in Chiang Mai, Thailand, found that a majority of the caregivers reported that their daily lives started early so as to get their grandchildren up, dressed, and fed for school, coupled with ensuring that they have food, shelter, and clothing. The caregiver role also models personal hygiene, integrity, and spirituality. For those living with HIV, part of their daily lives included medication management and making sure all the pills are taken at the right time along with being given a healthy diet (Hawkins, 2013).

Findings by Kosse (2012) in a study conducted in KwaZulu-Natal, South Africa, on the HIV/AIDS and elderly health: The experiences of caregivers living in HIV affected

households, indicates that elderly caregivers were involved in providing special treatment to the very sick as it was needed due to their inability to care for themselves. At times they could not express their feelings or needs hence had to be watched continually for their unspoken needs to be met, which was physically exhausting for the elderly. This is supported by the findings of Musangali, Daire, and DeLorenzi (2016) in their quantitative study in Kenya, which indicates the various support activities like walking, dressing, bathing, toileting to mention but a few.

Furthermore, caregiving does not only involve physical activities but also, financial responsibility. This is supported in various literatures where elderly caregivers were acknowledged to make important financial contributions to the household when they can access pension funds or other cash transfers targeting seniors (Kimuna & Makiwane 2007; Schatz & Ogunmefun, 2007). Akintola (2006) and Chepngeno-Langat et al. (2010) also identified financial care to include catering for financial needs such as daily subsistence like expenditure on scholastic items, food items and other essential items such as rent, energy for cooking or lighting and water. The financial care was also identified to include paying for medical expenses such as medication, transport to the facilities, among many others.

Elderly caregivers further perform a role of providing social and emotional support to their patients with HIV/AIDS. This is supported by findings by Evans and Thomas (2009) whose study in the three countries of Namibia, Tanzania, and the UK revealed that parents maintained their parental roles of providing love, emotional support, advice, guidance, and discipline to their children. The emotional support being provided by the caregivers included; talking and comforting their relative in dealing with the emotional impacts of living with HIV and related mental health problems, giving them hope and reassurance, offering advice, keeping them company and ‘being there’ for them when they needed support (Evans & Thomas, 2009).

Also, elderly caregivers help ill patients suffering from HIV/AIDS to prepare in facing death. Brown and Stetz (1999) found that caregivers at some point in the illness trajectory, shifted from caring for a chronically ill person to supporting a dying person. Sometimes this shift happened suddenly, coinciding with a major change in health status; sometimes it was part of a gradual decline. This initiated a transition to a psychological perspective focused on the dying process. On the other hand, the authors noted that caregivers took a significant role in managing events and interactions during the final days and hours of their loved ones' lives. This is because most participants wanted a peaceful death for their ill family member (Brown & Stetz, 1999). These findings are supported by Hutchison (2011) who observed that a person with prolonged terminal illness has more time and opportunity to accept and prepare for his or her own death, in addition to family members accepting and preparing for the death of a beloved one, than someone with an acute and fatal illness or sudden death.

2.4 Elderly Caregivers and Role Reversal

Kimuna and Makiwane (2007) define role reversal as when older people take on the role of sole caregivers to the younger generations contrary to the tradition in African society. Traditionally, parents had children as economic resource and security against old age (old age assets). Parents' investment in the health, education, and well-being of their children often were based on the expectation that children will care for them in their old age (Nhongo, 2004; Saengtienchai & Knodel 2001; Williams & Tumwekwase 2001), hence the proverb, "When your elders take care of you while you cut your teeth, you must in turn take care of them while they are losing theirs" (Apt, 1996, p. 22).

In present times, multiple sets of issues have challenged the expectations of elderly parents being taken care of by their children. Over the years, African communities have observed major changes in the roles older people play at the family level (Kosse, 2012; Nhongo, 2004).

In most cases, due to the AIDS epidemic parents are forced to assume the responsibility of providing full support, and care for their adult children with HIV/AIDS (Munthree & Maharaj, 2010; Nala- preukeser, 2014). This is due to circumstances like abandonment from the family as a result of marriage of the adult child, or because of being the HIV/AIDS adult sick child's mother, hence, forced to provide care (Nala- preukeser, 2014; Tarimo, Kohi, & Outwater, 2009). Also, due to the onset of the pandemic, the elderly have been placed in the spotlight by subsequently being increasingly involved in filling the gap left by other population groups, by providing care and the upbringing of their grandchildren, the situation which Nhongo (2004) terms as *'Africa's Newest Mothers,'* due to the new roles adopted at an old age. The elderly often provide economic, psychological and social support (Kosse, 2012). This is contrary to the central role the older people were expected to play in the past, which was to guide their families and communities. For instance, the elderly were responsible for socializing in the community, in addition to ensuring that the norms, values, and knowledge were carried on from one generation to another. Also, they were guardians of the tradition where they ensured that the "ancestral" knowledge was protected from older to younger generations (Nhongo, 2004).

Furthermore, it is usually expected that extended household members work together when providing care to their sick members (Lekalakala-Mokgele, 2011). Differing to the assistance the extended family provides, the issue of secrecy about HIV/AIDS restricts the number of people providing care (Nhongo, 2004). This is very different from the past where the whole community could be involved in assisting families in need (Kosse, 2012). As HIV/AIDS robs families young grown-ups, especially adults aged 15–49 years (UNAIDS, 2012), it is becoming hard to offer the needed support to all members of the society who are in need. Hence, elderly persons are at the front line of providing care in this period of AIDS termed as role reversal or change in roles by some authors. They have from being provided and cared

for by the younger generation, to being the sole care providers for the younger generation (Ainsworth & Dayton 2003; Kakooza, 2004; Kakooza & Kimuna, 2006; Kimuna & Makiwane, 2007; Nala-Preusker, 2014).

Besides, HIV/AIDS is changing demographics, and household structures as a result of missing generations (Kakooza & Kimuna, 2006). Currently, elderly women are increasingly heading households and caring for AIDS orphans, which make them primary breadwinners. For example, study findings by Kimuna and Makiwane (2007) indicate that nearly 76% of the participants were the sole breadwinners in the households that included more than one generation. It is worthy to acknowledge that under such circumstances, older people provide care not only to their biological children, but also to extended family members such as siblings, grandchildren, and sons-or daughters-in-law (Chepngeno-Langat, 2008). This varied nature of relationships among caregivers and care recipients make older people's role clear, as not only the heads of their immediate family, but also the extended family network, whose responsibility is not only limited to social roles but also includes a financial commitment. These statements are supported by Iwelunmor and Airhihenbuwa (2012) who noted that sickness, death, and loss from HIV/AIDS have altered the position of the elderly, especially women in many societies as many now assume the role of breadwinners, a role traditionally held by men. Other roles being assumed by the elderly women include household heads, which comes with the expectations of taking full responsibilities of the social, economic, and physical well-being of the persons with HIV/AIDS and the orphans.

Kimuna and Makiwane (2007) also observed that in caregiving, older family members are responsible for meeting the costs of medical treatment, basic resources such as water, energy, food, and funeral costs, in which cases some use their pensions to cover some of these expenses. Other authors further identified the roles some elderly caregivers must take on

especially being guardians and surrogate parents of their orphaned grandchildren (Ainsworth & Dayton, 2003; Help Age International, 2003). Thus, the elderly persons have an increased burden of care resting upon them. Additionally, Munthree and Maharaj (2010) indicated that participants reported of multiple support needs for their grandchildren such as meeting their basic needs, and being responsible for the health, welfare, and education of their grandchildren, which involved both paying school fees, and additional indirect costs, for instance, school uniforms and transport. All these roles would have been performed by younger relatives should they have lived or been in good health (Kakooza & Kimuna, 2006; Knodel & Im-Em, 2004).

2.5 Challenges faced by Elderly Women Caregivers

According to Chandran et al. (2016), caregivers of people with HIV/AIDS usually experience negative aspects of caregiving, which is described as “~~a~~ caregiver burden”. This manifests itself in the form of economic, emotional/ psychological, social, health, physical, and nutritional, as explained below.

2.5.1 Economic Challenges

The adverse economic challenges experienced by elderly caregivers due to HIV/AIDS pandemic is well documented (Knodel & Imem, 2004; Ssenzozi, 2007; Knodel, Watkins, & VanLandingham, 2003). These researchers indicate that in most cases, ill adult patients live with their parents, which necessitates the older parents to play a key role in caring for their ill children, which drains the limited resources that they might have, due to increased care demands by the ill child. Hence, leading to depletion of savings and other resources.

Knodel Watkins and VanLandingham (2003) in their quantitative study on AIDS and older persons in Thailand, found that one or both parents either stopped or reduced their economic activities in an attempt of getting enough time to care for the ill child, which created serious

economic difficulties. The authors further revealed that some parents giving care to people with HIV/AIDS had to sell their property to meet the expenses of medical treatment and other care expenditures like transportation to health facilities in addition to buying nutritious food for the care recipient. This is in line with the findings from a qualitative study done by Ssenkozi (2007) on the plight of older persons as caregivers to people infected/affected by HIV/AIDS in Uganda. Ssenkozi (2007) added that the adult sick children had not made proper planning for their families, which affected the elderly parents in case the ill adult child died, as the elderly had to continue with the obligation of providing care to the orphaned children.

Furthermore, Munthree and Maharaj (2010) in their study on the impact of AIDS on older men and women in KwaZulu-Natal, South Africa, using mixed method designs state that, one greatest critical economic impact of AIDS pandemic is its robbing of families their only social security system, since the economically active family members die after falling ill, hence leading to ultimate direct costs for funeral arrangements (Munthree & Maharaj, 2010). This compounds the elderly persons' financial difficulties, as they have to meet both their personal needs, coupled with those of the grandchildren, in a situation with no reliable source of income (Kakooza & Kimuna, 2006). On this matter, findings by Knodel and Imem (2004) on the economic consequences for parents losing an adult child to AIDS in Thailand, using a combination of quantitative and qualitative methods showed that in over 70% of the parental household's survey, the deceased child was providing material assistance to the parents before becoming ill.

Also, Knodel and Imem (2004) revealed that from the parental household's survey, almost one-third of the participants reported the deceased child being the main income provider to the elderly parent. This circumstance resulted in loss of remittances from the sick relatives,

loss of income and/or time to garden or work, and loss of savings and/or personal belongings, during the life stage when they are less productive and weak, thus being vulnerable.

2.5.2 Emotional/ Psychological Challenges

Older persons involved in a wide range of care activities experience negative psychological impact on their well-being in various forms, including grief, stress, fear, trauma and grieving, isolation, and hopelessness (Lekalakala-Mokgele, 2011), which all intensely result from perceived HIV/AIDS stigma in addition to worrying about the caregiving role (Scholten et al., 2011; Nyambedha et al., 2003; Seeley, Wolff, Kabunga, Tumwekwase, & Grosskurth, 2009).

As caregivers, the elderly can experience considerable psychological pain in witnessing the suffering and death of their child (Knodel, Watkins, & VanLandingham, 2003). These are related to study findings by Munthree and Maharaj (2010) in which many elderly people explained that they felt obliged to take responsibility for the care of the HIV-infected person and that they expressed frustration, desperation, and helplessness at their situation because of the enormous burden placed on them. Furthermore, a quantitative study on correlates of grief among older adults caring for children and grandchildren as a consequence of HIV and AIDS in South Africa by Boon et al. (2010) found that the majority of caregivers experienced pain and grief to a large extent as they dealt with the illness and gradual death of one or multiple children and grandchildren. This involved feeling very lonely, having difficulties in sleeping and denial about the current situation (Boon et al., 2010).

Additionally, Ssengozi's (2007) qualitative study in Uganda found that elderly caretakers frequently had episodes of worry, crying, depression and a sense of hopelessness about their present and future state. This was coupled with the caregiver's realization that no matter how much they tried, the sick relative would likely die, thus creating a sense of futility and

dilemma in their efforts, as they saw their efforts and resources spent to care for AIDS patients as waste (Ssengozi, 2007). The study also found that HIV/AIDS patients were hard to manage emotionally due to stigma, self-blame and view of self as having disappointed their parents and family members. Coupled with knowing that they were dealing with a terminal illness, they remained hopeless about the prospect of recovery, thus being fastidious, hard to please, and requiring constant attention and counseling, which many caregivers found to be emotionally draining and leading to lasting grief and anxiety (Ssengozi, 2007).

According to Pandit and Vishnuvardhan (2014), providing care to AIDS people is compounded with concerns like infection transmission, fear of disclosing the patient's HIV status, related stigma, and rejection thus caregivers resorting to isolation, which results to being cut off from valuable supports. Psychological distress, if not well managed with adequate coping strategies results in psychiatric disorders like depression, stress, and strain, a subject on the caregiver's age and sex. For example, in their study about the impact of age and gender on the coping styles and psychiatric morbidity faced by informal primary caregivers of HIV-infected individuals living in India, Pandit and Vishnuvardhan (2014) revealed that all age groups had a high prevalence of psychiatric disorders like anxiety and depression, which were noticed as being more common in female caregivers.

Also, Chandran et al. (2016) add that, one of the mental health-related challenges of caregiving is chronic stress, resulting from caregiver burden. Since the diagnosis of HIV is often withheld from society due to fear of stigma, caregivers experience more burdens of being secretive and not receiving additional help. Also, the caregiver burden is triggered by factors like female gender, residing with the patient, depression, social isolation, higher number of hours spent in caregiving and lack of choice in being a caregiver. This is evidenced in their quantitative study in Southern India about caregiver burden among adults

caring for people living with HIV/AIDS, where results indicated that out of the 360 caregivers who participated in the study, 24.4% of them had experienced moderate to severe burden, with 10% experiencing severe burden (Chandran et al., 2016).

2.5.3 Social Challenges

According to Burdge and Vanclay (1996), “Social impacts are consequences to human populations of any public or private actions that alter the ways in which people live, work, play, relate to one another, organize to meet their needs, and generally cope as members of society” (p. 59). Caring for people living with HIV/AIDS may come with a number of unfavourable social outcomes, which could limit the social life of the caregiver in terms of relationships with family and community members, negative attitudes, among others.

Findings by Ssengozi's (2007) qualitative study in Uganda indicated that elderly caregivers experienced limited mobility and they withdrew from most social functions such as parties, weddings, and religious meetings, coupled with missed interactions with their colleagues and therefore felt less free to move, which resulted to anxiety, stress, and deterioration of their health (Ssengozi, 2007). This supports findings from a quantitative study conducted by Knodel, Watkins, and VanLandingham (2003) in Thailand. Their study indicated that caregiving can divert time from social activities or lead to social shunning by others who have misgivings about being near the caregiver, in addition to intrafamilial relations becoming strained when caregivers perceive inequities in the contribution of other family members. In addition, the authors found negative community reactions in terms of the social stigma associated with AIDS toward the parents and other family members. This was as a result of fear of contagion since the caregiving role was associated with contamination by HIV, coupled with acts like avoidance and gossip, which cause social distress to the elderly caregiver (Knodel, Watkins, & VanLandingham, 2003).

Furthermore, social barriers hinder effective caregiving due to the denial by some patients that they are infected with HIV but rather bewitched. This prompted the patients to continue seeking treatment from traditional healers who promised them total healing (Ntozi & Nakayiwa, 1999) until they became bankrupt. Also, this prevented caregivers from seeking proper treatment for their patients in a timely manner when the resources were still available. On the other hand, patients who acknowledged their HIV status, often became depressed, irritable, picky, and at times angry at caregivers' suggestions, making the work of the caregivers hard (Ssengonzi, 2007).

2.5.4 Health, Physical, and Nutritional Challenges

Elderly persons experience health, physical, and nutritional challenges resulting from the caregiving roles to the HIV/AIDS patients. A mixed method study by Munthree and Maharaj (2010) on the impact of AIDS on older men and women in KwaZulu-Natal, South Africa, indicated that caregivers reported physical ailments and this was in most cases the women caregivers of persons infected by HIV/AIDS. This is in line with the findings by Ssengonzi's (2007) qualitative study in Uganda which revealed that the health and physical ailments, such as chest pains, leg pains, backache, pressure, and hypertension. These ailments were attributed to the elderly caregiving responsibilities frequently performed such as changing, lifting, and washing of adult patients, changing clothes, providing food and drink and administering drugs. The author further states that the elderly caregivers complained of exhaustion, loss of appetite, lack of rest and sleep, which affect their health.

Challenges of caring for sick patients by the elderly appear to be confounded by limited knowledge about proper caregiving practices and the likelihood of contracting HIV during the provision of care; lack of basic equipment, such as gloves during the process of caring for their relatives (Ssengozi, 2007; Knodel, Watkins, & VanLandingham, 2003), hence placing

them at higher risks of contracting the HIV. The findings are supported by Munthree and Maharaj's (2010) study in South Africa, which showed that the elderly caregivers felt being at risk of HIV infection due to a precarious financial situation, which made them vulnerable in acquiring necessary materials. As a result, they were less likely to adopt measures that would make them feel that they were protecting themselves in their role as informal caregivers. This is worsened when rural caregivers face additional challenges from factors such as geographical isolation and lack of health facilities.

In addition, Bejane, Van Aswegen, and Havenga (2013) in their qualitative study in South Africa about primary caregivers' challenges related to caring for children living with HIV in a semi-rural area, identified other caregiver challenges, including their inability to protect themselves and other family members from infection without showing discrimination. This was attributed to the feelings that using protective clothing, such as gloves, might cause the children to feel that they were treated differently from others. Additionally, the primary caregivers were also afraid that other members of the family or community, who did not know the children's HIV status, would start asking questions if they noticed the use of protective clothing (Bejane, Van Aswegen, & Havenga, 2013).

Also, as people age, they experience chronic non-communicable diseases such as hypertension, arthritis, diabetes, cardiovascular condition, stroke among others (Ayernor, 2012; Hutchison, 2011), which increase their medical needs. However, the elderly cannot afford to address their health needs due to emotional and financial drain associated with caregiving, which leaves them sunk in poverty, hence affecting their health and wellbeing (Kasiram & Hölscher, 2015). In their qualitative study about understanding the challenges and opportunities encountered by the elderly in urban KwaZulu- Natal, South Africa,

Kasiram and Hölscher's (2015) findings reveal that several participants reported how costly it was to address their health concerns, due to limited finances.

Food insecurity is also found to be prevalent in the older persons' households, and the caregiving responsibilities exacerbate their already compromised nutritional status. A study by Amoateng et al. (2015) on the psycho-social experiences and coping among caregivers of people living with HIV/AIDS in the North-West province of South Africa indicated that 65% of the caregivers reported that they had experienced challenges with food shortages. This supports earlier findings by Ssengonzi (2007) in a qualitative study in Uganda on the plight of older persons as caregivers to people infected/affected by HIV/AIDS which found that nutrition challenges were faced, due to hunger and poverty. This resulted in elderly caregivers having a negative change in their nutrition, in order to accommodate the increasing costs of healthcare and the higher number of household members. The author adds that the sudden increase in the household size of the elderly caregivers resulted from the transfer of the HIV/AIDS patient back to his/her parents' households, together with the patient's dependents. This ultimately affected the amount of food available for the household due to the elderly caregiver's reduced ability to garden. Furthermore, since the farming system used is usually manual, the new members in the household mainly children are unable to assist in gardening and other chores such as fetching water or collecting firewood (Ssengonzi, 2007).

In addition, findings by Nala-Preusker (2014) in her qualitative study about older caregivers' lived experiences of adult Aids-ill children in Umlazi Township, Kwazulu-Natal, revealed that the situation of food security made households miss meals and others beg for food, hence being difficult for caregivers to provide food for clients who were required to take their ART medication with a meal (Nala-Preusker, 2014). With that, people with HIV/AIDS are more

likely to experience malnutrition resulting from lack of balanced diet, weight loss, and increased risks of death due to a weak immune system.

2.6 Coping Strategies Employed by Elderly Caregivers for People with HIV/AIDS

Coping is viewed as a human personality trait and a time changing process in accordance with the situation we find ourselves (Birkeland & Natvig, 2009). It is a very stressful role for the elderly to provide care for people with HIV/AIDS. This stress comes about when there is a perceived discrepancy between environmental demands and one's ability to meet those demands (Kangethe, 2009). With regards to this, the caregiver's age and gender should receive due importance, as they have a significant effect on one's ability to cope with stress (Pandit & Vishnuvardhan, 2014). Therefore, in order to survive and continue with their caregiving role, caregivers resort to other strategies to respond to the challenging tasks of caregiving (Nala-Preusker, 2014). Kangethe (2009) acknowledges that the caregivers of people with HIV/AIDS require both the internal factors (knowledge) and external (money or friends) to cope with a stressful event.

According to study findings by Nala-Preusker (2014), caregivers coped by accepting that the caregiving role was part of their responsibility and seeing the ill person in a positive way. The author further found that caregivers coped through maintaining hope that the sick person would improve, which motivated them doing their best in providing and seeking treatment for their sick children during the illness. These findings support Shebi (2006) that caregivers accepted the illness as part of their daily living and resorted to assisting the patient deal effectively with the diagnosis, by encouraging and supporting them to correctly and regularly take their medication. Also, the author noted that caregivers expressed feelings of hope, that things would be fine for the patients; hoping that they would recover and do things for

themselves. Additionally, with the supply of ARV's, caregivers felt a sense of relief that the suffering of their loved ones would be over.

In addition, religion and spirituality help some caregivers cope with the caregiving burdens. For example, Hodge and Rohy (2010) in their study conducted in Uganda, found that spirituality was one of the most frequently coping means. This was represented by 28.4 % of the respondents who stated that God, Jesus, prayer, singing gospel music, as well as other spirituality expressions helped them cope with the challenges faced. These findings are supported by Bejane (2012), in her qualitative study on the experiences of primary caregivers caring for children living with Human Immunodeficiency Virus in Southern Africa. The author states that spiritual deepening which leads to faith, hope and trust in God helped caregivers cope and reduce the stress experienced. On the same note, Pallangyo and Mayers (2009) in their qualitative study on the experiences of informal female caregivers providing care for people living with HIV in Tanzania revealed that faith, expressed through praying for God's intervention, was a source of courage and strength. Additionally, spirituality is expressed through going to traditional healers. For instance, Ntozi (1995) in her study conducted in Uganda, identified caregivers going to traditional healers who claimed to know the cure for AIDS. Many people, believing in traditional healers, usually seek such means when modern medicine has failed. The traditional healers include herbalists who deal with the daily treatment of AIDS patients and diviners who seek the underlying causes of AIDS and work especially on the supposed supernatural causes (Ntozi, 1995). This finding is confirmed in the qualitative study by Ssengonzi (2007) in Uganda, who noted that denial led to seeking treatment from traditional healers who promised total healing, thus preventing caregivers from seeking proper treatment.

Additionally, seeking social support is another alternative for caregivers to cope with the burden of caregiving. Shebi (2006) reported that caregivers gathered support such as; seeking information regarding HIV/AIDS and care, as well as economic, physical, and psychosocial support from family, friends, healthcare workers, and community members. Also, those who needed practical help like cleaning, washing, bathing, and cooking, asked friends and neighbors to assist. These findings are supported by Amoateng, Kalule-Sabiti, and Oladipo's (2015) study conducted in South Africa, using a quantitative approach that found that some caregivers sought professional counseling to cope with the challenges experienced, while others sought emotional closeness to others, as a coping mechanism. With a view of reducing stigma and discrimination, Hassan's (2016) study findings on stigma reduction initiatives noted that to gain and ensure the flow of social support, caregivers prevented disclosure and maintained distance so that their caregiving activities could remain unnoticed. They also manipulated internet sites to create acceptable online identities. These actions may, on the other hand, keep the caregivers away from their support networks. The findings above support Munthre and Maharaj's (2010) study conducted in South Africa, where some of the caregivers complained that they were not able to draw on social networks for support, and often, in times of adversity, their friends turned their backs on them.

Furthermore, since food insecurity is always identified in households headed by the elderly caregivers due to the increased demand from dependents, Nankwanga, Phillips, and Neema (2009) in their study conducted in Uganda found that the elderly caregivers were trying to grow as much food as possible to feed the dependents. Their study also revealed that 55.4% of the caregivers in the rural area grew more food, compared to 54.7% of those who resided in the urban area. The authors also found other coping mechanisms the elderly caregivers utilized to include: asking for assistance from their surviving children, going for counseling

to avert the trauma, giving their lives to Jesus Christ, and appealing to ‘good Samaritans’ for help (Nankwanga et al., 2009).

In an attempt at mitigating and absorbing financial effects of HIV/AIDS illness, caregivers adopt varying strategies to minimize income losses and unexpected financial costs such as the substantial costs of care, treatment, and funerals. Regarding this matter, Chepngeno-Langat, Falkingham, Madise, and Evandrou (2010) identified such strategies to include the use of savings, borrowing, salaries and business/small enterprises which the majority of the respondents used. On the other hand, however, since not all parents can cover the costs from cash in hand or savings, the authors also noted a small proportion of the respondents (4%) indicated selling of assets, which was opted to when savings and available cash were used up. This is in line with findings by Sefasi (2010) and Fauk, Mwakinyali, Putra, and Mwanri (2017) that, coping strategies by the caregivers included selling of family assets in view of getting money to meet expenditures for medication and funeral rites.

More so, study findings by Knodel and Im-Em (2004) indicate that 10 % of parents took on extra work, 13 % sold assets, and 39% borrowed money to meet expenses. This is in relation to Maradik Harris and Kim’s (2014) qualitative study in Vietnam, which reveals that some caregivers even after retirement had to re-enter the workforce, borrowed money from individuals, and/or utilized various kinds of loans in order to resolve insufficient money for the family. The authors also found that the caregivers faced their daily challenges with resiliency, and accepted that the future would not be easy, making them get used to hardships and struggles, without expecting any changes in the future (Maradik Harris & Kim, 2014).

Shebi (2006) also reported that caregivers in most cases controlled their feelings, which helped them cope with extra stress that might have negatively affected both their state and that of the care recipients. The author states that caregivers expressed having made

themselves strong, by putting on a brave face when in the company of the care recipient, as they believed that showing real feelings of distress could affect the care receiver and worsen their condition. It was further noted that, accompanying care recipients for regular check-ups, supporting them emotionally, physically, socially and filling ordinary events with positive meaning, helped minimize the caregivers' fears, hence becoming emotionally stronger and feeling fulfilled in their caregiving (Shebi, 2006).

Furthermore, Fauk et al. (2017) in their current study conducted in Mbeya, a Rural District in Tanzania noted that, the adoptive families' coping strategies included renting out land, reducing the size of the family's cultivable land, reallocation of labor, and withdrawing children from school to support in providing labor, and also due to lack of school fees and other scholastic materials. These findings support the study by Mathilda et al. (2015) in Zimbabwe which noted that 83% of the respondents worked in the fields and gardens as means of coping with the surplus being sold to acquire money. With regard to withdrawing children from school to support in providing labor, Ssewamala's (2015) study support the findings of Fauk et al. (2017) and Mathilda et al. (2015) that, absence of enough income and other economic resources in families in addition to nonexistence of public safety nets in terms of government support, forces children to complement household income, hence dropping out of school to earn for the family. This led to child labor and the hazardous informal labor market, including transactional sex, coupled with other high-risk activities.

Unlike adopting the coping strategies mentioned above, some caregivers are likely to be involved in negative coping strategies. For example, Nala-Preusker (2014) in her qualitative study in South Africa found that some caregivers reported resorting to drug use such as taking alcohol. This finding is confirmed in the qualitative study by Kasiram and Hölscher (2015) in South Africa, about understanding the challenges and opportunities encountered by

the elderly, which found that poor mental health and stress often led to substance use by the elderly caregivers.

2.7 Support Services Available for Elderly Caregivers Caring for HIV/AIDS People

Support comes in diverse forms. Hutchison (2011) notes formal and informal resources as two major ways of meeting the needs of the elderly persons. The author defines informal support as one provided through families, friends, neighbors, and churches among others. She also defines formal support as one provided by formal service providers and in most cases, have eligibility requirements for a person to qualify (Hutchison, 2011). The support received from these two main forms can be social, financial, emotional and material support such as clothes and food.

2.7.1 Informal Support Systems

2.7.1.1 Support from Families

Tshoose (2010) observes that traditional support systems like kinship, depend on the principles of solidarity and reciprocity, and involve providing support and defense to its members unable to provide for themselves in times of difficulties. Study findings by Amoateng, Kalule-Sabiti, and Oladipo (2015) and Nala-Preusker (2014) indicated that some of the caregivers received moral support and help from members of the family (specifically other children who were not HIV positive), in form of making a visit, giving company to their parents, loaning or contributing money, and providing transport, hence reducing the elderly caregivers' loneliness. Naleppa and Schnitzenbaumer (2011) add that support from family members is provided in different types. For instance, it is the daughters who usually provide more of the caregiving and are much engaged in housekeeping and household chores whereas sons usually tend to assist with household repairs and finances.

On the other hand, families ought not to be regarded as uniformly available resources for support because not all family systems are functional and capable to provide the support needed. This is due to the AIDS epidemic which affects the working adults who are to provide such assistance (Munthre & Maharaj, 2010; Nala- preukeser, 2014), and the subject of secrecy surrounding AIDS which enforces restrictions on the support provided by the extended family and the number of caregivers (Nhongo, 2004). Also, some family members are willing to provide support to the elderly caregivers but are not able to do so due to financial inadequacy (Oduro, 2012).

2.7.1.2 Support from Friends and Neighbors

Friends and neighbors are other forms of informal support to elderly caregivers. Although they may be less inclined than family members would be to provide personal care, friends and neighbors often offer other forms of assistance such as running errands or performing household chores (Naleppa & Schnitzenbaumer, 2011). Oburu and Palmérus (2005) in their study conducted in Kenya reveal that, in addition to getting support from relatives, highly distressed grandmothers were more likely to look out for social support from friends, which is similar to study findings by Maradik Harris and Kim (2014) in Vietnam that, caregivers sought emotional and social support from their friends within the community, when feeling overwhelmed by their caregiving activities. These are supported by the study done by Knodel, Watkins, and VanLandingham (2003) where elderly caregivers reported positive reactions from others in the community (e.g. visiting, showing sympathy, bringing food). Ssengozi (2007) also noted that female elderly caregivers reported increased bonding with their friends who visited them to offer comfort and it strengthened their relationships.

2.7.1.3 Support from Religious and Community Groups

Hutchison (2011) stated that one of the informal resources is provided by religious and community groups and that these resources include social and emotional support through group activities and community events. Also, Nala-Preusker (2014) in her study in South Africa found that some of the caregivers reported getting assistance, sometimes from church groups and women's groups. Within communities, informal social security is generally identified through informal social arrangements that can be divided into traditional support systems and self-organized systems. Examples of self-organized informal social security include burial societies and rotation money schemes (Tshoose, 2010). This supports a study by Ntozi and Nakayiwa (1999), who noted that community groups such as the Munno Mukabi (friend in need) was identified to be responsible for community fundraising to help with funeral expenses and has evolved into a support group for AIDS families and orphans.

In addition, Ntozi and Nakayiwa (1999) in their study conducted in Uganda found that community groups assisted families with food, clothes, school fees and education on HIV/AIDS. Local communities also assisted in building homes where orphans can live with relatives (Ntozi & Mukiza-Gapere 1995). Naleppa and Schnitzenbaumer (2011) support the above findings, as it was noted in their study that religious groups provided services like meals and transportation. The authors also noted that religious- related resources include social and emotional support through group activities and community events.

2.7.2 Formal Support Systems

Social Security for the elderly is another source of support in caregiving. The government provides the elderly with an old-age pension, which is primarily a poverty relief program; however, it may also contribute toward other costs including food, clothing, medicine, and school fees for persons infected and affected by HIV/AIDS (Knodel & Saengtienchai, 2005).

Since the majority of the rural elderly persons do not contribute to formal pension schemes that can be used in their old age, they have no option but to benefit from non-contributory government cash transfers or grants in case the schemes are available to support them in caregiving (Nyirenda et al., 2012). This supports the study findings by Schatz and Ogunmefun, (2007) on the role of older women in rural South African multi-generational households in the HIV/AIDS era, which indicated that the older women used their pensions in caring for persons infected and affected with HIV/AIDS in their households. Also, Kimuna and Makiwane (2007) and Nyirenda et al. (2012) indicate that elderly people received government old-age grants/ old-age pensions in form of cash transfers as the main source of income to support household members. However, not all of older people have access to pensions or formal social security support, due to factors like inclusion criteria, inaccessibility and lack of support documents, and ignorance about the programs (Chepngeno-Langat, Falkingham, Madise, & Evandrou, 2010), which make their caregiving role difficult.

Furthermore, elderly caregivers are supported by providing education services to their orphaned grandchildren. Research findings by Kakooza and Kimuna (2006) in a study conducted in Uganda about HIV/AIDS orphans' education in Uganda indicated that, there is partial relief for all primary and secondary school-going children, through universal primary and secondary free education for all children, which reduces the amount of money the elderly caregivers could spend on orphaned grandchildren. However, this partial relief and support provided by the government of Uganda through the Ministry of Education provides only for tuition and not additional fees required such as building or development fund, equipment fees, transport and other required essentials like school uniforms and books (Kakooza & Kimuna, 2006). This situation could result in elderly caregivers being more sunk in poverty as they are forced to find for means by which they can meet the educational requirements for

these orphaned and vulnerable children. Another important finding according to Kakooza and Kimuna (2006) was that of the elderly caregivers withdrawing the Orphaned grandchildren from school, even after when they had partial support from the government. They found that in most cases, the reason for children not being enrolled in school was inability of the elderly caregivers to afford items like school uniforms among others, without which the children would not be accepted in school (Kakooza & Kimuna, 2006).

Finally, elderly caregivers of people with HIV/AIDS also receive support from non-governmental organizations. A study by Ntozi and Nakayiwa (1999) in Uganda indicated that non-governmental organizations such as The AIDS Support Organization (TASO), foreign NGOs and religious missions also give support by providing services such as counseling and treatment in a culturally appropriate manner. These support services received are vital in helping elderly caregivers to be emotionally strong and also provide good care for their people infected with HIV/AIDS.

2.8 Theoretical Framework

This study is guided by the Caregiver Identity Theory and Coping Theory

2.8.1 Caregiver Identity Theory (Montgomery, Rowe & Koloski, 2007)

According to Montgomery, Rowe & Koloski's (2007) Caregiver Identity Theory, caregiving is a change process that is dynamic and comprises a change in caregiving activities, the caregiver and the care recipient relationship, leading to the caregiver's identity change, involving changing from the actual identity as a mother, to being a caregiver (Montgomery et al., 2007). Montgomery et al. (2007) state that over time, as the quantity and intensity of the care recipients' needs increase, caregivers change their behaviors and also how they see their role in relation to the care recipient, because of the care tasks required. The change in identity finally triggers the type and level of stress or burden (Montgomery et al., 2007). This theory

helps caregivers in coping with their caregiving role. In addition, the authors note that, similar to other social actions, caregiving is directed by norms or social values, ethnic and cultural background, which influences one's expectations on the caregiving responsibility.

Montgomery et al. (2007) state that for most caregivers of persons with chronic conditions, the change in identity is a slow, insidious process that occurs in stops and starts. With this, therefore, it is expected that like any other disease, elderly caregivers for people with HIV/AIDS may initially experience minimal care needs with the care tasks representing only a minimal extension of their familial role relationships. However, as the illness progresses from one stage to another due to its chronic nature, the needs of the person infected with HIV/AIDS increase, which places demands on the elderly caregiver, hence resulting in experiencing high levels of stress. Therefore, the elderly parent begins to experience the "caregiver identity" due to the caregiving activities which alter the initial mother-child relationship into a caregiving relationship.

To elaborate more on this, Montgomery et al. (2007) provide five possible phases that influence the identity change process due to increased demand of the care recipient's needs.

Phase 1: This is the beginning period and it involves performing caregiving activities for the care recipient that have not been part of his/her familial or friendship role in the past. Under this phase, the caregivers are not conscious of their caregiving identity. In relation to the elderly caregivers, the phase is applicable to how they provide care and support to HIV/AIDS infected not recognizing that their identity is slowly turning to that of a caregiver.

Phase 2: This phase starts with the caregivers acknowledging that their caregiving activities have exceeded the usual range of the original familial role. Montgomery et al. (2007) state that during this stage, caregivers slowly notice some changes in their roles by being

somewhat changed from the previous one. In many cases, the care recipient's demands for assistance become more than the initial stage thus starting to cause discomfort to the caregiver. This may include the older caregiver's care to HIV/AIDS infected and affected people such as the child infected with HIV/AIDS and together with the grandchildren.

Phase 3: This is exhibited when the quantity and intensity of the care recipient's care needs increase to a stage that call for support that is considerably past the boundaries of the original familial relationship that is regarded normal (Montgomery et al., 2007). Furthermore, during this stage, it is said that the activities required are not comfortable to neither the caregiver nor the care recipient, which leaves the caregiver in dilemma, hence beginning to assume their primary identity as that of the caregiver role. Similarly, the elderly caregivers of people with HIV/AIDS experience the same dilemma as the illness progresses and begin to require additional assistance in all areas of caregiving life, such as financial, social, among others.

Phase 4: This is a more intense phase for caregivers as it requires them to provide more time as the care recipients need continuous and more intensive care (Montgomery et al., 2007). At this stage, most AIDS clients are bed-ridden and require their elderly parents to provide them with a lot of care and assistance. During this phase, most caregiving tasks are very strenuous for the elderly, such as washing, feeding, giving medicine, washing, visiting the hospital and caring for the sick person's children, which affect the already frail elderly parents.

Phase 5: It is the last stage of the caregiving career, and includes taking the care recipient into a setting that releases the caregiver of the main role of providing care (Montgomery et al., 2007). Usually, at this phase, the care recipient is placed in a nursing home, hospice or care center, or otherwise, move to the home of other family members. However, this stage may not be applicable in Uganda since in African culture, placing individuals in a hospice and other care facilities are perceived as forsaking or giving up on relatives, thus older people

continue with a great challenge of caregiving. Alternatively, most ill adult children choose being taken to the homes of their parents or the parents transfer into their children's home to provide the care, thus being the onset of role reversal since the elderly become full-time caregivers for their adult AIDS sick children (Nala-Preusker, 2014). However, during these processes, adjustment periods exist differentiating between what a caregiver is doing and what he/she thinks should be done, depending on their individual identity.

The theory's core tenet is that the caregiver experiences distress during these periods and feels overburdened due to engaging themselves in inconsistent roles in relation to the way they view themselves, hence prompting caregivers to seek help (Montgomery et al., 2007). Additionally, the elderly caregivers' experience added activities like caring for the children of the AIDS-sick child, which call for extra time, thus limiting their performances in the roles. Finally, the authors highlighted that "tremendous variation exists in the trajectory of individual caregiving careers and that not every caregiver goes through every phase and transitions are not necessarily unidirectional" (p. 50) or a smooth process. They also note that most caregivers withdrawal from the caregiving role in the course of the 2nd and 3rd Phases, hence moving straight to 5th phase, where they take their care recipients to other institutions that provide care. Also, elderly persons choose to provide care for their own HIV/AIDS sick children which exposes them to experience distress at numerous transitioning points in the course of their phases of providing care (Nala-Preusker, 2014). Therefore, their needs are expected to be identified to make certain that they are magnificently assisted in the process of their caregiving role.

2.8.1.1 Relevance of the Caregiver Identity Theory to the Study.

The theory helped to explain the various caregiving roles the elderly women performed when caring for people with HIV/AIDS. The theory helped to understand the role reversal elderly

women experience when caring for adult children with HIV/AIDS. The theory was also useful in explaining the challenges elderly women face in caring for people with HIV/AIDS due to increased roles. However, the theory did not provide an understanding of how the caregivers coped with the stress and other challenges resulting from caregiving. It also provided little understanding of the intervention and support systems these caregivers employed for assistance, due to multiple challenges faced.

2.8.2 Coping Theory by Lazarus & Folkman (1984)

Lazarus and Folkman (1984) contend that coping is a constantly changing process, which is based on specific efforts involving cognitive and behavioral aspects. In order to cope, people can employ to master, tolerate, reduce, or minimize stressful events (Lazarus & Folkman, 1984). The theory proposes two general coping strategies; that is problem-solving strategies which are efforts to do something active to alleviate stressful circumstances, and emotion-focused coping strategies which involve efforts to regulate the emotional consequences of stressful or potentially stressful events.

According to Lazarus and Folkman (1984), coping attempts are employed either to reduce the demands of the stress, to reduce the effects of the stress, or to help the person change the way he or she thinks about the demand of the stress. It could be stimulus-directed coping, where an attempt is made to eliminate or ameliorate the initial sources of the stress reactions; or cognitive coping, which involves changing the way the stressor is perceived; or response directed coping, which involves the reduction of the magnitude of the stress response. The central tenet of the theory is that the process of coping mediates the effects of stress on an individual's well-being. The theory furthermore upholds that, the psychological meaning of the event to the individual is the most influential element to the coping process. In summary, Lazarus and Folkman (1984) suggest that coping strategies can be based on problem-focused

coping and emotion-focused coping. Problem-focused coping include; confrontative coping, seeking social support, and plan full problem-solving. Whereas, emotion-focused coping includes; self-control, distancing, positive appraisal, accepting responsibility, and escape/avoidance.

Relating elderly caregivers of people with HIV/AIDS, stress emanates from a perceived discrepancy between environmental demands, the care receiver's demands and the caregiver's ability to meet those demands; hence presenting psychological, emotional and even physical distress. Also, the increased burden on caregivers of AIDS patients may develop feelings of anger, grief, loneliness, burnt-out and resentment, which may lead to poor quality of care and ill health of the caregivers. In this regard, for caregivers of HIV/AIDS patients, varying mechanisms are adopted with time to cope with the stressful events they encounter in their caregiving process. This is because the care they provide just manages the disease since it does not cure. Therefore, elderly caregivers utilize problem-focused strategies, where they seek social support from friends, relatives and community members to deal with the challenges. Moreso, they may seek more information on caring for their HIV/AIDS ill people from the health care professionals and counselors. And, they may confront people who may stigmatize them by speaking back to them. These actions are sought when elderly caregivers view their stressful situation as open to change. Under emotion-focused, strategies like acceptance, positive appraisal (such as praying), and so on are opted for as they come to believe that nothing can be done to change the situation of their care recipients. These efforts help elderly caregivers feel better about their situation.

2.8.2.1 Relevance of the Coping Theory to the Study

The coping theory was useful in facilitating the researcher's understanding, of the various coping strategies employed by elderly women, due to stressful situations and other caregiving

demands when caring for people with HIV/AIDS. The theory also helped the researcher to understand the support services available for caregivers of people with HIV/AIDS and how they are utilized.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Research Design

A research design is a type of inquiry that provides specific direction for procedures in a research study (Creswell, 2014). This study employed a qualitative research design. A qualitative design is a way of studying and making clear the meanings individuals or groups give to a social or human problem (Creswell, 2009). A qualitative research will enable the researcher to gain in-depth- information about participants, and also allow for a richer and an in-depth understanding of how people make meaning of their situation or interpret phenomena (Denzin & Lincoln, 2005). According to Creswell (2014), a major characteristic of qualitative research is that it takes place in a natural setting where participants experience the problem under study. This allows the researchers to have face-to-face interaction with the participants, thus collecting data by talking directly to people and making observations on how the participants behave and act (Creswell, 2014). Using a qualitative design enabled the researcher to study and reveal through stories, the lived experiences of elderly women caring for people with HIV/AIDS, hence understanding their roles and role reversal, challenges, coping strategies, and available support services for them.

This study used the phenomenological approach of qualitative research, which helps the researcher to describe the lived experiences of individuals about a phenomenon as described by participants (Creswell, 2009). According to Davidsen (2013), phenomenological methods focus on rich description of some aspects of experience, described through language. Phenomenological approach aims at illuminating the specific and identifying phenomena through how they are perceived by the actors in a situation, which challenges the structural or normative assumptions. Furthermore, phenomenological study translates into gathering

‘deep’ information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant(s) (Lester, 1999). All of these factors combined with the interpretive focus of qualitative research make it an ideal paradigm for exploring the experiences of elderly women caring for people with HIV/AIDS.

3.2 Study Location

Masindi district is located in Mid-Western Uganda, 216 Km North West of Kampala, the capital City of Uganda. It is bordered by Kiryandongo District in the North, Hoima in the West, Nakasongola in the East and Nakaseke in the south (Masindi District Local Government, 2015). It comprises a total area of about 5,000 sq.km of which about 4,000 sq.km is a land area, and 1,000 sq.km is wetlands and rivers (Masindi District Local Government, 2009). The district’s population as per the National Housing and Population Census in 2014 is 292,951 (Uganda National Population Census, 2014; MDLG, 2015), with the majority having their livelihood from agriculture (Kugonza et al., 2009). Masindi District is characterized by an ethnic diversity of 56 ethnic groups (MDLG, 2015). Immigrants and refugees from neighboring regions such as the North (due to war) and other countries have settled in this region for decades (Borchert et al., 2011).

A number of reasons underpin why the district was chosen as a study area. First, as discussed earlier in the HIV trend and burden in Masindi District, HIV/AIDS is a big issue in the district, with the January – March 2016 Masindi district HIV/AIDS bulletin indicating that 23,729 people were living with HIV/AIDS. This means that care and support from immediate family members would highly be required by both HIV/AIDS infected and affected individuals. Also, the researcher worked with TASO- Masindi branch as an intern, and while there, she witnessed the struggles and challenges which some elderly caregivers could go

through when they brought their people living with HIV/AIDS on clinic days, and when home visits were made to check how clients were doing. Therefore, as a social worker whose role is to help in addressing the problems of vulnerable members in communities, I did my study in this particular area to project the voices of elderly women, by finding out their experiences as caregivers for people with HIV/AIDS.

3.2.1 Study Sites

TASO– Masindi branch and Masindi Hospital were the sites for this study.

3.2.1.1 Background of Masindi Hospital

Masindi Hospital is government-owned with a status of a district general hospital, located in the town of Masindi. It was built in 1922, as a Health Aid Post for the East African Railway workers. In 1935, it was taken over by the colonial government and developed into a Health Center IV facility, and in 1965 it was handed over to the government of Uganda. It was elevated to a level of a general hospital in 1988 with a 100-bed capacity, and in 2008 it acquired an independent Female Ward with a bed capacity of 54 beds. The hospital's bed capacity was 160 as at January 2013. The hospital services patients from the districts of Masindi, Bulisa, Nakasongola, Nakaseke, Hoima, and Nebbi. Some patients come from as far as Democratic Republic of Congo (DRC) and Southern Sudan. It provides numerous services including, outpatient department (OPD) and in-patient management, lab services, X-Ray and ultrasound scanner services, physiotherapy, eye clinic, ear, nose and throat (ENT) services, etc. It also has special chronic care clinics for hypertension, diabetic, HIV and Sickle Cells. Its major wards include maternity, female ward, male ward, and children ward, in addition to a theatre unit. HIV care in the hospital is good, and this involves activities like prevention of mother to child transmission (PMTCT), blood screening and counseling among others. The hospital partners with The Aids Support Organisation (TASO), situated within the hospital to

provide better HIV services to people infected with the disease and their families (Daily Monitor, 2013; UMOH, 2016)

3.2.1.2 Background of TASO- Masindi Branch

In general, The AIDS Support Organization (TASO) is an indigenous HIV/AIDS service initiative, which pioneered in HIV/AIDS response in Uganda and sub-Saharan Africa. It was registered in 1991 as an NGO with the Uganda Government NGO Board (TASO, 2015). TASO was founded in 1987 by Noerine Kaleeba and a group of 15 volunteers, among whom, seven were living with HIV. They were determined to fight against AIDS, at a time when little was known about the disease, causing stigma and discrimination to infected individuals and their families. Their aim was to provide emotional support and compassionate care to persons and families affected by HIV/AIDS and making affected people feel accepted as human beings with dignity, and their hope restored to live with the challenges of the disease. The group's message to families was that, HIV was not transmitted by casual contact and that the sick needed better care, support, and treatment to live with hope, reduced pain and to die with dignity (TASO, 2015). TASO has since established 11 service centres, 4 regional offices, and 1 training centre of excellence and 1 capacity building project, which are all situated in Uganda's major towns of; Entebbe, Gulu, Jinja, Kampala (Mulago), Masaka, Masindi, Mbale, Mbarara, Moroto, Rukungiri, Soroti, Tororo. The organization's core services are; comprehensive HIV prevention using combination prevention package, HIV/AIDS counseling and testing, care and support services, HIV/AIDS treatment, including Anti-Retroviral Therapy, HIV/AIDS training and capacity development, and HIV/AIDS advocacy and networking. Through the years, TASO has cared for over 300,000 individuals living with HIV and reached out to over 900,000 members of their families (TASO, 2015).

In particular, TASO Masindi is the latest service center, situated in Masindi Hospital. Its founding was in line with the strategic plan of 2003 -2007 of increasing TASO services to other parts of the country. Its establishment followed a 2004 baseline survey, carried out in Bunyoro region, which showed that the district was a unique enclave with fewer AIDS service organizations, yet with high HIV prevalence rates. The center started offering its services to clients on August 17, 2005, in the former private ward of Masindi Hospital. However, later, a fifteen-room-building was constructed to improve on the working space. The center's catchment area covers the districts of Masindi, Buliisa, Hoima, Nakasongola, and Kibale. It also offers all TASO core services like counseling, medical care, social support, community mobilization and AIDS education, among others. Unlike other centers, TASO Masindi offers HIV Counseling and testing (VCT) services in its communities, due to limited VCT services in the region. In addition, it patterns and networks with government bodies and sister organizations including; Masindi Hospital, Christian Child Fund (CCF), Kinyara Sugar works, Masindi Military Hospital and District Offices. Others include: Action Aid, District health centers, Bunyoro Kingdom, institutions of learning, and radio stations (Kitara FM and Bunyoro Broadcasting Services) (TASO, 2015).

3.2.1.3 Justification for selection of the sites

The researcher's selection of these study sites was based on many factors, including the fact that Masindi Hospital and TASO partner and network in providing services to people living with HIV/AIDS and their families. They were reliable for getting participants who could provide the best information for the study. Also, a representation from the two agencies (public and private) would provide at least a balanced view of key informants about the experiences of elderly caregivers for people with HIV/AIDS and how effective their intervention and support services are in meeting caregivers' needs and their families. This

was to help identify the gaps in services, hence creating room for improvement and the involvement of the government and other stakeholders to support.

3.3 Target Population

For this research, the target population was all elderly women caring for people with HIV/AIDS in Masindi district, staff (counselors, social support department officers) from The Aids Support Organization (TASO) and nurses from Masindi Hospital.

3.4 The Study Population

Study Population refers to a subset of the population which have been selected by the researcher for study purposes. The study focused on elderly women caring for people with HIV/AIDS, aged 60 or more years. Key informants included counselors and social support department officers from The Aids Support Organization (TASO). Nurses from Masindi Hospital were also interviewed to ascertain their understanding of the caregiving roles elderly women perform when caring for people with HIV/AIDS, the challenges faced, coping strategies employed when caring for people with HIV/AIDS and the intervention/ support services available for elderly women caring for people with HIV/AIDS in Masindi district.

3.5 Sampling Techniques

Sampling refers to the process of selecting a portion of the population that conforms to a designated set of specifications to be studied (Nala-Preusker, 2014). Purposive sampling technique was adopted in selecting the sample for this study. In purposive sampling, attempts to select research participants is done according to criteria determined by the purpose of research (Tuckett, 2004) and the qualities possessed such as knowledge and experiences, regarding the subject matter and the willingness to participate (Creswell, 2009).

Participants were purposively selected according to the inclusion criteria. Their recruitment was through two main agencies, which are, The Aids Support Organization (TASO) and Masindi Hospital, after being granted permission. In both agencies, the researcher was introduced to gatekeepers (head of ART clinic in Masindi hospital and a counselor in TASO) who helped introduce the elderly women caregivers with stipulated criteria to the researcher. An informational session was done with the participants, to share details about the study.

The criteria for those eligible to participate in the study were explained and the elderly women caregivers were encouraged to ask questions, and also requested to voluntarily participate in the study. They were later interviewed at a place and time that was convenient for them. Key informants were selected through the head of departments. The head of ART clinic at the Masindi Hospital and the counseling coordinator at TASO identified the names of nurses and counselors respectively, who had knowledge and experience in working with people with HIV/AIDS and their caregivers. The researcher contacted them to verify their participation and also set dates and venues according to convenience.

3.6 Inclusion and Exclusion Criteria

3.6.1 Inclusion Criteria

The inclusion criteria for study participants was that, the caregivers for persons with HIV/AIDS were elderly women 60 years or more, giving care to 1) children with HIV/AIDS aged 3-17 years, 2) adults with HIV/AIDS, aged 18 or more years, either 3) caring for both children and adults in the given age groups. Also, the caregivers were residents in Masindi district, with caregiving role experiences of at least six months. The selection criteria for the key informants, who included the counselors, social support department officer from TASO and nurses from Masindi Hospital was that they must have worked with HIV/AIDS related

cases for a period of one year or more. Finally, both the caregivers and the key informants were to be fluent in either English or Runyoro (the local language).

3.6.2 Exclusion Criteria

Any of the following was regarded as a criterion for exclusion from the study: Elderly women caregivers under 60 years of age, with caregiving experience below six months, and are not residents in Masindi District. For key informants, those who were not working with HIV/AIDS-related cases and those who might have worked with HIV/AIDS-related cases but less than one year were excluded from this study.

3.7 Justification for Inclusion and Exclusion Criteria

The criteria are set to ensure a subject population will enable the investigation of the set objectives, and to provide equal opportunity for inclusion and not to exclude subjects that may provide the best information due to knowledge and experience possessed regarding the phenomenon under study (Johnson, Mugabo, Nell, & Syce, 2004). The selection of the elderly 60 years and above was because they are in a period when they are less productive and physically waning. Therefore, the caregiving role assumed at this age may come with other challenges. Hence, the researcher wanted to identify and compare the unique caregiving experiences which come with caring for persons with HIV/AIDS of different age groups or both. Also, the researcher wanted to find out if there is a role reversal, where the elderly are giving care to adults infected with HIV/AIDS, who are instead supposed to be caring for them in their old age, as it is expected in traditional African society. However, the inclusion of other age group caregivers may be considered in subsequent studies. Furthermore, the selection of key informants was based on their experience through interactions when working with caregivers in providing services to their sick persons, and their knowledge on how the epidemic affects these caregivers.

3.8 Sample Size

The researcher used a sample of twenty-four (24) participants for this study. These included; Eighteen (18) elderly women caregivers and six (6) key informants, that is; 4 officials (3 counselors and 1 social support department officer) from The Aids Support Organization and two 2 nurses from Masindi hospital. This is because according to Creswell (2009), an ideal sample size for a qualitative study should range from 5-25 participants to reach saturation. Thus, data collection from participants ended at 24 because saturation had been achieved, as no new additional data were being found. This was observed during the interviews, when the researcher began to hear the same comments as expressed in previous data, even after asking probing questions. Furthermore, by using small sample sizes, the researcher is committed to discovery through the use of multiple ways of understanding. It is also possible for the researcher to use more than one method (e.g. interviews and observations) (Speziale & Carpenter, 2003).

3.9 Sources of Data

The main source of information for the study was primary data, collected through the use of in-depth interviews with elderly women caregivers and staff members from The Aids Support Organization and Masindi hospital.

3.10 Methods of Data Collection

First, the researcher made initial contacts with the participants, with a permission letter from the Department of Social Work of the University of Ghana to collect data, where an informational meeting was held with the participants to explain the purpose of the study. Participants were identified and recruited through two main agencies. TASO (a Non-Profit Organization that provides HIV/AIDS services to infected people and their families) and Masindi Hospital (the district government health facility), were approached to help identify

clients being cared for by elderly persons and staff with required experiences of working with people with HIV/AIDS and their caregivers. This was to enhance the acquisition of relevant information required for the study. After explaining to them the purpose of the study, eighteen (18) eligible elderly women caregivers and six (6) key informants were voluntarily recruited within Masindi District, and their consent was sought by signing or thumb printing a consent form. This is because in most African traditional societies, caregiving is a role for women, making the elderly women in Masindi often take the responsibility of caring for the sick family members, including those infected with HIV/AIDS.

Interview guides were developed by the researcher and used to solicit information from participants through one-on-one interview at a place and time convenient for the participants. With permission from participants, oral interviews were recorded by the researcher using an audio recorder and were complemented with notes taking. The interview guides were designed in both English and Runyoro, and interviews were conducted in both English and Runyoro because these were the languages the participants understood. Each interview lasted for approximately 40 minutes to 1 hour 30 minutes. All the elderly women caregivers were interviewed in Runyoro, some in their homes, and others at the Masindi Hospital ART clinic, in a private room. Key informant interviews were conducted in English at their places of work. A set of two separate interview guides were designed by the researcher for elderly women caregivers and key informants, and both open-ended and closed-ended (demographics) interviews were used to solicit data from participants. A research assistant was employed by the researcher to assist in the data collection process.

3.11 Data Handling and Analysis

Data collected from the field was stored and kept as private and confidential on a password protected computer, with copies being stored on an external drive to serve as backup. The

recorded data from interviews were then transcribed from audio to a text format. The transcribed data were analysed using the six-step thematic analysis proposed by Creswell (2009).

The six phases are as follows;

Step 1: Data Transcription - Data from the field was transcribed into text format using Microsoft word 2010.

Step 2: Familiarization - Data was read through to obtain a general sense of information.

Step 3: Coding - Transcribed data was segmented into categories and labeled with a term based on the objectives of the study,

Step 4: Theme Development - Themes were then developed, which appeared as major findings in the presentation of findings.

Step 5: Data description - Data was described using multiple viewpoints and quotations from participants

Step 6: Interpretation of Data - Findings were compared with information from the reviewed literature.

3.12 Trustworthiness and Credibility

To ensure trustworthiness and credibility of the study, peer debriefing was used. According to Creswell (2014), peer debriefing is a process which involves locating a person (peer debrief) who reviews and asks questions about the qualitative study so that the account will resonate with people other than the researcher.

In ensuring peer debriefing, findings of the research were presented to reviewers knowledgeable in qualitative research such as colleagues in the Department of Social Work who asked questions about the qualitative study. Also, experts in the qualitative research, especially supervisors had an opportunity to question the research process and findings of the study, and also made their input.

3.13 Ethical Considerations

According to Creswell (2014), the researcher has an obligation to respect the rights, needs, values, and desires of the participants. For the researcher to comply with the requirements, the following were carried out.

- **Regulatory approvals:** The researcher sought out regulatory approvals for the study. This involved the study undergoing ethics review and approvals by TASO Research Ethics Committee (TASO REC) and the Ethics Committee for Humanities (ECH)-ISSER, University of Ghana Legon. Permission was also obtained from TASO–Masindi branch and Masindi Hospital to carry out the research using them as study sites.
- **Informed consent:** The purpose of the study was explained to participants before they willingly gave information without coercing. Signed consent was obtained from all eligible elderly women caregivers and key informants from TASO and Masindi Hospital.
- **Confidentiality:** The principle of confidentiality was considered vital in this study. The researcher held interviews at a place comfortable for the participants to ensure privacy, such as homes and a private room for elderly caregivers and offices for key informants. In reporting the findings, the researcher used pseudonyms in place of the

actual names of research participants. This was to ensure that participants' identities were not revealed.

- **Voluntary Participation:** Participants were not forced or coerced to partake in the research, rather they did so at their own free will. It was also made clear to them that refusal to participate in this study would not have any negative impact on the treatment, care and other services received for their care recipients.
- **No harm:** Participants were provided extra protection from mental discomfort, harm, and danger. An arrangement with a counselor was made for counselling services in case of any breakdown and mental discomfort.
- **Plagiarism:** Plagiarism was avoided by acknowledging all referenced sources.

3.14 Limitation of the Study

The present study might be limited in a sense that the researcher chose qualitative research design with a sample size of 24 participants, who were selected purposively. Again, the study was constrained to only one geographic location of Masindi district, and thus, the findings of the study cannot be generalized. However, the study still provides considerable and necessary first-hand accounts of elderly caregivers to people living with HIV/AIDS in Masindi district, enhancing a broad understanding of the numerous dimensions and challenges of HIV/AIDS-related caregiving. This enhances the ability to lessen these challenges by improving the services provided to people living with HIV/AIDS and their caregivers, hence pursuing and maintaining an improved quality of life. However in future studies, researchers studying HIV/AIDS caregiving among elderly women in the area may want to consider employing mixed methods which will ensure increased participant representation. This will allow for much generalized findings and conclusions.

Additionally, some of the interviews were conducted in the local language, especially with the elderly caregivers. Therefore, transcription from Runyoro to English was not verbatim and this could affect the data for the study. However, the researcher used the closest equivalent words that portray the ideas of the participants.

3.15 Dissemination of Findings

The researcher aims to share the study findings with the participants individually or in a group depending on the situation. A meeting will be held to share the information and participants will be educated on what to do to improve their health and wellbeing. Also, the researcher will meet with other stakeholders such as the local district officials and various NGOs such as TASO and FBOs dealing with HIV/AIDS-related issues to inform them of the results. This will inspire the stakeholders to review and if need be, adjust their programs and also collaborate to meet the needs of the elderly caregivers. The researcher will further share the findings more broadly through presentations at the conferences and publish the findings as an academic article in journals to enable people across the globe to have access to it. Again, copies will be given to TASO and Masindi Hospital where participants were recruited. A copy will also be given to the District Local Government and other relevant offices to help them in the design and implementation of policies that will effectively address the challenges confronting elderly women caring for HIV/AIDS patients.

CHAPTER FOUR

PRESENTATION OF FINDINGS

4.1 Introduction

This chapter consists of presentation and discussion of findings from the study. Emerging themes are: demographic characteristics of participants, the caregiving roles of elderly women caring for HIV/AIDS people in Masindi district, the role reversal experienced by elderly women when caring for adult children with HIV/AIDS, the challenges elderly women face in caring for people with HIV/AIDS in Masindi district, the coping strategies adopted by elderly women in caring for people with HIV/AIDS, and the support services available for elderly women caring for people with HIV/AIDS in Masindi district.

4.2 Demographic Characteristics of Participants

| Elderly Women Caregiver's Demographic Characteristics | | | | | | |
|--|------------|---------------|---------------------|-----------|---------------|-------|
| Age | 60-74 | 75-84 | 85 and above | | | Total |
| | 12 | 4 | 2 | | | 18 |
| Education | No Edu. | Prim. | Secondary | Vocation | Nursing inst. | |
| | 6 | 10 | 0 | 1 | 1 | 18 |
| Religion | Christian | Muslim | | | | |
| | 16 | 2 | | | | 18 |
| Marital status | Married | Single | Widowed | Separated | | |
| | 7 | 3 | 4 | 4 | | 18 |
| Employment status | Unemployed | Self-employed | Retired | | | |
| | 6 | 10 | 2 | | | 18 |
| Number of children | No child | 1-5 children | 6-10 children | | | |
| | 1 | 9 | 8 | | | 18 |
| People in the household | 1-4 people | 5-10 people | More than 11 people | | | |
| | 5 | 11 | 2 | | | 18 |

| | | | | | | |
|---|-------------------------------|----------------|---|--------------|----------------------|----|
| Bread winner | Elderly caregiver | Children alone | Grandchildren alone | Spouse alone | Combined support | |
| | 7 | 4 | 1 | 1 | 5 | 18 |
| Period of caregiving | 6-8 months | 1-5 years | 6-10 years | 11-15 years | 16-20 years | |
| | 3 | 4 | 5 | 4 | 2 | 18 |
| Relationship with care recipient | Child | Grandchild | In law | Niece | Child and grandchild | |
| | 5 | 8 | 1 | 1 | 3 | 18 |
| Age of care recipients | 3-17 years | 18 and above | Both age groups | | | |
| | 7 | 9 | 2 | | | 18 |
| HIV status of elderly caregivers | HIV Positive and on treatment | HIV negative | | | | |
| | 4 | 14 | | | | 18 |
| KEY INFORMANTS | | | | | | |
| Officials from TASO | | | Nurses from Masindi Hospital | | | |
| 3 counselors – Both female 1 Counselling coordinator/social support – Male | | | 2 nurses - Both female | | | |
| Level of Education – Degree-3, Diploma-1 | | | Level of Education – Diploma-1, Certificate-1 | | | |
| Working experience - 6 to 12 years | | | Working experience - 4 to 13 years | | | |
| 4 | | | 2 | | 6 | |

The previous table illustrates the demographic characteristics of study participants. The table consists of information of participating elderly women caregivers, and key informants from TASO and Masindi Hospital, who were selected for in-depth interviews. The study involved twenty-four (24) participants. The age characteristics of participants showed that out of 18 participants who were elderly caregivers, the majority (twelve) were in the age group 60-74, four were aged 75-84 and only two were in the group aged 85 and above. Of the 18, ten participants had primary education, one had vocational training, one had training from a nursing institute, and six participants had no formal education. Regarding the religion of the participants, sixteen were Christians and two were Muslims. The marital status of participants showed that seven were married, four were widowed, and four were separated, while three had never married. On the employment status of the participants, majority (ten) indicated they were self-employed, while six indicated they were unemployed and two were retired.

Nine of the 18 participants had 1-5 children, eight had 6-10 children, and one had no child. Concerning the number of people in the household, eleven of the 18 participants indicated to be living with 5-10 people, while five had 1-4 people, and two had more than 11 people. Most of the participants (seven) noted that they were breadwinners of their households, five indicated to have combined support from various people, four indicated children, one noted grandchildren as the breadwinners, and the last participant indicated the spouse as the breadwinner.

Five of the 18 participants had provided care for a period of 6-10 years, four for 11-15 years, another four for 1-5 years, three had provided care for 6-11 months and three for 16-20 years. Eight of the caregivers were providing care for their grandchildren, five were providing care for biological children, three were providing care for both biological children and grandchildren simultaneously, one was providing care to an in law, and the last participant

provided care to a niece. Half of the caregivers (nine) provided care for persons aged 18 and above, seven provided care for persons aged 3-17 years, while two provided care for both age groups. Finally, by the time the study was conducted, only four of the elderly caregivers were HIV positive and were enrolled on antiretroviral therapy (ART), whereas the majorities (fourteen) were HIV negative.

4.3 The Caregiving Roles of Elderly Women Caring For HIV/AIDS People

The researcher's first objective identified the caregiving roles performed by elderly women when caring for HIV/AIDS people. These ranged from activities of daily living (ADL) such as bathing, eating, among others to instrumental activities of daily living (IADL) such as home maintenance, dressing changes, assistance with medication, transportation, housework, among others. The study found that the caregiving roles of the elderly women included: physical care activities, nursing/ health-related care, psychosocial care, care and support for orphaned children, and financial care.

4.3.1 Physical Care Activities

Providing physical care is one of the key roles in caring for people with terminal illness, especially when they are bedridden, too weak or too young, and hence being unable to perform those activities themselves. Participants of the study indicated that the physical care they provided involved direct care to the physical wellbeing of the sick person, and it included cooking/feeding, bathing, washing clothes, and dressing, among others as expressed in the following narratives:

As you see her weak and lying down in the bed, it is me who help her do most of the activities such as cooking for her some food, boiling for her bathing water, bathing her, washing clothes for her, and providing medication (Caregiver 3, taking care of 44-year-old daughter).

Now she is sick and what I do is to find food and cook for her, buy her drinks since she needs it to regain her strengths. I must do the washing of all her clothes and bed sheets, underwears, it is me. The worst part of it all is bathing and lifting her, after which I have to dress her like a young child, since previously she has not been able to do it herself. I have to change her sleeping position after some time because even if she got tired sleeping on one side, she could not turn on the other. It is not easy, and I can feel that my back is cracking (Caregiver 16, taking care of 40-year-old daughter).

This is what a key informant had to comment on physical care:

The other thing they do is they provide food. You know they are on drugs, which require food ... most of them are young and they cannot have that ability to look for food. So these old caretakers have to struggle to get food, so they are involved in their diet, which is key when you are living with HIV (Key informant 4, TASO).

The above quotations point to participants' assertion that caregiving roles involved providing physical care to people with HIV/AIDS.

4.3.2 Nursing/ Health-Related Care

The study found nursing/ health-related care as one of the caregiving roles performed for people with HIV/AIDS. Participants indicated assisting the ill person with seeking treatment and accompanying the care recipient to the hospital, or consulting with health professionals on their behalf, managing and treating wounds, administering medications, among others as noted in their voices below:

I also bring him to the hospital on every appointment day so that he does not miss his drugs and since he is young, I cannot leave him to move on the way

alone as something might happen to him with no one to help (Caregiver 6, taking care of 10-year-old grandchild).

... I give him his drugs daily. I put on an alarm at every 7:00 am and 7:00 pm, in that when it rings I leave whatever I am doing and give him the drugs because that is very important for his life and health (Caregiver 14, taking care of 13-year-old grandchild).

She has a very big wound which covered some parts of her back and the whole of her private parts, and all the time it could bleed or bring pus in it, I had to clean it using gloves. She could not sit but stay sleeping and crying of pain. In the hospital, I would call the nurses to come and check on her in case of any acute pain or symptoms which are not clear to me, like changes in the way of breathing. Even at night, I must monitor the drip so that when it is finished I call the nurse to come and help (Caregiver 16, taking care of 40-year-old daughter).

On nursing/ health-related care, this is what a key informant had to say in line with what the elderly women caregivers said on how they support their HIV/AIDS ill people:

These elderly caregivers, first of all, are drug companions (someone who is always available at the exposure of the client to always help them whenever they are taking their drugs). Their roles include reminding them of their time, encouraging them when they feel down and they're like no, I can't take it in anymore... In case the potential client is not able to make an appointment, still are the ones who come here to get the services (to take drugs for those clients) (Key informant 1, TASO).

4.3.3 Psychosocial Care

Some of the participants cited psychosocial care as one of the vital caregiving role performed by caregivers to people with HIV/AIDS. This involves activities like providing counseling and advice, encouragement, spending time with the ill person, among others. Participants in this regard made the following remarks:

I encourage her to take her drugs daily in order for her not to get tired or give up. I do this to give her hope and even use myself as an example since I have lived for more than 10 years just because of constantly taking my drugs as directed by doctors (Caregiver 10, taking care of 7-year-old grandchild).

... and also advising him, teaching him morals especially when he tries to misbehave and thinks that since he is 21, he can do whatever he wants. I spend time with him to make sure I have shown him the love he needs from a mother. He still needs someone to talk to and encourage him, and someone to share with his happiness and sadness (Caregiver 18, taking care of 47-year-old son and 21-year-old grandchild).

An informant attested to the fact that the elderly caregivers, among the many roles they perform, also provide the psychosocial care as noted:

They provide the care and the love. The warmth, that comfort required, which shows the sick persons that they are accepted, and therefore a first step in improving one's health (Key informant 1, TASO).

Psychosocial care elderly caregivers provided to the care recipients help to build and strengthen the psychological and social wellbeing of the people living with HIV/AIDS, which also contribute to the improvement of their health, as they feel loved and accepted by their caregivers.

4.3.4 Care and Support for Orphaned Children

The study found that the participants were also playing child-rearing roles within their extended families, where they provided for the basic needs of their orphaned grandchildren, including meeting their educational and financial needs, as indicated in the following narratives:

Another thing is that I take care of his educational needs by helping him to do homework and I have to be going to his school for meetings and sometimes just to check how he is performing (Caregiver 14, taking care of 13-year-old grandchild).

As old as you see him, his mother had never enrolled him in school, and now when I started staying with him, I took him to school and he has been promoted to primary two... So, my daily life starts early so that I get ready my grandchild, dressed, and fed for school. ... I ensure that his personal hygiene and spirituality is good (Caregiver 6, taking care of 10-year-old grandchild).

When I get some money, I buy a glass of sugar, I buy soap and other things he requires as a child (Caregiver 6, taking care of 10-year-old grandchild).

Key informants added on how elderly caregivers support their orphaned grandchildren in terms of care, finance, education among others as commented in the following voices:

...of course, taking up those other responsibilities of the young ones. Because if I am a mother and I get sick, obviously it is my parent who takes on those responsibilities of caring for grandchildren. So, the responsibilities shift to the old women. They provide the basics, even if it is buying books for these children to go to school, still it is them (Key informant 1, TASO).

And they look for money to help in providing care, in things like buying them what they want, paying for their transport to the hospital, since the patients are weak, and they cannot walk, and the distance from their homes to the hospital may be far. Now because they are old and some don't work, they try to do what they can so that they get money to look after their patients (Key informant 5, Masindi Hospital).

4.4 The Role Reversal Experienced by Elderly Women when Caring for Adult Children with HIV/AIDS

The second objective explored the role reversal experienced by elderly women when caring for adult children with HIV/AIDS. The study found that elderly women experienced a change in roles due to the overwhelming responsibility of caring for adult sick children. Participants noted that they had always wished to have a free life, enjoying provisions and care from their children in old age, which was not the case. They had to take on new roles of being full-time caregivers to their HIV/AIDS adult children, who were the breadwinners before illness. In addition, they also have to care for the children of their adult children who ended up dying from the disease. Hence, they become the main source of support for these new members in the home. Some participants recounted:

... I am also responsible for heading my household which includes planning for them and being a primary breadwinner, as it is comprised of my adult sick child and young grandchildren (Caregiver 1, taking care of 34-year-old daughter).

I now have to look for food to feed the whole of this family because we have to survive. No resting even at this age. The activities I provided to my child when

she was young I am repeating them even now that she is 44. Is it not a shame for me in the community? (Caregiver 3, taking care of 44-year-old daughter).

... Children are like a bank for us in our old age like this, where they have to provide all the support to you. So I as an 86 aged mother, when I start providing the same support I provided to her when she was still young and dependent, such as looking for her food to eat, paying for her needs, persuading and sometimes forcing her to take medicine, it is different from what I expected and this grieves my heart (Caregiver 4, taking care of 60-year-old daughter).

A key informant commented on providing full-time care responsibilities to adult sick children:

... So, the time these elderly parents would have been resting, when these roles are being carried out by their older children, they are like beginning afresh some roles they did some time back. That is what disturbs most of them. Some tell us when we go for home visits, “when I see my neighbors’ children bringing them this and that, these are washing, and those are cooking for them, I feel bad, because in my case, it is me to wash for these children, to cook for them, and so on and so forth” (Key informant 2, TASO).

With the HIV/AIDS illness of the participants’ adult children, all the dreams and expectations of good life and care from their children are not fulfilled, as they have to repeat the roles they had done earlier for their children when they were still young. Providing physical and financial support, planning, etc., is very challenging with regard to their age and deteriorating health.

4.5 Challenges Elderly Women Face in Caring for People with HIV/AIDS

The researcher's third objective looked at the challenges elderly women face in caring for people with HIV/AIDS. Participants faced various challenges from economic, emotional/psychological, social, health, nutritional, and physical, making caregiving roles a burden. These challenges caused discomfort to both the caregivers and care recipients, due to the inability of the elderly caregiver to meet the demands of care, and the care recipient's feelings of being a burden on the other side.

4.5.1 Economic Challenges

According to participants, their sources of income for caregiving were insufficient and unreliable as they were only involved in small scale farming and business. A few used their pension funds, reported to be inadequate in meeting the expenses. The participants expressed:

When they put my pension money in my bank account, I withdraw all of it and then do the shopping of foodstuffs, some fruits and juice for her, and buy paraffin. I buy small amount as the money is too small ... (Caregiver 3, taking care of 44-year-old daughter).

Where is it? Do I have money? I have told you the only thing I do is selling Pancakes (eats). If I get some money, I buy something and we eat ... (Caregiver 6, taking care of 10-year-old grandchild).

More so, almost all participants stated that, the overwhelming caregiving needs resulted into financial depletion and poverty due to increased expenditure on the care needs, without a reliable source of income. Participants' voices are summarized as:

It has drained our little finances. You see, these people are very expensive. They have to eat good food like meat, fish, vegetables, drink a lot of juice, and this boy likes eggs and milk so much ... that is why my husband went to ask for

a job in the hotel, so that he can raise more money to supplement our business of selling local brew (Caregiver 5, taking care of 6-year-old grandchild).

I have become poorer than I am already, hence no option but begin to beg. I am tired of begging for money around. You tell people ... “Tomorrow I am going to the hospital, give me some money. Only three thousand for transport”. Some will give you and others ignore you. And on reaching the hospital, she asks for bread (Caregiver 2, taking care of 12-year-old niece).

On financial depletion and poverty, key informants from TASO and Masindi Hospital added:

They (the caregivers) lack sustainable livelihoods to support them in their roles as caregivers, hence you find that most of them are living in absolute poverty and yet they have to make sure that they support these sick persons to survive. So as a result, some end up selling their resources... Some of them they don't have clothing, now it is a dry season, a “maama” (mother) will walk here bare footed, or in a shoe that is really torn, because the little she acquires is for upkeep at home, for food, and she does not think about any other thing because food is key (Key informant 1, TASO).

These elderly women caregivers are old and don't have enough money...they spend much on transport as they can't walk and the clinic is very far, so they use it for transport, they also use the money for buying some drugs which are not in the hospital and even buy food for the family. Another thing which affects them economically is that some patients take long time bed ridden, so they spend much on those who are bed ridden (Key informant 5, Masindi Hospital).

In addition to the above, some participants also expressed that due to poverty, they had an urgent need for housing and lacked sleeping materials to cater for the increased household members. Again, some indicated that due to financial challenges, their grandchildren withdrew from school as they cannot afford to cater for their education. They narrated:

... We are over 12 people living in this two-roomed house, and because of this, we have inadequate space and privacy is affected. Sometimes you need to bath and dress her up and so you have to first chase out children for you to do that. First, see the state of the house alone. It's of mud and can fall any time. It doesn't have enough ventilation (Caregiver 3, taking care of 44-year-old daughter).

We are lacking enough sleeping materials and this has affected the sleeping environment of my sick grandson. He never sleeps comfortably because the mattress is thin and torn making the sleeping place hard. The blanket he uses is also light, old and thus does not give him enough warmth ... (Caregiver 13, taking care of 13-year-old grandchild).

...I also find it hard to meet the education needs of these children. That is why the two have already dropped out of school moreover in primary six. Now it is only this sick child remaining in school, and she requires scholastic materials which I have not yet got and the term is almost beginning. Her uniform is also old and she keeps asking for the new one which we have not yet got (Caregiver 10, taking care of 7-year-old grandchild).

With regard to lack of sleeping materials and inability to cater for their grandchildren's education due to poverty, key informants from TASO commented:

Sometimes you find these elderly caregivers do not have beddings like mattresses and they are sleeping on mats, lack blankets, and it becomes a very challenging situation for them since they have no money to buy such materials where a child can sleep and feel comfortable... (Key informant 2, TASO).

They also need school fees and other scholastic materials for these children ... they need to study and build a future generation...even in the Universal primary education where there is cost sharing with the government, you find when some of these people failing the little money they pay, to buy the school uniform, books among other scholastic materials since the government does not provide them, hence children just sitting at home because of lack of such items (Key informant 1, TASO).

Also, the study gathered that there was reduction in finance due to the amount of time needed when providing care, necessitating the participants to stop their income generating activities.

They noted:

My business of selling local brew has stopped because I have to provide quality time in providing the care ... (Caregiver 5, taking care of 6-year-old grandchild).

...for two years now, I have not done any farming because of lack of time as I have to keep with my sick child when providing her care, and yet that is my main source of income for survival. This means that my finances have been cut off. (Caregiver 16, taking care of 44-year-old, daughter).

Still commenting on stopping income generating activities to provide care, a key informant noted:

These people are not so much economically productive, and they spend much time in providing care. The time they would use for income generating activities is used to provide care to the sick, and the hospitalized, and the orphans (Key informant 1, TASO).

Findings also indicated that participants experience difficulty accessing transport services to the health facilities as a result of economic challenges. Since the care recipients are so frail and cannot walk to and from the health facilities, caregivers would have to hire transport services which come with a high cost. She lamented:

I face the problem of transportation to and from the health facility because she cannot walk, we charter for transport services which we are unable to afford due to economic challenges we face. (Caregiver 1, taking care of 34-year-old daughter).

A key informant also admitted the caregiver's transport challenges in accessing the health facilities for their care recipients, as indicated below:

Transport is usually a problem to these elderly caregivers especially those who have to travel long distances to reach the health facility. Sometimes they can remember the appointment dates, but due to lack of the means to take the child to the hospital, and her inability to walk due to age, they decide to just sit home and wait until they have some money for transportation (Key informant 2, TASO).

4.5.2 Emotional/Psychological Challenges

Most participants confirmed that their caregiving role was strenuous and very demanding, causing a great deal of stress and anxiety. Also, as they witnessed the suffering and deterioration of their care recipient's health, they went through psychological pain, leading to

emotions like worries and fear, sadness, anger, and hopelessness. The following highlight their responses to this effect:

I feel hopeless about the future. This is because she has been my only source of support, the apple of my eye, and now see, who will take care of me. I feel I do not want to live more years because I see suffering in future... (Caregiver 3, taking care of 44-year-old daughter).

Because of my old age, sometimes I get fear within me that if I die, who will take up this responsibility. His parents do not want to know anything concerning him. It seems they wanted him to die. Will these aunties of his do it? I also get confused (Caregiver 13, taking care of 13-year-old grandchild).

Key informants also noted that elderly women caregivers encounter some emotional challenges:

Most of the times these people think in terms of death and think of only negative things. This brings worry to them as they think of who will take care of the orphaned grandchild in case she died. Sometimes, they also worry about the grandchildren they are taking care of, as what if they died after putting all the little resources and their efforts on them, they doubt the drugs we give the children may affect them since they are taking it every day. So psychologically, they live in fear, doubt, and worry (Key informant 2, TASO).

Psychologically, they begin losing hope, and thinking that they are disadvantaged. They begin regretting and reattributing it to so many things. Absolutely they have not been so God-fearing, perhaps they are not appeasing the ancestors, and they keep thinking that they have a debt with a creator, they ask themselves a lot of questions ... because HIV has taken a trend in that,

when you get one person infected in the family, there is a high opportunity of getting another person ... So these elderly are like, why my family? (Key informant 1, TASO).

As noted in the above responses, participants were of the view that providing care to people with terminal illness and the needs that follow cause them so much emotional difficulties.

Also, findings showed that participants encountered stress because of the long waiting hours at the health facilities, from where their care recipients received treatment, thus, the whole process being tiresome to the elderly caregivers. A participant lamented:

... Also, the long waiting hours at the hospital are disgusting, because you are already tired due to walking, and you have to sit in the lines and wait to see the doctor. You see I came here at around 9:00 am but now it is some minutes past 4:00 pm and I have just received the medicines... (Caregiver 6, taking care of 10-year-old grandchild).

To add on the long waiting time, a key informant from Masindi Hospital noted:

... And of course sometimes they themselves coming here you know, the long waiting time even stresses them up... (Key informant 6, Masindi hospital).

4.5.3 Social Challenges

From the study findings, it was noted that the social life of participants was affected as some faced stigma in case the HIV status of their ill person was disclosed. So due to fear of such negative reactions, most of the caregivers reported not disclosing the HIV status of their care recipients, especially to people outside their family. Some participants had this to say:

You know the stigma people have for HIV/AIDS; wherever I pass, people say that those ones got finished long ago (literally meaning being infected by HIV)... Those days, people even used to fool me, that, do not drink on our

cups and eat from our plates and so on. When I heard this, I started being careful not to touch their things to avoid words (Caregiver 10, taking care of 7-year-old grandchild).

The greatest challenge was letting the outside people know. I have never told them because they would have gossiped about him and also labeled my family with HIV/AIDS. They knew that my son was infected and this one's older brother also died of the same. So I didn't want them to know that this one too is suffering from the same disease (Caregiver 14, taking care of 13-year-old grandchild).

Key informants from TASO and Masindi Hospital also agreed that the caregivers' social lives are affected, due to stigma and fear of disclosure. They noted:

Because of HIV/AIDS, people begin labelling the homes of these elderly persons, they do not want to associate with them. They also begin nicknaming them. Because of their caregiving roles, the community members may even deny them opportunities to take up roles in specific areas in the community and even their opinions undermined because they have an HIV/AIDS family member (Key informant 1, TASO).

Though they are caregivers, some are stigmatized, they fear telling their fellow family members, they can't even tell outsiders, and this affects them (Key informant 5, Masindi Hospital).

As noted above, stigma surrounding HIV/AIDS made the elderly caregivers disconnected from social life and prevented them from participating in community activities.

The study also found that participants' mobility was limited, because caring for people living with HIV was a priority. Hence, opting to remain home and not involving themselves in any social activity. A participant lamented:

I want to assure you that I do not step my feet out of my home. Going to the trading center and interacting with people, visiting so and so, I don't. All I have to do is to stay with my daughter here, from day to day. You can even see her condition, leaving her alone that you are going to relax your mind does not make sense ... and if anything at all happens when you are away, it can be a big embarrassment (Caregiver 3, taking care of 44-year-old daughter).

Commenting on caregiving and how it affects the mobility of caregivers, a key informant said:

Their social life is affected because they have to provide care for these people. They will not go out to socialize with others, visit friends, fellowship at church because they are restricted at home or in the hospital ... (Key informant 1, TASO).

Participants revealed the demand for full-time care by the care recipient makes them sacrifice the social commitments that could have taken them away from home.

The study also found out that failure of the elderly caregivers to control their adolescent grandchildren was another challenge experienced by service providers, which prevented the young HIV/AIDS ill grandchildren from responding to drugs. It was noted that sometimes, they like to pamper these grandchildren so much and thus in the end, fail to command them to take their drugs:

Sometimes they are not authoritative enough to command the young child to take the drugs. In the long run, the child does not adhere well, the viral load

shoots high and even the child's health deteriorates. That is the reason why we are having high viral loads among children and adolescents who are in the care of elderly persons (Key informant 1, TASO).

When it comes to morality, they fail to control the children, those adolescents, because as they grow, they tend to show that they can look after themselves, and they neglect the advice of the caregivers. And some of the adolescents are getting spoilt in the hands of their grandparents, because they are not taking full control over them (Key informant 3, TASO).

4.5.4 Health, Nutritional, and Physical Challenges

Participants in the study face various health, nutritional, and physical challenges in their caregiving role.

4.5.4.1 Health Challenges

Some participants indicated the health impacts of providing care for people with HIV/AIDS to include lack of basic equipment such as gloves and disinfectants, which are necessary for their caregiving role. As a result, the participants admitted to being extremely afraid of contracting HIV and other opportunistic infections like TB, while taking care of their care recipients, hence living in fear of the unknown:

On the basic equipment, I will not lie to you, I do not have. They tell us to use gloves when touching wounds or blood of the people we are caring for, and yet they do not give them to us... (Caregiver 1, taking care of 34-year-old daughter).

... I do not have protective clothing like gloves to wear and disinfectants while washing things, having her stools and while bathing her ... (Caregiver 3, taking care of 44-year-old daughter).

I really know deep inside me that I am risking my life. I am also scared of getting TB since I always come near her and yet do not cover my mouth and nose when coming close to her. She sometimes coughs directly at me, and I cannot tell her to stop it, because I do not want to be embarrassing my child (Caregiver 3, taking care of 44-year-old daughter).

4.5.4.2 Nutritional Challenges

Nutritional challenges expressed by the participants in the study included food insufficiency and inability to provide balanced diet for the care recipients. This impacted their ability to comply with treatment as expected. They narrated:

... getting two meals which is lunch and supper when drugs are supposed to be taken is very hard because the piece of land is very small and like last season the harvest was very poor, hence being affected now. So, we have to buy food, very expensive since it is near town. Sometimes we only eat a snack with tea or porridge and then sleep (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

As I said, I have not done farming for these two years and this has had an implication on our feeding ... Food is not always as balanced as we are told to give her, and buying nutritious food is so expensive, that sometimes we fail... So as a result, she has lost weight and looks very weak because she is not able to eat well (Caregiver 16, taking care of 40-year-old daughter).

To complement on the same issue of caregiving and nutrition, a key informant commented:

Nutrition wise, since they spend most of the time providing care, they fail to dig and this causes food insufficiency ... Also, you find that they have at home some chicken, eggs, but now instead of eating them, they sell them off so that

they can have some money to meet other needs like transportation to health facilities, buying some drugs that are lacking in our pharmacy. These cause malnourishment of the sick child since they lack some of the nutrients or fail to be fed with a well-balanced diet (Key informant 2, TASO).

4.5.4.3 Physical Challenges

The study also found that participants faced physical challenges. They reported experiences of physical ailments, like chest and leg pains, backache, and loss of sleep. They narrated:

I get pains especially in the legs and back after I spend the whole day moving up and down, doing a whole lot of activities for both my daughter and grandchildren... (Caregiver 3, taking care of 44-year-old daughter).

Ummm, I usually have aches especially in my back, chest, and hands after doing some extensive activities, and yet I am weak ... At this age, I ought to have enough sleep and rest. Unfortunately, this does not happen in that, even at night, I have difficulty in sleeping. I keep thinking of what to do next and explore various alternatives to ease my challenges. Lack of enough sleep makes me feel tired all the time (Caregiver 16, taking care of 40-year-old daughter).

On the same note of physical ailments due to caregiving, a key informant also commented:

... These elderly women suffer from a lot of physical pains such as chest and backache, and many others in trying to ensure that the patient is fine. You see, some of these children have stunted growth that they look malnourished and look young yet they are old. So when they are weak, these grandparents have to carry them at their backs to help them in doing some activities (Key informant 2, TASO).

The strenuous physical activities performed and being stressed with the demand of providing care resulted into caregivers suffering from various physical challenges as mentioned above.

4.6 Coping Strategies Adopted by Elderly Women in Caring for People with HIV/AIDS

The fourth objective of the study ascertained the coping strategies adopted by elderly women in caring for people with HIV/AIDS. The elderly women caregivers have established both problem and emotion-focused coping strategies to cope with the challenges experienced during their long-term term caregiving roles.

4.6.1 Problem-focused coping strategies

Participants employed various problem-focused coping strategies, which included; seeking support from within the family and outside, adjustment in time, dealing with negative reactions (confrontation), and dealing with fears of infection.

4.6.1.1 Seeking support from within the family and outside

Most of the participants indicated that the practical repercussions of extensive demands resulting from providing care could not help them cope with everything on their own without the support of other people, such as the family, friends, and community. They noted:

I go begging from people who are close to me to support me. Those who are kind enough, they give me some material and financial support (Caregiver 2, taking care of 12-year-old niece).

I call my daughter and ask her to come and take over so that I may spend some time out of the home environment, see friends and even fellowship with church members. That way, I rest from the caregiving activities for a while and relax my mind (Caregiver 11, taking care of 21-year-old grandchild).

I speak to my friends and share with them what I'm going through. This gives me relief and even advise me on how to go about some issues ... I find myself overcoming the challenges I face (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

On this matter of seeking support, some of the key informants also commented:

They also keep seeking for emotional support by coming for counseling to help them cope. They keep telling us every step they are going through (Key informant 1, TASO).

... They meet their fellow elderly people in the village and they share issues, so as to be supported and others talk to relatives and friends on where there is need to be supported (Key informant 3, TASO).

Participants confirmed that seeking social, emotional, material and financial support from family and community members help them deal with their diverse caregiving challenges experienced.

It was also found from the study that when assistance expected from within and outside the family had failed, participants borrowed money and sold off their resources like land to ease their financial burden:

When all has failed, I borrow money from friends who understand the condition I am going through, and so they don't put me on much pressure to pay it back (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

... I begged from relatives and got tired, until we started selling our land, and you know if you have a challenge, you sell it at a lower price, ... some of us

also go for loans (Caregiver 18, taking care of 47-year-old son and 21-year-old grandchild).

One of the key informants expatiated on the caregivers' actions of seeking for loans:

Others go ahead to look for loans from micro finances, which money they use as capital to begin small businesses and also meet other expenses that are unexpected/unplanned for (Key informant 2, TASO).

Receiving support from within and outside the family was not guaranteed, hence, participants opting for other measures like borrowing/getting loans and selling off their resources.

4.6.1.2 Adjustment in time

Also, findings showed that providing care to a person with terminal illness consumed a lot of time, especially if they were in a critical condition or when the care recipients were young and therefore needed constant monitoring. Therefore, they had to adjust their time to deal with the overwhelming caregiving tasks required. This involved waking up early enough in a bid to effectively perform their caregiving roles. Some participants noted:

If there is a need to go somewhere, I wake up very early and do every activity, make sure she takes her morning medication, put her lunch near her bed, and then go quickly and come back as soon as possible (Caregiver 1, taking care of 34-year-old daughter).

I wake up by 5:00 am and start preparing for my grandchild to go to school, by preparing breakfast and boiling bathing water. I also cook my pancakes for sale, come back and go to farm a little for our food, and so on like that and the day ends (Caregiver 6, taking care of 10-year-old grandchild).

4.6.1.3 Dealing with negative reactions (confrontation)

The study found that some elderly caregivers adopted confrontative coping strategy as a way of dealing with the negative reactions from people due to stigma towards their care recipients with HIV/AIDS. Some of the participants recounted:

There are some people who try to stigmatize her, but I talk and correct them on how to behave well towards her (Caregiver 2, taking care of 12-year-old niece).

There are some people around who had started beating my grandchildren for no cause, whenever they went to their homes to play. ... I personally went and faced them. I warned them never to do it again if they wanted peace with us. These children they were treating that way are innocent and suffering because of what their parents brought to them. So, when I see people treating them badly I cannot keep quiet ... (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

In dealing with people's negative reactions towards their HIV/AIDS care recipients, participants faced those people directly and warned or corrected them to behave well.

4.6.1.4 Dealing with fears of infection.

From the study findings, participants had information about their low risks of contracting HIV from their caregiving role if they took the right precautions. They, therefore, tried their level best to provide care in the best way without infecting self and others. They narrated:

I am always careful when providing the care, and I keep the instructions which the nurses provide me. For example, when she gave birth, I could wash her clothes stained with blood when wearing gloves to avoid infection in case I had an open wound (Caregiver 7, taking care of 18-year-old grandchild).

I wear gloves when touching in stains or washing her wound to avoid being infected. Also, the razor blade she uses, we throw it in the toilet to avoid using it when not knowing. For TB, we got her eating equipment like folk/spoon, plate and cup, and separated them from the general plates to avoid sharing them and being infected (Caregiver 16, taking care of 40-year-old daughter).

To avoid infections, being careful by using gloves was frequently mentioned especially when dealing with bodily fluids. Also, getting separate utensils was done for care recipients who had double infections of TB and HIV/AIDS.

4.6.2 Emotion-focused coping strategies

Various mechanisms were noted to be adopted by participants under this type of strategy, and these included, acceptance of the caregiving role, positive reappraisal, spirituality, isolation, and avoidance.

4.6.2.1 Acceptance of the caregiving role

Participants indicated that although the caregiving period was difficult for them, they had willingly undertaken the role. The following responses were noted from the participants:

... I also accepted it that my child is infected, now paralyzed and it's me as a mother who has to take care of her until God decides to make her rest. Nothing to do. She is my blood so I cannot abandon her. I have to show her love, concern, and care (Caregiver 1, taking care of 34-year-old daughter).

... as time went on, I had to accept the illness as part of our daily living and decided to opt in assisting her deal effectively with the disease. I decided that I should encourage and support her to correctly and regularly take her drugs (Caregiver 4, taking care of 60-year-old daughter).

From the study findings above, participants accepted their role because they noted it is part of their responsibility as parents. Hence, wanting to do their best in helping their care recipients improve.

4.6.2.2 Positive reappraisal

Participants indicated that in order to continue providing care to their care recipients suffering from a terminal illness, they developed a positive mind towards HIV/AIDS illness in addition to hoping that the situation will change for the better. They narrated:

Firstly, I learnt to console myself by removing from my mind all the bad thoughts people may have on HIV/AIDS. I often remind myself that HIV is a disease or any other illness like cancer, heart disease, and many others. Also, I tell my self that, no matter what people say, no one will remain in the world as we are all dying of different causes (Caregiver 16, taking care of 40-year-old daughter).

I just remained silent and I did not bother about their reactions because I knew that they were still ignorant about the disease. But I keep hoping that her health will improve soon since she is on these ARVs (Caregiver 7, taking care of 18-year-old grandchild).

From the narratives, positive reappraisal helped participants become stronger to face challenges, and also strengthened their feelings towards the care recipient.

4.6.2.3 Spirituality as a coping mechanism

Some of the elderly women reported that prayer, trust in God, reading bible and other spiritual expressions enhanced them in dealing with their challenges experienced. They commented:

I trust God because he is the only one who knows why I am going through this. If he decides that she dies, I will not stop him, because God gives and God takes away (Caregiver 1, taking care of 34-year-old daughter).

I pray and trust in God. This increases my hope in God that he will make everything alright for me. At the end, I get encouraged to provide care and not give up (Caregiver 5, taking care of 6-year-old grandchild).

I usually read my bible; by especially going through the verses ... They give me hope and help me in drawing comfort from my faith (Caregiver 11, taking care of 21-year-old grandchild).

One of the key informants had this to comment on religion as a coping mechanism:

They also go to church and fellowship. They tell you that I have given up all to Jesus, which increases their faith by putting their total trust in God (Key informant 1, TASO).

Participants expressed satisfaction with the role played by their religion towards helping them cope with the caregiving challenges. They felt that their constant belief and trust in God keeps them motivated not to give up, and also gives them hope for their care recipients' improvement.

In addition, findings from the study indicate that some participants expressed their form of spirituality through consultation and seeking treatment from traditional healers. One of the participants noted that denial and thinking that the sick person was suffering from witchcraft and not HIV/AIDS, resulted into seeking treatment from traditional healers, thus delaying to take the sick person early enough to the health facility, as stated:

We took her to traditional doctors to find out what was happening, because she was saying that she has been be-witched by people who are envying her development. ... However, nothing changed on her health and we spent a lot of money buying expensive traditional medicine by then, but all did not work (Caregiver 16, taking care of 40-year-old daughter).

Some key informants from TASO and Masindi Hospital confirmed this:

Yes, some of these elderly persons think that this is witchcraft, a curse or they are paying up for something and so they choose to go to the witch/traditional doctors to find out what is happening, which calamity is befalling on them... they even end up going for African medicine, and stop bringing them for medication in hospitals, thus deteriorating their health and some end up losing their lives in such scenarios (Key informant 1, TASO).

Some of these elderly caretakers, when they see that their clients are HIV positive, they don't think of hospital first ... they will think of going to the witch doctor. ... So they continue trusting the witch doctor, not the health worker who tested... (Key informant 3, TASO).

Some went to witch doctors, thinking that they had bewitched their patients, so they go to look for treatment from those traditional healers (Key informant 5, Masindi Hospital).

In a bid to find out what calamity is befalling their sick relatives and also seeking a cure for their HIV/AIDS, some caregivers prefer going to traditional healers as the best alternative. However, some end up ignoring the hospital drugs hence affecting their care recipients' improvement.

4.6.2.4 Isolation and avoidance

Some elderly caregivers withdrew from people, by avoiding interactions and visitations so as not to let people they felt insecure of, from knowing what their care recipients were suffering from:

... I also avoid people from visiting me at home to avoid them from finding out that my daughter is in this condition, else they will start asking me a lot of questions (Caregiver 3, taking care of 44-year-old daughter).

I keep alone here at home most of the times. Where can you go or whom will you tell your problems to start gossiping about you as I already said? ... (Caregiver 10, taking care of 7-year-old grandchild).

I keep alone at my home and I avoid going to inconvenience people with my sick grandson... (Caregiver 12, taking care of 8-year-old grandchild).

Because of stigma surrounding HIV/AIDS, the elderly caregivers resorted to disassociate themselves from outside people to avoid their awareness of the care recipients' illness.

4.6.2.5 Negative emotion-focused coping strategies

The findings indicated that some caregivers opted to negative emotion coping strategies, such as attempting to commit suicide and alcoholism, which they thought would better help them in dealing with the caregiving challenges they faced. Some participants indicated that when feeling overwhelmed and stressed with their caregiving burdens, they contemplate committing suicide while others also resorted to spending the little money to buy alcohol, as narrated below:

... I keep thinking day and night on how I will manage. ... I have hated myself and the whole life, even I had decided to commit suicide in order to stop going

through all this and also rest from this suffering (Caregiver 4, taking care of 60-year-old daughter).

Sometimes when the problems are too much for me to handle, I take waragi (local brew), to at least forget what is worrying me (Caregiver 5, taking care of 6-year-old grandchild).

These comments are supported by the key informants below:

Some caregivers get overwhelmed on the bad news of their children being infected and end up committing suicide. This happened to a parent of one of our clients, who committed suicide after the daughter had disclosed to her that she was HIV positive, which was a way of getting rid of seeing her only child suffer and die before her... (Key informant 2, TASO).

Some feel like committing suicide, at least if I die and leave this world, so things like that we get them (Key informant 5, Masindi Hospital).

Of course alcohol here is a disease, so you find some people resorting to taking especially the local brew if problems are too much to handle, hoping that she will be relieved from worrying when she drinks (Key informant 3, TASO).

There are some who take alcohol, because they feel that when maybe you take alcohol, you forget what is worrying you (Key informant 5, Masindi Hospital).

4.7 Support services available for elderly caregivers caring for HIV/AIDS people

The last objective explored the support services available for elderly caregivers caring for HIV/AIDS people. Findings from the study indicated that participants were at least receiving support from two major sectors, including the informal and formal support systems.

4.7.1 Informal support systems

Under this system, the study found that participants were receiving support from their family members, friends and neighbors, and then from religious and community groups.

4.7.1.1 Support from family members

Findings indicated that majority of the participants received support from their family members, especially their other children. They also agreed that the support is not adequate but it is better than not getting anything at all. The supports are in the form of financial, material (foodstuffs, clothes), and social in terms of visitation. This is how they put it.

... My children sometimes send us money to help in various things here at home. Though it is little, it is better than nothing, because it pushes us to some level (Caregiver 3, taking care of 44-year-old daughter).

... Another one is in form of social support by visiting and staying with me to provide company. When you have people around you, loneliness and burden of providing care is reduced (Caregiver 5, taking care of 6-year-old grandchild).

From my family, especially children, I get support in terms of money, material things like foodstuffs and clothes, and then they usually call to check how our day went and of course once in a while, come and visit (Caregiver 14, taking care of 13-year-old grandchild).

On the other note, however, findings indicated that some participants lamented not receiving support from their family members:

My children do not provide me any single support. They do not even mind me. It seems I annoyed God. I asked them to come and build for me but they refused. Now I am just watching ... (Caregiver 6, taking care of 10-year-old grandchild).

... My family has not supported me in anything, and when you ask for their support they will tell you they have a lot of challenges and problems to solve. So you even get ashamed to keep asking (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

Key informants also had this to comment on lack of support by the elderly caregivers from their family members:

Some families are very poor, and don't have extended family members or many relatives, and so there is nobody to help them (Key informant 5, Masindi Hospital).

They generally have issues, some of them don't get support from the "so called children" who have brought the kids to them... (Key informant 6, Masindi hospital)

4.7.1.2 Support from friends and neighbors

Participants reported that they received support from friends and neighbors, and this was often in terms of materials such as food items, financial and social support in terms of visitation as noted:

Friends support also once in a while, for example when one is visiting, brings at least a kilogram of sugar, a loaf of bread, or leave you with money for sugar, which is also very helpful in reducing the care needs (Caregiver 7, taking care of 18-year-old grandchild)

...my neighbors are very good to me. Like that man there, he usually comforts us, you see him coming or sending children to bring us food when he has harvested. He shares with us everything he harvests. Friends have also been by my side and I run to them when I need to borrow money, or speak to them for comfort and advice when faced with a challenge. I do not know if I could have managed without them (Caregiver 15, taking care of 33-year-old daughter and 2 HIV/AIDS ill grandchildren).

From the responses, support from friends and neighbors through financial assistance and provision with food was reported to reduce the caregiving burdens of the elderly women. Visitation also was reported to strengthen their relationship as they felt still loved.

4.7.1.3 Support from religious and community groups

Some of the participants have religious and community groups that they belong to.

a. Religious groups

Few of the participants indicated that they received spiritual, material, and social support (visitation) from their churches. Also, it was noted that some churches have welfare policies for the vulnerable members of the church, although it is not specifically for the elderly, they benefit from these policies because of their membership in the church. On sharing their views on the support they got from the church, participants commented:

From the church, they give me household items like soap, salt, matchbox, and money. This is given to all vulnerable people in the church of which I am one ... (Caregiver 8, taking care of 20-year-old grandchild).

There is a church group called “Katwesengerenze” where I am a member. This is a spiritual group which moves to households of its members to pray with them, support them when they are in a problem like death, sick family member, and so on. In this group, we share testimonies and encourage our members in challenges. Unfortunately, I stopped joining them because I have to be home, though they still support me... (Caregiver 12, taking care of 8-year-old grandchild).

It could be observed that even though some participants were not active members of the church and other organized church groups, they continued to receive household items such as soap, salt, and sugar. Also, visiting them created a spirit of togetherness.

b. Community groups

From the findings, there are groups in the community which participants benefit from. They include saving groups, charity organizations, among others. Also, individual community members were said to be supporting the elderly caregivers, such as visitation and providing food items. Some of the participants indicated how these groups help them:

Community members once in a while come to check on us, how we are doing, and sometimes they bring us food items since most of us here are farmers... (Caregiver 4, taking care of 60-year-old daughter).

I am in a support group in the community known as “Twekambe”, which is for children having a disability, he is a beneficiary because he has a learning

disability. They gave us a she-goat and even come to give it treatment (Caregiver 13, taking care of 13-year-old grandchild).

I am in a group in our community known as “HEMUKA” saving group where we keep our little money and at the end of the year we get our savings plus our profits. In this group, I have been able to learn saving skills and how to use the money, and other business skills. In it, we also have a welfare bag where we can contribute to a member who is having occasion... We socially support each other (Caregiver 14, taking care of 13-year-old grandchild).

It was also noted that participants who belong to associations have emotional, economic, and social support, which help them to cope, due to connections with various people, as compared to those who do not join any association.

However, some participants indicated that they had been part of the community groups but left due to the full-time care, which was required of them, as noted below:

I was in a group, but I left last year because I saw I could not manage balancing going for meeting and providing care ... Another challenge was on the money to be depositing every week, which I failed sometimes to raise, so I quit (Caregiver 5, taking care of 6-year-old grandchild).

Being an active member in a group required payment of dues, which was challenging to some caregivers, due to lack of money for payment, and lack of time to attend the various meetings, thus, quitting the groups and not being beneficiaries anymore.

4.7.2 Formal support systems

The findings indicated that participants received services from two major organized arrangements. That is, the Non-governmental organization (TASO), and government sector.

4.7.2.1 Support from Non-Governmental Organizations

Some participants indicated that they receive support from TASO (The Aids Support Organization). Though some of the services were not directly benefiting them as caregivers, they at least assisted in reducing their caregiving burdens. Some of the intervention/support services received from TASO include: counselling services, sensitization on HIV/AIDS, support to OVCs, free treatment, material support, and home visits.

Participants noted that counselors from TASO provided counseling to them, which was seen as helpful in dealing with psychological effects of caregiving. They commented:

... And of course, providing us with counseling services for free. When the counselors come for a home visit, they will talk to you, give you advice, and also encourage you (Caregiver 7, taking care of 18-year-old grandchild).

I do receive counseling from the counselors on every visit I go. They make sure they have talked to me or I tell them what is bothering me and they advise accordingly. When I consult them of anything about the disease, they open up freely to me and explain very well to the level of my understanding (Caregiver 14, taking care of 13-year-old grandchild)

On this account, key informants from TASO emphasized the provision of counseling services to HIV/AIDS clients and their caregivers:

TASO provides counseling services to the caregivers and persons living with HIV/AIDS. We also try to build rapport with them so that they may open up when talking to them, which helps in identifying some issues that need to be attended to (Key informant 2, TASO).

... We offer them counseling services to deal with the emotional challenges they face or may face in the future (Key informant 3, TASO).

The above narrations summarized responses regarding counseling services elderly caregivers receive from TASO. Thus, they are able to cope with emotional challenges faced.

It emerged that information and education about HIV/AIDS was being received by elderly caregivers from counsellors and medical personnel. Participants mentioned that they were taught on modes of transmission and prevention, how to provide good care and nutrition as noted:

When they come, they also teach and provide us with information on what to do in order to provide her good care without us infecting ourselves (Caregiver 7, taking care of 18-year-old grandchild).

TASO educates us about HIV/AIDS, especially, about how to avoid contracting the infection. This has erased some misconceptions which I had about HIV/AIDS, thus, improving my caregiving roles (Caregiver 18, taking care of 47-year-old son and 21-year-old grandchild).

A key informant also had this to say in support of sensitization on HIV/AIDS:

We give them the information on how best they can provide care for these people living with HIV/AIDS. Because remember there is a problem of myths by these elderly people, and most of them are not educated. If we do not give them the information, they are not going to offer the best service to these people. So we give them the information both at the health facility and at home, when we conduct home visits (Key informant 1, TASO).

The above participants' narration supports the fact that information with regard to caring for HIV/AIDS people is provided to elderly caregivers both at the health facility and during home visits.

The study also gathered from interactions with participants that they receive free treatment services for their care recipients. The following voices highlight their responses to this effect:

TASO gives free medication to this child. They told us that if she gets sick, we should not buy any medicine but take her to the offices for the doctors to treat her (Caregiver 7, taking care of 18-year-old grandchild).

The free medication it provides has improved our health and they even treat other diseases which are not HIV related as long as you are their client (Caregiver 10, taking care of 7-year-old grandchild).

Key informants from TASO stated the following to show that elderly caregivers received free treatment and other medical services for their clients:

We give them free medication related to HIV/AIDS, and also treatment to any other sickness, such as malaria, cough, flu, and many others (Key informant 2, TASO).

In TASO, we provide free medication for whatever illness the client might be having, and this prevents the caregivers from incurring medical expenses on other diseases that the client might fall sick of, other than HIV/AIDS related illness (Key informant 3, TASO).

As noted in the above responses, participants received free treatment not only ARVs, but also to other illnesses of their care recipients such as coughing and malaria treatment.

The study also found that when the services required by the caregiver to her client are not available at the organization, linkages and referrals are enacted. This was to help the elderly caregivers get services for their care recipients from other service providers without many challenges, thus reducing their burden of providing care as noted:

We also refer them to other service providers as long as we see that the services one needs we cannot offer them at the center. They may include legal aid, referral to big hospitals, and other agencies (Key informant 2, TASO).

It was noted from the study findings that participants got material support in form of clothes and food to support the elderly caregivers in their role. The following responses were noted:

From TASO, we have received a lot of things ... She was being given food items and powdered milk. Even recently, she was given a 6 inched brand new mattress and a blanket and at least now she has a comfortable place to sleep on (Caregiver 11, taking care of 21-year-old grandchild).

It is also TASO that gives us cloths to wear. You see counsellors bringing us clothes from the offices (Caregiver 10, taking care of 7-year-old grandchild).

On the account of material support in form of nutritional support, a key informant indicated:

We also do carry out nutrition assessment here, and if we find out those who need to be supported, we normally give them some food. There is food supplement provided by USAID, which we normally give them, but this is only to those clients who are diagnosed and found malnourished (Key informant 3, TASO).

It was found from the study that TASO carried out home visits, which is meant to check how the clients are doing, and also monitor how the caregivers were performing their caregiving roles. Additionally, during home visits, HBHCT (Home Based HIV Counseling and Testing) services, which include voluntary testing, are extended to the caregivers and other household members, which helps them to know their HIV status and also continue to provide care without fear. Participants had this to say:

They even come and visit her at home to check on how she is doing, how she is taking her medicine, and even advise us on what to do if at all we have challenges (Caregiver 7, taking care of 18-year-old grandchild).

The counselors from TASO usually come to check how their boy (client) is doing. This encourages and motivates us to continue providing care (Caregiver 9, taking care of 10-year-old grandchild)

We do home visits. It is within our work plan to do home visit follow ups, more especially when we identify children with high viral load, and we target those families... (Key informant 3, TASO).

We extend to them our services, HBHCT. We prioritize this to our clients' homes, since there is a considerable risk in homes which have history of HIV/AIDS. ... Some of these caregivers were exposed long time ago and they have not had an opportunity to test, so they do not know their status. We therefore help them to know their status. When they are found positive, we enroll them on care (Key informant 1, TASO).

4.7.2.2 Support from the government

From the study findings, some participants are noted to receive some intervention and support services from the government. The most cited support include: free medication, sensitization, counseling services, pension/ old age benefit, and free education to their orphaned grandchildren.

With regard to accessing medication, participants noted getting free medical services from the hospital for both their HIV/AIDS sick family members and other people in the household.

However, it was also reported that the hospital services are not always the best due to lack of drugs, thus necessitating the caregivers to buy them. In their own words:

My whole household is treated at our government hospital and everything is free, though sometimes their services are not all that good, but nothing to do since we can't afford going to the private hospitals (Caregiver 4, taking care of 60-year-old daughter).

We get free treatment and free ARVs from the government hospital where she gets her ART from. However, when some other drugs are missing such as for appetite, blood, and so on, we are required to buy them, which is a little bit expensive (Caregiver 17, taking care of 30-year-old sister in law).

It was also found that elderly women were given information on HIV/AIDS and care whenever they visited the hospital. They also reported receiving counseling services from the nurses. These helped them deal with their emotional challenges in addition to knowing what to do when providing care for their care recipients:

The nurses also try their best to provide us with information, if you visit them. Also, they can give you more tips on how to best care for your sick person (Caregiver 17, taking care of 30-year-old sister in law).

When we come to the hospital, the nurses provide us with counseling and this helps so much. ... Sometimes you come with a lot of things running on your mind (Caregiver 1, taking care of 34-year-old daughter).

Key informants confirmed:

For us, our side is to give them the information ... We do our best to provide it to them on radio stations, those who come with their clients here we tell them the importance of nutrition, the importance of adherence ... Ours is just giving

the care, giving the information, do this, do that ... (Key informant 6, Masindi Hospital).

Usually we mostly give them on-going counseling, because if you don't continue counseling them, they forget, even they can't fulfill their duties properly. You see, sometimes when you are counseling them they are absent minded, and so you have to keep on reminding them (Key informant 5, Masindi Hospital)

From the study, findings indicated that only two participants were benefiting from the government's pension scheme due to retirement. This money was used to meet the cost of some basic needs in their caregiving role, thus depending less on their family for support than those who are not on pension. Participants noted:

I do get my retirement benefit every month though it is small to meet the increasing needs I have at hand ... It is very helpful in meeting the needs required in providing care such as medication, transportation, buying food for the house hold, among others (Caregiver 3, taking care of 44-year-old daughter).

I do receive my pension from the government. With that at least I am able to meet some of the basic needs (Caregiver 17, taking care of 30-year-old sister in law).

However, most of the participants expressed helplessness as they had been in the informal sector, thus never receiving any pension. Also, they expressed concern about their inability to receive any other form of benefit from the governments, as lamented:

I have never received any thing from the government. ... Even I have never heard our local leaders telling us of any services available for us (Caregiver 11, taking care of 21-year-old grandchild).

Furthermore, findings indicated that participants received free education services for their orphaned grandchildren, which reduced their economic burden of paying school fees for these young ones. However, it was noted that the elderly caregivers had to meet some costs such as examination fee, and also provide all the required scholastic materials. They narrated:

... The government provides us with free education for our grandchildren. ... So we as the elderly poor people are saved from straining ourselves with looking for school fees (Caregiver 5, taking care of 6-year-old grandchild).

Even though we are told the education is free, we are being asked money for exams, or this and that and sometimes if you are having more than five grandchildren you suffer because the money goes high. ... Still, we have to buy uniforms, books, and other things needed at school as you know them. And once the children are not having them, they are chased from school, hence missing the classes (Caregiver 13, taking care of 13-year-old grandchild).

From the findings, some participants noted that the intervention and support services in place were not efficient for optimal caregiving roles, as enough had not been done to support the elderly caregivers and their care recipients as summarized by a participant:

The support we receive is not enough to efficiently sustain us in undertaking this important task of caregiving. This leaves us in a situation where our personal needs are neglected, and that is why sometimes an elderly caregiver can end up dying before the care recipient due to stress (Caregiver 16, taking care of 40-year-old daughter).

Key informants also supported that the intervention and support services in place were not efficient for the elderly caregivers' optimal caregiving roles. They commented:

No, it is not enough because the support they receive is so meager and sometimes we don't reach everyone. Then, sometimes, due to our workload, we don't get time to talk to these people. We the counselors, we can even spend a year without sharing information with the caregivers, and to check how they are managing with their caregiving role. By the time we realize, their health is deteriorating, due to much stress. (Key informant 4, TASO).

We live in a limited resource setting where we can't give it all and thus prioritize the clients since most of our support comes from donors ... We are given targets prioritizing a given activity, and you end up compromising some activities. And also the number is very overwhelming, that we may not reach out to everyone or all the homes because the burden of HIV has almost hit every home. So we look out for those who may be more vulnerable than others due to limited resources (Key informant 1, TASO).

They are given some basic materials like books and school fees for their school going children. However, this support has got a limited coverage as anyone who is outside the central division does not benefit (Key informant 6, Masindi Hospital).

However, findings also showed that the intervention and support services received from both TASO (NGO) and Masindi Hospital (Government), helped to alleviate some of the challenges caregivers face in performing their caregiving roles. Some participants expressed a feeling of satisfaction of their caregiving roles as a result of seeing the health of their care recipients improve due to treatment received from service providers. These contributed to the caregivers' experiences of the positive impacts of caregiving amidst challenges:

I feel satisfied that I have taken care of my daughter instead of her dying alone somewhere abandoned without treatment and care. I see a very big change in improvement from the way she was before starting these ARVs (Caregiver 3, taking care of 44-year-old daughter).

I am happy with how the boy is coping with the drugs ... Nowadays, he never gets sick as he used to be before starting ARVs. Before, he used to have wounds, malaria, cough, weight loss, and so on but they all disappeared ... You can also see how he looks like. You can't tell that he is infected with the disease (Caregiver 13, taking care of 13-year-old grandchild).

4.8 DISCUSSION OF FINDINGS

The study found that participants performed numerous roles when caring for people living with HIV/AIDS. These ranged from physical activities (cooking/feeding, bathing, washing clothes), nursing/health-related care roles (accompanying clients to the hospital, administering medications etc.) and psychosocial care roles (counseling, advice, encouraging, and spending time with the ill persons). These findings support those by Chepngeno-Langat et al. (2010); Evans and Thomas (2009); Kosse (2012) and Nygard (2003), which showed similar roles being performed by caregivers for HIV/AIDS infected people.

Also, from the current study, after the death of their care recipients, elderly caregivers were noted to care for the orphaned grandchildren, which came with a financial obligation. They had to provide for their basic needs including education, by enrolling them in school, providing the scholastic materials and helping them do their homework. Due to this role, the elderly caregivers are forced to wake up early to prepare their grandchildren for school and administer drugs to them. This supports a study by Nhongo (2004) that older people play a

key role in bringing up children, the world's future capital, where they provide physical, economic, and social support. Furthermore, it agrees with Hawkins (2013) that caregivers' daily lives started early to get ready their grandchildren dressed, fed for school, and given medication.

Present findings on the caregiving roles of elderly women relate to caregiver identity theory by Montgomery, Rowe, and Koloski (2007) that over time, as the needs of the care recipient increase in quantity and intensity, caregivers change their behaviors, and how they see their role in relation to the care recipient, due to care tasks required. In the current study, the more HIV/AIDS people became frail as the disease advanced from one phase to another, the more difficult the caregiving role and the more challenging the care recipient's needs also became, especially when they were resource constrained. Therefore, it is the intensity and frequency of the caregiving activities performed by the elderly parents towards their HIV/AIDS people that altered the initial mother-child relationship into a caregiving relationship.

Findings further established that elderly women experienced role reversal when caring for adult children with HIV/AIDS. Role reversal as noted by participants occurred because they had always wished to have a free life, enjoying provisions and care from their children in old age, which was not the case. The findings indicate that the elderly caregivers have now taken on full-time care responsibilities to their adult sick children. Thus, repeating the roles they had earlier on performed for their children when they were still young; such as providing the physical and financial care, material support, among others. This agrees with studies by Nhongo (2004); Saengtienchai and Knodel (2001); Williams and Tumwekwase (2001) that, parents' investment in the health, education, and well-being of their children often were based on the expectation that children will care for them in their old age. It is also in agreement with studies by Munthre and Maharaj (2010); Nala- preukeser (2014) and Kosse

(2012) that, due to the AIDS epidemic, parents are forced to assume the responsibility of providing full support and care for their adult children with HIV/AIDS, where the elderly often provides economic, psychological and social support.

Additionally, it was found that participants became the main source of support and breadwinners to the new members in the home. This was because the adult children who were responsible for providing for the family were now sick and bed-ridden, hence the elderly women taking up the responsibility. This is in line with Kimuna and Makiwane (2007) who indicate that nearly 76% of the participants were the sole breadwinners in the households that included more than one generation. The study further supports Iwelunmor and Airhihenbuwa (2012) who observed that sickness, death, and loss from HIV/AIDS altered the position of many elderly especially women, by assuming the role of breadwinners, a role traditionally held by men. The present findings on role reversal experienced by elderly women when caring for their adult children with HIV/AIDS conform to the caregiver identity theory by Montgomery et al. (2007) that, like many other social actions, caregiving is governed by norms or social values, ethnic and cultural background, which influences one's expectations on the caregiving responsibility. In the current study, the elderly caregivers' perceptions of the existence of role reversal depended on the dilemma of the cultural expectations of children towards their older parents. It also depended upon the activities that were performed in their caregiving responsibility towards their adult sick children, who required assistance in all areas of life.

The current study also found that due to insufficient and unreliable sources of income for caregiving, and increased expenditure on care needs, participants experienced economic challenges. These included financial depletion and poverty, inability to meet the education needs of their grandchildren, thus withdrawing from school and stopping to participate in

their income generating activities due to much time spent in caregiving. Also, the elderly caregivers experienced transport challenges to the health facilities as the distance was long, hence their inability to observe regular clinic appointments. These findings are similar to studies by Fauk et al. (2017); Knodel et al. (2003) and Ssengozi (2007) in Tanzania, Thailand, and Uganda respectively, which observed challenges such as financial depletion, poverty, increased transport expenses, inability to meet the education needs of grandchildren, among others. Another economic challenge demonstrated in this study is the inability of the participants to provide good caregiving environment, due to poor housing and lack of sleeping materials to cater for the increased household members. The finding confirms Nalapeukeser's (2014) study in South Africa, which indicated that almost all participants were living in informal settlements, with their houses dilapidated, untidy and overcrowded.

Further evidence in the study indicated the emotional/psychological challenges of caregiving, which caused a great deal of stress and anxiety, psychological pain and emotions (worries and fear, sadness, anger and sense of hopelessness). This resulted from witnessing the suffering and deterioration of their care recipient's health, and the strenuous and very demanding care activities. Additionally, the caregivers' stress resulted from long waiting hours at the health facilities where their care recipients received treatment from. This involved waiting for their care recipients' files and medication, thus the whole process being tiresome to the elderly caregivers. The emotional/psychological effects of caregiving reported by this study have been identified in previous studies as resulting from the enormous burden of care placed on the elderly caregivers and long waiting periods at the health facility (Boon et al., 2010; Jones, 2012; Lekalakala-Mokgele, 2011; Munthre & Maharaj, 2010).

Socially, the study found that participants were affected due to the stigma surrounding HIV/AIDS. Also, the elderly caregivers experienced limited mobility, thus being

disconnected from social life and participation in community activities. The finding is in line with a study by Knodel et al. (2003) that negative community reactions in terms of social stigma like avoidance and gossip toward the parents and other family members affected the social wellbeing of the elderly caregivers. Also, it agrees with Ssenkozi's (2007) study that elderly persons faced limited mobility and withdrew from social functions like parties, weddings, religious meetings, and missed interactions with colleagues.

Other challenges the current study established were health, nutritional and physical challenges. Healthwise, caregivers lacked the basic equipment required for caregiving like gloves and disinfectants, lack of which would lead to infection and fear of infection since some care recipients had a double infection of HIV/AIDS and TB. Therefore, as these elderly caregivers already have weak immune system due to their age, they are prone to easily contracting these infections. On nutrition, participants reported food insufficiency and inability to provide a balanced diet for their care recipients. It was indicated that it is sometimes hard to provide the sick people with all the three meals, hence, failing to comply with treatment as expected. Also, they reported physical ailments, like chest and leg pain, backache, loss of sleep etc., resulting from strenuous physical activities performed and stress with the demand of providing care. Similar findings on health, physical and nutritional challenges elderly caregivers experience have been reported in previous studies (Amoateng et al., 2015; Munthre & Maharaj, 2010; Nala-Preusker, 2014).

Findings of challenges faced by elderly caregivers are consistent with phase 4 of the caregiver identity theory by Montgomery et al. (2007) which is regarded as a more intense phase that requires more time from the caregiver, as the care recipient needs constant and very intensive care. Some elderly caregivers in the study had HIV/AIDS sick patients at the bed-ridden stage, which required a lot of care and assistance. Most caregiving tasks like

washing, bathing, making hospital visits, etc. were very strenuous for the already frail elderly caregivers, thus increasing their physical ailments, stress, and expenditure.

Coping strategies adopted by the elderly women caregivers in this study included both problem-solving and emotion-focused coping strategies. Problem-solving coping strategies included seeking support from within the family and outside, adjustment in time, dealing with negative reactions (confrontation), and dealing with fears of infection by using gloves when touching bodily fluids. Emotion-focused coping strategies adopted included acceptance of the caregiving role, positive reappraisal, isolation, avoidance, and spirituality (trusting and praying to God and going to the traditional healers and witch doctors to seek for healing and also find out the calamity befalling their care recipients). On the contrary, participants indicated that some elderly caregivers adopted negative emotion-focused coping strategies such as alcoholism, and attempting to commit suicide, which they thought would better help them in dealing with the caregiving challenges they faced. The findings agree with Amoateng et al. (2015); Nala-Preusker (2014) and Nankwanga et al. (2009) who noted the same coping strategies being adopted by elderly caregivers to deal with various challenges. Findings also confirm studies by Ntozi (1995) and Ssengonzi (2007), both conducted in Uganda that, caregivers sought treatment from traditional healers with a view of receiving treatment for their HIV/AIDS sick people. Also, the negative emotion-focused coping strategy of alcoholism observed in the current study, is noted to be similar to other studies by Kasiram and Hölscher (2015) and Nala-Preusker (2014), both conducted in South Africa, which found that some caregivers resorted to drug use, such as taking alcohol to forget their challenges.

These findings above on the coping strategies relate to the coping theory by Lazarus and Folkman (1984) that coping strategies can be based on problem-focused coping (e.g. confrontative, seeking social support, and plan full problem-solving) and emotion-focused

coping (e.g. self-control, distancing, positive appraisal, accepting responsibility, and avoidance). Thus, elderly women caregivers in this study adopted various coping strategies which they felt were informed by their individual evaluations of the challenges faced.

Concerning the support services, it is evident from the study that, elderly caregivers for PLWHA receive support from various sources, which are both formal and informal. Participants are noted to receive financial, material, social and emotional support from an informal system which includes family members, friends, neighbors, religious and community groups. The current finding supports those by Amoateng et al. (2015); Hutchison (2011); Maradik Harris and Kim (2014) which showed similar sources of support for the elderly caregivers. However, it is also clear from the study that the family system is not as effective as it used to be in supporting its members. Hence, some participants were really finding it hard to meet their needs, especially those neglected by their children and family due to financial issues. In this situation, participants resorted to borrowing money and selling their resources like land to ease their financial burden. These strategies are unsustainable as they provide temporary relief, leaving households in permanent effects of the cycle of poverty. This is consistent with a study by Oduro (2012) that children are not able to provide support to their elderly parents due to financial inadequacy. Similarly, it also corroborates others by Faulk et al. (2017); Knodel and Im-Em, (2004); Maradik Harris and Kim (2014) that selling of family assets and borrowing money were used to solve the problem of insufficient money.

The study found that participants received support from two major formal support systems (TASO which is an NGO and the Government). When it comes to the support from TASO, the study found that various services were received such as counseling, sensitization on HIV/AIDS, free treatment, linkages and referrals and home visits. This confirms a study by

Ntozi and Nakayiwa, (1999) in Uganda that NGOs such as TASO, foreign NGOs and religious missions give support by providing services like counseling and treatment in a culturally appropriate manner. Also, the finding supports a study by Hodge and Rohy (2010) in Uganda, where participants noted receiving counseling, food, and medicine from TASO.

From the government, it was evident from the study that elderly caregivers received support in form of free medication and education to grandchildren, pension, sensitization and counseling services. Similar findings have been reported by Knodel and Saengtienchai (2005) in their study conducted in Thailand. Furthermore, participants indicated that even though the education system was free for their grandchildren, they had to pay some fee requirements and also meet scholastic materials, which was hard, thus withdrawing their grandchildren from school. This confirms a study by Kakooza and Kimuna (2006) that the government of Uganda through the Ministry of Education does not provide other kinds of fees required like development fund, equipment fees, school uniforms, and books. Again, the authors emphasize that the main reason for children not being enrolled in schools was the elderly caregivers' inability to afford such items, without which children were not accepted in school. Also, even though medication for clients was free, the elderly caregivers reported lack of drugs in the hospital thus buying them expensively.

The findings above on the support services available for caregivers of PLWHA agree with the Coping Theory by Lazarus and Folkman (1984), who noted that seeking social support is helpful for individuals to cope with the problems they face. In this case, elderly women caring for people living with HIV/AIDS in Masindi District utilized both formal and informal support services in place to help them in meeting their care needs. These included depending on the government, NGOs (TASO) and family members.

When it comes to welfare programs and policies, participants indicated that there is no welfare program put in place specifically for elderly caregivers for PLWHA. This finding is in relation to a study by Osafo et al. (2017) in Uganda that, there is no social protection policy for Home-based caregivers in Uganda. The authors also emphasize that the piloting of the Senior Citizens Grants (SCG) in six districts can be targeted to include senior citizens who are engaged in home-based care for children living with HIV/AIDS. Yet it is interesting to know that only two of the participants benefit from the government pension because most of them work in the informal sector. This made the caregiving role burdensome for the elderly caregivers in the district as the majorities were not on pension scheme and at the same time not beneficiaries of the Senior Citizens Grants (SCG). The finding also supports Shofoyeke and Amosun's (2014) study in Nigeria that government and policy leaders have not paid attention to the elderly because they believe that provision for the care of the elderly had always been a responsibility of the family.

Nonetheless, both government and NGOs still play key roles in the lives of elderly caregivers when it comes to supporting in their own ways, as participants reported positive experiences like satisfaction due to their care recipients' improvement resulting from the services received from both agencies. This finding corroborates a study by Bejane (2012) where service providers were seen as lifesavers due to the improvement of the care recipients. Furthermore, despite the appreciation of the health services received from both the government and NGOs, participants noted that enough had not been done to equip them with the necessary information and basic materials required for optimal caregiving. This finding supports a study by Jones (2012) in South Africa, where participants were dissatisfied with the services received when visiting the hospital.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In this chapter, the researcher presents a summary of the major findings, and draws conclusions accordingly. Some recommendations are made as to how elderly women caregivers to PLWHA in Masindi district and Uganda in general can be supported. The chapter ends by specifying what social workers can do to help elderly women caring for people living with HIV/AIDS based on the study findings.

5.2 Summary of findings

The study sought to find out the caregiving roles elderly women perform, the role reversal experienced when caring for adult children with HIV/AIDS, challenges faced, coping strategies adopted and the support services available for them.

With regard to the caregiving roles, the study found that elderly women caring for people with HIV/AIDS in Masindi district performed numerous roles, ranging from physical activities, nursing/ health-related care roles, psychosocial care roles, support for orphaned children and financial care.

The findings also revealed that the elderly women experienced role reversal when caring for adult children with HIV/AIDS. The only investment some of them made had to do with their children's education, with the expectation of these children supporting and caring for them in their old age. Unfortunately, some elderly women noted that this was different from the situation they found themselves, since they provide full time care for their totally dependent

HIV/AIDS adult children, where they repeat the roles they had earlier on performed, when these care recipients were young children.

It was further found that the challenges elderly women face when caring for people with HIV/AIDS in Masindi district were economic, emotional/psychological, social, health, nutritional and physical. Again, it was found that elderly caregivers faced challenges of poor housing, lack of beddings, and withdrawing their grandchildren from school as a result of not being able to provide for their scholastic materials and other school needs. In addition, the study found that the elderly women caregivers adopted both problem-focused coping strategies (seeking support, adjustment in time etc.) and emotion-focused coping strategies (acceptance of the caregiving role, Positive appraisal etc.) in dealing with the challenges faced. However, some employed negative emotion-focused coping strategies, such as alcoholism, and attempting to commit suicide.

It was revealed that from the informal support system, elderly women caregivers received support from family members, friends, neighbors, religious and community groups. The elderly caregivers receive financial, material, and social support from their family members, though this family support was stated not to be as consistent and sufficient as it used to be. On the other note, support received from friends, neighbors, religious and community groups was in the form of material (food items), financial and social support (visitation), and spiritual. Additionally, the elderly caregivers received formal support from TASO and the government. The services included counseling, sensitization on HIV/AIDS, support to OVCs, free treatment, material support, home visits, and educational support for grandchildren, free medication, pension, and counseling services.

5.3 Conclusions

From the findings of study and discussion, the researcher concludes that the situation of elderly women caring for people with HIV/AIDS in Masindi District is worrisome. This makes it a social problem that needs to be solved like any other social issue in the district and the country at large. The findings have made it clear that despite the elderly women being weak with deteriorating health due to aging, they perform a wide range of roles when caring for their people with HIV/AIDS, including adult children and orphaned grandchildren. The intensity of these roles depend on the phase of illness; this is to say, the more imminent the terminal stage, the more intense the workload and the higher the level of stress. Hence, the elderly persons start viewing themselves as caregivers. This testifies the caregiver identity theory by Montgomery, Rowe, and Koloski (2007) that, as the needs of the care recipient increase in quantity and intensity over time, more care tasks are required, thus making caregivers change their behaviors and how they see their role in relation to the care recipient.

As shown by the findings of the study, elderly women caregivers experience role reversal when caring for their totally dependent adult children with HIV/AIDS. This is because they are forced to provide full-time care and also repeat some of the roles they had earlier done for these adult sick children when they were young. This situation makes the life of elderly parents miserable, as the adult children who are meant to serve as an economic security and also care for them in their old age are very weak and cannot support. This conclusion undergirds the caregiver identity theory that, like many other social actions, caregiving is governed by norms or social values, ethnic and cultural background, which influences one's expectations on the caregiving responsibility.

Furthermore, conclusions are drawn from the study that, elderly women caring for people with HIV/AIDS encounter some challenges in their attempt to perform their caregiving roles. These challenges adversely affect not only their lives but also the lives of their care

recipients. Thus, their caregiving role is made burdensome, and ineffective, due to their frailty, the overwhelming care needs, and the inability to meet them. However, the elderly caregivers are able to cope with these challenges by adopting both problem- focused (seeking support, adjustment in time, confrontation, etc.) and emotion-focused (acceptance of the caregiving role, positive reappraisal, avoidance etc.) coping strategies. These coping strategies are the same as those explained by Lazarus and Folkman's (1984) coping theory. On the other note, some elderly caregivers opted for negative emotion-focused coping strategies such as taking alcohol and contemplating to commit suicide.

Although elderly caregivers for people with HIV/AIDS receive some form of support services from the informal support system (family members, friends, neighbors, religious and community groups) and formal support system (TASO and government), this support is not consistent and efficient for optimal caregiving. Therefore, more needs to be done by making both the informal and formal support systems fully available for elderly caregivers so as to help in meeting their care needs.

5.4 Recommendations

From the findings of the study, majority of the elderly women indicated that there was no welfare program in place, specifically for elderly caregivers of PLWHA in Uganda, hence making caregiving burdensome, since they go through a lot of challenges when providing care for their HIV/AIDS infected and affected family members. Also, at the time the study was conducted, it was realized that Uganda had introduced a welfare program for elderly persons known as the Senior Citizens Grants (SCG), which was still effected in only few targeted districts and Masindi was not among them. In addition, this program does not include elderly persons engaged in home-based care for people living with HIV/AIDS. Based on this, the researcher recommends that the government of Uganda expand the Senior

Citizens Grants (SCG) to include elderly women caregivers engaged in home-based care, or design a new policy that targets elderly caregivers of people infected and affected with HIV/AIDS.

In addition, it was found that majority of the participants worked in the informal sector, thus not beneficiaries of the pension scheme, and so had no reliable income generating activities to help generate funds required in their caregiving role. The researcher therefore recommends that the government of Uganda can have a budget allocation to support elderly caregivers or a policy that gives elderly caregivers of PLWHA financial assistance through direct transfer of money every month, to help in their caregiving role. Also, the government, both at the central and local level, and various NGOs need to include elderly caregivers in policy development and program planning, on issues affecting them, to ensure that the policies/programs are working to meet their caregiving needs.

The study revealed that elderly caregivers have poor housing, lack beddings, and food for their care recipients, among others. Therefore, the Ministry of Gender, Labour and Social Affairs that deals with the elderly, together with other agencies and donors should focus on direct intervention and support services by providing physical and material support like food, housing projects, and beddings, to help elderly caregivers in a resource limited setting within their homes.

On health issues, the caregivers in the current study reported that they sometimes felt physically and emotionally drained by their work. Death of their care recipients was an especially difficult part of the caregiving; witnessing suffering and dying, influenced the emotional toll of caring and had a negative effect on the caregivers' well-being. The health implications include distress, being frustrated, stigmatized, demoralized, witnessing a patient with an incurable disease deteriorate over a long period of time could surely affect health.

Participants were also clear about lack of adequate support from the government, the NGOs, and family members, which also put a drain on them. Though participants indicated that they assist their care recipients to seek treatment and accompany them to the hospital, consult with health professionals on their behalf, administer medications, there is still the need for the government to provide these care givers basic training that covers the necessary aspects of HIV/AIDS care and support, as well as education on how to care for themselves, and support for their health care needs.

Participants in the study expressed their concern about education for grandchildren with HIV/AIDS in their care, since they were unable to meet the school requirements, such as uniforms, books, among others; thus, withdrawing their grandchildren from school. The researcher thus recommends that the Ministry of Education should provide or exempt orphaned children due to HIV/AIDS from such requirements, so as to help build an educated future human resource base for the country, by maintaining such children in school, and providing for their needs. This will relieve the elderly caregivers from the stress of meeting the educational needs and the pain of seeing their grandchildren drop out of school.

More so, elderly women caregivers should be sensitized and empowered continuously with information about HIV/AIDS to help deal with the myths about HIV/AIDS and also prevent infecting themselves and others when providing care. Various education sessions can be put in place by service providers to cater for elderly caregivers who come late at the health facilities. Furthermore, with regard to some elderly caregivers taking care of care recipients with double infections of HIV/AIDS and TB, thus fearing infection, the researcher recommends that HIV/AIDS service providers both government and NGOs should also target on testing these elderly caregivers, so as to enable them to know their status and also start treatment in time in case they are found to be infected.

It was found that the government hospital does not make home visits to their HIV/AIDS clients, to monitor how they are managing with the disease. Also, drugs were noted to lack sometimes at the facility, hence the elderly caregivers buying them costly from the pharmacies. The study recommends that there should be improvement in health care services by the Ministry of Health in collaboration with other service providers both national and internal NGOs to promote community based health care, coupled with home visits to ensure follow up on HIV/AIDS people under the care of elderly caregivers within different communities. Additionally, there should be stocking of enough drugs in the hospital, in order to avoid expenses of the already poor elderly caregivers.

Furthermore, the government and NGOs should assist in the establishment of community support networks in various communities that will target elderly caregivers of PLWHA, by providing them assistance in all areas of life, such as social, physical, emotional, material, financial and spiritual. Additionally, in order to ensure that psychosocial support is effectively provided to the elderly caregivers, the government and NGOs need to assess, strengthen and reduce insufficient numbers of trained health care personnel. Hence, there is a need to train adequate personnel such as social workers, counselors, psychologists, and psychiatrists who can provide sophisticated psychological care to the elderly caregivers. This will improve and sustain the mental health and supportive services available. Also, it would help the elderly caregivers to cope more effectively with the caregiving challenges, thus, enhancing their quality of life due to reduced psychological and emotional burden.

Also, the study targeted only elderly women caregivers, thus lacking male's perspectives on lived experience as caregivers to persons with HIV/AIDS. Therefore, future researchers can include male caregivers to share their experiences since men also participate both in the

informal caregiving. This will help improve the caregiving roles of elderly persons to PLWHA.

5.5 Implication for social work practice

As educators, social workers can assist in educating and sensitizing families and communities on the role of elderly women in providing care to persons infected with HIV/AIDS, the challenges they go through and the support they need so as to ease their caregiving burden. Still, due myths and stigma on people with HIV/AIDS and their caregivers, medical social workers could embark on collaborating with health facilities in making community awareness creation on issues of HIV/AIDS, such as mode of transmission, prevention, and care.

Given that there are no specific policies and programs targeting elderly persons engaged in home-based care for people living with HIV/AIDS, social workers could advocate for change in the existing policies and programs and formulation of new policies that would focus on elderly caregivers to persons living with HIV/AIDS.

The study indicated further that some caregivers opt to use negative emotion-coping strategies to cope with their challenges and lack of support from family members and the community as a whole. Ecological perspective on interventions explores the merging of family, community, and institutional factors in human behavior. It posits that stress can be reduced by restoring support offered within “social ecologies” created by the interaction of the familial, cultural, communal, spiritual, and socioeconomic factors that surround and influence individuals (Wilder, 2010). Such relationship building and support is particularly critical for the health and wellbeing of care givers of HIV/AIDS patients. Social workers can help in building a support group of care givers to assist group members tap into their strengths, which may foster conversations, and will ultimately help the group find solutions to their challenges. Social workers can also help the care givers build caregiving skills by

providing them the opportunity to discuss the stressors in their lives, encourage them to share their best practices in caring, and offer them some tools they can use in the mentoring group, as well as with their care recipients. Psychosocial care from social workers could include activities like providing individual/group counseling and advice, spending time with the ill person, linking them to organisations that seek to improve the well being of HIV/AIDS recipients. Last but not the least, social workers could involve both care givers and care recipients in creational activities, and identify ways to combat stigma and discrimination associated with HIV/AIDS.

REFERENCES

- Ainsworth, M., & Dayton, J. (2003). The impact of the AIDS epidemic on the health of older persons in northwestern Tanzania. *World Development*, 31(1), 131–148.
- Akintola, O. (2006). Gendered home-based care in South Africa: More Trouble for the Troubled. *African Journal of AIDS Research*, 5(3),237-247.
- Amoateng, A. Y., Kalule-Sabiti, I., & Oladipo, S. E. (2015). Psycho-social experiences and coping among caregivers of people living with HIV/AIDS in the North-West province of South Africa. *South African Journal of Psychology*, 45(1), 130-139.
- Apt, N. A. (1996). *Coping with old age in a changing Africa: Social change and the elderly Ghanaian*: Avebury Aldershot.
- Ayernor, P.K. (2012). *Diseases of ageing in Ghana*. *Ghana Medical Journal*, 46 (2), 18-22
- Beales, S. (2000). Why we should invest in older women and men: the experience of HelpAge International. *Gender & Development*, 8(2), 9-18.
- Bejane, S. M. (2012). *Experiences of primary caregivers caring for children living with human immunodeficiency virus attending the wellness clinic at Jubilee Hospital Hammanskraal* (Unpublished Master's Thesis, University of Limpopo, Medunsa Campus, South Africa).
- Bejane, S., Van Aswegen, E., & Havenga, Y. (2013). Primary caregivers' challenges related to caring for children living with HIV in a semi-rural area in South Africa. *Africa Journal of Nursing and Midwifery*, 15(1), 68-80.
- Birkeland, A., & Natvig, G. K. (2009). Coping with ageing and failing health: a qualitative study among elderly living alone. *International Journal of Nursing practice*, 15(4), 257-264.
- Boon, H., Ruiter, R. A., James, S., van den Borne, B., Williams, E., & Reddy, P. (2010). Correlates of grief among older adults caring for children and grandchildren as a

- consequence of HIV and AIDS in South Africa. *Journal of Aging and Health*, 22(1), 48-67.
- Borchert, M., Mutyaba, I., Van Kerkhove, M. D., Lutwama, J., Luwaga, H., Bisoborwa, G., . . . Roddy, P. (2011). Ebola haemorrhagic fever outbreak in Masindi District, Uganda: outbreak description and lessons learned. *BMC infectious diseases*, 11(1), 357.
- Brannen, C., & Petite, K. (2008). An alternative framework for understanding women's caregiving stress: A qualitative application of the ways of coping model. *Journal of Health Psychology*, 13(3), 355–365.
- Brown, M.-A., & Stetz, K. (1999). The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qualitative health research*, 9(2), 182-197.
- Burdge, R. J., & Vanclay, F. (1996). Social impact assessment: a contribution to the state of the art series. *Impact Assessment*, 14(1), 59-86.
- Chandran, V., Madi, D., Chowta, N., Ramapuram, J., Bhaskaran, U., Achappa, B., & Jose, H. (2016). Caregiver burden among adults caring for people living with HIV/AIDS (PLWHA) in southern India. *Journal of clinical and diagnostic research: JCDR*, 10(5), OC41.
- Chepngeno-Langat, G. (2008). *HIV/AIDS and Older People: A case of Nairobi City Slums, Kenya* (Unpublished Doctoral dissertation, University of Southampton).
- Chepngeno-Langat, G., Falkingham, J., Madise, N. J., & Evandrou, M. (2010). Socioeconomic Differentials Between HIV Caregivers and Noncaregivers: Is There a Selection Effect? A Case of Older People Living in Nairobi City Slums. *Research on Aging*, 32(1), 67–96. Doi: 10.1177/0164027509348116
- Choudhary, M. (2013). Impact of old age allowance among rural aged: An empirical investigation. *International Journal of Sociology and Anthropology*, 5(7), 262–268. doi: 10.5897/IJSA2013.0453

- Corless, I. B., & Nicholas, P. K. (2000). Long-term continuum of care for people living with HIV/AIDS. *Journal of Urban Health*, 77(2), 176-186.
- Creswell, J. W. (2014). *Research design: qualitative, quantitative, and mixed method approaches* (4th ed.). Thousand Oaks, CA: Sage.
- Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Los Angeles: SAGE Publications, Incorporated.
- da Silva Francisco, A. A. (2017). _Gerontogrowth_ and population ageing in Africa and the Global AgeWatch Index. *The Journal of the Economics of Ageing*, 9, 78-89.
- Davidson, A. S. (2013). Phenomenological approaches in psychology and health sciences. *Qualitative research in psychology*, 10(3), 318-339.
- Denzin, N.K. and Lincoln, Y.S. (2005). *Handbook of qualitative research*. (3rd ed). Thousand Oaks, CA: Sage
- Evans, R., & Thomas, F. (2009). Emotional interactions and an ethics of care: Caring relations in families affected by HIV and AIDS. *Emotion, Space and Society*, 2(2), 111-119.
- Fauk, N. K., Mwakinyali, S. E., Putra, S., & Mwanri, L. (2017). Understanding the strategies employed to cope with increased numbers of AIDS-orphaned children in families in rural settings: a case of Mbeya Rural District, Tanzania. *Infectious diseases of poverty*, 6(1), 21.
- Gordon-Garofalo, V. & Lynch, V. (2000). –Social work treatment with caregivers: Taking care of them so they can take care of their loved one”. In Lynch, V. J. (Ed.), *HIV/AIDS at Year 2000: A Sourcebook for Social Workers*. Boston: Allyn and Bacon, 107-122.
- Hassan, Z. (2016). Stigma reduction initiatives: caregivers of multi faces. *Asia Pacific Journal of Social Work and Development*, 26(2-3), 152-166.

- Hawkins, S.-K. (2013). *Impact of HIV and AIDS on Elderly Caregivers in Chiang Mai, Thailand* (Unpublished Doctoral Dissertation, Walden University).
- He, W., Goodkind, D., & Kowal, P. (2016). An aging world: 2015. International population reports. *Last modified March, 31*.
- Help Age International (2003). *Forgotten families: Older people as carers of orphans and vulnerable children*. London: Help Age International.
- Hodge, D. R., & Roby, J. L. (2010). Sub-Saharan African women living with HIV/AIDS: an exploration of general and spiritual coping strategies. *Social Work, 55*(1), 27-37.
- Hutchison, E.D. (2011). *Dimensions of human behavior: The changing life course*. London: Sage Publications.
- Iwelunmor, J., & Airhihenbuwa, C. O. (2012). Cultural implications of death and loss from AIDS among women in South Africa. *Death studies, 36*(2), 134-151.
- Jones, P. S. (2012). Mind the gap: Access to ARV medication, rights and the politics of scale in South Africa. *Social Science & Medicine, 74*(1), 28–35.
- Kakooza, J. (2004). *HIV/AIDS and the changing role of the aged: Understanding the role, constraints and consequences for the elderly as providers of education to children orphaned by HIV/AIDS*. Paper presented at the African Conference on Ageing, Johannesburg, South Africa.
- Kakooza, J., & Kimuna, S. R. (2006). HIV/AIDS orphans' education in Uganda: The changing role of older people. *Journal of Intergenerational Relationships, 3*(4), 63-81.
- Kang'ethe, S. M. (2009). Challenges impacting on the quality of care to persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home-based care programme. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 6*(1), 24–32. Doi: 10.1080/17290376.2009.9724926

- Kasiram, M., & Hölscher, D. (2015). Understanding the challenges and opportunities encountered by the elderly in urban KwaZulu-Natal, South Africa. *South African Family Practice*, 57(6), 380-385. Doi: 10.1080/20786190.2015.1078154
- Kautz, T., Bendavid, E., Bhattacharya, J., & Miller, G. (2010). AIDS and declining support for dependent elderly people in Africa: retrospective analysis using demographic and health surveys. *Bmj*, 340, c2841.
- Kimuna, S. (2000). *Population aging: unraveling challenges of socioeconomic support for elderly Zimbabweans*. Retrieved October 21, 2017 from <http://elibrary.ru/item.asp?id=5325687>.
- Kimuna, S., & Makiwane, M. (2007). Older people as resources in South Africa: Mpumalanga households. *Journal of Aging & Social Policy*, 19(1), 97–114.
- Kipp, W., Tindyebwa, D., Karamagi, E., & Rubaale, T. (2006). Family caregiving to AIDS patients: the role of gender in caregiver burden in Uganda. *Journal of International Women's Studies*, 7(4), 1–13.
- Knodel, J., & Im-Em, W. (2004). The economic consequences for parents of losing an adult child to AIDS: Evidence from Thailand. *Social Science & Medicine*, 59(5), 987-1001.
- Knodel, J., Watkins, S., & VanLandingham, M. (2003). AIDS and older persons: an international perspective. *JAIDS-HAGERSTOWN MD-*, 33, S153-S165.
- Knodel, J., & Saengtienchai, C. (2005). Older-aged parents: The final safety net for adult sons and daughters with AIDS in Thailand. *Journal of Family Issues*, 26(5), 665-698.
- Kosse, A. K. . (2012). HIV/AIDS and elderly health: *The experiences of caregivers living in HIV affected households*. (Unpublished Master's thesis, University of KwaZulu-Natal, Durban).
- Kugonza, A., Buyinza, M., & Byakagaba, P. (2009). Linking local communities livelihoods and forest conservation in Masindi District, North Western Uganda. *Research Journal of*

Applied Sciences, 4(1), 10-16.

Kyobutungi, C., Ezeh, A. C., Zulu, E., & Falkingham, J. (2009). HIV/AIDS and the health of older people in the slums of Nairobi, Kenya: results from a cross sectional survey.

BMC Public Health, 9(1), 153.

Lazarus, R. S., and Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York: Springer.

Lekalakala-Mokgele, E. (2011). A literature review of the impact of HIV and AIDS on the role of the elderly in the sub-Saharan African community: review article. *Health SA Gesondheid*, 16(1), 1-6.

Lester, S. (1999). *An introduction to phenomenological research*. Retrived October 10, 2017 from

https://www.researchgate.net/profile/Stan_Lester/publication/255647619_An_introduction_to_phenomenological_research/links/545a05e30cf2cf5164840df6.pdf.

Maradik Harris, L., & Kim, B. J. (2014). Problem-focused coping: Skipped-generation caregivers affected by HIV/AIDS in Vietnam. *Qualitative Health Research*, 24(8), 1048-1056. Doi: 10.1177/1049732314541010

Marešová, P., Mohelská, H., & Kuča, K. (2015). Economics aspects of ageing population. *Procedia Economics and Finance*, 23, 534-538. Doi: 10.1016/S2212-5671(15)00492-X

Masindi District HIV/AIDS Bulletin January – March (2006). *Towards an HIV free generation*.

Masindi District Local Government (MDLG) (2015). *District HIV and AIDS Strategic Plan 2015/2016- 2019/2020*

Masindi District Local Government (MDLG) (2009). *District Environment Policy*.

Mathilda, Z., Mukombwe, O., Doreen, M., & Clara, H. (2016). Coping Strategies of Caregivers of HIV/AIDS Orphans in Ward 15 Bikita District, Masvingo Province, Zimbabwe. *Nova Journal of Medical and Biological Sciences*, 4(4).

Doi: 1 0.20286/nova-jmbs-040470

- Ministry of Health (MOH) (2010). The status of HIV/AIDS Epidemic in Uganda: *Epidemiological surveillance report*.
- Mugisha, J. O., Schatz, E. J., Randell, M., Kuteesa, M., Kowal, P., Negin, J., & Seeley, J. (2016). Chronic disease, risk factors and disability in adults aged 50 and above living with and without HIV: Findings from the Wellbeing of Older People Study in Uganda. *Global health action*, 9(1), 31098. Doi: 10.3402/gha.v9.31098
- Munthree, C., & Maharaj, P. (2010). Growing Old in the Era of a High Prevalence of HIV/AIDS: The Impact of AIDS on Older Men and Women in KwaZulu-Natal, South Africa. *Research on Aging*, 32(2), 155-174. Doi: 10.1177/0164027510361829
- Musangali, M., Daire, A. P., & DeLorenzi, L. (2016). The impact of caregiver coping strategies and patient level of functioning on perception of caregiver burden among caregivers of persons living with HIV/AIDS in Kenya. *Journal of HIV/AIDS & Social Services*, 15(4), 450–463. Doi: 10.1080/15381501.2014.912176
- Montgomery, R., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Generations*, 33(1), 47-52.
- Nala-Preusker, H.-P. M. (2014). *An investigation into older caregivers' lived experiences of adult AIDS-ill children in Umlazi Township, KwaZulu-Natal* (Unpublished Master Thesis, University of South Africa).
- Naleppa, M.J. & Schnitzenbaumer, R (2011). *Late Adulthood*. In E.D. Hutchison, *Dimensions Of human behavior. The changing life course*. London: Sage publications.
- Nankwanga, A., Phillips, J., & Neema, S. (2009). Exploring and curbing the effects of HIV/AIDS on elderly people in Uganda. *JCHS*, 4(2), 19-30.

- Nhongo, T. M. (2004). The changing role of older people in African households and the impact of Ageing on African family structures. *Paper presented at the Ageing in Africa conference, Johannesburg.*
- Ntozi, J. P., & Nakayiwa, S. (1999). AIDS in Uganda: how has the household coped with the epidemic. *The continuing African HIV/AIDS epidemic*, 2, 155-181. Retrived January 25, 2017 from http://htc.anu.edu.au/pdfs/ContinuingHIV/Ntozi_Naka.pdf
- N Ntozi, J. P. (1997). AIDS morbidity and the role of the family in patient care in Uganda. *Health transition review*, 1-22.
- Ntozi, J. P. M., & Mukiza-Gapere J. (1995). Care for AIDS orphans in Uganda: Findings from focus group discussions. *Health Transition Review*, 5(Suppl.), 245–252.
- Nyambedha, E. O., Wandibba, S., & Aagaard-Hansen, J. (2003). –Retirement lost”—the new role of the elderly as caretakers for orphans in western Kenya. *Journal of cross-cultural gerontology*, 18(1), 33-52.
- Nygård, L. (2003). Instrumental activities of daily living: a stepping-stone towards Alzheimer's disease diagnosis in subjects with mild cognitive impairment? *Acta Neurologica Scandinavica*, 107(179), 42-46.
- Nyirenda, M., Chatterji, S., Falkingham, J., Mutevedzi, P., Hosegood, V., Evandrou, M., . . . Newell, M.-L. (2012). An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC Public Health*, 12(1), 259.
- Oburu, P., & Palmérus, K. (2005). Stress related factors among primary and part-time caregiving grandmothers of Kenyan grandchildren. *The International Journal of Aging and Human Development*, 60(4), 273-282.
- Otagé, S. (2013, January 21). Tourists shun Masindi hospital over services. *Daily Monitor. Kampala*. Retrived November 20, 2017 from

<http://www.monitor.co.ug/News/National/Tourists-shun-Masindi-hospital-over-services/-/688334/1670966/-/v8dqr/-/index.html>.

- Osafo, J., Knizek, B. L., Mugisha, J., & Kinyanda, E. (2017). The experiences of caregivers of children living with HIV and AIDS in Uganda: a qualitative study. *Globalization and Health, 13*(1), 72. Doi: 10.1186/s12992-017-0294-9
- Pallangyo, E., & Mayers, P. (2009). Experiences of informal female caregivers providing care for people living with HIV in Dar es Salaam, Tanzania. *Journal of the Association of Nurses in AIDS Care, 20*(6), 481-493.
- Pandit, L. V., & Vishnuvardhan, G. (2014). Impact of age and gender on the coping styles and psychiatric morbidity faced by informal primary caregivers of HIV-infected individuals living in India. *Journal of the International Association of Providers of AIDS Care, 13*(1), 24-28. Doi: 10.1177/2325957412456742.
- Saengtienchai, C., & Knodel, J. (2001). *Parents providing care to adult sons and daughters with HIV/AIDS in Thailand*. UNAIDS.
- Sefasi, A.P. (2010). Impact of HIV and AIDS on the elderly: A case study of Chiladzulu district. *Malawi Medical Journal, 22* (4), 101-103.
- Shebi, M. (2006). *The experiences and coping strategies of HIV/AIDS primary caregivers within two disadvantaged communities in the Western Cape metropole* (Unpublished Doctoral Dissertation, University of the Western Cape).
- Shofoyeke, A. D., & Amosun, P. A. (2014). A Survey of Care and Support for the Elderly People in Nigeria. *Mediterranean Journal of Social Sciences, 5*(23), 2553-2563
- Schatz, E., & Ogunmefun, C. (2007). Caring and contributing: The role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development, 35*(8), 1390-1403.

- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*, *66*(2), 191-200.
- Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubukwa, S., Kowal, P., & Grosskurth, H. (2011). Health and functional status among older people with HIV/AIDS in Uganda. *BMC Public Health*, *11*(1), 886. Doi: 10.1186/1471-2458-11-886
- Seeley, J., Wolff, B., Kabunga, E., Tumwekwase, G., & Grosskurth, H. (2009). ‘This is where we buried our sons’: people of advanced old age coping with the impact of the AIDS epidemic in a resource-poor setting in rural Uganda. *Ageing and Society*, *29*(01), 115-134. Doi: 10.1017/s0144686x08007605.
- Shannon, K. M., & Ammann, A. J. (1985). Acquired immune deficiency syndrome in childhood. *The Journal of pediatrics*, *106*(2), 332-342.
- Ssewamala, F. M. (2015). Optimizing the “demographic dividend” in young developing countries: The role of contractual savings and insurance for financing education. *International journal of social welfare*, *24*(3), 248-262.
- 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*(4), 339-353. Doi: 10.1007/s10823-007-9043-5
- Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS care*, *21*(3), 309-314.
Doi: 10.1080/09540120802183461
- Speziale, H.J.S. & Carpenter, D.R. (2003). Qualitative research in nursing: *Advancing the humanistic imperative (3rd ed.)*. Philadelphia: Lippincott Williams & Wilkins.
- Tarimo, E., Kohi, T., & Outwater, A. (2009). Gender roles and informal care for patients with

- AIDS a qualitative study from an urban area in Tanzania. *Journal of Transcultural*, 20(1), 61–68. Doi: 10.1177/1043659608325843
- The Aids Support Organisation (TASO) (2015). *TASO Masindi*. Retrived November 20, 2017 from <http://www.tasouganda.org/index.php/services-programmes/taso-service-centers/taso-masindi>.
- The Aids Support Organisation (TASO) (2015): TASO Background. Retrived November 20, 2017 from <http://www.tasouganda.org/index.php/34-taso-background/taso-background>
- Tshoose, C. I. (2010). The impact of HIV/AIDS regarding informal social security: issues and perspectives from a South African context. *PER: Potchefstroomse Elektroniese Regsblad*, 13(3), 408-447.
- Tuckett, A. G. (2004). Qualitative research sampling: the very real complexities. *Nurse researcher*, 12(1), 47-61.
- UBOS (2010). *Uganda National Household Survey 2009–2010. Socio-economic module. Abridged report*. Kampala, Uganda: Uganda Bureau of Statistics.
- Muzooru, G. (2006, August 18). Masindi AIDS Prevalence Rate Increases to 7.7%. *Uganda Health Report*. Retrived November 25, 2017 from <https://www.google.com/search?client=opera&q=Masindi+AIDS+Prevalence+Rate+&sourceid=opera&ie=UTF-8&oe=UTF-8#>.
- Uganda Bureau of Statistics. (2014). National population and housing census 2014.
- United Nations (UN) (1982). *Report of the world assembly on aging*, Vienna, 26 July to 6 August. New York: United Nations.
- United Nations (2002). *Report of the second world assembly on ageing*. New York: United Nations.
- UNAIDS (2012). *Global Report. Report on the Global AIDS Epidemic (2012)*. UNAIDS. Geneva.

- UNAIDS (2014). Uganda: *Developing subnational estimates of HIV prevalence and the number of people Living with HIV*. Retrived February 16, 2017 from www.unaids.org/sites/default/.../2014_subnationalestimatessurvey_Uganda_en.pdf.
- UNAIDS (2016). Global AIDS update 2016. *Geneva, Switzerland: World Health Organization Library*. Retrived March 7, 2017 from http://www.unaids.org/sites/default/files/media_asset/global-AIDS-update-2016_en.pdf.
- UNAIDS (2017). Global HIV statistics. *Fact sheet July 2017*. Retrieved November 27, 2017 from <http://www.unaids.org/en/resources/fact-sheet>
- UMOH (2016). Profile of Masindi Hospital. *Uganda Ministry of Health (UMOH)*. Retrived November 20, 2017 from <http://health.go.ug/docs/masindi.pdf>.
- UN (2013). *World Population Prospects: The 2010 Revision*. Retrived December 13, 2016 from <http://esa.un.org/unpd/wpp/unpp/p2k0data.asp>.
- Wacharasin, C., & Homchampa, P. (2008). Uncovering a family caregiving model: Insights from research to benefit HIV-infected patients, their caregivers, and health professionals. *Journal of the Association of Nurses in Aids Care, 19(3)*, 385–396.
- Waliser, M. ., Spriggs, A., & Feldman, P. H. (2002). Informal Caregiving: Differential Experiences by Gender. *Medical care, 1249-1259*.
- Wilder, A. (2010). Ecological systems theory as applied to family caregivers of aging adults Retrived September 9, 2018 from https://www.researchgate.net/publication/242623839_Ecological_Systems_Theory_as_Applied_to_Family_Caregivers_of_Aging_Adults
- Williams, A., & Tumwekwase, G. (2001). Multiple impacts of the HIV/AIDS epidemic on the aged in rural Uganda. *Journal of cross-cultural gerontology, 16(3)*, 221-236.
- WHO (2017). *HIV/AIDS*. Global Health Observatory (GHO) Retrived October 1, 2017 from <http://www.who.int/gho/hiv/en/>.

APPENDICES

APPENDIX A: TASO RESEARCH ETHICS COMMITTEE (REC) APPROVAL LETTER



The AIDS Support Organisation (TASO) Uganda Ltd.

TASO Headquarters
Mulago Hospital Complex
P.O. Box 10443, Kampala-Uganda
Tel: +256 414 532 580/1
Fax: +256 414 541 288
E-mail: mail@tasouganda.org
Website: www.tasouganda.org

29th November, 2017

TASO TRAINING CENTRE
Kanyanya Off Gayaza-Road,
After Mpanwe
P.O. Box 10443, Kampala
Tel: +256 414 567 637
Fax: +256 414 566 704
E-mail: training@tasouganda.org

SERVICE CENTRES
TASO ENTEBBE
Plot 15-17 Lugard Avenue
P.O. Box 235, Entebbe
Tel: 0414 323 030/0752 774 135
E-mail: entebbe@tasouganda.org

TASO GULU
Plot 4 Malhevi Lukwya Road
P.O. Box 347, Gulu
Tel: 0471 43743/0752 774142
Fax: 0471 432569
E-mail: gulu@tasouganda.org

TASO JINJA
Jinja Referral Hospital
P.O. Box 577, Jinja
Tel: 0593 260 117/0752 774 147
Fax: 0434 120 382
E-mail: jinja@tasouganda.org

TASO MASAKA
Masaka Hospital
P.O. Box 1679, Masaka
Tel: 0592 749 998/ 0752 774 145
E-mail: masaka@tasouganda.org

TASO MASINDI
Masindi Hospital
P.O. Box 112, Masindi
Tel: 0465 420 638/ 0752 774 144
Fax: 0465 420 635
E-mail: masindi@tasouganda.org

TASO MBALE
Mbalale Hospital
P.O. Box 2250, Mbalale
Tel: 0454 433 507/ 0752 774 137
Fax: 0454 435 851
E-mail: mbalale@tasouganda.org

TASO MBARARA
Plot 25 and 27 Hospital Road
P.O. Box 1010, Mbarara
Tel: 0485 421 323/ 0752 774 136
Fax: 0485 421 323
E-mail: mbarara@tasouganda.org

TASO MULAGO
Mulago Hospital
P.O. Box 11486, Kampala
Tel: 0414 530 034/ 0752 774 139
Fax: 0414 541 288
E-mail: mulago@tasouganda.org

TASO RUKUNGIHI
Ishasha Road
P.O. Box 380, Rukungiri
Tel: 0486 442 610/ 0752 774 141
Fax: 0486 442 613
E-mail: rukungiri@tasouganda.org

TASO SOROTI
Soroti Hospital
P.O. Box 422, Soroti
Tel: 0454 481 389/ 0752 774 143
Fax: 0454 481 042
E-mail: soroti@tasouganda.org

TASO TORORO
Plot 30, Cox Road
P.O. Box 771, Tororo
Tel: 0454 442 039/0752 774 140
Fax: 0454 445 334
E-mail: tororo@tasouganda.org

GRANTS MANAGEMENT UNIT / GLOBAL FUND
House of Hope, Plot 10,
Windson Loop,
P.O. Box 10443, Kampala
Tel: 0414 259 059/ 0752 774 109
E-mail: grants@tasouganda.org

TASO-KARAMOJA PROJECT
Plot 10, Independence Avenue
P.O. Box 131 Merolo
Tel: 0752 744 792
E-mail: karamoja@tasouganda.org

TORORO LABORATORY HUB
Tororo Hospital
P.O. Box 777, Tororo
Tel: 0454 442 039/ 0752 774 723
Fax: 0454 445 334
E-mail: tororo@tasouganda.org

Our Ref: TASOREC/70/17-UG-REC-009

Ms. Kyomuhendo Clare,
University of Ghana
Clare.kyomuhendo@gmail.com

Dear Clare,

RE: RESEARCH APPROVAL "EXPERIENCES OF ELDERLY WOMEN CARING FOR PERSONS WITH HIV/AIDS IN MASINDI DISTRICT, UGANDA"

Thank you for submitting an application for initial ethics review of the above-referenced research study. Thank you for submitting responses to queries raised by TASO REC dated 28th November 2017 for the regular review research project.

TASO REC is content to give a favorable ethical opinion of the research and annual approval has been granted, effective 29th November 2017, valid until 28th November 2018.

The review and approval includes the following:

| Document Type | Date | Version |
|--|------------|---------|
| 1. The Study Protocol. | 28/11/2017 | 2.0 |
| 2. Informed Consent Form with Translation. | 28/11/2017 | 2.0 |
| 3. Data Collection Instruments with translation. | 28/11/2017 | 2.0 |
| 4. TASO REC Research Review Application and DOC of Interest Form | 31/10/2017 | 1.0 |
| 5. Letter of Introduction University of Ghana | 01/11/2017 | |

Amendments: All proposed changes to the study (including personnel, procedures, or documents) must be approved by the REC in advance through the amendment process before implementation.

Adverse Events/Unanticipated Problems: You must inform the REC of all unanticipated problems and adverse events that occur during your research study.

Site Monitoring: TASO REC undertakes site monitoring visits to verify that the rights and welfare of participants are being protected; to ensure that data is accurate, complete and verifiable data and that the protocol is in compliance with the guidelines and SOPs.

Study Reports: It is a requirement by the TASO REC that you submit timely annual progress reports.

We recommend that you proceed with the registration and final clearance of your study by the Uganda National Council of Science and Technology (UNCST) before commencement.

Renewal of the study approval. This should be through submission of the Annual Report and a Continuing Review Application Form, at least 60 days prior to expiration date. The study cannot continue until renewed by the TASO REC.

Sincerely,



Mr. Bakanda Celestin,
Chairperson, TASO RESEARCH ETHICS COMMITTEE (REC)
CC: Executive Director, TASO (U) Limited
CC: Uganda National Council for Science & Technology (UNCST)

**APPENDIX B: UNIVERSITY OF GHANA ETHICS COMMITTEE FOR THE
HUMANITIES (ECH) APPROVAL LETTER**



**UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)**

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No

15th December, 2017

Ms. Clare Kyomuhendo
Department of Social Work
University of Ghana
Legon

Dear Ms. Kyomuhendo,

**ECH 070/17-18: EXPERIENCES OF ELDERLY WOMEN CARING FOR PERSONS WITH HIV/AIDS
IN MASINDI DISTRICT, UGANDA**

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

| | |
|---------------------|--------------------|
| Expiry Date: | 12/06/18 |
| On Agenda for: | Initial Submission |
| Date of Submission: | 13/11/17 |
| ECH Action: | Approved |
| Reporting: | Quarterly |



Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante
ECH Chair

CC: Prof. Mavis Dako-Gyeke, Department of Social Work, University of Ghana.

APPENDIX C: INTERVIEW GUIDE FOR CAREGIVERS

TOPIC: Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda.

INTRODUCTION

My name is Kyomuhendo Clare from the University of Ghana, Department of Social Work. I am conducting a study on Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda. This study seeks to gather information about the topic, which could assist the government and other NGOs to develop policies and intervention strategies that can be useful to support elderly women as they care for persons with HIV/AIDS. Thank you very much for your co-operation.

SECTION A: Demographic Information

1. How old are you?
2. What is your ethnicity?
3. What is your religion?
4. What is your highest level of education?
5. What is your current marital status?
6. How many children do you have?
7. How many people are living in the house?
8. Who is the breadwinner?
9. What work do you do/ what is your employment status?
10. For how long have you been a care giver to your care recipient?
11. How are you related to the person you are caring for?
12. How old is your care recipient?

13. Was s/he employed prior to the illness and if yes, what kind of a job was he/she doing?
14. What is your current source of income that you use for caregiving?
15. How many hours do you spend a day in giving care to your care recipient?
16. What is the distance between your home and the medical facilities for your care recipient?

SECTION B: CARING FOR PERSONS WITH HIV/AIDS

1. What circumstances led you to become the primary caregiver of the person you are taking care of?
2. Please describe the methods you use in caring for your care recipient.
3. Which daily caregiving activities do you usually perform for your care recipient?
4. Which of these activities are more demanding? Why?
5. In what ways was your care recipient beneficial to your well-being before his/her illness?
6. Can you please explain your sources of income that you use for caregiving?
7. Can you please explain to me what you know about HIV/AIDS (knowledge and awareness of HIV)?
8. Do you have any positive experiences of caregiving? Please explain
9. Please describe, in as much detail as you would like, your caregiving experience.
10. What according to your opinion would make the caregiving task easier and effective?
11. Is there anything else you would like to add about, your experience, being a primary caregiver of your care recipient?

SECTION C: ELDERLY CAREGIVERS AND ROLE REVERSAL

1. What are your experiences of being a primary caregiver of your adult HIV/AIDS sick child?
2. In relation to the African traditional setting, what were your cultural expectations of your adult child as an elderly person?
3. In what ways have your roles changed during the caregiving process?
4. Please explain to me the following relationships between your new caregiving roles to your adult sick child and those earlier on performed when he/she was a child:
 - a. Differences
 - b. Similarities

SECTION D: CHALLENGES FACED BY ELDERLY WOMEN IN CAREGIVING

Economic Challenges

1. How has your caregiving role affected your financial wellbeing?
2. Is there any way in which the illness of your care recipient has reduced your financial and material support? explain
3. Can you please explain to me generally your economic experiences as a care giver to a person with HIV/AIDS?
4. When it comes to financial issues, how are you managing?

Emotional / psychological challenges

1. If you can still remember, when you first heard about his/her illness, how did you feel/react to the news then?
2. What emotional experiences do you face when caring for an adult child living with HIV?
3. How does thinking about your present and future status affect you psychologically?

4. In what other ways is your emotional/ psychological wellbeing affected due to the caregiving roles?
5. How do you deal with the perceived stigma associated with HIV/AIDS?

Social Challenges

5. Do other people (family members, friends, neighbours, community) know what the person is suffering from? If yes, how did they get to know about it?
6. If not aware of the patient's condition, why don't you want them to know?
7. In what ways has your relationship with others (other family members, friends neighbors, community) been affected by your caregiving role?
8. How do people react towards you as well as to the person you are caring for?
9. Please explain to me how you deal with these reactions?
10. How have the caregiving roles to your care recipient limited your mobility?
11. In what ways has your social life been affected due to your involvement in the caregiving role?
12. What other social challenges do you experience in caring for a person with HIV/AIDS?

Health, physical, and Nutritional challenges

1. What physical ailments do you experience as a result of your caregiving roles?
2. What do you do to respond to those physical ailments?
3. Can you please explain what you think are the causes of the physical ailments experienced?
4. How has your caregiving roles affected your health and wellbeing generally, in relation to your age?

5. What challenges do you have in relation to accessing the health care for your care recipient?
6. Do you think you have enough information on the proper care giving practices and the basic equipment required in your caregiving? Please explain
7. Have you ever had fears of being infected when providing care to the person? If yes explain why
8. How do you deal with the fears in question number 7?
9. What other health and physical challenges do you experience in your caregiving roles?
10. Do you experience nutritional challenges in your caregiving roles? Please explain.
11. How has the challenges in feeding and nutrition affected the treatment for your care recipient?

General information on the challenges faced

1. Do you think your caregiving roles to the recipient are a burden to you? Please explain
2. What other caregiving challenges are you faced with as a caregiver to persons infected with HIV/AIDS?
3. Please describe how your caregiving experience affects other aspects of your life and your living conditions.
4. Please describe how your caregiving challenges may affect your care recipient

SECTION E: COPING STRATEGIES

1. How do you cope with the following burdens/ challenges you face as a care giver?
 - a. Economic
 - b. Social
 - c. Emotional/psychological
 - d. Health challenges.

2. When feeling stressed due to caregiving burdens, what do you do?
3. How do you respond to your social life demands?
4. What other activities do you engage in to reduce the caregiving burdens?
5. How do these activities help to reduce your caregiving burdens?
6. What other information would you want to share with me about your coping experiences?

SECTION F: INTERVENTION/ SUPPORT SERVICES AVAILABLE FOR CAREGIVERS OF PERSONS WITH HIV/AIDS

1. Can you describe the intervention and support services you receive from the following?
 - a. government
 - b. NGOs
 - c. Church
 - d. community and support groups
 - e. Family members and friends
2. Are there any processes involved in getting those services? If yes, what are the processes and how have they affected you?
3. Do you receive any old age benefits from the government? If yes, what are they?
4. How helpful are the benefits in supporting your caregiving roles?
5. What other support services available do you utilize in your caregiving roles?
6. Please can you explain to me if the intervention and support services are efficient for your optimal caregiving?
7. What other interventions do you think are appropriate in response to the caregiving challenges you experience?
8. Explain why you think the interventions suggested in question number 7 will be appropriate

APPENDIX D: TRANSLATED INTERVIEW GUIDE FOR CAREGIVERS

EBIKAGUZO OMURUNYORO

OKWEYANJURA

Amabara gange ninyowe Kyomuhendo Clare omwegi ha itendekero erikuru erya Ghana. Nimbasaba okwetaba omukutoolereza kunu okukwetaga okumanya biki ebimuramu obwo nimuroolera/ nimujanjaba abarwaire abaine akahuka kasilimu. Mwebale muno.

EBIKUKUKWATAHO

1. Oina emyaka eingaha?
2. Oli worulimi ki?
3. Osaba dini ki?
4. Okasooma kukanga nkaha?
5. Oine amaka/ osweirwe?
6. Oina abaana baingaha?
7. Oikara na bantu baingaha omuka yaawe?
8. Noha ayemerezaaho eka yaawe?
9. Iwe kiki ekyokora okweyemezaho/ okora omulimo ki?
10. Omazire akasumi ki nojanjaba omurwaire waawe?
11. Owokujanjaba okumweta ota?
12. Aina emyaka eingaha?
13. Omurwaire waawe akaba nakoora obwakaba atakarwaire? Obuharaba ego, mulimo ki?
14. Esente zokujanjabisa okuziha nkaha?
15. Omu kiro omara esaha zingaha omukuroleera omurwaire wawe?
16. Aroho oburaira ki okuruga omuka na hali omurwaire waawe atungira obujanjababi?

OKUROLEERA OMURWAIRE AINE AKAHUKA KA SILIMU

1. Kiki ekyakuletereize okuba omujanjabo omukuru owomurwaire waawe?
2. Nsobora ha mirigo eyokozesa okujanjabo/okuroleera omurwaire waawe.
3. Emirimo ki eyokora mukujanjabo/okuroleera omurwaire waawe?
4. Mumirimo ki egyo eyetagisibwa muno? Habwaki?
5. Omurwaire waawe obwakaba atakarwaire ya kuyambaga mumiringo ki/ akaba womugaso ki?
6. Nsobora hali esente ezokujanjabo no kuroleera omurwaire waawe hali oziha?
7. Okusobora okugambira ha biiki ebyomanyire ebikukwata ha kahuka ka silimu?
8. Oine oburungi bwona obwohire omukujanjabo omurwaire waawe? Nsobora
9. Nsobora nkokurukwetaga omuligo okujanjabo no okuroleera omurwaire waawe nkokurabya/nkokukuli.
10. Omuntekereza yaawe, biki ebyokunihira ebikusoborwa kukolebwa mukuyamba omukuheheza omulimo ogwokujanjabo/okuroleera abarwaire?
11. Araho ekintu kyona ekyorukwetaaga okwongeraho habyorabamu nojanjabo/noroleera omurwaire waawe?

OKUROLEERA OMWANA OMUKURU AINE AKAHUKA KA SILIMU

NEMPINDUKA MUBUJUNANIZIBWA

1. Nsobora ebyorabamu nkomujanjabo owomwana waawe omukuru aine akahuka akasilimu?
2. Okusigikira ha buhangwa bwaitu, biki ebyokaba nonihira omumwana waawe onu omukuru owokurwaza, iwe nkomuntu akuzire omumyaka?
3. Mumiringo ki obujananzibwa bwaawe buhindukiremu habwokujanjabo?
4. Nsobora ha enkoragana zinu eziri hagati eyo bujananzibwa bwawe obuhya obwokurwaza omwana onu omukuru hamu nobwo obuwamukoleire nakyali omuto

- a. Ensisana b. Enyahukana

OBUZIBU OBURABIBWAMU

Obuzibu obwefuna/esente

1. Okujanjaba/ okuroleera omurwaire kukwasire kuta ha hanfuna/ esente zaawe?
2. Haroho omulingo gwona okurwara okwomurwaire waawe kuleterizemu okukendeera omubuyambi obwesente no mubintu ebyabulikiro? Nsobora
3. Nsobora habyenfuna yaawe nkomujanjabi owomurwaire owa akahuka aka silimu?
4. Wubikwija omu bye sente, okweyemezaho ota?

Obuzimu omubitekerezo no kweralikira

1. Obworaba no kyaijuka, okehuura ota/ kikakurabya kita obuwahuliire ha burwaire obwo muntu wokujanjaba?
2. Biki ebyorabamu omubitekerezo habwokujanjaba omurwaire aine akahuka aka silimu?
3. Okutekereza ha bwomezi bwawe obwahati no bwo mumaiso, bukutalibanize buta omubwongo?
4. Mumiringo ki endi ebitekerezo byawe bitalibanizibwemu habwemirimo eyokujanjaba?
5. Okora ota okuraba mu biki abantu bibatekerezamu, hamu no kusoroora okukwatagana na kahuka aka silimu?

Obuzibu omunkoragana nabandi

5. Abantu abandi (abeganda, abanywani, abalirwana, nabekyaro) bamanyire oburwaire omuntu owokurwaza obwarwaire? Obuharaba ego, bakakimanya bata?
6. Obubaraba batakimanyire, habwaki otarukwetaga bakakimanya?

7. Mumiringo ki ekoragana yaawe na bandi (abeganda, abanywani, abalirwana, nabekyaro) etalibanizibwemu habwomulimo gwawe ogwo kujanjaba?
8. Abantu berabya bata hali Iwe hamu no murwaire wawe oworukujanjaba?
9. Ninsaba onsobore omuligo orabamu mukwerabya okwabantu okwo?
10. Okujanjaba/okuroleera omurwaire waawe kukendeize kuta okurubata kwawe?
11. Mumiringo ki obwomezi bwawe bwabulikiro butalibanizibwemu habwo bujunazizibwa obwo kujanjaba?
12. Buzibuki bundi obwenkoragana obworabamu habwokujanjaba omurwaire owa kahuka aka silimu?

Obuzibu mu bwobwomezi, ebyomubiri ne byo mundisa

1. Buzibu ki omubiri obwofuna ha bwemirimo ekolebwa mukujanjaba?
2. Biki ebyokora omukuyamba omubuzibu obwofuna omu mubiri?
3. Okusobora kunsobora endugiro eyoburumi/obuzimu obwofuna omu mubiri?
4. Okujanjaba kutalibanize kuta ebyobwomezi bwawe, kusigikira ha myaka yaawe?
5. Buzibuki obwosanga/obworabamu omukufuna obujanjabi obwomurwaire waawe?
6. Okunihira oine okumanya okukumara ha endoleera/enjajaba ehikire, ne bintu ebikwetagisibwa omukujanjaba? Nsobora.
7. Wali otungire okweralikira omukutunga akahuka kasilimu habwo kujanjaba omurwaire wawe? Obuharaba ego, nsobora habwaki?
8. Biki ebyokora mukuraba mukutina okwotunga mu kigaguzo ekya kasitale ako musanju (7)?
9. Obuzibuki obundi omubyobwomezi no mubyomubiri ebyorabamu mukujanjaba?
10. Ofuna obuzibu omubyomundisa nojanjaba? Nsobora
11. Obuzibu mu byomundisa, butalibaniize buta obujanjabi obwomurwaire waawe?

Okumanya okundi habuzibu oburabibwamu

1. Okunihira ngu omulimo gwawe ogwokujanja guli muguugu hali iwe? Nsobora
2. Obuzibuki bundi obworabamu omukujanja omurwaire owakahuka kasilimu?
3. Nsobora omulingo okujanja kutalibaniizemu obwomeezi bwawe obwabulikiro ne nyikara yaawe?
4. Nsobora omulingo obuzibu obworabamu mukujanja busobora kutalibanizamu omurwaire waawe?

Ebyokora kuraba omuzibu obworabamu

1. Okoraki kuraba mu buzibu bunu obworabamu nko mujanjabi?
a) Ebyenfuna/esente b) Enkoragana nabandi c) Ebitekerezo d) ebyobwomezi.
2. Bwuhura obwongo butalibanizibwe ha bwo bujunanizibwa bwokujanja, okoraki?
3. Okora ota okuhikiriza obwetaago obwokukoragana nabandi hamu nokweyunga mu bintu byabulikiro?
4. Bintu ki ebindi ebyokora okukendeza ebitekerezo no bwetaago ha bwobujunanizibwa bwawe obwokujanja?
5. Mumiringo ki ebintu ebyokora biyambamu okukendeza ebitekerezo no bulemezi obwo bujunanizibwa no bwetaago obwokujanja?
6. Oine ekindi kyona akyorukwetaga okungabira ha mirigo eyo kendeza ebitekerezo no buzibu obwokujanja?

OBUYAMBI OBUROHO MUKUYAMBA ABAKURWAZA ABARWAIRE ABA

KAHUKA AKASILIMU

1. Okusobora okusobora omubwijwire okuyambibwa okwofuna okuruga mu banu?
a. Gavumenti b. Ebitongole c. Ekanisa d. Ebiteebe omubyaro

e. Aboruganda na banywani

2. Aroho ebi kukwetagisibwa okurabamu mukufuna okuyambibwa kunu? Obu haraba ego, biki byoine okurabamu kandi bikutalibanize bita?
3. Haroho obusiimo bwoona obwa abantu abakuru mummyaka obwofuna kuruga mu gavument? Bu haraba ego, nubwo bulinkaha?
4. Obusiimo bunu obwofuna bukuyambire buta mu mulimo gwawe ogwokujanjaba?
5. Obuyambi ki bundi oburoho obwokozeesa mukuhikiriza omulimo gwawe ogwokujanjaba?
6. Okusbora kunsobora oba okuyambibwa okwofuna mubuli nsonda obukuraba nikumara kurungi mukuhikiriza omulimo gwawe ogwokujanjjaba?
7. Obuyambi ki obundi bwokunihira nibwetagibwa mukuyamba okumaraho obuzibu obumusanga/obumurabamu mu kujanjaba/okuroleera omurwaire?
8. Nsobora habwaki okunihira ngu obuyambi obwogambireho omu kikaguzo kasitale musanju (7) kwija kuba kwomugaso mu kubayamba?

APPENDIX E: INTERVIEW GUIDE FOR KEY INFORMANTS

TOPIC: Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda.

INTRODUCTION

My name is Kyomuhendo Clare from the University of Ghana, Department of Social Work. I am conducting a study on Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda. This study seeks to gather information about the topic, which could assist the government and other NGOs to develop policies and intervention strategies that can be useful to support elderly women as they care for persons with HIV/AIDS. Thank you very much for your co-operation.

SECTION A: Demographic Information

1. What is your sex?
2. How old are you?
3. What is your ethnicity?
4. What is your religion?
5. What is your highest level of education?
6. What is your current marital status?
7. Which form of employment sector are you working with?
8. For how long have you been working in the sector/office?

SECTION B: Views about the elderly, as HIV/AIDS caregivers

1. In your opinion, what do you think could have caused the elderly women become caregivers for persons with HIV/AIDS?
2. In what ways do you work with elderly care givers?

3. What are your experiences in working with persons with the elderly caregivers to persons living with HIV/AIDS (PLWHA)?
4. What caregiving styles do the elderly women use in caring for the persons with HIV/AIDS?
5. In what ways do you see their styles as effective?
6. In what ways do you see the elderly women's caregiving roles as effective?
7. In what ways do you help the elderly care givers in effectively performing their caregiving roles towards the PLWHA?

SECTION C: Views on elderly caregiving and role reversal

1. What are the cultural expectations of elderly persons from their adult children?
2. In what ways do the roles of elderly women change during their caregiving process?
3. According to your experience, what do the elderly women go through as primary caregivers of their adult HIV/AIDS sick children?

SECTION D: Challenges faced by elderly women in caregiving

8. In what ways do you think the elderly women are affected economically, socially, psychologically, health and nutrition wise, due to their caregiving roles?
9. Do you think enough has been done to equip the elderly caregivers with the necessary information and basic materials required in caring for persons with HIV/AIDS?
Please explain.
10. What other caregiving support needs of the elderly persons are you aware of?
11. What strategies have been taken to address those needs?
12. Do you think the strategies are efficient in supporting their caregiving experiences?
Please explain

SECTION E: Coping strategies

13. What coping strategies are you aware of that the elderly employ to cope with the challenges faced?
14. Do you think those strategies are helpful in coping with the challenges? Explain how
15. Are you aware of any negative coping strategies that the elderly employ in dealing with the challenges faced? Explain what they are.
16. What do you recommend for the elderly caregivers to do in dealing with the challenges faced?

SECTION E: Support services available for caregivers of persons with HIV/AIDS

17. How do the following agencies support older caregivers of persons living with HIV/AIDS (PLWHA)?
 - a. Government
 - b. NGOs
18. Are there policies in the country that benefit the elderly persons caring for PLWHA? Please explain.
19. In your own views, what do you think should be done to improve the care giving roles of the elderly women in the District and the country as a whole?
20. What other information would you want to share about the elderly caregiving roles in relation to HIV/AIDS?



APPENDIX F: INFORMED CONSENT FOR CAREGIVERS

Name of the Researcher: Clare Kyomuhendo

Name of the Institution: University of Ghana

Title of Study: Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda.

PART 1: Information Sheet

Introduction

I am Clare Kyomuhendo, currently studying a Master's Degree at the University of Ghana within the Department of Social Work. You are invited to take part in this study which seeks to understand the Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District.

During the study, you may talk to anyone you feel comfortable talking with about any information concerning this study. The purpose of this document is to give you information you will need to help you decide whether or not to participate. If you find any unfamiliar word, do not hesitate to ask for the meaning because the researcher is willing to take her time to explain everything for you to understand. Also, you are free to ask questions about anything related to the interview which is not clear to you at any time.

This is a study which is purely academic rather than provision of clinical care. The study involves research which will include asking you a few questions which will capture the lived experiences of caring for persons with HIV/AIDS, as well as how you deal with these experiences. The interview is expected to last for about forty five (45) minutes to one (1) hour.

Purpose of the Research Project

This study involves research which will include twenty two (22) participants (17 caregivers and 5 key informants). The purpose of this study is to explore the Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda. This will involve in-depth interviews on the styles/methods used when caring for persons with HIV/AIDS, the challenges faced and how they are dealt with, and the intervention/ support services available for assistance. The aim of this is to obtain information so that the elderly women caregivers' plight is understood from their own perspectives.

Type of Research Intervention

This research involves an in-depth interview carried out on a one-on-one basis.

Participant's Selection (why you are being asked to participate)

You are being asked to participate because you possess the qualities such as knowledge and experiences regarding the subject matter being studied, which can provide the researcher with the best information.

Voluntary Participation

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at TASO or any Health facility will treat you differently if you decide not to be in the study. You will also continue to receive all the services you usually get even when you choose not to participate. If you decide to join the study now, you can still change

your mind and withdraw at any time during the study, without being affected with the services you receive or entitled to.

***Question to elucidate understanding:** Do you know that you have a right not to take part in this research study, if you do not wish to? Do you know what your options are if you decide not to take part in this research study? Do you have any questions?*

Procedures

An interview guide will be used to solicit information through one-on-one interview at a place and time convenient to you. This means that, I will ask you a few questions and you will tell me your story in your own words. The interview will be audio-recorded, and complemented with taking notes. This is for analysis purposes, but at no point in the transcription will the information be linked by your name. This calls for your consent for the interview to be audio recorded.

Also, the questions will be both opened and closed ended during the interviews. This is to help in getting enough and meaningful information required for the study.

Duration

The researcher will meet with you two times. The first interview will take about forty five (45) minutes to one (1) hour to answer the interview questions. The second interview will take less than 30 minutes to clarify your recorded and written words.

***Questions to elucidate Understanding:** If you decide to take part in the study, do you know how much time the interview will take? Where will the interview take place? Do you know how many times you will meet with the researcher? Do you have any more questions?*

Risks

The researcher does not expect any harm or risk during this research. It only requires the participant to tell her own story as it is. However, being in this type of study may involve

some minor discomforts and other emotional experiences that can be encountered in daily life, such as becoming upset. However to deal with these mental discomfort, an arrangement with a counsellor will be made for counselling services in case of any breakdown.

Benefits

Although there are no direct benefit of this research, the study findings are expected to be helpful to both the participants, the community, and the country as a whole in the following ways.

- The participants will benefit because they will be given counseling on how to cope with stress that arise from the burden of giving care. Also, their challenges will be known and through their suggested recommendations, better intervention strategies can be adopted through collaboration of the government, NGOs and individual groups both nationally and internationally in meeting the needs of elderly caregivers.
- Another potential benefit of the study to the community and the nation at large is that, it will provide information to policy makers on the vulnerability of elderly caregivers. This could motivate and draw attention of the Government of Uganda to invest in creating policies that will improve the lives of caregivers and their families.

Reimbursements/Compensation

The participants will receive snacks after participating in the study.

Confidentiality

The interview will be conducted with respect for your privacy. Any information you provide will be kept confidential, and only the researcher will have access to any identifiable data. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept out of reach of public domain by storing it

on a password protected computer. However, confidentiality may not be upheld if the information involves risks to life. This may be shared with only concerned persons in a bid to find possible solution to the problem.

Sharing the Results

The researcher aims to share the study findings with the participants individually or in a group depending on the situation. A meeting will be held to share the information and also participants will be educated what to do to improve their health and wellbeing. Also, the researcher will meet with other stakeholders such as the local district officials and various NGOs such as TASO and FBOs dealing with HIV/AIDS related issues to inform them of the results. This will inspire the stakeholders to review and if need be, adjust their programs and also collaborate to meet the needs of the elderly caregivers. The researcher will further share the findings more broadly through presentation in the conferences and publish the findings as academic article in journals to enable people across the globe have access to it. Again, copies will be given to TASO where participants will be recruited. A copy will also be given to the District local Government and other relevant offices to help them in the design and implementation of policies that will effectively address the challenges confronting the elderly women caring for HIV/AIDS patients.

Right to Refuse or Withdraw

Participation in this study is completely voluntary. You may refuse to participate or withdraw from it at any time without supplying reasons and without penalty. This will have no influence on the regular treatment, care or any other benefit that your sick person receives from TASO and other Health facilities.

Who to Contact

For questions regarding the research study, contact Ms. Clare Kyomuhendo on +256 784811056; and for questions regarding your rights and welfare during the study participation, contact the Chairperson, Mr. Bakanda Celestin, +256 758 222100.

If you want to talk privately about your feelings and ideas of this study, and any research-related injury, you can contact my main supervisor:

Dr. Alice Boateng

Senior Lecturer Department of Social Work

University of Ghana

P.O.BOX LG 419

Legon, Accra

Tel: +233 264449536

Email: aboateng@ug.edu.gh / ohemaa2000@outlook.com

This proposal has been reviewed and approved by TASO REC, which is a committee whose task is to make sure that research participants are protected from harm. If you wish to find out more about the REC, contact [MR. Bakanda Celestin, P.O.BOX 10443 Mulago, 0752774178]

You may ask any questions you have about any part of the research study, if you wish to. Do you have any questions?

Part II: Certificate of Consent

The main purpose of the researcher for carrying out a study entitled experiences of elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda is sufficiently clear to me. Also, it has been explained to me the benefits and procedures for the research project

and given adequate time to rethink the issue. I am fully aware that the results of this study will be used for academic purposes and may be published, and that my privacy is guaranteed.

I have read the information, or it has been read to me. I have been provided with the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I have not been pressurized to participate in any way. I hereby give consent to voluntarily participate in this study by signing below.

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/Month/Year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/Month/Year



APPENDIX G: TRANSLATED INFORMED CONSENT FOR CAREGIVERS

EKIHANDIIKO EKIKUSABA OKWIKIRIZA KWAVE OKWETABA

OMUKUTOLEEREZA KUNU

Amabara ago mutoleerezi: Clare Kyomuhendo

Eitendekero erikuru: Yunivaasite eya Ghana

Omutwe omukuru ogukutorolezebwoho: Biki abakaikuru ebibarabamu obu nibaroolera/ nibajanjaba abarwaire abaine akahuka kasilimu omu kicweka ekya Masindi, Uganda.

Ekicweka Ekikubanza: Ebyokumanya

Okwanjura

Amabara gange ninyowe Clare Kyomuhendo omwegi ha itendekero erikuru erya Ghana, omukitongole ekikwegesa omulingo ogwokukora nabantu. Nimbasa okwetaba omukutoleereza kunu okukwetaga okumanya biki abakaikuru ebibarabamu obu nibaroolera/ nibajanjaba abarwaire abaine akahuka kasilimu omu kicweka kinu ekya Masindi, Uganda. Mwina obugabe obwokubanza ha buli kimu kyona, kimukuhuura nimwetanga ekikukwata ha kutoleereza kunu. Obulyo obwe kihandiiko kinu buli okubahereza amakuru agaija okubayamba okusaramu okwetaba omukutolereza kunu obundi okwanga. Obumuraba mwina ebigambo ebimutarukwetegereza obundi ekikaguzo kyona mwina obugabe okukaguzo akaire koono, habwokuba akutolereza nayetaaga okubayamba kwetegereza bulikimu.

Kunu kuli okutolereea okukukwata ha kusooma kandi hatali okugaba obujanjabi. Nahabwekyo mwija kuba nimukaguzibwa ebikaguzo bitaito ebikukwata ha biki ebimuramu obwo nimuroolera/ nimujanjaba abarwaire abaine akahuka kasilimu, na mumiringo eyimuraba omu beera ezo. Okukaguzibwa kunu nikwija okumara hagati yedakiika ana naitanu (45) no mu saha emu (1).

Ekigenderwa ekyokutolereza kunu

Okutolereza kunu kwija kuba na bantu abiri nababiri (22), obu a bakaikuru abakurwaza baija kuba ikumi namusanju (17) kandi abatanu (5) nibaija kuba abantu abandi abaina okumanya okukumara ha kahuka kasilimu na bantu abarwaza abarwaire abaina oburwaire bwomunywereero. Ekigenderwa ekyokutolereza kunu kiri okumanya biki abakaikuru ebibarabamu obu nibaroolera/ nibajanjaba abarwaire abaine akahuka kasilimu omu kicweka kinu eky Masindi, Uganda. Kinu nikija kwetagisa okukagusa ebikaguzo ha emirigo eyimurwazamu abarwaire banyu abaine akahuka kasilimu, obuzibu obumurabamu ni murwaza kandi nomulingo eyimuraba mubizibu binu, na obuyambi obumutunga okubayamba mukurwaza/kuroleera abarwaire banu. Omugaso gwabinu bwona kuli okyamba okufuna okumanya okukumara habiki abakairu ebibaramu ni barwaaza/nibaroleera abarwirwe abaina akahuka ka silimu okuraba mukusobora kwabu.

Ebija okukozesebwa omukutolereza

Okukaguzibwa okwa muntu ha muntu nikwo kwija kuba nikukozesebwa omukutoleereza kunu.

Okukoma abakwetaba omukutoleereza kunu (Habwaki nosabibwa kuba nowetabamu)

Nosabibwa okwetaba omukutoleereza kunu habwokuba oine ebintu ebikwetagisa nka amagezi/okwetegereza no bumanye ha kiki ekirukotolerezebwo, ekija kuba nikiyamba okufuna okumanya okukwetagisa kandi okwomugaso.

Okwetaba omukutoleereza kwokusaraho

Okwetaba omukutoleereza kunu kuli kwokusaraho kwawe. Buli omu naija kuha kitiinisa okusaraho kwawe kwona kworaba ocwireemu (okwetaba mu kutoleereza obundi okwanga). Busaho omuntu weena okuruga ha TASO obundi hairwaro lyona aija kuba nakuryabya omumulingo ogundi obworaba osazireho obutetaaba omukutoleereza kunu. Kandi, oija kugenda mumaiso notunga obuyabi bwona no kuherezebwa kwofuna kuruga mubicweka binu. Nobworaba ocwiremu okwetaba omukutoleereza kunu, oine obugabe obwokurugamu akaire koona, obworahindirumu muntekereza yawe. Kandi, nakyo tikija kutalibaniza mukuherezebwa kwawe mumulingo gwona.

Ekikaguuzo okumanya okwetegereza: Omanyire ngu oine obugabe obwobutetaaba omukutoleereza kunu bworaba otagondeze? Omanyire biki ebyoine kukora bworaba otagondeze okwetaba omukutoleereza kunu? Oine ekikaguuzo ekindi kyona?

Ebyokurabibwamu

Ebikaguzo habuli muntu omu - omu nibija kuba nibikozesebwa okufuna okumanya, obwo kinu nikija kuba omu kicweka no mukaire okokuhura norora ngu kakusemereire. Kinu nikimanyisa ngu nija kuba ninkukaguza ebikaguzo bitaito obwo nongabira/nongarukamu mu bigambo byawe. Okukagulizibwa kunu nikwija kukwatibwa amaraka, oteireho no kuhandika. Binu bija kuyamba mukuhandika ebirugire omukutoleereza kunu, baitu busaho nahamberi hali hoona eibara lyawe liija kuba nirihandikibwa. Kinu nikyetagisa okwikiriza kwawe ngu okugagulizibwa kunu kube nikukwatibwa amaraka.

Kandi, ebikaguuzo bija kuba ebikwetagisa okugarukamu okurairhire ahamu no kugufu (ego/nangwa). Kinu kija kuyamba omukutunga okumanya okukumara kandi okuwetagisibwa omukutoleereza kunu.

Obwire/ Akasumi

Arukutoleereza najja okubaitirana emirundi ebiri. Okukaguzibwa okwokubanza kwija kutwara hagati yedakiika ana naitanu (45) na mu saha emu (1). Okukaguzibwa okwakabiri kwija kuba hansi yedakiika makumya asaatu (30) obwo nimungumiza ebihandikirwe ne kikwasirwe omumaraka obubiraba nibyo byenyini.

Ekikaguuzo okumanya okwetegereza: Obworasaraho okwetaba omukutoleereza kunu, omanyire akasumi ki okukagulizibwa kwija kuba nikutwaara? Okugagulizibwa nikwija kuba nkaha? Omanyire emirundi eingaha eyoija kuba noitirana akutoleereza? Oine ekikaguuzo kindi kyona?

Obuziibu

Arukutoleereza taina ekigenderwa kyona okyokuleteereza obuziibu habajja kuba nibetaaba omukutoleereza kunu, okwihaho okubaaza biiki ebirabibwamu obwo nibarwaaza/nibajanjaba omurwaire aine akahuka akasilimu. Baitu, obuzibu butaito nko kwehuura kubi hamu nokutalibanizibwa omu bitekerezo kusobora kubaho.

Ebyomugaaso

Nobuharaba ataroho okufunamu okwabwangu omukutoleereza kunu, ebija kuba nibirugamu bija kuyamba abantu boona abajja kuba nibetabaamu, abe kyaaro kandi neihanga lyaitu Uganda, omumiriigo enu hansi.

- Abakwetabamu nibajja okufuna okubudabudibwa ogwembaganiza omumulingo ogwokuraba mukuntuntura no kweralikiira okuruga omukujanjaba/okuroleera omurwaire. Kandi, obuziibu obubarabamu nibwija kumanywa, hamu nokuraba mukuhanuura kwabu, obuyambi obukwetagisibwa nibusoborwa kutekwaho okuraba mukorangana nokuteerana okwa gavumenti, ebitoongole ahamu na bantu kinomu, kurunga omwihanga na aheru yeihanga okuyamba okumaraho obuzimu nobwetaago

obwabantu abakuziire omumwaka kandi nibarwaaza/nibajanjaba abarwaie abakahuuka akasilimu.

- Ekyomugaaso ekindi kiri ahali abekyaro ahamu nabantu boona abeihanga lyaitu Uganda, habwokuba okutoleereza kunu nikwija kuha amakuru abakukwatagana no kukoora amateeka agakukwata ha buceeke nembera eya bakaikuru abakurwaza abarwaie abakahuuka kasilimu. Kinu nikija okuhaliriiza Gavumenti eya Uganda okuteeka ensimbi/esente mukutekaho amateeka agajja okuhindura obwomeezi obwabakurwaza ahamu nabantu baabu abomuka.

Akasiimo

Abajja okwetaaba omukutoleereza kunu nibajja okutungwa akokulya kaake akajja kubayamba okutuunga amaani hanyuma yo kukaguliribwa.

Okulinda Ensita.

Okukaguliriza kwijakuba omukicweeka ekyensita, kandi ebikwija kuba nibibalizibwaho namabara ganyu gajja kwikaara gali gensinta, obwo bimanyirwe akutoleereza wenka. Kandi, busaho okumanya okumukumpereza kwija kuba nikukozesebwa omumulingo ogutali ogwekigenderwa ekyo kutolereza kunu. Okwongeraho hali ebyo, ebikugambibwa bija kwahurwa ha kyoma kalimagezi kine ne namba etarukumanywa omuntu ondi weena. Oihireho, ensita teija kulindwa obuharaba haroho ebiragambibwa ebija kuba nibikwata ha bwomezi obwomuntu. Binu bija kuba nibibalizibwaho no muntu arukujunanizibwa mukutungwa okuyambibwa okukumara kandi okusemreire.

Okusoboora ebirugire omukutoleereza

Arukutoleereza aine ekigenderwa ekyo kusoboora ebirugiire omukutoleereza kuraba muntu ha muntu obundi omukitebe okusigikira ha mbeera erabaho. Orukurato nirwija kukolebwa okusoboora abetabiire omukutoleereza, okubagambira biki ebiruguremu, kandi

nokwegesebwa omulingo ogwo kulinda obwomeezi bwabu nenyikara yabu eyabulikiro obwo nibarwaaza. Kandi, Arukutoleereza najja okwitirana abantu abandi abakuru omukicweka nka abakozi abakukwatibwaho ha distrikiti nebintogoole ebikuru nka TASO ahamu nebindi ebyediini ebirikukoora ha bintu na bantu abaine akahuka akasilimu, okubasoboora eburugire omukutoleereza. Kinu nikija kuyamba okutunga omulingo kandi nokukoragana omu kugabiira no kumaraho obwetago obwa bantu abakuzire omumwaka kandi nibarwaza abarwaire abakahuka kasilimu. Emiringo endi eijakuba nekozesebwa eija kuba okuraba omukubaaza nokweegesa omumisoomo nenkurato ezitekanizibwe hamirengo erukwahukana, hamu no kuturukya ebitugirume ha mikutu ya internet hali abantu omumahanga egembaganiza baija kuba nibabisanga. Kandi, ebitaabu abihoire okuhandikwa bija kuba nibiherezabwa ha office eya TASO, office enkuru eya goveminti eyomukicweka, ahamu ne office ezindi ezomugaso, ekija kuba nikibayamba okutekaho amateeka agaija kuyamba omukumaraho obuzibu abaikuru baitu obubarabamu obwo nibarwaza/nibaroleera abarwaire abaine akahuka akasilimu.

Obugabe obwokwanga orundi okurugaamu

Okwetaba omukutoleereza kunu kuli kwo kusaramu kwawe. Nosobora okwetabamu orundi okurugamu otaine okulemesebwa kwona ahamu nokuha ensoga, kandi nokulehera. Kinu tikwija kutalibanizibwa omu bujanjabi no buyambi obundi obumutunga okuruga omu TASO ahamu namarwaro agandi.

Owe kwehanuzaho

Obworaba oine ebikaguuzo ebikukwata ha kutoleereza kunu, teera ha simu eyogu arukutoolera ha kwegu kunu, owubakweta, Clare Kyomuhendo ha, +256 784811056; kandi obworaba oine ebikaguuzo ebikukwata ha bugabe bwawe hamu ne byendoleera yawe, teera omukuru owubakweta, Mr. Bakanda Celestin ha, +256 758 222100.

Obworaba oine ensiita eyorukwetaga kubaza ha kwehura kwawe ne bitekerezo ebindi ebirukukwata ha kutoleereza kunu, teera omusomera omukuru akujunanizibwa no kuroleera omulingu gukukoramumu okutoleereza kunu ha itendekero erikuru erya Ghana, owubakweta:

Dr. Alice Boateng

Senior Lecturer Department of Social Work

University of Ghana

P.O.BOX LG 419

Legon, Accra

Tel: +233 264449536

Email: aboateng@ug.edu.gh / ohemaa2000@outlook.com

Okutoleereza kunu kumazire kuba nikwikirizibwa akatebe akakuru aka TASO REC, akakujunanizibwa nokutolereza okukwata habantu, hamu no kubalinda bataba nobuzibu. Obworaba noyetaaga okumanya ebikusingaho, handika obundi teera esimu, [MR. Bakanda Celestin, P.O.BOX 10443 Mulago, 0752774178]

Nosobora okukaguza ekikaguzo ha kacweka koonna akakukwata ha kutoleerza kunu. Oine ekikaguzo kyona?

Ekicweka Ekyakabiri: Ekihandiiko ekikusaraamu/ ekikwikiriza

Ekigenderwa ekikuru ekyokutoleereza kunu okukukwata biki abakaikuru ebibarabamu obu nibaroolera/ nibajanjaba abarwaire abaine akahuka kasilimu omu kicweka eky Masindi, Uganda, kingambirwe kandi nakikenga. Kandi, insoborwoire kurungi oburungi nebiki ebija kurabibwamu mukutoolereza kunu, ahamu nahebwa akaire akakumara okubitekerezaho. Ninkimanya kurungi ngu okutoleereza kunu kuli kwokwega kandi nikusobora kutekwa ha mukutu gwa internet, ahamu nokulinda ensita hamu nokumanyibwa abantu abandi.

Nesomeire amakuru agali omukikihandiko kinu, orudi bakinsoimeire. Mperezibwe omugisa ogwokukaguza ebikaguzo kandi byangarukibwamu kurungi. Tibampambirize okwetaba mukutoolereza kunu omumulingo gwona. Hati ninyikiriza nokugonza kwange okwetaba mukutoolereza kunu obwo ninteka omukono hansi hanu.

Eibara eryarukwetaba mukutoolereza _____

Omukono _____

Ebiro byokwezi _____

ekiro/Omwezi/Omwaka

Atarukkusobora okusooma hamu no kuhandiika

Mbaire omwakaiso obwo nibamusoomera amakuru agali omu kihandiiko, kandi yaherezebwa omugisa ogwokukaguza ebikaguzo. Ningumya ngu omuntu onu aikirize okwetaba mukutoolereza kunu ayegondeize wenka.

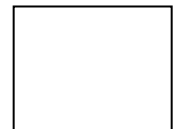
Eibara eryomwakaiso _____ *Ekinkumu* ekyarukwetaba

mukutolereza

Omukono ogwamwakaiso _____

Ebiro ebyokwezi _____

Ekiro/Omwezi/Omwaka



Siteetimenti eyarukutoleereza/ Omuntu akubasaba okwikiza okwetaba mukutoolereza

Kunu

Nsomeire kurungi abarukugenda okwetaba mukutoolereza kunu, amakuru agali omu kihandiiko, Kandi nabayamba okwetegereza biki ebikugenda okukolebwa.

Ningumya ngu arukugenda okwetaba mukutoolereza kunu ahairwege omugisa ogwokukaguzza ebikaguzo, kandi byagarukibwamu kurungi. Kandi ningunya ngu omuntu onu tahambirizibwe okwikiriza okwetaba mukutoolereza kunu, baitu aikirize wenka mukuginz kwe.

Ekihandiiko kinu nakyo kihairwe omuntu onu arukugenda okwetaba omukutoolereza kunu.

Eibara eyarukutoleereza/ akubasaba okwikiza kwawe _____

Omukono ogwarukutoleereza/ akubasaba okwikiza kwawe _____

Ebiro ebyokwezi _____

Ekiro/Omwezi/Omwaka



APPENDIX H: INFORMED CONSENT FOR KEY INFORMANTS

Name of the Researcher: Clare Kyomuhendo

Name of the Institution: University of Ghana

Title of Study: Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda.

PART 1: Information Sheet

Introduction

I am Clare Kyomuhendo, currently studying a Master's Degree at the University of Ghana within the Department of Social Work. You are invited to take part in this study which seeks to understand the Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District.

During the study, you may talk to anyone you feel comfortable talking with about any information concerning this study. The purpose of this document is to give you information you will need to help you decide whether or not to participate. If you find any unfamiliar word, do not hesitate to ask for the meaning because the researcher is willing to take her time to explain everything for you to understand. Also, you are free to ask questions about anything related to the interview which is not clear to you at any time.

This is a study which is purely academic rather than provision of clinical care. The study involves research which will include asking you a few questions which will capture your

views about the elderly, as caregivers for persons with HIV/AIDS. The interview is expected to last for about forty five (45) minutes to one (1) hour.

Purpose of the Research Project

This study involves research which will include twenty two (22) participants (17 caregivers and 5 key informants). The purpose of this study is to explore the Experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda. This will involve in-depth interviews on your views about the elderly, as caregivers for persons with HIV/AIDS, the challenges you think they face and how they deal with them, and the intervention/ support services available for assisting them.

Type of Research Intervention

This research involves an in-depth interview carried out on a one-on-one basis.

Participant's Selection (why you are being asked to participate)

You are being asked to participate because you possess the qualities such as knowledge and experiences regarding the subject matter being studied, which can provide the researcher with the best information.

Voluntary Participation

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study now, you can still change your mind and withdraw at any time during the study.

Procedures

An interview guide will be used to solicit information through one-on-one interview at a place and time convenient to you. This means that, I will ask you a few questions and you will tell me your views about the elderly, as caregivers for persons with HIV/AIDS in your

own words. The interview will be audio-recorded, and complemented with taking notes. This is for analysis purposes, but at no point in the transcription will the information be linked by your name. This calls for your consent for the interview to be audio recorded.

Also, the questions will be both opened and closed ended during the interviews. This is to help in getting enough and meaningful information required for the study.

Duration

The researcher will meet with you two times. The first interview will take about forty five (45) minutes to one (1) hour to answer the interview questions. The second interview will take less than 30 minutes to clarify your recorded and written words.

Risks

The researcher does not expect any harm or risk during this research.

Benefits

Although there are no direct benefit of this research, the study findings are expected to be helpful to both the participants, the community, and the country as a whole in the following ways.

- The participants' views will help voice out the challenges which the elderly women caregivers face, and through your suggested recommendations, better intervention strategies can be adopted through collaboration of the government, NGOs and individual groups both nationally and internationally in meeting the needs of elderly caregivers.
- Another potential benefit of the study to the community and the nation at large is that, it will provide information to policy makers on the vulnerability of elderly caregivers. This could motivate and draw attention of the Government of Uganda to invest in creating policies that will improve the lives of caregivers and their families.

Reimbursements/Compensation

The participants will not receive any payment for participating in the study.

Confidentiality

The interview will be conducted with respect for your privacy. Any information you provide will be kept confidential, and only the researcher will have access to any identifiable data. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept out of reach of public domain by storing it on a password protected computer.

Sharing the Results

The researcher aims to share the study findings with the participants individually or in a group depending on the situation. The researcher will meet with other stakeholders such as the local district officials and various NGOs such as TASO and FBOs dealing with HIV/AIDS related issues to inform them of the results. This will inspire the stakeholders to review and if need be, adjust their programs and also collaborate to meet the needs of the elderly caregivers. The researcher will further share the findings more broadly through presentation in the conferences and publish the findings as academic article in journals to enable people across the globe have access to it. Again, copies will be given to TASO where participants will be recruited. A copy will also be given to the District local Government and other relevant offices to help them in the design and implementation of policies that will effectively address the challenges confronting the elderly women caring for HIV/AIDS patients.

Right to Refuse or Withdraw

Participation in this study is completely voluntary. You may refuse to participate or withdraw from it at any time without supplying reasons and without penalty. This will have no influence on your employment or any benefit received from your employers.

Who to Contact

For questions regarding the research study, contact Ms. Clare Kyomuhendo on +256 784811056; and for questions regarding your rights and welfare during the study participation, contact the Chairperson, Mr. Bakanda Celestin, +256 758 222100.

If you want to talk privately about your feelings and ideas of this study, and any research-related injury, you can contact my main supervisor:

Dr. Alice Boateng

Senior Lecturer Department of Social Work

University of Ghana

P.O.BOX LG 419

Legon, Accra

Tel: +233 264449536

Email: aboaeng@ug.edu.gh / ohemaa2000@outlook.com

This proposal has been reviewed and approved by TASO REC, which is a committee whose task is to make sure that research participants are protected from harm. If you wish to find out more about the REC, contact [MR. Bakanda Celestin, P.O.BOX 10443 Mulago, 0752774178]

You may ask any questions you have about any part of the research study, if you wish to. Do you have any questions?

Part II: Certificate of Consent

The main purpose of the researcher for carrying out a study entitled experiences of Elderly Women Caring for Persons with HIV/AIDS in Masindi District, Uganda is sufficiently clear to me. Also, it has been explained to me the benefits and procedures for the research project and given adequate time to rethink the issue. I am fully aware that the results of this study will be used for academic purposes and may be published, and that my privacy is guaranteed. I have read the information, or it has been read to me. I have been provided with the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I have not been pressurized to participate in any way. I hereby give consent to voluntarily participate in this study by signing below.

Print Name of Participant _____

Signature of Participant _____

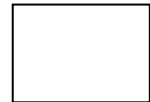
Date _____

Day/Month/Year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____ **Thumb print of participant**



Signature of witness _____

Date _____

Day/Month/Year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/Month/Year