

Exploring the Relationships Between Supports and Depression Among Elderly  
Caregivers Raising Children Orphaned by AIDS in Rural Namibia

A DISSERTATION  
SUBMITTED TO THE FACULTY OF  
UNIVERSITY OF MINNESOTA  
BY

Eveline Ndinelao Kalomo

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF  
DOCTOR OF PHILOSOPHY

David Hollister, Advisor

May 2015

## Acknowledgements

Thank you, Lord, for loving me the way you do and for giving me strength and a persevering spirit to undertake this project. My thanks go to many people and organizations that have assisted me through to the completion of this project. A heartfelt thank you to my wonderful husband, Brian Hafeni Kalomo, and sons, Hafeni and Wetu, for always supporting and encouraging me throughout this journey. I thank the Lord for blessing me with three wise men that love and care for me so deeply. You mean the world to me. Special regards to my parents for bearing the pain of separation for all these years so that I can fulfill my dreams. Thanks to my sisters Martha and Jenette for believing in me and praying for me. A special thanks to my extended family and in-laws for your love, care, and support.

Special gratitude goes to Dr. David Hollister, my advisor, for his unconditional support, understanding, and encouragement. Dr. Hollister's knowledge, availability, and accessibility have been a major impetus in fulfilling this project. For these and many other things, I am sincerely grateful. It is with sincere gratitude that I extend my appreciation to my committee members, Drs. Liz Lightfoot, Priscilla Gibson, and Zha Blong Xiong, for their limitless patience in guiding me through the research. I am sincerely indebted to each one of you for your advice, support, and trust in my abilities and skills.

I also wish to express my sincere appreciation to Catholic AIDS Action and all my participants. Without your time and cooperation, this study would not have been possible. Thanks to my research assistants from the Omusati Region for supporting and

helping me in the data collection. You have gone out of your way to help me in the writing of this dissertation. Finally, very special thanks to everyone at the School of Social Work at the University of Minnesota.

## **Dedication**

This dissertation is dedicated to my parents, Silas and Katrina Nuujoma, who instilled in me values of perseverance, independence, and the love for all humanity in my life.

### **Abstract**

Using the ecological systems theory, the present study examined the levels of depression in elderly caregivers of AIDS orphaned children in relations to those caregivers' financial stability, social support, informational support, and personal characteristics. Cross-sectional data were collected through face-to face interviews using the Center for Epidemiological Studies Depression Scale (CES-D) of depression and the Multidimensional Scale of Perceived Social Support (MSPSS). Measures for financial stability and informational supports were specifically developed for this study. Multiple regression analysis found elevated levels of depressive symptoms, with all caregivers in this study scoring above the threshold criteria for depression ( $\geq 16$  points). The mean score of CES-D for the entire sample was 48. Findings also revealed a significant negative association between financial stability and depression. In addition, results showed a negative association between caring for an HIV-infected child and depression after controlling for caregiver age and caring for an HIV-infected child. Findings suggest the need for greater economic security and mental health interventions for elderly caregivers.

## Table of Contents

|   |    |
|---|----|
| List of Tables .....  | ix |
| List of Figures .....   | x  |
| CHAPTER 1: INTRODUCTION .....                                       | 1  |
| Statement of the Problem.....                                       | 5  |
| Significance of the Problem.....                                    | 7  |
| Purpose of the Study .....  | 9  |
| Definition of Terms .....   | 10 |
| CHAPTER 2: LITERATURE REVIEW .....                                  | 14 |
| Context of African Caregiving .....                                 | 14 |
| Setting the Scene: Namibia at a Glance.....                         | 16 |
| Population, Poverty, and Inequality.....                            | 17 |
| Literature Review on Orphan Caregiving in the Era of HIV/AIDS ..... | 18 |
| Methodological Characteristics of Studies .....                     | 18 |
| Salient Research Findings: State of Knowledge.....                  | 19 |
| Mental Health and HIV/AIDS Caregiving .....                         | 19 |
| Supports and HIV/AIDS Caregiving .....                              | 23 |
| Identified Gaps in Research.....                                    | 57 |
| Research Questions and Hypotheses .....                             | 59 |
| CHAPTER 3: THEORETICAL FRAMEWORK.....                               | 61 |
| Ecological-System Theory.....                                       | 61 |
| CHAPTER 4: METHOD .....   | 67 |

|  |    |
|--|----|
| Participants .....   | 67 |
| Study Setting.....   | 68 |
| Omusati Region, Northern Namibia .....                     | 68 |
| Procedures.....  | 71 |
| Training of Research Assistants.....                       | 72 |
| Inclusion and Exclusion Criteria.....                      | 73 |
| Protection of Human Subjects .....                         | 73 |
| Administration of Survey.....                              | 73 |
| Sample Size and Power.....                                 | 75 |
| Measurement.....   | 75 |
| Study Variables.....                                       | 80 |
| Independent Variables .....                                | 80 |
| Control Variables .....                                    | 82 |
| Dependent Variable: Depression .....                       | 83 |
| Data Collection Procedures .....                           | 85 |
| Entry Into the Community and Cultural Considerations ..... | 85 |
| Research Design .....                                      | 85 |
| Data Analysis.....   | 86 |
| Descriptive Statistics.....                                | 86 |
| CHAPTER 5: RESULTS.....                                    | 89 |
| Sample Characteristics.....                                | 89 |
| Financial Stability.....                                   | 94 |

|   |     |
|---|-----|
| Informational Supports .....                | 94  |
| Social Supports .....                       | 95  |
| Depression.....                             | 95  |
| <i>T</i> test.....                          | 96  |
| Pearson Correlation.....                    | 97  |
| Hierarchical Multiple Regression .....      | 98  |
| CHAPTER 6: DISCUSSION.....                  | 101 |
| Characteristics of Elderly Caregivers ..... | 101 |
| Research Question 1 .....                   | 105 |
| Research Question 2 .....                   | 107 |
| Informational Supports .....                | 109 |
| Social Supports .....                       | 110 |
| Research Question 3 .....                   | 112 |
| Research Question 4 .....                   | 113 |
| Depression Among Elderly Caregivers .....   | 114 |
| Limitations of the Study .....              | 116 |
| Sampling Limitations.....                   | 116 |
| Instrument Limitations.....                 | 117 |
| CHAPTER 7: STUDY IMPLICATIONS.....          | 119 |
| Implications for Social Work Practice.....  | 119 |
| Microsystem.....                            | 119 |
| Mesosystem.....                             | 121 |

|  |      |
|--|------|
|  | viii |
| Implications for Social Work Policy .....                    | 121  |
| Exosystem .....  | 121  |
| Macrosystem .....  | 126  |
| Areas for Future Research .....                              | 126  |
| References .....   | 129  |
| Appendix A: Survey Instrument (English Version).....         | 144  |
| Appendix B: Consent Form .....                               | 154  |
| Appendix C: Survey Instrument (Oshiwambo Version).....       | 156  |
| Appendix D: Letter of Approval by Catholic AIDS Action ..... | 167  |

**List of Tables**

|  |     |
|--|-----|
| Table 1. Summary of Studies Included in Literature Review.....   | 29  |
| Table 2. Correlations of the Financial Questions.....  | 78  |
| Table 3. Variable Table.....   | 84  |
| Table 4. Demographic Characteristics of Children and Elderly HIV/AIDS Caregivers.....                                      | 89  |
| Table 5. Caregiver Receiving Remittance from Family ( <i>N</i> =89) .....  | 92  |
| Table 6. Caregiver Receiving Government Foster Care Grant for OVC ( <i>N</i> =89).....                                     | 94  |
| Table 7. Means and Standard Deviations for Variables of Interest in this Study .....                                       | 95  |
| Table 8. Depression Among Caregivers ( <i>N</i> =89) .....   | 96  |
| Table 9. Comparison of Caregivers Caring for a HIV-Positive Child/ren .....  | 97  |
| Table 10. Intercorrelations for Age and Caring for an HIV-Infected Child/ren.....  | 98  |
| Table 11. Multiple Regression Analysis Summary Predicting Depression from Five<br>Predictor Variables ( <i>N</i> =86)..... | 100 |

**List of Figures**

Figure 1. Ecological-system theory for the study .....65

Figure 2. Conceptual model for the study.....66

Figure 3. Map of Namibia locating the Omusati Region.....71

## CHAPTER 1: INTRODUCTION

The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have created an unprecedented orphan crisis in Africa in general and in Namibia in particular. Together they have had a devastating impact on caregivers (United Nations Joint Program on HIV/AIDS [UNAIDS], 2008). By 2007, it was reported that close to 22.5 million African adults and children were living with AIDS (United Nations Children's Fund [UNICEF], 2008). Today, sub-Saharan Africa is the region hardest hit in the world by the HIV/AIDS epidemic and is home to 67% of the world's HIV/AIDS cases (World Health Organization [WHO], 2008). Compared to the rest of the world, nations in this region have witnessed a disproportional increase in the number of AIDS-orphaned children (UNAIDS, 2008). During 2009 alone, approximately 16.6 million orphans aged 0-17 were reported to have lost either one or both parents due to AIDS (2012; UNAIDS, 2012; WHO, 2010), and more than 90% of these children live in sub-Saharan (UNICEF, 2011; WHO, 2012). This phenomenon has had an overwhelming toll on the elderly African generation (Mokegela, 2011; Njororai & Njororai, 2012).

Over the past several decades, the HIV/AIDS epidemic in southern Africa has had a tremendous impact on the elderly (Kanyamurawa & Ampek, 2007; Mokegela, 2011; Njororai & Njororai, 2012; Oburu, 2005; Orner, 2006). This crisis has created rapid and dramatic changes in HIV/AIDS caregiving among this population, especially grandmothers (Boon et al., 2010; Govender, Penning, George, & Quinlan, 2011; Help Age International [HAI], 2003; Kuo & Operario, 2009; Mokegela, 2011). Today, the

elderly are stepping into care for their HIV-infected adult children and AIDS-infected and/or affected grandchildren and other children (Kimuna & Makiwane, 2007; Lightfoot & Kalomo, 2010; Njororai & Njororai, 2012). Thus, orphanhood in much of Africa often leaves the extended family responsible for the care of AIDS-orphaned children (Foster, 2000).

Elderly caregiving in sub-Saharan Africa is often performed amid adverse conditions (Kuo & Operario, 2009; Ssengonzi, 2009). Scholars Ankrah(1993), Foster (2000), and Madhavan (2004), argued that AIDS-orphaned children have a major impact on extended families and households and might affect the capacity of elderly caregivers to care for thousands of these children. In Namibia, the country of focus in this study, the majority of AIDS-orphaned children are being cared for by aging, impoverished grandparents who often struggle to meet the needs of their grandchildren and other children (UNAIDS, 2011). As HIV/AIDS infected parents pass away unexpectedly, elderly caregivers step in to raise and care for many of these children who are either HIV infected and/or affected by HIV and AIDS. Caring for these dependent children entails a range of responsibilities, including tending to their medical, financial, social, and emotional needs. Importantly, AIDS-affected children may have additional needs that amplify caregiving demands on the caregiver: They are more likely to be HIV infected and to experience AIDS-related stigma and emotional problems (Cluver & Garder, 2007; Govender et al., 2011).

Additionally, studies have revealed that many elderly caregivers raising AIDS-affected children live in dire poverty (George et al., 2011; Lindsey et al., 2003; Skovdal

et al., 2011); experience stigma and isolation (Boon et al., 2010a; Ogunmefun & Schatz, 2011); lack information and knowledge on how to access welfare grants (Boon et al., 2010b) and how to provide care for grandchildren living with HIV and AIDS (Boon et al., 2009); and have significantly lower levels of social support and/or social connections (Kuo et al., 2012; Oburu & Palmerus, 2003; Schatz et al., 2010). Further, researchers have shown that elderly caregivers providing care to AIDS-orphaned children struggle financially (i.e., they experience intense financial hardship). Thus, many caregivers have limited financial resources or means to meet the needs of orphans, such as schooling, food, and medical care (Heymann et al., 2007; Kidman & Thurman, 2014; Moore, 2007-2008). Consequently, these demands may have the potential to place caregivers at risk of developing negative mental health outcomes that could lead to high levels of stress manifesting as anxiety and/or depression (Abasiubong, Bassey, Ogunsemi, & Udobang, 2011; Kup & Operario, 2011; Kuo, Operario, & Cluver, 2011).

Despite progressive legislation and policies, including supportive program initiatives that have been put in place, these approaches often remain largely underdeveloped, poorly coordinated, and inadequate (Schatz, Madhavan, & Williams, 2011), leaving many caregivers and their AIDS-orphaned children to fend for themselves (Kautz et al. 2010; Njororai & Njororai, 2012). Currently, there are international (Stephen Lewis Foundation, 2006) and national (Ferreira, 2004) concerns regarding the caregiving role of AIDS-affected grandparents. Although scholarship in Africa on aging in the context of HIV/AIDS is still in its earliest stages, a small but growing body of research has examined the impact of HIV/AIDS on extended family networks, specifically on

elderly caregivers (Njororai & Njororai, 2012) and their declining supports (Kautz et al., 2010; Kimuna & Makiwane, 2007; Njororai & Njororai, 2012; Reddy, 2005). However, despite the heightened awareness and public outrage, elderly caregivers remain “invisible” (Chazan, 2008, p. 937) when it comes to the allocation of resources and support. As Marias (2005) wrote,

While most of the attention is directed at the prospects of those in their care, little of note is being done to meet the material, emotional, and social needs of elderly caregivers and fosters-the “reverse orphans” who, in the twilight of their lives and grossly disadvantageous circumstances, are transforming themselves again into mothers and fathers. (p. 82)

Improving the mental well-being of elderly caregivers is critical to the care of children orphaned by AIDS. This improvement is imperative especially among grandmothers, who disproportionately shoulder enormous caregiving roles in households affected by HIV and AIDS in sub-Saharan Africa (Ardington et al., 2010; Kipp et al., 2007). Elderly caregiving and poor mental health outcome well-being has primarily been attributed to the loss of financial providers (i.e., adult children who have died of AIDS) who no longer are around to assist with remittance to caregivers (Foster, 2000; Kuo et al., 2012). To this end, little is known about the caregivers who provide care to orphaned children in Namibia. In addition, no publication was found that examined the association between mental health (i.e., depression) and supports of caregivers raising children orphaned by HIV and AIDS. For these reasons, this study explored this phenomenon with a specific focus on elderly rural women. The study applied the ecological systemic lens,

which focuses on examining the environment and social context in which individuals reside (Bronfenbrenner, 1979).

### **Statement of the Problem**

The HIV/AIDS epidemic has had an insurmountable impact on elderly caregivers' "*omufilishisho*" (a caregiver in the local language Oshiwambo) and has left thousands without adequate supports. Southern Africa remains the region most severely affected by HIV/AIDS (UNAIDS, 2012). It is a tragedy of epic proportion that has left this region with the highest rates of orphanhood in the world (UNICEF, 2010). Emerging evidence has suggested that the AIDS epidemic increasingly affects the elderly (Foster, 2000; Kuo & Operario, 2011). Moreover, some scholars have found that thousands of grandparents, especially grandmothers, have become "Africa's new mothers" (Lewis, 2005), stepping in and taking on enormous caregiving responsibilities to people infected and/or affected by HIV/AIDS, including orphans (Foster, 2000; Hlabyago et al., 2009; Kuo & Operario, 2011; Ssengonzi, 2007). This change in caregiving roles is primarily due to the fact that most infections and deaths are occurring among individuals in their prime age, and their deaths mark subsequent loss of financial support for the family (Hlabyago et al., 2009; Ssengonzi, 2007).

Various scholars have postulated that HIV/AIDS morbidity and mortality has had a significant impact on the younger generations, especially those in the 15-40 age group, and has had greater impact on women than men in sub-Saharan Africa (UNAIDS, 2006). This toll has resulted in a reduced number of adults who would rear or parent children (Lightfoot & Kalomo, 2010). Moreover, this "missing generation" that should consist of

caregivers attending to the elderly is becoming sick with HIV/AIDS and dying, leaving aging grandmothers to provide care and support to orphans and vulnerable children (OVC) instead of being cared for themselves (Schatz & Gilbert, 2012). Thus, this missing generation of middle-aged adults has altered the contours of living and caregiving arrangements, consequently reducing household income among thousands of households headed by the elderly in much of southern Africa (Yamano & Jayne, 2004).

Researchers have shown that the elderly, especially those 50 years and older, are caring for AIDS-orphans in Namibia (GRN/MGECW & World Health Food Program [WFP], 2006; Project Hope, 2006). In addition, a study found that in 2006, 56% of the primary caregivers of orphans were grandmothers aged 60 years and older (Project Hope, 2006). Today, elderly caregivers are assuming the responsibility of caring for their sick/and or dying adult child as well as raising their orphaned grandchildren, often with inadequate and inefficient social welfare services, incentives, interventions, and supports (Lekalakala-Mokgele, 2012; Moore & Henry, 2005; Reddy, 2005; Schatz, 2007). As the elderly remain behind to nurse the sick and raise AIDS-orphaned grandchildren, they may experience financial challenges (Kimuna & Makiwane, 2007; Oluwagbemiga, 2007; Tanga, 2008), multiple stressors (Drimie & Casale, 2009), deterioration in physical and mental well-being (Kamya & Poindexter, 2009; Oburu & Palmerus, 2003; Ssengonzi, 2009), increased loneliness, isolation and stigma (Hejoaka, 2009; Moore & Williams, 2011; Thupayagale-Tshweneagae, 2008), and a heightened caregiver burden (Kipp, Matukala, Laing, & Jhangri, 2006).

Although studies have shown pride, strength, and resiliency among caregivers raising OVC (Cattell, 1993; Kanya & Poindexter, 2009), the limited state-funded and government-run initiatives to assist caregivers have resulted in the elderly having to sacrifice their own self-interests, including financial resources, to take on full-time caregiving responsibilities (Ssengonzi, 2007, 2009). There is a dearth of research but an increasing concern regarding the implications of such responsibilities of care to elderly caregivers raising multiple orphaned children in poor environment, particularly in southern Africa. No publication focused in this region was found that has examined the relationships between mental health outcomes and supports of caregivers, signaling the need for research in this area.

### **Significance of the Problem**

The Namibian government has declared HIV/AIDS a major public health concern and the highest national public health priority (Ministry of Health and Social Services, [MoHSS], 2010). National HIV prevalence measured through the estimation of pregnant women attending antenatal clinics has shown a steady decrease among pregnant women aged 15-49, from a high of 22% in 2002 to 18.8% in 2010 (MoHSS, 2010, 2012; UNICEF/UNAIDS, 2011). Current estimates show that Namibia has 25,000 OVC below the age of 18 (Government of the Republic of Namibia [GRN]/Demographic Health Study [NDHS], 2006). Many AIDS-orphaned children live in poverty, and about 22% of these children are living with a pensioner in the home (NSA/Child Poverty in Namibia, 2012). About 14,000 children are living with HIV/AIDS themselves, and 1 in 10 is living with at least one sick or chronically ill adult (GRN/MGECW, 2010; NDHS, 2006;

USAID, 2011). Studies found that the number of orphans cared for by grandparents increased from 44% in 1992 to just over 60% in 2000 (UNAIDS, 2004). It is worth noting that not all children are vulnerable, not all orphans are orphaned by AIDS, not all orphans are vulnerable, and not all vulnerable children are affected by AIDS (UNICEF/UNAIDS, 2011).

Although a study found that OVC in Namibia thrive better and are more likely to have their psychosocial needs met and be integrated into their local communities when in the care of kin caregivers rather than when placed in institutions (Haihambo, Hayden, Otaala, & Zimba, 2004), a small but growing number of studies have shown that Namibian-kin caregivers are grappling with the upkeep of children in their care (Hayden et al., 2004; Ruiz-Casares, Thombs, & Rousseau, 2009; Social Impact Assessment and Analysis Corporation [SIAPAC], 2002; Steintz, 1998). For example, caregivers are frequently unable to pay school fees (Hayden & Otaala, 2005; Kuhanen, Shemeikka, Notkola, & Nghixulifwa, 2008; SIAPAC, 2002; Steintz, 1998) or provide nutritional food for children (Haihambo et al., 2004; Hayden & Otaala, 2005), and many do not have transportation or means to afford proper health care (Steintz, 1998).

The literature is replete with evidence of the pivotal role of the elderly in HIV/AIDS caregiving. In comparison to literature on the impact of HIV/AIDS on older adults in developing nations (National Research Council, 2006), little is known about supports and mental well-being of the elderly in Africa. Their caregiving role is often overlooked, underreported, or unrecognized in policy initiatives and intervention programs (Kautz et al., 2010; Kyobutungi et al., 2009; Ssengonzi, 2009). In the absence

of this awareness, examining supports and the mental well-being of the elderly becomes a critical phenomenon. The gap exists to develop a body of research that will build on this phenomenon.

Clearly, there is such a compelling need that elderly caregivers merit attention from researchers, social work professionals, program planners, policy makers, national governments, civil society, and society in general. Caregivers' supports have the potential to strengthen or weaken family resources that serve to protect the family from the full impact of challenges. Understanding how caregivers cope and what they need to alleviate the burden of care may help to bring about changes necessary to assist this vulnerable population in the fight against the HIV/AIDS epidemic and enhance efforts to bolster the well-being of families living in socioeconomically deprived communities in sub-Saharan Africa.

Consequently, to assist caregivers in their caregiving role, it is important to understand how caregivers' supports affect the mental well-being of this population. This study aimed to examine elderly caregivers' mental well-being and supports in rural Namibia. Findings from this study can contribute to scholarship on aging in an African context and have the potential to affect change and advance policies and culturally relevant interventions toward productive and healthy aging in southern Africa (Makoni, 2008).

### **Purpose of the Study**

The purpose of this study was to examine the relationships between depressive symptoms and supports of caregivers raising children orphaned by AIDS in the Omusati

Region of northern Namibia. Being an elderly HIV/AIDS caregiver is associated with a plethora of negative outcomes (Kuo & Operario, 2010; Ssengonzi, 2007; Schulz & Beach, 1999) it is important to identify the supports associated with HIV/AIDS caregiving. This study, guided by ecological systems theory, aims to examine whether caring for an HIV-infected child/ren, financial stability, informational, and social support are associated with symptoms of depression and assess which personal characteristics are most likely to be associated with depressive symptoms.

### **Definition of Terms**

This section of briefly defines some important terms and concepts that will be used throughout this study.

*Acquired immune deficiency syndrome (AIDS):* A group of diseases caused by the human immunodeficiency virus.

*African context:* Countries in Africa, especially those in the sub-Saharan Africa.

*AIDS orphan:* The Namibian definition for children under the age of 18 who have lost a parent(s) or guardian(s) due to AIDS-related illnesses.

*Caregiver:* An individual who is taking care of OVC. These individuals are eligible to receive supports on behalf of OVC to provide for their basic needs.

*Caregiver burden:* Both subjective factors, such as feelings of being overwhelmed by demands of caregiving, and objective factors, such as task and financial burden (Bedard, Pedlar, Martin, Malott, & Stones, 2000)

*Caregiver outcomes:* Consequences experienced by caregivers who are faced with demanding stressors, such as those experienced by HIV/AIDS-affected elderly caregivers raising orphans and vulnerable children.

*Chronic illness:* An adult who has not been able to take part in basic household chores for at least 3 of the last 12 months (NDHS, 2006).

*Depression:* In this study depression is the mental health illness that caregivers manifest in symptoms that meet the threshold criteria (CES-D>16)

*Elderly:* An individual who is 60 years or older (Ssengonzi, 2007).

*Extended family:* Those residents who reside elsewhere whose relationships with each other are tied through kinship or affinity (Ansell & van Bleak, 2004).

*Food security:* When all people at all times have access to sufficient, safe, nutritious food to maintain a healthy and active life. It includes both physical and economic access to food that meets people's dietary needs as well as food preferences (WHO, 2012).

*Financial stability:* In this study financial stability denotes a state in which a caregiver has a comfortable amount of money to care for orphaned children in their care and themselves. It also means being able to acquire all basic necessities such as food, clothing, medical care and pay school fees for children in their care.

*Financial supports:* In this study financial support denotes monetary or cash assistance given to caregivers to cover for household needs for which they did not have to pay. These forms include, among others, money, food, healthcare, education, clothing, funeral costs, and transportation.

*HIV*: Human immunodeficiency virus.

*HIV/AIDS-caregiver*: Those who are caring for or recently cared for someone who was HIV-positive or were currently or recently caring for or raising someone affected by HIV/AIDS (Rajaraman, Earle, & Heymann, 2008).

*HIV-infected child*: Any child who is 18 years or younger who is also infected with the HIV/AIDS virus.

*Household*: Those who normally reside together and eat from the same pot (Ansell & van Bleak, 2004).

*Informational supports*: Essential knowledge about how to access welfare grants for OVC; knowledge about how to provide psychosocial support to OVC; knowledge about how to administer medication to an HIV-positive child; and knowledge about caregiver supports available in the community or village.

*Kin caregivers*: Individuals such as aunts, uncles, grandparents, cousins, and nephews who provide care and support to a child or children (who are related) in the home of the caregiver.

*Primary caregiver*: An individual who is most responsible for the day-to-day responsibilities of providing care and support to orphans and vulnerable children (Kipp, Tindyebwa, Karamagi, & Rubaale, 2007).

*Old age pension*: A universal grant for persons above the age 60.

*OVC - Orphans and vulnerable children*: The Namibian definition for children under the age of 18 whose mother, father, or both parents and primary caregiver have

died and /or are in need of care and protection (GRN/Ministry Gender Equality and Child Welfare [MGECW], 2007).

*Poor households:* Total number of households or proportion of population living below N\$377.96 per month (NAS/NIES, 2012).

*Poverty severity:* Both the depth of poverty (i.e., how far off the poor are from the poverty line) and inequality within the poor (i.e., how deep or severe the poverty is), placing a higher weight on those farther away from the poverty line (NAS/NIES, 2012, p. 10).

*Rural area:* An area with sparsely populated places, far from the influence of large cities and towns. These areas have limited available services and resources. In Namibia, these areas are referred to as villages or settlements (Nekundi, 2007).

*Social supports.* Any form of social assistance given to the caregiver to alleviate their caregiver burden. Assistance can be either by friend, family members, or significant other

*Supports:* Any form of assistance such as financial, social, or informational that is employed by caregivers to alleviate their caregiver burden.

*Vulnerable child:* Anyone below the age of 18 (whether orphaned or not) whose parent is very sick, who lives in a household where an adult is very sick, or in which a very sick adult died within the last 12 months (NDHS, 2006).

## CHAPTER 2: LITERATURE REVIEW

This literature review aims to (a) highlight African caregiving in general, (b) provide brief background on Namibia's population growth, poverty and inequality, and (c) discuss the current literature on orphan caregiving in the era of HIV/AIDS in sub-Saharan Africa.

### Context of African Caregiving

African life is known for its significant feature of large kin groups that transcend the nuclear family (Kayongo-Male & Onyango, 1984). Early ethnographers who studied African clans closely established that the extended family, especially grandparents, have been an important social support for members who are connected by virtue of reciprocal support obligations and responsibilities (Fortes, 1969; Kayongo-Male & Onyango, 1984). The elderly are important sources of wisdom, imparting knowledge, passing on traditional rules and regulations, and serving as mediators in conflict situations. Adult children, in turn, have a traditional obligation to provide support to their parents, grandparents, siblings, and children (Ncube et al., 1997). This expectation continues to be practiced among many people of these communities and is embedded in cultural norms and values. There are even proverbs that remind children of their parental and grandparent obligations. For example, the *Kwanyama* tribe in Namibia have a proverb that says: *Kahuhwena hadela nyoko, nyoko onale ekuhadela*. A literal translation in English means, "We have to help our parents/elders because they helped us."

Historically, fosterage, which means raising a child or children by someone other than the child's biological mother and father, has been a common traditional

practice across much of Africa (Kuyini, Alhassan, Tollerud, Weld, & Haruna, 2009).

Traditionally, children are viewed as a precious gift from God, and the entire clan has a responsibility to bring up each child. The saying, “It takes a village to raise a child,” has its roots in this philosophy (Clinton, 1996). Consequently, children are often given to extended family members or relatives not just to be provided with care and support but to be part of that family (Isiugo-Abanihe, 1985).

Today, grandparents in Africa continue to be at the heart of caregiving. For example, Zimmer and Dayton’s (2005) secondary data analysis of national demographic and health surveys (DHS) from 24 sub-Saharan countries showed that 8% of older adults live with a grandchild who has lost at least one biological parent, while 1.7% live with a grandchild who lost both parents, and HIV/AIDS was found to be the leading cause of death. In a recent study in rural South Africa, research showed that over 50% of grandparents were caregivers to double or single orphans (Beegle, Filmer, Strokes, & Tiererova, 2008) and that elderly caregivers lived in extended family households with their children, grandchildren, and often other dependents with an average of no fewer than four dependents per caregiver (Boon et al., 2009).

However, the nature of caregiving is being debated in the literature. Foster (2000), Lippman and James (1993), and Seeley and Kajura (1993) have argued that the “informal” caregiving system, or what is best known as the traditional African safety net, is not a “social sponge” with infinite capacity to absorb caregiving demands. They argued that amid already strained family resources, the AIDS epidemic is adding to caregivers’ burdens, affecting families, and depriving African elders of their normal sources of

income (i.e., remittance) and support (Foster, 2000; Lippman & James, 1993; Seeley & Kajura, 1993). Thus, some scholars have asserted that caregiving in the era of HIV and AIDS is changing the African family structure and its ability to cope with the plight of children orphaned by AIDS in Sub-Saharan Africa (Foster, 2000; Seeley & Kajura, 1993).

Northern Namibia (Ovamboland) is governed by a matrilineal system (Brown, 2011). In patrilineal societies, the primary responsibility of a man is to support his mother, siblings, and other next of kin rather than his wife and children. In matrilineal systems, children essentially belong to the mother's side of the family (Brown, 2011). It is not uncommon for patrilineal systems to take the property of the deceased member such as clothes, cattle, land, houses, money, or cars, among others (Kayono-Male & Onyango, 1984), often with little consideration of the welfare of the children and remaining family members. For example, a study of child- and youth-headed households in northern Namibia (Caprivi, Kavango and Omusati regions) revealed that after the death of their parents, some children and youth in these households experienced property loss at the hands of their paternal relatives, who left the children and youth with only basic kitchen utensils, clothes, and small personal items from their deceased parents (Ruiz-Casares, 2009).

### **Setting the Scene: Namibia at a Glance**

This section provides a brief background of Namibia. Specific attention will be paid to issues pertaining to the country's population growth, poverty, and inequality.

## **Population, Poverty, and Inequality**

Namibia has a population of just over 2.1 million people (National Planning Commission [NPC]/Census Report Preliminary Report, 2011). Situated in the southwestern corner of Africa, the country gained its independence from South African colonial rule and its apartheid regime in 1990. Since independence, the country has seen a substantial growth in its economy and is classified as an upper-middle income country by the World Bank (UNICEF/UNAIDS, 2011; World Bank, 2007). As such, the nation should be striving to meet higher-level needs and not merely seek to provide basic requirements such as food and other material needs (Namibia Statistics Agency [NSA], 2012). On the contrary, however, the country's social development has not kept pace with its strong national economic development (UNICEF/UNAIDS, 2011). Namibia continues to have the highest income inequality in the world, where poverty, unemployment, and inequality remain unchanged since the early 1980s (Schmidt, 2009; UNICEF/UNAIDS, 2011).

Reports revealed that close to 28% of Namibian households are classified as being poor, with 50% of these households severely poor (UNICEF/UNAIDS, 2011). Thirty-five percent of the population survives on US\$1/day and 56% on US\$2/day (Human Development Report, UNDP, 2006). It is worth noting that the country's pervasive inequality is not only evident in terms of income distribution between the richest 1% and poorest 50%. This trend is likewise revealed in access to basic public services such as electricity, sanitation, clean piped water, education, and health care facilities (NSA/Child Poverty in Namibia, 2012). Furthermore, the intersection of the lack of access to essential

basic services and poverty may have detrimental effects at the household level, especially on the ability of caregivers to provide needed care and support for OVC (UNICEF/UNAIDS, 2011).

### **Literature Review on Orphan Caregiving in the Era of HIV/AIDS**

The goal of this review is to synthesize what is known about elderly caregivers raising children orphaned by AIDS in sub-Saharan Africa and to identify gaps in knowledge to guide future research in this area. In organizing this review, studies were summarized by constructing a table presenting studies' authors, sites, sample size, sampling strategies, measures techniques, and salient research findings for each study selected for this review of the literature (see Table 1). Next, is a brief summary of the methodological characteristics of studies found in this review.

#### **Methodological Characteristics of Studies**

All studies examined for this literature review were conducted in Africa, with the majority of studies conducted in sub-Saharan Africa in countries including Botswana, Kenya, Malawi, Nigeria, South Africa, Togo, Uganda, and Zimbabwe. The majority of studies were from South Africa (20), Uganda (6), and Malawi (2). Based on the findings in this review, the majority of studies were qualitative (19), followed by quantitative studies (17), and mixed-methods studies (1). Qualitative studies ranged from semistructured interviews (Casale, 2011; Casale et al., 2013; Ogunmefun & Schatz, 2007), ethnographic studies (Seeley, Wolf, Kabunga, Tumwekwase, & Grosskurth, 2009), focus group discussions (Reddy, 2005), and one phenomenological study (Tshilio

& Davhana, 2009). There were in total 13 studies that used cross-sectional survey methods. Study size, methods, measures and findings are summarized in Table 1.

### **Salient Research Findings: State of Knowledge**

The existing literature revealed a number of emerging themes pertaining to the impact of HIV/AIDS on elderly caregivers. This section highlights salient research findings most prevalent in this review. The section also provides a critique of these studies with specific focus on the measures, sampling, and theory used in these studies.

#### **Mental Health and HIV/AIDS Caregiving**

Several studies examined the mental well-being of elderly caregivers. A growing number of studies have found significant differences between HIV-orphan caregivers and nonorphan caregivers (George et al., 2014; Moore & Henry, 2005; Oburu, 2005; Rajaraman et al., 2008; ). In general, the caregiving literature has documented that psychological trauma of depression is often related to caregiver responsibilities (Schulz & Beach, 1999). Evidence abounds demonstrating that caregivers, regardless of the cause of orphanhood, face multiple negative health outcomes, such as stress (Abasiubong et al., 2011; Kuo & Operario, 2010; Oburu & Palmerus, 2003; Ssengonzi, 2007) and depression (Kuo et al., 2012).

Ssengonzi's (2007, 2009) qualitative study in Uganda reported that elderly caregivers experienced anxiety about their future health and well-being. Caregivers' anxiety was related to their daily struggle to meet school-related expenses and provide full-time care to younger AIDS-orphaned children (Ssengonzi, 2007, 2009). Similarly, Kagotho and Ssewamala's (2012) cross-sectional survey of 297 participants found that

the majority of AIDS-orphaned caregivers suffered from depression, particularly due to a lack of social support. Additionally, other scholars found that caregivers raising OVC in HIV-endemic communities experienced loneliness, sense of failure, intense grief, and loss (Boon et al., 2010; Thupayagale Tshweneagae, 2008); had higher levels of poorer health and chronic illness (Chepngeno-Langat, Falkingham, Madise, & Evandrou, 2010; Govender et al., 2011; Kipp, Tindyebwa, Karamagi, & Rubaale, 2007; Kruger & Wentzel-Viljeon, 2011; Muliira & Muliira, 2011); suffered from posttraumatic stress (Kuo & Operario, 2011); were more likely to be concerned that children were not receiving adequate academic support; indicated that children in their care needed help for physical, mental, or behavioural problems (Govender et al., 2011; Olley, 2008; Oburu & Palmerus, 2003; Reddy, 2005); and had less help and appeared to be overwhelmed with the magnitude and multiplicity of caregiving responsibilities (Govender et al., 2011; Lindsey, Hirschfeld, Tlou, & Ncube, 2003). Furthermore, families affected by HIV/AIDS face an even greater number of stressors when confronted with issues of stigma (Lindsey et al., 2003; Moore & Henry, 2005; Ogunmefun, Gilbert, & Schatz, 2011; Thomas, 2006).

Kuo et al.'s (2012) study in Umlazi Township, South Africa, examined the prevalence of depression in a sample of 1599 adults who were primary caregivers from four subgroups: AIDS-orphan caregivers, other-orphan caregivers (e.g., caregivers of children lost parent[s]) through other health reason (excluding HIV/AIDS), traffic accidents, and violence. The study found 30% of the participants reached the clinical threshold of depression, regardless of whether they were caregivers of AIDS-orphaned children or other-orphaned children. A Ugandan study focusing on the challenges faced

by elderly caregivers showed that caregivers reported experiences of emotional distress (Ssengonzi, 2007). Similarly, a study in Kenya, one of the few studies that specifically examined stress outcomes among the elderly with respect to orphan caregiving, found that primary caregivers reported high levels of distress (Oburu & Palmerus, 2005). It is evident that scholarship on the mental health outcomes, particularly distress and depression, of caregivers raising children orphaned by AIDS is growing in this region.

**Measures.** In this review the majority of studies that examined the mental health of elderly caregivers used established measures and scales to assess the negative outcomes experienced by caregivers, but the same measures were not used across studies. The commonly used measure of depression was Radloff's (1977) Center for Epidemiological Studies Depression scale (Kuo & Operario, 2011; Kuo, Operario & Cluver, 2012). Other studies used the Geriatric Depression Scale (Boon et al., 2010a), Hopkins Symptom Checklist-25 (Boon et al., 2009), Zung's (1965) Self-Rating Depression Scale (Abasiubong et al., 2011), and the Shona Symptom Questionnaire (Skeen et al., 2014). Several scales were used to measure other negative outcomes of caregivers. These include Zarit and colleagues' (1980) Burden Interview (Kidman & Thurman, 2014), the Anticipatory Grief Scale (Boon et al., 2010a), and the Parenting Stress Index-short form (Oburu & Palmerus, 2005). Using literature in the field of HIV/AIDS caregiving, some researchers also developed instruments to measure caregiver burden (Boon et al., 2010b; Littrell et al., 2012). The use of established measures provides greater confidence in the validity and reliability of research findings. In addition, studies that use the same measures can be easily compared with one another,

allowing for more in-depth comparative examination of sample-specific findings across studies.

**Sampling.** Several of the studies that examined negative outcomes of caregivers, including depression, used quantitative cross-sectional designs (Abasiubong et al., 2011; Boon et al 2010; Boon et al , 2009; Kuo & Operario, 2011, 2012). A study used national probability samples from 22 countries in sub-Saharan Africa, including Namibia, to examine how older people in Africa have been affected by the HIV/AIDS epidemic and how the epidemic has altered the living arrangements and supports of the elderly in the region (Kautz et al., 2012). The majority of studies used purposive, convenience, and snowball samples. Generally, the use of purposive and convenience sampling strategies limit generalizability and comparability across studies. Participants were recruited from informal settlements, health clinics, and rural villages. The size of samples varied from studies including only nine caregivers (Casale, 2011; Hlabyago & Ogunbanjo, 2009) to studies with as many as 2993 (Kuo & Operario, 2011; Kuo et al., 2012). There were 12 studies with fairly large samples (greater than 100) that could be used to compare populations among studies (Abasiubong et al., 2011; Boon et al., 2010a, 2010b; Boon et al., 2009; George et al., 2011; Heymann et al., 2007; Ice et al., 2008; Kidman & Thurman, 2014; Kuo & Operario, 2011; Kuo et al., 2012; Littrell et al., 2012; Oburu & Palmerus, 2003).

**Theory.** Only one study in this review used a conceptual model of stress-coping (Oburu & Palmerus, 2005). The double ABCX stress-coping model was used to examine whether the total stress experienced elderly caregivers raising children affected by HIV

and AIDS was mediated by the availability of family resources (i.e., social and instrumental support) and the caregivers' perception of child manageability of behavioural challenges (Oburu & Palmerus, 2005). The majority of studies were atheoretical, relying heavily on empirical generalization. In other words, many of the studies lacked a theoretical underpinning and were overall exploratory. Although emerging evidence has suggested that empirical research on elderly caregivers' mental well-being and HIV/AIDS caregiving is slowly growing in sub-Saharan Africa, no publication was found that examined the prevalence of mental health, specifically depression, among caregivers of children orphaned by AIDS in Namibia.

### **Supports and HIV/AIDS Caregiving**

In this review a large body of literature points to the importance of providing supports to caregivers raising children orphaned by HIV and AIDS (Hlabyago & Ogunbanjo, 2009; Lekalakala-Mokgele, 2012; Reddy, 2005; Schatz, 2007; Seeley & Kajura, 1993). Kagotho and Sswamala's (2012) study in Uganda was one of the few studies that examined the factors that influence depression of caregivers of children orphaned by AIDS. Their study of caregivers raising children affected by HIV/AIDS in rural Uganda showed that economic status and social supports for caregivers was highly correlated with caregivers' levels of depression (Kagotho & Sswamala, 2012). In addition, researchers have examined the importance of social support for caregivers raising children affected by HIV and AIDS (Kuo et al., 2012; Kuo, Fitzgerald, Operario, & Casale, 2012; Myint & Mash, 2008; Okaw et al., 2011); financial supports, such as child maintenance grants or microlending loans to start small income-generating projects

(Plageron, Patel, Harpham, Kielmann, & Mathee, 2011; Schatz & Ogunmefun, 2007); material support, such as food, clothing, blankets, and school uniforms (Nyambedha, Wandibba, & Aagaard-Hansen, 2003); and medical supports (Schatz et al., 2011).

However, emerging evidence has suggested that supports' for caregivers from the social environment is insufficient to meet the needs of HIV-affected families (Lekalakala-Mokgele, 2012; Reddy, 2005; Schatz, 2007; Seeley & Kajura, 1993). Hlabyago and Ogunbanjo's (2009) study of caregivers of AIDS-orphaned children showed that caregivers reported a lack of assistance from social support services and a lack of support from other extended family relatives. Similarly, Orner (2006) examined a sample of caregivers of people living with AIDS in South Africa and reported that caregivers identified various supports that would have a positive impact on their caregiving role and mental well-being. These resources included, among others, acknowledgement for their work as caregivers, financial and material support (especially for those who were unemployed), sufficient food, counseling, respite care, and psychosocial support from health care providers (Orner, 2006).

A study in Botswana found that caregiving often prevented adults from working full-time or earning their previous level of income (Heymann & Kidman, 2009). Similarly, a study in Malawi on family resources needed by caregivers found that 75% of children's families received assistance from a social network, but that the financial support provided was equivalent on average to a meager US\$81 annually (Kidman & Heymann, 2009). A recent study, the Effectiveness of Child Welfare grants in Namibia (GRN/Ministry of Gender Equality and Child Welfare [MGECW], 2010) reported that

caregivers in many parts of the country are unaware of the available governmental assistance (i.e., foster care grants).

A review of 32 studies on survival strategies employed by HIV/AIDS-affected households found that many caregivers reported having to sell their assets, including land and property, or using their savings to support OVC in their care (Naidu & Harris, 2005). The lack of free treatment and affordable, accessible medication adds to caregivers' financial burden (Mathambo & Gibbs, 2009). It is not uncommon for grandparents to depend primarily on their government-funded pensions. Studies have shown that the elderly often have no choice but to use their monthly state pension to supplement household income to buy food, clothing, and shelter; pay school fees; and provide transportation as well cover funeral costs and medical expenses (Moore, 2007-2008; Schatz & Ogunmefun, 2007). Due to preexisting conditions of poverty and extremely high rates of unemployment common in much of southern Africa, the elders' pension is often the most stable and reliable income for many households (Ogunmefu & Schatz, 2009). Thus, pensions are an important safety net in southern Africa, serving to mitigate the many consequences that elderly could suffer when their adult child dies and leaves behind OVC (Ardington et al., 2010).

Strengths of the studies that examined the critical role of supports in HIV/AIDS caregiving included drawing attention to elderly caregivers in the developing world where the AIDS epidemic has had a disproportionate impact to those who were caring for their sick and dying adult child while raising AIDS orphans. In addition, 22 studies explored the financial, physical, mental, and/or social vulnerabilities experienced by

elderly caregivers. Another strength included the 19 qualitative studies that employed multiple methods to triangulate data. It is evident that supports for elderly caregivers are critical for the survival of households headed by the elderly, especially those affected by the AIDS epidemic. However, in this review no publication was found that explored supports of this population in rural Namibia.

**Measures.** Unlike in the studies that examined the mental well-being of caregivers, the majority of studies that investigated supports for this population did not use established measures. Only one study was found that employed the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988) to capture social support disparities among caregivers of AIDS-orphaned children (Kuo et al., 2012). Most of the studies relied on open-ended questions to capture the nature of economic or financial resources of caregivers (Hlabyago & Ogunbanjo, 2009; Kamya & Poindexter, 2009; Moore, 2007-2008; Ogunmefun & Schatz, 2009; Reddy, 2005; Schatz & Ogunmefun, 2007; Schatz et al., 2011; Ssengonzi, 2007;). Other researchers developed their own scales, using multiple items to assess financial resources through Likert-scale responses (Boon et al., 2010; Kidman & Thurman, 2014; Kuo & Operario, 2011; George, Govender, Bachoo, Penning & Quinlan, 2014). No publication in this review was found that utilized an established instrument to measure financial stability or resources. Studies that explored knowledge/informational supports of caregivers typically asked participants if they had knowledge about accessing government social grants or caring for an HIV-infected child through open-ended questions (Boon et al., 2010; Skovdal, Campbell, Madanhire, Nyamukapa & Gregson, 2011).

Although studies in this review have drawn attention to the critical role of supports for caregivers raising children orphaned by AIDS, there was no publication found that examined the relationship between depression and supports among this population. A general weakness of studies was the lack of theoretically framed approaches to guide research on HIV and AIDS caregiving in this region. Only a few studies found in the literature have focused on the extended family childcare arrangements of children affected by HIV and AIDS (Chirwa, 2002; Kuo, 2007).

In summary, this review revealed several trends among caregivers raising AIDS-orphaned children in sub-Saharan Africa. First, grandparents, particularly elderly grandmothers, have generally stepped in to become primary caregivers to OVC. Second, evidence has suggested that the HIV/AIDS pandemic has altered the contours of living arrangements among the African family and has created a “missing generation” (Foster, 2000). Third, the literature revealed the gendered patterns of caregiving. Fourth, the caregiving experience in the era of HIV and AIDS can impose myriad challenges on caregivers. Fifth, the multiple challenges that compound elderly caregiving may be attributed to the lack of caregiver supports, consequently pushing elders beyond their capacities to care for AIDS-orphaned children.

**Sampling.** The majority of the studies examining supports used convenience and purposive sampling designs and were qualitative. Participants were recruited from informal settlements, health clinics, rural villages, support groups, and churches. Generally, when samples are small and not random, it becomes a challenge to make inferences about the nature and characteristics of the population. Thus, issues of external

validity become a concern for future studies. Small purposive or convenience samples may be the result of the sensitive nature of this topic and/or of the challenges that may come with recruitment. However, it is important to give some credibility to these findings that offer researchers with preliminary results that could be used in future studies in this area.

Table 1

*Summary of Studies Included in Literature Review*

| <b>Reference</b>        | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b>               | <b>Sample</b>  | <b>Measures</b>  | <b>Salient Findings</b>  |
|-------------------------|-------------------|-----------------------|-----------------------------------|--|--|--|
| Abasiubong et al., 2011 | Nigeria           | 293                   | Cross-sectional survey            | Caregivers of people living with HIV/AIDS. A total of 293 caregivers of whom 98 males & 195 females were analyzed. | Zung's Self – Rating Depression Scale (SDS) & Self-Report Questionnaire (SRQ-20) | Study found that 134 caregivers had anxiety only, 23 depression only, 52 had a mix of anxiety and depression, and 11 exhibited suicidal tendencies. There is increasing level of stress in caregivers.   |
| Ardington et al., 2010  | South Africa      | 2993                  | Secondary analysis of survey data | Representative sample of Colored & older African adults aged 50 & older in metropolitan Cape Town                  | Survey instrument /questionnaire   | Grandparents play a key role in caring for grandchildren who are orphaned due to AIDS deaths. The study findings show that this burden does not have significant effects on these grandparents' quality of life. An obvious caveat is that this result is due to the unique features of the South African social safety net. |

| <b>Reference</b>   | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b>    | <b>Sample</b>  | <b>Measures</b>   | <b>Salient Findings</b>   |
|--------------------|-------------------|-----------------------|------------------------|--|---|---|
| Boon et al., 2010a | South Africa      | 820                   | Cross-sectional survey | Convenience sample of isiXhosa-speaking adults aged 60 years & older providing care to children & grandchildren as a result of HIV/AIDS. Recruited from Uitenhage & Motherwell informal settlements in Eastern Cape Province of South Africa | Grief was measured using the Anticipatory Grief Scale. Depression was assessed with the Geriatric Depression Scale. Coping was assessed using the Ways of Coping Scale and stigma related to HIV and AIDS | Elderly caregivers were found to be involved in a wide range of activities & caring for multiple dependents. Grief among elderly caregivers was reported to be strongly predicted by perceived stigma around HIV & AIDS & worries about caring for OVC. |

| Reference          | Study Site   | Study Size (n) | Study Design           | Sample   | Measures   | Salient Findings   |
|--------------------|--------------|----------------|------------------------|--|--|--|
| Boon et al., 2010b | South Africa | 401            | Cross-sectional survey | Convenience sample of isiXhosa-speaking adults aged 60 years & older, caring for their sick adult children and/or grandchildren as a result of HIV/AIDS. Recruited from Uitenhage and Motherwell informal settlements in Eastern Cape Province of South Africa | Survey instrument/questionnaire developed based on existing literature   | Study found that perceived ability among elderly caregivers to provide care was primarily dependent on their level of knowledge on accessing grants and personal norm towards providing care.  |
| Boon et al., 2009  | South Africa | 202            | Cross-sectional survey | Convenience sample of 202 isiXhosa-speaking adults aged 60 years & older looking after sick or orphaned children or grandchildren as result of AIDS. Recruited from Uitenhage & Motherwell informal settlements in Eastern Cape Province of South Africa       | Depression was assessed using the Hopkins Symptom Checklist-25. Ways of coping was assessed using the Ways of Coping Checklist | Elderly caregivers who participated in all the training sessions on how to provide care for grandchildren and adult children living with HIV & AIDS were more likely to have a more positive attitude towards people living with HIV and AIDS. |

|              |              |   |                   |  |                            |  |
|--------------|--------------|---|-------------------|--|----------------------------|--|
| Casale, 2011 | South Africa | 9 | Qualitative study | <p>Purposive &amp; snowball sampling method was used. Inclusion criteria: At least one primary caregiver present in household, at least two children in household &amp; one younger than 12 years of age.</p> <p>Respondents' age range between 30 &amp; 90 years of age. Respondents were recruited from Amajuba district KwaZulu-Natal Province, South Africa.</p> | Semi-structured-interviews | <p>Two contextual themes were explored, focusing mainly on older (grandmother) caregivers: (a) their strength and resourcefulness in responding to adversity to ensure families' survival and (b) their leadership role in confronting HIV &amp; related stigma within their own families (p. 1265). Study found that the elders were not merely 'rural passive grandmothers' or 'absorbing' gradual change of the HIV/AIDS crises. Rather they were responding to and engaging with the AIDS crises using human and financial resources at their disposal to care for their families.</p> |
|--------------|--------------|---|-------------------|--|----------------------------|--|

| <b>Reference</b>    | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b> | <b>Sample</b>  | <b>Measures</b>                     | <b>Salient Findings</b>  |
|---------------------|-------------------|-----------------------|---------------------|--|-------------------------------------|--|
| Casale et al., 2013 | South Africa      | 12                    | Qualitative study   | 12 HIV-positive primary caregivers of children living in an HIV-endemic, low-resourced, urban South African community. | In-depth semi-structured interviews | Study found that health interventions should seek to combine both emotional & tangible support. Support interventions should pay particular attention to the qualities of support providers and the caregiver's relationship to these providers. |

| Reference           | Study Site   | Study Size ( <i>n</i> ) | Study Design           | Sample  | Measures          | Salient Findings  |
|---------------------|--------------|-------------------------|------------------------|---|-------------------|---|
| George et al., 2011 | South Africa | 616                     | Cross-sectional survey | Random stratified cluster sampling based on age & school registration of “recent” orphans. Study compared the effects of economic burden of childcare in the context HIV and AIDS. By comparing orphan households ( <i>n</i> =153); mixed households or orphan& non-orphan households ( <i>n</i> =135); and non-orphan households ( <i>n</i> =336). Respondents were recruited from Amajuba District KwaZulu-Natal, South Africa. | Survey instrument | Study found that the situation was one of dire poverty in which over 60% of households fell below the poverty line. Social grants from government were found to be an economic safety for many households |

| Reference            | Study Site | Study Size (n) | Study Design           | Sample  | Measures            | Salient Findings  |
|----------------------|------------|----------------|------------------------|---|---------------------|---|
| Heymann et al., 2007 | Botswana   | 1033           | Cross-sectional survey | Sample of working adults caring for AIDS orphans in three locations in Botswana: Gaborone, Lobatse, and Molepolole. | Face-to-face survey | Findings showed that over one third of working adults were caring for orphans, many with limited financial resources. Almost half of caregivers found it challenging to meet the needs of orphans.<br>(table continues) |

| Reference                  | Study Site   | Study Size ( <i>n</i> ) | Study Design      | Sample   | Measures                       | Salient Findings  |
|----------------------------|--------------|-------------------------|-------------------|--|--------------------------------|---|
| Hlabyago & Ogunbanjo, 2009 | South Africa | 9                       | Qualitative study | Purposeful sample of nine family caregivers, mostly grandmothers (67%). Respondents were recruited from Hoekfontein Clinic, North West Province, South Africa. | One-on-one in-depth interviews | Study aimed to capture the lived experiences of caregivers raising AIDS orphans. Emergent themes from the study were “poverty and lack of money; bureaucratic difficulties & the lack of assistance from the social support services; lack of support (financial, physical & emotional) from other family members; frustrations of coping with rebellious orphans; pain of caring for the terminally ill; feelings of despondency; conflicts in the family; and the rejection of orphans by their fathers” (p.506). |

| Reference        | Study Site | Study Size ( <i>n</i> ) | Study Design           | Sample  | Measures   | Salient Findings   |
|------------------|------------|-------------------------|------------------------|---|--|--|
| Ice et al., 2008 | Kenya      | 287                     | Cross-sectional survey | Caregiver ( <i>n</i> =143) & noncaregiver ( <i>n</i> =144).<br>Inclusion criteria: 60 years or older; must be a grandparent; & must be caregiver for at least one child or grandchild | Subjective measures include perceived health & functional status (including mental health & distress) measured with the SF-36 (MOS Short-Form 36);<br>Objective measures include anthropometric measurements, blood pressure, and hemoglobin levels. | This study examined the health & health perceptions of grandparents raising HIV/AIDS affected orphans. Findings found that caregiving was significantly associated with mental health. The mental health of caregivers was reported to be better than those of non-caregivers. |

| Reference                 | Study Site | Study Size (n) | Study Design        | Sample   | Measures   | Salient Findings  |
|---------------------------|------------|----------------|---------------------|--|--|---|
| Kagotho & Ssewamala, 2012 | Uganda     | 297            | Longitudinal survey | Caregivers of AIDS-orphaned children in two rural communities heavily affected by AIDS in Uganda- Rakai and Masaka districts.  | The study used the baseline data from the Suubi-Maka study and used the ordinary least squares regression methods. | Caregiver's economic status & social support system were highly correlated with caregiver's depression scores. Caregivers with cash savings and a strong family support system reported better depression scores.   |
| Kamya & Poindexter, 2009  | Uganda     | 11             | Qualitative study   | Sample of older women/ grandmothers who are raising orphans because of a parent's death from HIV infection. Participants were recruited from the Entebbe-Kampala area in Uganda. | In-depth interviews  | Study investigated stresses & strengths of HIV-affected grandmothers. Themes emerging from the study include "extreme economic deprivation; feeling physically challenged with caregiving; concern for the welfare of children in their care; & struggling to cope through action, resilience, and relationships" (p. 5). |

| Reference          | Study Site | Study Size (n) | Study Design        | Sample   | Measures   | Salient Findings   |
|--------------------|------------|----------------|---------------------|--|--|--|
| Kautz et al., 2010 | Africa     | 123<br>176     | Longitudinal survey | A sample of 123,176 individuals over the age of 60 from 22 African countries | Investigated how three measures of the living arrangement of older people have been affected by the HIV/AIDS epidemic: The number of older individuals living alone, The number of older individuals living only with dependent children under the age of 10 and the number of adults age 18-59 per household where an elderly person lives. | Increase in annual AIDS mortality of one death per 1000 people was associated with a 1.5% increase in the proportion of older individuals living alone and a 0.4% increase of older individuals living in missing generation households. Findings suggest that in countries that encompass 70% of the sub-Saharan population, the HIV-AIDS epidemic could be responsible for 582,200-917,000 older individuals living alone without prime age adults & 141,000-323,100 older individuals being the sole caregivers for young children. |

| Reference              | Study Site   | Study Size ( <i>n</i> ) | Study Design           | Sample   | Measures                   | Salient Findings  |
|------------------------|--------------|-------------------------|------------------------|--|----------------------------|---|
| Kidman & Thurman, 2014 | South Africa | 726                     | Cross-sectional survey | Primary caregivers of all adolescents aged 14-17 who were then currently enrolled in the Networks Hope program. From a total of 876 caregivers who participated in the baseline survey, 726 (83%) were fostering an orphan; that group of 726 was taken as the sample. | The Zarit Burden Interview | Approximately 40% of caregivers reported high levels of orphan caregiving burden. Feelings of stress and inadequacy concerning their care responsibilities as well as anger towards the child are common. Household food insecurity was the most important predictor of orphan caregiving burden. Income was also a significant determinant. When AIDS impacts were added to the model, only the AIDS-related illness of the caregiver was significantly associated with burden. This study suggests that caregivers with economic vulnerability and those struggling with their own AIDS-related illness feel most overburdened. |

| <b>Reference</b>  | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b> | <b>Sample</b>  | <b>Measures</b>     | <b>Salient Findings</b>   |
|-------------------|-------------------|-----------------------|---------------------|--|---------------------|---|
| Kipp et al., 2007 | Uganda            | 16                    | Qualitative study   | Family caregivers of AIDS patients. Sample was drawn from a list of home-based care program in three rural districts in western Uganda. Only participants with care experiences of least one year were recruited. A total of 16 caregivers, 12 females and 4 males, made up the sample | In-depth interviews | Study examined the burden & health related issues of family caregivers. Study found that family, friends, & churches in the community provided most support to AIDS patients. Family caregivers were predominately elderly women and young girls. |

| Reference            | Study Site   | Study Size ( <i>n</i> ) | Study Design           | Sample  | Measures  | Salient Findings   |
|----------------------|--------------|-------------------------|------------------------|---|---|--|
| Kuo & Operario, 2011 | South Africa | 1599                    | Cross-sectional survey | Representative sample of adult primary caregivers of AIDS-orphaned children. Multistage cluster sampling of HIV/AIDS orphan caregivers. Of sample, 359 were orphan caregivers, 171 were caregivers of children orphaned by other causes, and 1069 were caregivers of nonorphan children. Respondents were recruited from Umlazi Township in KwaZulu Natal, South Africa | Depression was assessed using the Center for Epidemiological Studies Depression Scale (CES-D). Anxiety was assessed using the Kessler Scale (K10). Post-traumatic stress disorder (PTSD) was assessed using the Harvard Trauma Questionnaire (HTQ). | There was a significant difference between caregivers of orphaned children & nonorphan caregivers. Caregivers of AIDS orphaned children reported poorer general health & functioning and had higher rates of depression and post-traumatic stress compared with caregivers of non-orphaned children. |

| Reference        | Study Site   | Study Size ( <i>n</i> ) | Study Design           | Sample   | Measures   | Salient Findings  |
|------------------|--------------|-------------------------|------------------------|--|--|---|
| Kuo et al., 2012 | South Africa | 1599                    | Cross-sectional survey | Representative sample of adult primary caregivers of AIDS-orphaned children. Multistage cluster sampling of HIV/AIDS orphan caregivers. Of sample, 359 were orphan caregivers, 171 were caregivers of children orphaned by other causes, and 1069 were caregivers of non-orphan children. Respondents were recruited from Umlazi Township in KwaZulu Natal, South Africa | Depression was assessed using the Center for Epidemiological Studies Depression Scale (CES-D). | This study explored the prevalence of depression among caregivers of AIDS orphans. Study compared depression among three groups: AIDS-orphan caregivers, other orphan caregivers (i.e., of children orphaned by non-AIDS causes such as violence, traffic accidents, & other reasons). Findings showed orphan caregivers, regardless of whether they cared for AIDS-orphaned and other orphaned children, were significantly more likely to meet the clinical threshold of depression than non-orphaned caregivers. |

| Reference        | Study Site   | Study Size (n) | Study Design           | Sample   | Measures   | Salient Findings   |
|------------------|--------------|----------------|------------------------|--|--|--|
| Kuo et al., 2012 | South Africa | 1599           | Cross-sectional survey | Representative sample of adult primary caregivers of AIDS-orphaned children. Multistage cluster sampling of HIV/AIDS orphan caregivers. Of sample, 359 were orphan caregivers, 171 were caregivers of children orphaned by other causes, and 1069 were caregivers of non-orphan children. Respondents were recruited from Umlazi Township in KwaZulu Natal, South Africa | Multidimensional Scale of Perceived Social Support (MSPSS) | The study sought to investigate whether perceived social support varied among the three groups. Findings revealed that caregivers of AIDS-orphaned children reported significantly lower levels of support compared with caregivers of other orphaned children & nonorphan children after controlling for sociodemographics. |

| Reference             | Study Site | Study Size ( <i>n</i> ) | Study Design                        | Sample   | Measures   | Salient Findings  |
|-----------------------|------------|-------------------------|-------------------------------------|--|--|---|
| Littrell et al., 2012 | Malawi     | 1,219                   | Longitudinal survey (Mixed methods) | Comparison of caregiving experiences among older & younger caregivers. Age range 56 to 80 (median 73). | Qualitative study: Ethnographic with in-depth interviews & focus groups ( <i>N</i> =62) & group discussions ( <i>N</i> =4).<br>Quantitative study: Survey instrument | Compared to younger caregivers, elderly caregivers were reported to be more stable as primary caregivers for orphans. However, their caregiving was threatened by multiple challenges such as provision of food. Older caregivers also reported poorer health status; however, levels of emotional distress & social capital were similar among older & younger caregivers. |

| Reference            | Study Site | Study Size ( <i>n</i> ) | Study Design      | Sample  | Measures | Salient Findings   |
|----------------------|------------|-------------------------|-------------------|---|----------|--|
| Lindsey et al., 2003 | Botswana   | 70                      | Qualitative study | Convenience sample<br>70 respondents.<br>Respondents included: family caregivers of people living with AIDS, key informants (i.e., community home-based care members)<br>Of 35 interviewed, 15 were caring for one or more family members with HIV/AIDS, and 20 were caring for family member with a chronic/terminal illness. Participants were recruited from three districts in Botswana (Kweneng, Kgatleng, and Old Naledi) |          | The exploratory & descriptive study examined the experiences of elderly & young caregivers caring for family members living with HIV/AIDS. Caregivers reported feeling overwhelmed in their caregiving role; were exhausted, malnourished, depressed; & often were neglectful of their own health. Younger caregivers reported having to miss school because of caring responsibilities. Elderly & young caregivers experienced social isolation, stigma, psychological distress, poverty, and a lack of basic caregiving education. |

| Reference        | Study Site | Study Size ( <i>n</i> ) | Study Design      | Sample   | Measures            | Salient Findings   |
|------------------|------------|-------------------------|-------------------|--|---------------------|--|
| Moore, 2007-2008 | Togo       | 7                       | Qualitative study | Poor adult parents & grandparents aged 50 and older (7 female; 2 male) who lost an adult child due to AIDS. Respondents were mostly farmers. Three participants were widowed, 2 were married, 2 divorced. All participants except one cared for grandchildren left behind. 6 of the grandchildren had HIV/AIDS. Participants were recruited from Lome and surrounding areas. | In-depth interviews | Caregivers reported experiencing four kinds of challenges: financial & social difficulty, psychological difficulty, caregiving difficulty, & disclosure difficulty. Socioeconomic challenges due the loss of financial providers were taxing on many caregivers. |

| Reference              | Study Site | Study Size ( <i>n</i> ) | Study Design           | Sample  | Measures   | Salient Findings   |
|------------------------|------------|-------------------------|------------------------|---|--|--|
| Nyambedha et al., 2003 | Kenya      | 565                     | Qualitative study      | Data were derived from a survey of 100 caretakers of orphans and 465 households, which were headed by a person aged 55 years or more  | In-depth interviews, questionnaires, narrative, focus group discussions, observations, & semi-structured interviews  | Findings reveal that relatives cared for most orphans. About one out of five caretakers were 55 years of age or above. Elderly caretakers faced major difficulties in caring for the orphans in terms of schooling, food, and medical care.  |
| Oburu & Palmerus, 2003 | Kenya      | 241                     | Cross-sectional survey | 128 full-time & 113 part-time caregiving grandmothers of 1- to 10-year old grandchildren. Age range of caregivers was between 42-82 years. Participants were recruited from rural areas of Rachuonyo district of Nyanza Province, Kenya | Parental Discipline Interview (PDI) was used to assess disciplinary strategies; Parenting Stress Index short form (PSI-SF) was used to assess stress from individuals' perceptions of their own incompetence, role restrictions, social isolation, depression, and relationship problems | Findings revealed that full-time caregiving grandmothers experienced significantly higher levels of stress than their counterparts, part-time grandmothers. Caregivers' stress was related to participants' perceptions of child behavioral difficulties and limited instrumental support. |

| <b>Reference</b>         | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b> | <b>Sample</b>   | <b>Measures</b>            | <b>Salient Findings</b>   |
|--------------------------|-------------------|-----------------------|---------------------|---|----------------------------|---|
| Ogunmefun & Schatz, 2009 | South Africa      | 30                    | Qualitative study   | 30 women aged 60-75 years in the MRC/Univ. of Witwatersrand (Agnicourt) who act as caregivers for the sick and orphaned | Semi-structured interviews | The study shows that when there is an illness in the family, older women take up the responsibility of giving care to the sick and the children of the sick. They take over physical as well as financial responsibilities. These expenses go beyond the amount of their pensions, and they make sacrifices that sometimes leave them vulnerable to financial hardship. |

| Reference                | Study Site   | Study Size (n) | Study Design      | Sample   | Measures            | Salient Findings   |
|--------------------------|--------------|----------------|-------------------|--|---------------------|--|
| Ogunmefun & Schatz, 2011 | South Africa | 60             | Qualitative study | 60 women aged 50-75. Sample drawn from the <i>Gogo</i> Project in the MRC/Wits Rural Public Health & Health Transitions Unit (Agincourt) in South Africa. Of the 60 women in the sample, 19 had acted as a caregiver to someone who was HIV-positive | In-depth interviews | Study explored older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. Findings show that older caregivers experienced various forms of secondary stigma as “isolation and separation from family members; voyeurism, verbal sigma in the form of being gossiped about, and finger pointing” (p. 86). |
| Orner, 2006              | South Africa | 45             | Qualitative study | Purposive and snowball sampling methods were used. 45 primary caregivers age 18 years and older, with an average age of 40. Of all respondents, 43 were women  | In-depth interviews | This study explored the psychosocial impacts at household level on caregivers of people living with AIDS. Study reported that caregiving placed high demands on caregivers, which were exacerbated by insufficient support, dire poverty, lack of basic resources, & stigma  |

| Reference   | Study Site   | Study Size (n) | Study Design      | Sample  | Measures                       | Salient Findings   |
|-------------|--------------|----------------|-------------------|---|--------------------------------|--|
| Reddy, 2005 | South Africa | 89             | Qualitative study | Elderly caregivers caring for adult HIV-infected child and raising orphaned grandchildren. Respondents were recruited from townships in South Africa: Motherwell Township, Port Elizabeth, KwaNobuhle Township and Uitenhage. | Focus groups <sup>a</sup> (12) | The study examined the scope of elderly caregiving as well as the social, psychological, & economic factors that facilitate or inhibit caregivers' ability to provide quality care to family members. Themes include "the elderly provide a variety of care services to a range of dependents; the elderly must carry out multiple parenting roles; pensions & grants are a vital sources of income for the elderly; social and community activities are important sources of support for the elderly; & the elderly feel that they have little influence on the behavior of the youth" (p.2-5). |

| <b>Reference</b>    | <b>Study Site</b> | <b>Study Size (n)</b> | <b>Study Design</b> | <b>Sample</b>   | <b>Measures</b>     | <b>Salient Findings</b>   |
|---------------------|-------------------|-----------------------|---------------------|---|---------------------|---|
| Schatz et al., 2010 | South Africa      | 16                    | Qualitative study   | Female households from the AIDS-death stratum, households currently or recently providing care to someone sick with AIDS related illness, households affected by the AIDS-death of kin outside the household, and/or households providing care for fostered children whose mother and/or father likely have/had AIDS. | In-depth interviews | Findings reveal substantial heterogeneity among rural female-headed households and their access to resources to combat AIDS-related hardship. Struggling households have weak social connections & more difficulty coping with AIDS-related disruptions. Those that lack support from important relatives are challenged more and rely heavily upon government-sponsored child grants and pensions. |

| Reference                | Study Site   | Study Size ( <i>n</i> ) | Study Design      | Sample  | Measures                   | Salient Findings  |
|--------------------------|--------------|-------------------------|-------------------|---|----------------------------|---|
| Schatz & Gilbert, 2011   | South Africa | 30                      | Qualitative study | 30 women over the age of 60 in rural South Africa   | In-depth interviews        | Findings show that women view their own physical, mental, & social wellbeing as impaired and make use of a variety of health and help-seeking behaviors to feel better. However, poverty and the unavailability of health resources shape older women's constructions of the meaning of their health. |
| Schatz & Ogunmefun, 2007 | South Africa | 30                      | Qualitative study | A sample of 30 elderly women from the MRC/Wits Rural Public Health & Health Transitions Unit (Agincourt) in South Africa, aged 60-75, who were eligible for pension | Semi-structured interviews | This study explored the role of older women's coping strategies in households affected by HIV and AIDS in rural South Africa. Older women's pensions were a critical & a reliable source of household-income, regardless of the households' mortality profiles.                                       |

| Reference           | Study Site            | Study Size ( <i>n</i> ) | Study Design                     | Sample   | Measures  | Salient Findings  |
|---------------------|-----------------------|-------------------------|----------------------------------|--|---|---|
| Seeley et al., 2008 | Uganda                | 8                       | Qualitative study (Longitudinal) | Eight people in advanced old age living in rural Uganda who were informants in an ethnographic study of the impact of HIV & AIDS on households during 1991-92 & again 2006-07. | Case studies of past and current experiences of these eight people            | Findings show that family size, socioeconomic status, and some measure of good fortune in sustained health enabled these people to live to an advanced stage.   |
| Skeen et al., 2014  | South Africa & Malawi | 979                     | Cross-sectional study            | 979 children-carers (children aged 4-13 years) pairs attending 28 randomly selected CBOs (community based organizations) in South Africa and Malawi                            | Interviews, Shona Symptom Questionnaire, and the Patient Health Questionnaire | Overall 28% of the carers scored above the clinical cut off for current psychological morbidity, and 12.2% reported suicidal ideation. Carers of children affected by HIV are at risk for mental health problems as a result of HIV, socioeconomic, care-giving, and community factors. |

| Reference            | Study Site | Study Size (n) | Study Design      | Sample   | Measures   | Salient Findings  |
|----------------------|------------|----------------|-------------------|--|------------|---|
| Skovdal et al., 2011 | Zimbabwe   | 33             | Qualitative study | Mix of purposeful and snowball sampling of 25 nurses and eight elderly guardians of children enrolled in antiretroviral therapy(ART) program. The age of the elderly guardians (all female) ranged from 52-79, with a mean of 61. Respondents were recruited from three rural communities in Manicaland Province, Zimbabwe | Interviews | Researchers explored challenges faced by elderly caregivers in sustaining adherence to ART in HIV-infected children. Findings revealed the following as barriers to pediatric ART: “poverty, immobility, deterioration memory and poor comprehension of complex treatments” (p. 957). |

| Reference       | Study Site | Study Size (n) | Study Design      | Sample   | Measures                             | Salient Findings   |
|-----------------|------------|----------------|-------------------|--|--------------------------------------|--|
| Ssengonzi, 2009 | Uganda     | 27             | Qualitative study | Purposeful sample of 27 elderly caregivers aged 50 years and older who were caring for at least one person with AIDS and/or OVC in the past 10 years. Participants were recruited from Kamuli and Luwero, two rural districts in Uganda. | In-depth interviews                  | Study examined the impact of HIV/AIDS on living arrangements and well-being of elderly caregivers in rural Uganda. Researchers reported a sharp increase in household consumption; drastic disruptions in living arrangements; prolonged travels; and absence from their homes to care for the sick & dying family members.  |
| Ssengonzi, 2007 | Uganda     | 27             | Qualitative study | Purposeful sample of 27 elderly caregivers aged 50 years and older who were caring for at least one person with AIDS and/or OVC in the past 10 years. Participants were recruited from Kamuli and Luwero, two rural districts in Uganda. | Focus groups and in-depth interviews | This study investigates the challenges faced by elderly caregivers to people (including children) infected by HIV/AIDS in Uganda. Findings revealed that caregiver's responsibilities in caring for an adult or sick parent were compounded by the responsibility of caring for affected children. Majority of caregivers reported feeling anxious about their future health and well-being. |

*Note:* <sup>a</sup>The number of focus groups is denoted in parentheses

### **Identified Gaps in Research**

Based on findings of this review of literature on HIV/AIDS caregiving, it is clear that there are many gaps in the current state of research knowledge. One significant gap is the lack of literature that focused exclusively on the relationship of supports for caregivers raising OVC and mental health outcomes. Researchers have begun to examine the impact of HIV/AIDS on the physical, psychosocial, and mental well-being of caregivers. However, little is known about formal supports as well as ongoing poor health conditions of caregivers. There is a paucity of research on the relationship between supports and mental health outcomes of elderly caregivers living in resource-poor households, such as those headed by grandmothers raising multiple orphaned children, signaling the need for more research in this area.

Another significant gap that remains is the dearth of understanding about how caregivers cope, what they need, and how their needs can be met to alleviate the caregivers' burdens. In fact, caregivers' burden is seldom applied to elderly caregivers but rather to adults caregiving for elders. Although studies in sub-Saharan Africa have explored coping strategies employed by caregivers in resource-poor settings severely affected by the HIV/AIDS pandemic, more details are necessary about the changing socioeconomic and cultural contexts, structural factors, specific practices of how caregivers deal with their day-to-day responsibilities, and how the caregiving and support (or lack thereof) impacts caregiver mental well-being.

Further, it is evident that HIV/AIDS impacts all age groups, but in Namibia there has been limited research on the age group of 60 and older. In addition, evidence suggests

that the vast majority of caregiving research has examined the experiences of family caregivers providing assistance to older adults who are HIV-positive (Moore, 2007-2008; Moore & Henry, 2005; Palattiyil & Chakrabarti, 2008). However, little is known about caregivers raising a HIV-positive grandchild and/or other vulnerable children in rural Namibia.

While there is a growing body of literature on the mental health outcomes of children orphaned by AIDS (Cluver & Gardner, 2007) in sub-Saharan Africa, there is a dearth of research on the epidemiology of mental health and the prevalence of depression among caregivers in Namibia. Thus, more research regarding the mental well-being of caregivers raising OVC is needed in southern Africa. To this end, studies in Namibia have focused primarily on psychosocial supports for OVC (Hayden et al., 2004; Haihambo, Kalomo, & Ashton, 2006). Few studies have paid attention to supports targeted directly to caregivers raising OVC. Yet the majority of caregivers are old and unemployed, and their financial, material, and social well-being is dependent on the everyday survival of orphaned children (Rajaraman et al., 2008).

Based on this literature and identified gaps in research, this study examined the degree to which caregiver supports and characteristics predict their mental health outcome such as depression. Specifically, this study addressed the following research questions and hypotheses:

## Research Questions and Hypotheses

Since the purpose of this study was to examine the relationship between supports and depression among elderly caregivers raising children orphaned by AIDS, the following questions were examined:

Research Question 1: Do elderly caregivers who care for an HIV-infected child/ren experience financial stability, informational support, social support, and depression differently than caregivers who do not care for a non HIV-infected child/ren?

*Hypothesis 1:* It is expected that elderly caregivers who care for an HIV-infected child/ren will report lower scores on financial stability, informational support, and social support and higher score on depression compared to caregivers who do not care for an HIV-infected child/ren.

Research Question 2: Does caring for an HIV-infected child/ren relate to elderly caregivers' financial stability, informational supports, social supports, and depression?

*Hypothesis 2:* It is expected that there is a significant association between caring for an HIV-infected child/ren and financial stability, informational supports, social supports, and depression.

Research Question 3: Does the age of elderly caregivers relate to their self-reported financial stability, informational supports, social supports, and depression?

*Hypothesis 3.* It is expected that there is a significant association between age and financial stability, informational supports, social supports, and depression.

Research Question 4: To what extent do financial stability, informational supports and social supports predict elderly caregivers' levels of depression above and beyond caring for an HIV-infected child and age?

*Hypothesis 4.* It is expected that financial stability, informational supports, social supports will significantly predict elderly caregivers' levels of depression above and beyond caring for an HIV-infected child and age.

The next chapter summarizes the relationship between the independent and dependent variables within the context of the ecological systems theory Bronfenbrenner (1979).

### CHAPTER 3: THEORETICAL FRAMEWORK

This chapter discusses the conceptual framework for understanding the relationship between supports and depressive symptoms of caregivers raising children orphaned by AIDS. The chapter first provides a brief introduction to Bronfenbrenner's (1979) ecological systems theory, a theory that has been used as a theoretical framework to guide that this study. Next, it discusses the theory's applicability in explaining the association between supports and depressive symptoms among caregivers.

#### Ecological-System Theory

Bronfenbrenner (1979) used theories of ecology and systems to map out a model for understanding how human beings interact with their environments, family systems, community systems, and other significant systems. Bronfenbrenner (1979) asserted that individuals' interactions and experiences with their social environments can help determine the extent to which individuals can develop their capabilities and maximize their full potential. Instead of viewing individuals as independent beings, the ecological-systems theory positions human beings within a dynamic system of interconnections and influence with other people, physical environments, and institutions. Each of these parts has an influence on human behavior and human development. In other words, the ecological environment is conceived "as a set of nested structures, each inside the other like a set of Russian dolls moving from the innermost level to the outside" (Bronfenbrenner, 1979, p. 3).

Bronfenbrenner (1979) identified four essential levels or systems that constitute an ecological framework. The first level is the *microsystem*, which describes immediate

relationships and surroundings. This level consists of small-scale systems such as extended family, significant other, social network, church community, or neighborhood/village. In this study, the extended family is seen as a microsystem. For example, a caregiver who receives supports (i.e., financial, material, or social) or a lack thereof may be affected in some way at this level because the caregiver has direct contact with these individuals within the social environment. Bronfenbrenner asserted that this interaction was bidirectional within a system.

The next level is the *mesosystem*, which refers to linkages between two or more systems, such as the extended family, neighborhood/village, or church or religious community. The caregivers' ability to raise and provide care and support to children orphaned by AIDS is facilitated by and is interdependent on these systems. In this study the interaction between the caregiver and his or her family, friends, or significant other are examples of the *mesosystem*. For example, this study explored financial and social supports from family to caregivers caring for children orphaned by AIDS. If a severe lack of financial or social support exists in these households, and caregivers and children are unable to cope adequately (e.g., by experiencing a lack of food to eat), then this inability may in turn generate distress for the elderly caregiver because he or she is unable to meet the needs of children in their care.

The third level is the *exosystem*, which refers to settings not directly affecting the individual but that influence the microsystem. According to Bronfenbrenner (1979), this level encompasses those interactions between systems that do not involve an individual's active participation; however, events or changes within these systems may affect the

person in some way. This study examined the role of a caregiver policy directed to elderly caregivers. For example, such policy could address issues pertaining to food security, economic opportunities and address antipoverty strategies for families affected by the AIDS. Policy initiatives of this nature have potential to alleviate the financial burden shouldered by the elderly and, consequently, decrease the possibilities of stress or depressive symptoms among caregivers.

The fourth level, the *macrosystem*, is generally considered the outer layer of the ecological systems theory framework (Bronfenbrenner, 1979). The macro system encompasses the broad societal, political, legal, economic, and cultural values guiding society. When a child loses one or both of his parent(s) to HIV/AIDS and circumstances force the child to live with the grandparents in a society riddled with HIV/stigmatization, this experience may affect the mental well-being of caregivers. In this study the cultural values surrounding African caregiving were explored. Culturally, women in much of Africa are perceived as nurturers and caretakers of those who are vulnerable, including children affected or infected by HIV/AIDS. This study explored how caregivers are supported in their caregiving role. Caregivers who have supports may be less likely to display mental health challenges.

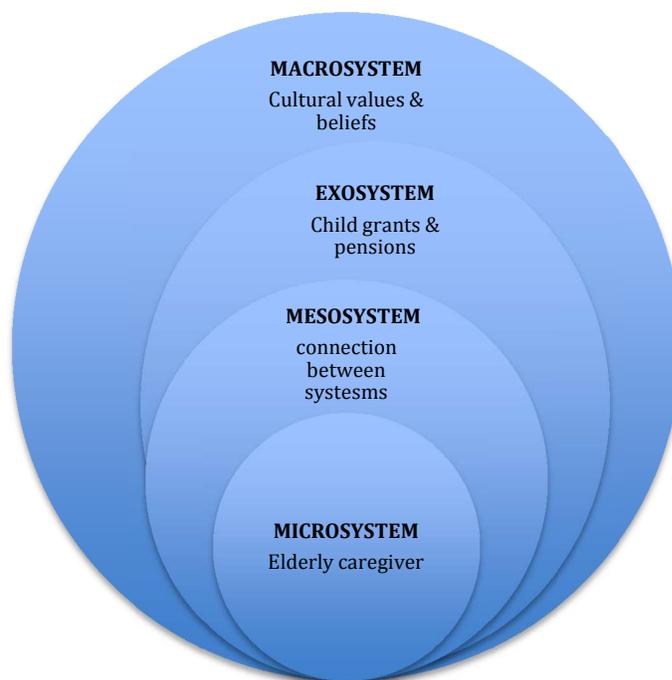
A central thesis of ecological system theory is the importance of the environment and social context in which individuals reside (Bronfenbrenner, 1979). For the system to function effectively, all of its parts need to work together for the survival and maintenance of that system. At best, the ecological perspective operates well when all levels work as a team. Because the eco-system is a system, any changes in any part of

that system will have a ripple effect on other systems. In other words, a change in one part of the system can effect change in other parts of the system (Bronfenbrenner, 1979). Thus, it is essential for systems to maintain a balance or state of equilibrium. Any disruption or failure to maintain such a balance may cause disturbance in the entire system. For example, the lack of financial or material support (e.g., food, clothing, shelter, and health care) can seriously threaten the survival needs of poor families affected by the AIDS epidemic. An eco-systemic perspective underscores the importance of various levels' interconnectedness and the interaction among them for the functioning of the system as a whole (Bronfenbrenner, 1989). Any attempt to apply the ecological systems lens to families affected by HIV/AIDS should encompass analyses of all four levels (Bronfenbrenner, 1989).

From this perspective, families such as those headed by the elderly caring for children orphaned by AIDS and their social environments are interdependent. To understand caregiver supports and mental health outcomes of the elderly, it is helpful to examine the ecology of their experiences. In addition, such an analysis should include an assessment of each system and the interactions that take place among family members and the different systems in the family (Bronfenbrenner, 1979).

The ecological-systems theory is a good fit for this study. The theory has been used in similar studies in Namibia (Hayden et al., 2004) and Zimbabwe (Tsiwo-Chigubu, 2000). Although the ecological system theory constitutes a major vantage point from which to understand the relationship between supports and depressive symptoms among elderly caregivers raising children orphaned by AIDS, a limitation of the theory is that it

is difficult to test because it is more descriptive than explanatory (Marshall, Roberts, Barton, Stephany & Lighty, 1998). The theory lends itself well, however, to social work practice and policy in child and family welfare. See Figure 1 for the ecological-systems theory that frames this study.



*Figure 1.* Ecological-system theory for the study

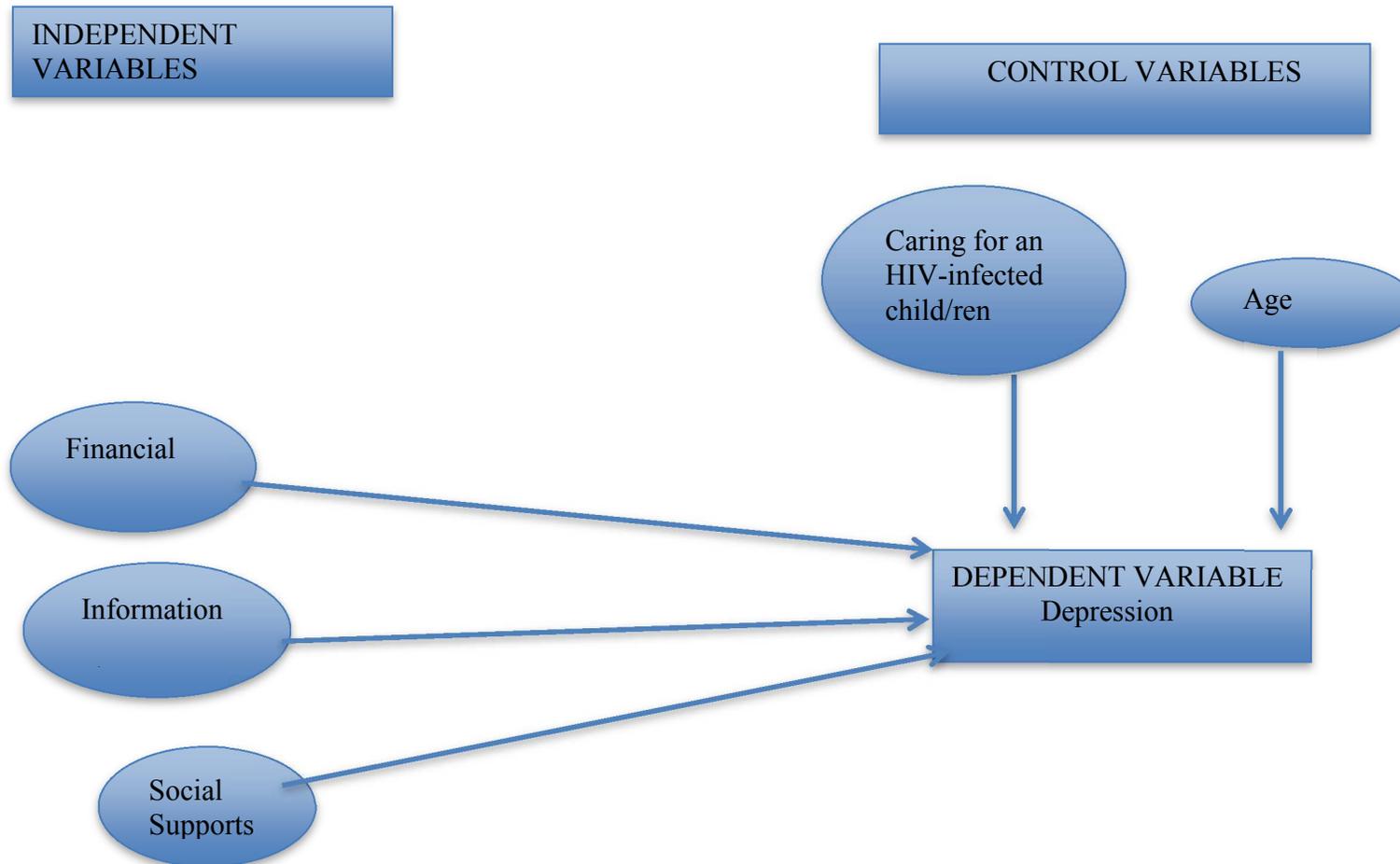


Figure 2. Conceptual model for this study

## CHAPTER 4: METHOD

This chapter presents the participants, measures, study variables, study setting, sample size and power, data collection procedures, measures, and data analysis of the study.

### Participants

Catholic Aids Action (CAA) using a non-probability sampling design recruited participants for this study. Convenience sampling was used to select elderly caregivers for this study; it is a type of a non-probability sampling where participants are selected because of their convenient accessibility for the study and the researcher (Dillman, Smyth, & Christian, 2009).

For this study a sample was drawn from CAA caregivers' client list. The list is comprised of caregivers who were providing care to their adult HIV-positive sick child or grandchildren and other children orphaned by AIDS. Caregivers were primarily selected from the following villages: Uutsima; Oshikushashipya; Uukwanashikare; Oshitutuma A; Oshitutuma B; Oshuuli; and Okaleke. The rationale for choosing these villages was the close proximity to the tarred road for accessibility by of the research team. A total of 91 caregivers were identified for the sample; however only 89 participants (i.e., elderly HIV/AIDS caregivers) were included in this study. Two of the participants were excluded from the study because they were not caring for children orphaned by AIDS; instead, they were caring for their HIV-positive adult child. All 89 participants were caring and/or raising grandchildren and/or other children orphaned by AIDS.

The 89 elderly caregivers who participated in the study ranged from 60 to 92 years in age and a ( $M=71.24$ ,  $SD=8.82$ ). The gender composition was female 85.4% and male 14.6%. Forty one percent were married and 34.8% were widowed caregivers. Fifty five percent had some primary education and only 31.5% completed primary education. In this study, 50.6% of caregivers and a ( $M=2.36$ ,  $SD=1.43$ ) were caring for children affected by HIV and AIDS. In total the number of children (i.e., children under the age of 18 years) living with elderly caregivers in their household ranged between 1 and 18 with a ( $M=5.38$ ,  $SD=3.03$ ) and adults (i.e., those over the age of 18 years) ranged between 1 and 20 with a ( $M=5.61$ ,  $SD=.392$ ). Sixty-three percent of caregivers were caring for a HIV-positive child/ren; 98.9% were pensioners; and 51.2% of the caregivers had a chronic illness. Sixty-percent of caregivers were receiving government financial support (i.e., foster care grants) for children in their care. However, 96% of caregivers were not receiving remittance from family. Sixty-eight percent of caregivers had a monthly income of \$500 (Namibian dollars) and only 3.4% received a monthly salary or wages while a mere 2.2% had their own business.

### **Study Setting**

#### **Omusati Region, Northern Namibia**

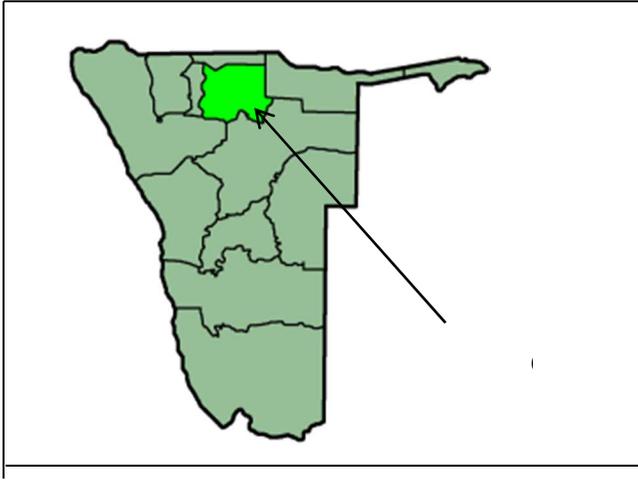
This study was conducted in the Omusati Region, northern Namibia Figure 4 depicts a map of Namibia, locating the Omusati Region. There are 12 constituencies in this region: Anamulenge, Elim, Etayi, Ogongo, Okahao, Okalongo, Onesi, Oshikuku, Outapi, Ruacana, Tsandi, and Otamanzi. The rapid socioeconomic change since the country's independence, coupled with the advent of the HIV/AIDS epidemic, has left

thousands of children in this region vulnerable (SIAPAC, 2002). Due to the prevailing economic circumstances (i.e. labour migration to cities and towns during the colonial period), families and couples were separated for long periods, with men working or seeking employment outside the common home while women stayed at home to care for and raise children and run the households. These long separations between couples have often led to extramarital relationships and increased the risk of HIV/AIDS infection (Kuhanen et al., 2008).

The region was purposely selected for the study to ensure representation of one of the rural areas with the highest rates of HIV prevalence rate (NSA/NHIES, 2012). In addition, it is one of the regions with highest number of OVC and elderly caregivers (GRN/MoHSS, 2006). Historically the Omusati region has been home to predominantly Oshiwambo population (Namibia's largest ethnic group) and portrays a rich cultural heritage. According to the latest preliminary results of the Population Housing Census of 2011, the region has a population of 181,600, including 94,600 females and 87,000 males (NPC, 2011). The estimated average household size in this region is 5.2 persons (NSA/Namibia Household Incomes and Expenditure Survey [NHIES], 2012). The majority of households in this region are headed by women (GRN/NPC, 2006). More than 50% of women in this region of childbearing age are unmarried, and cohabitation or consensual unions are common (Kuhanen et al., 2008). The spread of HIV/AIDS in this region has grown rapidly since the early 1990s. Studies have reported that in 2006, the average HIV prevalence rate was 24% among pregnant women attending prenatal clinics (GRN/MoHSS, 2006; GRN/NPC, 2006). Life expectancy at birth has fallen by almost 13

years (GRN/NPC, 2006). Based on the MGECW's (2009) social grant system, there are 16,389 OVC benefiting from social welfare grants in this region. Recipient or caregiver age trends show that from 2007 to 2009 there has been a gradual increase of caregivers between the ages of 50 to 70 years (MGECW, 2009). In summary, the poor who are primarily women are subsistence farmers and pensioners who are disproportionally located in rural areas (NSA/NHIES, 2012).

The region is predominantly rural with small peri-urban centres. It experiences occasional seasonal floods and has limited infrastructure. Compared to urban cities and towns, living conditions in rural areas are different and can pose challenges to many who are poor. About 20.4% of population in this region are considered severely poor (NAS/NHIES, 2012). Nearly half of the inhabitants (48%) live off subsistence farming as their main source of income, followed by wages and salaries (NPC, 2011). The region has one of the highest unemployment rates in the country. However, the literacy rate has improved from 84% in 2001 to 88% in 2011 (NSA/NHIES, 2012).



*Figure 3.* Map of Namibia locating the Omusati Region.

### **Procedures**

Participants for this study were recruited from CAA in the Omusati Region, northern rural Namibia. CAA is Namibia's first and largest faith-based nongovernmental organization (NGO) fighting the country's HIV/AIDS crises. The agency works in close collaboration with local churches and faith communities in all 13 regions of Namibia. The primary focus of this NGO is to provide home-based families and care to those infected and/or affected by HIV/AIDS, including OVC. It also provides counseling, psychosocial support, youth education, and prevention and care.

Catholic Aids Action staff members between March and May 2013 conducted the recruitment process. The staff approached caregivers who met the selection criteria and informed participants by word of mouth about the research and research protocols (i.e., confidentiality, risks and benefits of the study, and voluntary nature of the study), and their consent was sought. Once participants decided to take part in the study, they were

informed where and when interviews were going to be held in their respective villages. CAA arranged most of the locations where the interviews were held, many of which were at clinics, churches, schools, village halls, or out in the open under a tree. Thus, at no point did I have access to the list of potential participants or have any contact with potential participants. CAA compiled a list of 91 caregivers that consisted of the following: (a) caregiver's name; (b) village name; (c) homestead identification; and (d) number of OVC being cared for. Only then were the names of interested participants passed on to me. Consequently, CAA performed the initial screening and scheduled interviews accordingly. Of note, this sample was not a true random sample and therefore may not be representative of elderly caregivers raising children orphaned by AIDS in the Omusati region.

### **Training of Research Assistants**

I provided training to staff and home-based volunteers of CAA. Training for the CAA officials covered knowledge and understanding of informed consent, participant rights and benefits in research, the importance of reducing coercion in research studies, interviewing technique, ethical considerations in interviewing persons about sensitive subject matter, interviewing elderly people, and the administration of the instruments. I used the home-based volunteers at CAA as research assistants (RAs) in the study. The volunteers' role at CAA is primarily to provide grief counseling and HIV/AIDS home-based care to people infected with and/or affected by AIDS including children and elderly caregivers. The RAs attended a one-day training. This training covered aspects pertaining to research ethics, consistency of asking questions, clearly providing different

responses, and capturing respondents' responses. All 10 RAs carried out several role-plays with each other. Additionally, each RA interviewed an elderly caregiver who was not included in this study. The training was essential for RAs to become comfortable and gain confidence in their interview skills needed for the study.

### **Inclusion and Exclusion Criteria**

To be included in the study, participants needed (a) to be a primary caregiver who was caring for and raising a child or children infected or affected by HIV/AIDS; (b) not to be the child's biological parent; (c) to reside in the Omusati region of Namibia; (d) to be registered with CAA; and (e) to be 60 years or older. The exclusion criteria were being a caregiver who was not registered with CAA and being under 60 years of age.

### **Protection of Human Subjects**

Informed consent was obtained from each participant. Consent forms were translated into Oshiwambo. I protected the privacy of participants by not identifying which participants took part in the study. The Institutional Review Board at the University of Minnesota approved this study on June 25, 2013.

### **Administration of Survey**

At every interview location the research team followed a culturally appropriate protocol prior to conducting the interviews (Marshall & Batten, 2003). Each RA was responsible for receiving and welcoming participants to the study at their respective villages. Participants were given a brief introduction about the purpose of the study. RAs and researcher administered the survey face-to-face. Consent forms explaining the risks associated with the study were given to all participants. In instances where the respondent

was illiterate in Oshiwambo, the RAs and the researcher read aloud the consent form to the participant. In addition, participants were informed that they were free to opt out of the study at any point in time. Since the study dealt with HIV/AIDS related questions, they were free to not answer any question(s) that made them uncomfortable. A copy of the consent form was given to all participants to keep. All respondents were asked a series of questions. Questions on the survey instrument were read aloud to all participants in their local language, Oshiwambo, by the researcher and the RAs. The research team also collected data from elderly caregivers' homesteads. In this study six caregivers were bedridden and thus unable to come to the the identified interview locations. Consequently, the research team drove to the homesteads of the participants and conducted six interivews in caregivers' homes.

Interviews lasted approximately 60 minutes. When the total number of the 91 participants was reached, caregivers who could not be included in the study were thanked for the willingness to be part of the study and informed that they unfortunatley could not be included in the study. At the end of each interview, I thanked caregivers individually and personally and gave them an N\$ 50.00 (i.e., approximately U\$5 at the time of the study) as a token of appreciation for their contribution to be part of the study. On occasion, participants extended a word of gratitude for being included in the study. Many of the caregivers went as far as performing Oshiwambo cultural songs; dancing and/or *okukwilila* (a traditionally Oshiwambo "shout" that represents someone that is sincerely grateful and happy) as a way of expressing their gratitude of being accorded the

opportunity to be in the study. This was a very special moment for me that sealed a mutually beneficial research partnership with the community.

### **Sample Size and Power**

Sample size was calculated using the software G\*power 3. The software can successfully do power analysis and calculate sample size at the 95% confidence interval and 80% power. G\*power 3 calculated the sample size to be 84 HIV/AIDS caregivers between the age of 60 years and older in the Omusati region of northern Namibia. According to Cohen (1992), a small effect size is 0.2, a medium is 0.5 and a large is 0.8. In this study, assuming an effect size of  $R^2 = .15$  and power at .80 with five predictors, a sample size of 84 with a significance level of  $\alpha = .05$  was needed (Cohen, 1992). In this study 91 respondents were interviewed.

### **Measurement**

**Multidimensional Scale of Perceived Social Support.** In this study caregivers' social support was assessed using the Multidimensional Scale of Perceived Social Support [MSPSS] (Zimet, Dahlem, Zimet, & Parly, 1988). The MSPSS is a 12-item scale that assesses support from three sources: family, friends, and significant others (Zimet et al., 1988). The MSPSS has 12-items ranging from (1=*very strongly disagree*) to 7 = *very strongly agree*). The 12-items are summed and averaged to create a social support score. Caregivers reported a mean score of 5.31. The MSPSS has good internal and test-retest reliability (Zimet et al., 1988) and has been used previously in South Africa (Kuo et al., 2012b; Myint & Mash, 2008;) and Kenya (Okawa, 2011). In this sample, the overall

internal reliability was good for the overall scale, with Cronbach  $\alpha=.73$ , ( $M=5.31$ ,  $SD=.733$ ). See Appendix 1 Section C.

**Centre for Epidemiologic Studies Depression Scale (CES-D).** The CES-D is a self-report instrument developed to assess symptoms of depression in the general population. The 20-item scale is one of the most widely used depression measures designed to assess levels of depressive symptomology (Radloff, 1977). The CES-D was chosen because its main focus is on depressive symptoms found among non-psychiatric populations and is not intended as a measure of clinical depression but of depressed mood (Schwarz, 1999). Scores range from 0 to 60, with a score of 16 or more used to indicate clinical depression (Radloff, 1977). According to Radloff, the CES-D reported a high alpha coefficient of .85 for non-psychiatric individuals. In this study Cronbach's alpha was  $\alpha=.881$ . Four items (i.e., 4, 8, 12, and 16) were reverse coded: *I felt that I am just as good as other people; I felt hopeful for the future, I was happy and I enjoyed life* respectively. The CES-D has been administered in South Africa (Hamad, Fernald, Karlan, & Zinman, 2008; Kuo & Operario, 2011; Kuo et al, 2012) and Rwanda (Brown, Thurman, & Snider, 2005). Although not used with this population, the CES-D has been used in Namibia (Ruiz-Casares, Thombs & Rossseau, 2009). See Appendix 1 Section D.

**Financial stability measure.** The researcher devised the financial stability measure specifically for this study. In this study, participants were asked seven Likert type questions to assess their financial situation (see Appendix 1 Section A). While all seven items had four response options, the wording for each varied. However, because

these items could not be combined as a measure of financial stability, a single question was chosen as the measure of financial stability:

“Overall, how easy or difficult is it for you to meet the financial costs of raising orphaned children in your care” (meet costs). The response options for meet costs were reverse coded (*1=very difficult to 4=very easy*), (see Appendix 1 Section A item A8).

In this study, a higher score reflected greater financial stability while a lower score on these items indicated lesser financial stability. The mean score in this sample was  $M= 1.75$ ,  $SD= .76$ . This reverse coded question was chosen as an indicator of financial stability because it was positively correlated with ‘difficult to cope financially’ (cope) where a higher score also indicated greater financial stability. In addition, three additional questions assessing one’s financial situation were negatively or inversely correlated with meeting costs. These questions assessed, worrying about financial challenges, selling household assets to meet needs of raising orphaned child/ren, and using savings to meet financial needs of orphaned child/ren. (See Table 2).

Table 2

*Correlations of the Financial Questions*

| Measure                                   | 1      | 2      | 3      | 4      | 5   | 6   | 7 |
|---|--------|--------|--------|--------|-----|-----|---|
| 1. Meet financial costs (reverse coded)   | 1      |        |        |        |     |     |   |
| 2. Difficulty to cope financially         | .47    | —      |        |        |     |     |   |
| 3. Financial worry                        | -.45** | -.58** | —      |        |     |     |   |
| 4. Use pension for needs of children      | .16    | .13    | -.20** | —      |     |     |   |
| 5. Sell assets in past 12 months          | -.47** | -.37** | .45    | -.22** | —   |     |   |
| 6. Involved in income-generating projects | -.11** | -.14** | .06    | .01*   | .20 | —   |   |
| 7. Savings past 12 months: use savings    | -.30** | -.24** | .20    | -.26** | .36 | .26 | — |

Note. \*  $p < .05$ ; \*\*  $p < .01$

**Informational supports scale.** The researcher specifically developed the informational supports measure for the current study. In this study, participants were asked a series of 5 Likert-type questions assessing their informational supports (see Appendix 1 Section B). An example of these questions includes the following: “Are you a caregiver who has knowledge about how to access government welfare grants for children affected by HIV/AIDS?” Questions were scored on a four-point scale ( $1 = \text{strongly disagree}$  to  $4 = \text{strongly agree}$ ). Higher scores on informational supports indicate adequate information or knowledge about essential informational supports needed for caregivers raising children orphaned by AIDS.

The fifth question was dropped in the final analysis because it was highly correlated with the second item (i.e., caregiver knowledge/information on how to access government welfare grants). Thus, informational supports measure developed for this study was derived from the four items that were summed and averaged to create the informational supports measure. Cronbach's alpha for the four items was  $\alpha=.69$ , which indicates the items form a scale that has reasonable internal consistency reliability. The mean score in this sample was  $M=3.42$ ,  $SD=0.57$ .

**Development of the financial stability and informational supports questionnaire.** Noteworthy, is the development of the financial stability and informational supports measures. The instrumentation for this study, the supports questionnaire, was adapted from various sources. Items were developed from qualitative and quantitative studies reviewed in this study, including the Poverty Dynamics in Namibia: A Comparative Study NIES Survey (2012), the Child Poverty in Namibia: A Child-Centered Analysis (2012), the Namibia Demographic and Health Survey 2006-07, and the Project Hope: Sustainable Strengthening of Families of Orphans and Vulnerable Children in Mozambique and Namibia Baseline Report- Namibia August 2006. Reviewing these studies assisted in the development of culturally appropriate questions and limited inappropriate phrasing or biasing response options.

The construction of these two measures required instrumentation rigor, given that these questions were developed for the purpose of this study. First, the content validity of the HIV/AIDS supports was established through extensive review of the literature and by consulting with experts in the field on HIV/AIDS caregiving in Namibia. The initial step

was consulting with a team of experts through my established contacts with CAA. Second, a representative from CAA reviewed the questionnaire to assess its face and content validity. After revisions based on the experts' comments, questions were incorporated into the survey instrument. The third step required translating the instrument into Oshiwambo, the local language spoken by participants in Omusati region. In order to enhance the instrument's reliability, I used qualified and experienced interpreters for the translation of the questionnaire from English into Oshiwambo. Finally, pilot testing of the instrument was conducted from July 1-3, 2013. The RAs and I carried out pilot testing with eight elderly caregivers who were not included in the survey. Pilot testing was done to help ensure coherency and cultural validity of the instrument. Revisions were then incorporated accordingly.

## **Study Variables**

### **Independent Variables**

The independent variables for this study include financial stability, informational support, and social support. These are discussed below and in Table 3 following this section.

**Financial stability.** Financial stability or how well caregivers are able to financially provide for OVC in their care is of interest in many caregiving studies because the economic burden of caring for AIDS-affected people is often beyond the family's means (George et al., 2011; Heymann et al., 2007; Kagotho & Sswamala, 2012; Kanya & Poindexter, 2009; Moore, 2007-2008; Njororai, & Njororai, 2012; Nyambedha et al., 2003; Schatz & Ogunmefun, 2007; Ogunmefun & Schatz, 2009; Reddy, 2005; Rioio et

al., 2005; Ogunmefun & Schatz, 2009). Studies have consistently demonstrated that economic hardship is a predictor of depression (George et al., 2011; Heymann et al., 2007; Kagotho & Sswamala, 2012; Rioio et al., 2005). Additionally, scholars have also shown that women living in financial hardship and raising children, such as elderly kin caregivers raising OVC, are particularly vulnerable to experiencing depression (Bell, 1990). Thus, financial stability can place individuals at risk because of their inability to sufficiently fulfill caregiving obligations and responsibilities (Cole & Eamon, 2007). Further, financial constraints can impact access to mental health services (Everson, Maty, Lynch, & Kaplan, 2002). Moreover, the medical and/or funeral costs of an HIV-infected child or grandchild may drain the limited resources of an elderly caregiver. Taken together, these indirect effects are interrelated to other social, economic, and psychological factors that may negatively impact the general health and mental well-being of caregivers (Ssengonzi, 2007).

**Informational supports.** Studies have reported inadequate training, ignorance, and a lack of sufficient accurate information, particularly in relation to providing basic HIV/AIDS prevention and basic care among HIV/AIDS caregivers (Boon et al., 2009; Lindsey et al., 2003). Olenja's (1999) study in Kenya found that caregivers were worried about their lack of skills in providing appropriate care to children and family members who were affected by AIDS. A recent study, the Effectiveness of Child Welfare Grants in Namibia (GRN/MGECW, 2010), reported that caregivers in many parts of the country are unaware of available governmental assistance (i.e., foster care grants). Many of these grandmothers do not know how to access social welfare grants meant for children under

their care and often do not have the legal documentation such as birth certificates to apply for these grants (GRN/MGECW, 2010). Similarly, Mudavanhu, Segalo, and Fourie's (2006) study in Zimbabwe found that grandmothers caring for grandchildren orphaned by HIV and AIDS were often illiterate and seemed to be overwhelmed by the paperwork needed to navigate governmental departments for assistance. Thus, informational support may have the potential to positively or negatively affect the mental well-being of caregivers.

**Social supports.** From the literature reviewed for this study, it is evident that there is a large body of literature that has examined the impact of social support on caregiving. Social support has been shown to be associated with lower levels of depression because it has the potential to buffer individuals from adverse effects of stressful life circumstances, such as those experienced by the elderly raising OVC (Cole & Eamon, 2007; Cohen & Wills, 1985; Kuo et al., 2012; Landman-Peeters et al., 2005).

### **Control Variables**

**Age.** Age is of particular interest in this study. Age can impact the physical and mental well-being of caregivers. Blustein, Cham, and Guanais's (2004) study in the United States found elevated depressive symptoms among grandparents caring for grandchildren in their homes as compared to grandparents not caring for a child or children. Recent studies have also reported a direct correlation between age and depression (Kim et al., 2009). Grandmothers assuming extensive caregiving roles at a time when they are advanced in age may lack physical abilities and strength required for caring for young AIDS infected/affected children. Thus, old age might be associated with

increased risk for depression among caregivers raising AIDS-orphaned children. In this study, respondents were asked to state how old they were. Age was a control variable and it was categorized as follows: 60-69; 70-79; 80-89; and 90-99.

**Caring for HIV-infected child/ren.** Studies have found that caregivers caring for an HIV-infected child experience stigma (Demmer, 2011; Hejoaka, 2009) as compared to those not caring for a child infected by the HIV/AIDS virus. In addition, caregivers were found to struggle to buy food and provide the needed medical assistance to their sick grandchild, consequently putting the child's health at risk (Demmer, 2011). A study in Kenya on stigma in families caring for an HIV-infected children found that caregivers who had more knowledge about care and support of an HIV-infected child was associated with less expressed stigma (Hamra, Ross, Karuro, Orrs, & D'Agostino, 2005). Thus, caring for an HIV-infected child may have the potential to impact the mental well-being of caregivers, especially those with limited resources. In this study, participants were asked if they were caring for an HIV-infected child/ren or not. This variable was dichotomized in that respondents who reported "yes" were coded as (1) and those who responded as "no" were coded as (0).

**Dependent Variable: Depression**

As pointed out earlier, the impact of HIV/AIDS on families is hardly debatable in southern Africa. Given that grandmothers are a vulnerable population playing a critical role in providing care and support to Namibia's 250,000 OVC (UNAIDS, 2011), an understanding of caregivers' mental well-being can inform the development of culturally appropriate health and psychosocial interventions for elderly caregivers. In this study,

caregivers' symptoms of depression were assessed using the Centre for Epidemiologic Studies Depression scale [CES-D] (Radloff, 1977).

Table 3

*Variable Table*

| <b>Type of Variable</b> | <b>Variable</b>                      | <b>Level of Measurement</b> | <b>Measurement of Variable</b>  | <b>Item Example</b>  |
|-------------------------|--------------------------------------|-----------------------------|---|--|
| Dependent Variable      | Depression                           | Scale                       | Centre for Epidemiologic Studies Depression scale (CES-D)<br>20 items | 'I felt depressed'<br>'I felt sad'<br>'My sleep was restless'  |
| Independent Variable    | Financial Stability                  | Ordinal                     | Supports Questionnaire<br>1 Likert item                               | Overall, how easy or difficult is it to meet the financial costs of raising children in your care?                       |
| Independent Variable    | Informational Supports               | Ordinal                     | Supports Questionnaire<br>7 Likert items                              | Are you a caregiver who has information about how to access government welfare grants for children affected by HIV/AIDS? |
| Independent Variable    | Social Supports                      | Scale                       | Perceived Social Support Scale- 12 items                              | 'There is a special person who is around when I am in need'  |
| Control Variable        | Age                                  | Ordinal                     | 60-100yrs or older  | How old are you?   |
| Independent Variable    | Caring for an HIV-infected child/ren | Dichotomous                 | Dummy variable<br>Yes=1; No=0   | Are you caring and raising an HIV-infected child or children?  |

## **Data Collection Procedures**

### **Entry Into the Community and Cultural Considerations**

Cross-cultural research requires researchers to enter communities from a premise of “cultural sensitivity” (Marshall & Batten, 2003,p.144). Although I am Namibian and Oshiwambo speaking (i.e., from the same ethnic group as the majority of caregivers) I was born and grew up in the urban capital city, which is vastly different from the rural village life of the Omusati Region. In addition, due to the sensitive nature of this topic and the age of this population, entering the field in this community required consideration of cultural norms and practices by the investigator as an outsider in order to gain trust from participants (Liamputtong, 2005; Marshall & Batten, 2003). To achieve this, acceptance, I worked closely with CAA staff and ensured that research assistants were themselves from the villages where participants were from. Further, RAs were either known and/or had relationships with the identified caregivers. Additionally, the research team dressed appropriately and addressed participants in a respectful and empathetic manner so as to engage elderly more.

### **Research Design**

The research design for this study utilized a cross-sectional, face-to-face interview survey. The purpose of survey research is to collect original data of individual people to describe attitudes and characteristics of behavior in a population too large to observe (Dillman, Smyth, & Christian, 2009). This study sought to explore the relationships between independent variables of (i.e., caring for an HIV-infected child/ren; financial, informational, and social supports) and the outcome dependent variable of depression

## Data Analysis

### Descriptive Statistics

Data were analyzed using the statistical software IBM Statistical Package for the Social Sciences (SPSS), Version 22. I completed the data cleaning. Descriptive statistics were devised using frequency tables, mean, medians, ranges, and standard deviations. Descriptive statistics provide an overview of the features of the respondents in the study. The  $p$ -value of  $<0.05$  was used to determine the level of statistical significance (Leech, Barrett, & Morgan, 2011). Some of the data were recoded into categories. For example, the number of adults and children in the household was recoded into four groups: (1-3); (4-7); (8-11); and (12-20).

**Pearson correlation.** In this study, Pearson correlation analysis was used to determine the nature of the relationships among depression and all other variables (i.e., age, caring for HIV-positive child/ren, financial stability, informational supports, and social supports). It was also used to analyze the correlations among the predictor variables. Pearson correlation coefficient measures the relationship between variables, in terms of both the strength and direction. It is used when the data meet the assumptions of normality and homoscedasticity (Leech et al., 2011).

***T* test.** A  $t$  test was performed to examine the difference between caregivers who were caring for an HIV-infected child/ren and those who were not. Generally, a  $t$  test is used to compare the mean values on a continuous variable (i.e., depression in this case) to determine whether the two means differ from each other. Thus, the  $t$  test was performed to indicate whether there is a statistically significant difference in the mean scores

between caregivers caring for an HIV positive child/ren and those not caring for an HIV-infected child/ren in terms of their levels of depression. A *t* test is used when data meet the assumptions of normality, variance of the dependent variable in the two groups is equal, and the data are independent (Leech et al., 2011).

**Hierarchical multiple regression.** The present study employed hierarchical multiple regression to examine whether financial stability, informational supports, and social supports were associated with depression after controlling for caregiver age and caring for an HIV-positive child/ren. Hierarchical multiple regression is helpful in predicting an outcome variable (e.g., depression) from a combination of several predictor variables (e.g., financial stability, informational supports, and social supports). Thus, multiple regression indicates how much variance in the dependent variable can be explained by the independent variables (Leech et al., 2011). Eighty-six respondents were included in this analysis instead of 89, because three of the respondents had missing data on one of the variables (i.e., caring for an HIV-infected child/ren). Before performing multivariate analysis, variables with multicollinearity were examined. In this study, caregiver age and caring for an HIV-positive child were entered first into the model. Financial stability, informational supports and social supports were entered into the second model. In the current study, multiple regression tested whether financial stability, informational supports and social supports explain symptoms of depression over and above that which is explained by caregiver's age and whether the caregiver was caring for an HIV-positive child or not.

**Missing value analyses.** In this study mean imputation for missing values was assigned. Mean imputation is a statistical procedure that calculates the mean value for a specific variable and assigns every missing case this value (Acock, 2005). Most cases in this study had complete data; however, some questions in the survey had between one to six cases of missing data.

## CHAPTER 5: RESULTS

This chapter provides the research findings for this study. The chapter begins with demographic data about elderly caregivers raising children orphaned by AIDS. Next, descriptive data on financial stability, informational support, social support, and depression are presented. Finally, the chapter presents the results from the *t* test and step-wise regression conducted in this study.

### Sample Characteristics

A variety of demographic information was gathered from each participant. A summary of this information can be found in Table 2. Seventy-six (85.4%) of the subjects were female, and 13 (14.6%) were male (see Table 3); their ages ranged between 60 to 92 years old. The mean age of the participants was  $M=71.24$ ,  $SD= 8.83$ .

Table 4

#### *Demographic Characteristics of Children and Elderly HIV/AIDS Caregivers (N=89)*

| <b>Characteristic</b>      | <b>n</b> | <b>%</b> |
|----------------------------|----------|----------|
| <b>Gender</b>              |          |          |
| Male                       | 13       | 14.6     |
| Female                     | 76       | 85.4     |
| <b>Relationship status</b> |          |          |
| Single                     | 19       | 21.3     |
| Married                    | 37       | 41.6     |
| Widowed                    | 31       | 34.8     |
| Divorced/Separated         | 1        | 1.1      |
| Cohabit                    | 1        | 1.1      |
| <b>Age</b>                 |          |          |
| 60-69                      | 46       | 51.7     |
| 70-79                      | 25       | 28.1     |
| 80-89                      | 14       | 15.7     |
| 90-99                      | 4        | 4.5      |

| <b>Characteristic</b>                              | <b>n</b> | <b>%</b> |
|--|----------|----------|
| <b>Caregiver education</b>                         |          |          |
| No schooling                                       | 1        | 1.1      |
| Some primary                                       | 49       | 55.1     |
| Completed primary                                  | 28       | 31       |
| Some secondary                                     | 9        | 10.1     |
| Completed secondary                                | 2        | 2.2      |
| <b><sup>a</sup>Number adults in household</b>      |          |          |
| 1-3  | 23       | 27.1     |
| 4-7  | 44       | 51.8     |
| 8-11   | 18       | 14.1     |
| 12-20  | 6        | 7.1      |
| <b><sup>b</sup>Number of children in household</b> |          |          |
| 1-3  | 28       | 32.2     |
| 4-7  | 39       | 44.8     |
| 8-11   | 17       | 19.5     |
| 12-20  | 3        | 3.4      |
| <b>Caring for HIV positive child/ren</b>           |          |          |
| Yes  | 54       | 62       |
| No   | 32       | 37.2     |
| <b>Duration of being caregiver</b>                 |          |          |
| Since birth  | 45       | 50.6     |
| 1 year   | 2        | 2.2      |
| 2-5 years  | 7        | 7.9      |
| 6-10 years   | 35       | 39.3     |
| <b>Main source of income</b>                       |          |          |
| Pension  | 87       | 97.8     |
| Salary and wages                                   | 3        | 3.4      |
| Own business                                       | 2        | 2.2      |
| Child grant  | 50       | 56.2     |
| Micro-lending                                      | 3        | 3.4      |
| Veterans grant                                     | 1        | 1.1      |
| Remittance   | 5        | 5.6      |
| <b>Caregiver chronic illness</b>                   |          |          |
| Yes  | 44       | 51.2     |
| No   | 42       | 48.8     |

| <b>Characteristic</b>                                       | <b>n</b> | <b>%</b> |
|---|----------|----------|
| <b>Monthly household income</b>                             |          |          |
| N\$ 500 or below  | 61       | 68.5     |
| N\$ 501-1000  | 24       | 27.0     |
| N\$ 1001-1500   | 4        | 4.5      |
| <b>Caregiver is a pensioner</b>                             |          |          |
| Yes   | 87       | 98.9     |
| No  | 1        | 1.1      |
| <b>Caregiver receives financial support from government</b> |          |          |
| Yes   | 53       | 60.9     |
| No  | 34       | 39.1     |

*Note.* <sup>a</sup>Number of missing cases, adults: 4; <sup>b</sup>Number of missing cases, children: 1

Nearly half (41.6%) of the participants were married. More than half (55.1%) had some primary education, while far fewer (2.2%) completed secondary education (i.e., completed Grade 12). The number of adults (i.e., 18 years and older) living in a household with an elderly caregiver had a mean score of  $M= 5.61$ ,  $SD= 3.62$ , and children (i.e., 18 years and younger) had a mean score of  $M= 5.38$ ,  $SD=3.03$ . More than two thirds (62.8%), reported caring for a HIV-infected child/ren. Over half (50.6%) of the respondents were raising children orphaned by HIV/AIDS since birth, and 35 (39.3%) were raising children between the ages of 6 and 10.

Respondents were asked if they were receiving a monthly old-age pension. The majority of the caregivers (97.8%) were receiving an old-age pension of 500 Namibian dollars (N\$500.00), which was equivalent to about US\$48.00 at the time of the study. See Figure 5. Participants were asked to rank their monthly main source of income. Results

showed that old-age pension and child welfare grants (i.e., child maintenance, foster care grant, disability grant, or special maintenance grant) ranked as the annual top main sources of income for caregivers in this sample.

Participants in the study were also asked to identify their monthly main source of income. Over two thirds (68%) of caregivers had a monthly income of about N\$500.00, and less than one third (27%) had a monthly household income that ranged between N\$501 and N\$1000.00 (approximately U\$96.00) at the time of the study. Furthermore, respondents were asked if they received a remittance from extended family. Almost all participants (94.4%) were not receiving remittances from family or relatives; see Table 5. More than a half (51.2%) of the respondents reported having a chronic illness that had prevented them from working for about 3 months.

Table 5

*Caregivers Receiving Remittance from Family (N=89)*

| <b>Question</b>                            | <b>Response</b> | <b>N</b> | <b>%</b> |
|--|-----------------|----------|----------|
| Caregiver receiving remittance from family | No              | 84       | 94.4     |
|  | Yes             | 5        | 5.6      |
|  | Missing data    | 1        | 1.1      |

In this study, participants were also asked how difficult it was for them to cope financially in the caregiving role. Forty-two (47%) of the caregivers reported that they found it very difficult to cope financially as they were raising children orphaned by HIV and AIDS. In addition, 37 (41.5%) of the elderly caregivers reported that they were usually worried about the financial challenges in meeting the needs of their households

(see Figure 9). Furthermore, 31 (57.3%) of respondents indicated that they usually needed to use their pension money to cover household costs to meet the needs of children in their care (e.g., food, health care, education, clothing, funeral costs, and transport).

Participants in the study were asked how often during the past 12 months they had to sell their household goods or assets such as goats, sheep, cow, *mahangu* (pearl millet), chicken, cars, clothing or equipment in order to meet the needs of orphaned children, 37 caregivers (41.6%) reported they had to sell their assets five or more times during the past 12 months. Forty-nine (55.1%) of the caregivers reported they needed to use their savings during the past 12 months to meet the financial costs of OVC in their care. An analysis was done to examine which caregivers received financial supports from government, specifically, foster care grants on behalf of OVC in their care. A total of 61 (68.5%) respondents reported that they received financial supports from government (i.e., government foster care grants), while 28 (31%) were not receiving financial supports from government. Descriptive statistics showed that 25 (42.4%) caregivers in this sample were very dependent on government foster care grants to meet the financial demands of OVC, and just over half (32.6%) of caregivers found foster grants to be helpful, while more than two thirds (57.4%) were satisfied with the actual amount given.

Table 6

*Caregiver Receiving Government Foster Care Grant for OVC (N=89)*

| <b>Question</b>                                     | <b>Response</b> | <b>N</b> | <b>%</b> |
|---|-----------------|----------|----------|
| Caregiver receiving government foster grant for OVC | No              | 28       | 31.5     |
|   | Yes             | 61       | 68.5     |

Furthermore, 15 (25%) of the respondents needed to borrow money to care for OVC, while 20 (33.3%) of the caregivers reported having problems with a lack of money to buy food and clothing for children in their care. More than a quarter (26.7%) of the caregivers were unable to pay school fees for OVC, and one third (33.3%) were unable to purchase school uniforms.

### **Financial Stability**

Participants were asked how easy or difficult it is for them to meet the financial costs of raising orphaned children in their care as a measure of the construct financial stability. As seen in Table 8, financial stability scores ranged from 1 to 4. The mean score in this sample was  $M=1.75$ ,  $SD=.75$ . Only two (2.2%) of elderly caregivers scored high on the financial stability variable, and 37 (41.6%) of the caregivers reported a low score. In this current study, most respondents scored low on financial stability. See Table 8.

### **Informational Supports**

In this study scores from the informational supports measure ranged from 2 to 4. The entire sample had a mean score on informational support of  $M= 3.41$ ,  $SD=.568$ . Twenty-nine (32%) of the caregivers had a high score of 4 for all items on the informational supports scale, and only three caregivers (3.4%) scored a low score.

Overall, caregivers in this sample were knowledgeable about informational supports. See Table 7.

### **Social Supports**

The MSPSS assessed perceptions of social support among elderly caregivers (Zimet et al., 1988). In this study scores ranged between 2.58 and 6.58. The sample had a mean score on perceived social support of  $M= 5.31$ ,  $SD= 0.733$ . See Table 7. In this study, the family support scale had  $\alpha=.751$ , the friends support scale had  $\alpha=.797$ , and the significant others support scale was  $\alpha=.72$ . In terms of sources of social support, elderly caregivers ranked significant others  $M=5.69$ ,  $SD=.879$  as the most important source of support, followed by friends  $M=5.41$ ,  $SD=1.116$  and family ( $M=4.83$ ,  $SD=1.298$ ).

Table 7

*Means and Standard Deviations for Variables of Interest in this Study*

| <b>Variable</b>       | <b><i>M</i></b> | <b><i>SD</i></b> | <b>Std. Error of Skewness</b> | <b>Std. Error of Kurtosis</b> | <b>Minimum</b> | <b>Maximum</b> |
|-----------------------|-----------------|------------------|-------------------------------|-------------------------------|----------------|----------------|
| Financial Stability   | 1.75            | .75              | 0.25                          | 0.51                          | 1.00           | 4.00           |
| Informational Support | 3.42            | 0.57             | 0.25                          | 0.51                          | 2.00           | 4.00           |
| Social Support        | 5.31            | 0.73             | 0.25                          | 0.51                          | 2.58           | 6.58           |

### **Depression**

High levels of depression were recorded in this sample. The CES-D scale had a mean score of  $M=48$ ,  $SD=12.45$ . The range was between 24 and 76. Thus, the entire sample scored above the threshold criteria for elevated depression ( $\geq 16$  points). See Table 8.

Table 8

*Depression Among Caregivers (N=89)*

| <b>Variable</b> | <b><i>M</i></b> | <b><i>SD</i></b> | <b>Std.<br/>Error of<br/>Skewness</b> | <b>Std.<br/>Error of<br/>Kurtosis</b> | <b>Minimum</b> | <b>Maximum</b> |
|-----------------|-----------------|------------------|---------------------------------------|---------------------------------------|----------------|----------------|
| Depression      | 48.11           | 12.45            | 0.25                                  | 0.50                                  | 24.00          | 76.00          |

***T test***

An independent sample *t* test was conducted to compare the depression scores for caregivers caring HIV-infected child/ren. As seen in Table 10, scores for caregivers caring for a HIV-infected child/ren were significantly different from those of caregivers not caring for a HIV-infected child/ren. Inspection of the two groups means indicates that the average depression score for caregivers caring for HIV-infected child/ren ( $M= 44.6$ ,  $SD=10.4$ ) is significantly lower than the score ( $M=54.8$ ,  $SD=13.2$ ) for caregivers not caring for a HIV-infected child/ren;  $t=(84) = 3.94$ ,  $p<.001$  The magnitude of the difference between the means is 10.17, 95%CI: 5.04 to 15.30. The effect size is  $d = 0.85$ . According to Cohen (1988), this is a large effect.

Table 9

*Comparison of Caregivers Caring for a HIV-Infected Child/ren*

| <b>Variable</b>                       | <b><i>M</i></b> | <b><i>SD</i></b> | <b><i>t</i></b> | <b><i>df</i></b> | <b><i>p</i></b> | <b><i>D</i></b> |
|---------------------------------------|-----------------|------------------|-----------------|------------------|-----------------|-----------------|
| Caring for HIV-infected child/ren     | 44.6            | 10.4             | 3.94            | 84               | <.001**         | 0.85            |
| Not caring for HIV-infected child/ren | 54.8            | 13.3             |                 |                  |                 |                 |

*Note.* \*  $p < .05$ ; \*\*  $p < .01$ ;  $N = 32$  not caring for HIV-positive child/ren;  $N = 54$  caring for HIV-positive child/ren

**Pearson Correlation**

Pearson correlations were computed to examine the intercorrelations of the variables. Table 10 shows that age was significantly correlated with informational support,  $r(87) = -.22, p < .05$ . This means only informational supports were related to age and the variables were not related. The correlation between caring for an HIV-infected child was significantly negatively correlated with depression,  $r(87) = -.40, p < .001$ . See Table 10. In other words only caring for an HIV-infected was related to depression and not the other variables. Because age and caring for an HIV-infected child were related to the dependent and independent variable they were entered first in the hierarchical multiple regression model.

Table 10

*Intercorrelations for Age and Caring for an HIV-Infected Child/ren*

| <b>Measure</b>                          | <b>1</b> | <b>2</b> | <b>3</b> | <b>4</b> | <b>5</b> | <b>6</b> | <b>7</b> |
|---|----------|----------|----------|----------|----------|----------|----------|
| 1. Age                                  | 1        |          |          |          |          |          |          |
| 2. Caring for an HIV-infected child/ren | .08      | —        |          |          |          |          |          |
| 3. Informational Support                | -.22*    | -.09     | —        |          |          |          |          |
| 4. Financial Stability                  | -.001    | .16      | -.09     | —        |          |          |          |
| 5. Social Support                       | -.01     | -.06     | .29*     | .54**    | —        |          |          |
| 6. Depression                           | -.08     | -.40**   | .17      | .46**    | .05      | —        |          |

*Note.* \*  $p < .05$ ; \*\*  $p < .01$

**Hierarchical Multiple Regression**

To investigate how well financial stability, informational and social supports predict depressive symptoms in elderly caregivers after controlling for age and caring for an HIV-infected child/ren, a hierarchical linear regression was conducted using SPSSv22.0. Preliminary analyses were conducted to ensure no violation of assumptions occurred. The assumptions of linearity, normally distributed errors, uncorrelated errors, and multi co linearity were checked and met (Leech et al., 2011). The correlation between age and depression was ( $r = -.08$ ) not significant, while the correlation between raising an HIV-positive child and depression was ( $r = -.40$ ), this correlation was significant,  $p < .001$ . When age and caring for an HIV-infected child/ren were entered first,

the model significantly predicted depression,  $F(2,83) = 7.78, p < .001$ , adjusted  $R^2 = .138$ . However, as indicated by  $R^2$ , only 13.8% of variance in depression could be predicted by caregivers' age and whether the caregiver was caring for an HIV-infected child/ren. Of note, only caring for an HIV-positive child /ren was significant in this model. However, when the other variables (i.e., financial stability informational supports and social supports) were added, they significantly improved the prediction,  $R^2$  change = .182,  $F(3,80) = 13.8, p < .001$ , adjusted  $R^2 = .30$ . Thus, the full model accounts for 30% of the variance in depression.

This is a medium effect, according to Cohen (1988). The beta weights and significance values, presented in Table 11, indicate which variables contribute most to predicting depression when age, caring for an HIV-infected child/ren financial stability, informational supports, and social supports were entered together as predictors. With this combination of predictors, financial stability had the highest beta (-.41), followed by caring for an HIV-infected child/ren with beta (-.32). The final results showed that only financial stability and caring for an HIV-infected child remained statistically significant in the full model. This means only financial stability and caring for an HIV-infected child/ren significantly predicted depression among elderly caregivers raising children orphaned by AIDS in this sample.

Table 11

*Multiple Regression Analysis Summary Predicting Depression from Five Predictor Variables (N=86)*

| Predictor                            | Step 1   |            |         | Step 2   |            |         |
|--------------------------------------|----------|------------|---------|----------|------------|---------|
|                                      | <i>B</i> | <i>SEB</i> | $\beta$ | <i>B</i> | <i>SEB</i> | $\beta$ |
| Age                                  | -0.02    | 0.13       | -0.14   |          |            |         |
| Caring for an HIV-infected child/ren | -10.09   | 2.6        | -0.39** | -8.16    | 2.38       | -.32**  |
| Financial stability                  |          |            |         | -6.6     | 1.5        | -0.41** |
| Informational supports               |          |            |         | 2.7      | 2.1        | 0.12    |
| Social supports                      |          |            |         | -0.9     | 1.6        | -0.5    |
| Total R <sup>2</sup>                 |          | 0.16       |         |          | 0.34       |         |
| $\Delta R^2$                         |          | 0.16       |         |          | 0.18       |         |

*Note.* \*  $p < .05$ ; \*\*  $p < .01$

## CHAPTER 6: DISCUSSION

This chapter interprets the findings of the study and links them to the literature and conceptual framework of Bronfenbrenner's (1979) ecological systems theory. The ecological systems theory that underpins this study allows examination of the caregivers in the context of their environment. The chapter discusses the characteristic features of elderly caregivers raising children orphaned by AIDS in northern Namibia and the relationships between the major predictor variables (i.e., age, caring for a HIV-infected child/ren, financial stability, informational supports, and social supports) and depression. Limitations of the study are also addressed.

As described in earlier chapters, no publication was found that specifically examined the association between financial stability, informational supports, social supports, and depression among caregivers raising children orphaned by AIDS in southern Africa. This study attempts to fill this gap in the literature. It was designed to examine the relationships between financial stability, informational supports, social supports, and depressive symptoms of 89 elderly rural Namibian women aged 60-92 raising AIDS-affected children.

### **Characteristics of Elderly Caregivers**

It is important to first understand the characteristics and cultural milieu of caregivers raising children orphaned by AIDS in this region. The results show a preponderance of female (i.e., grandmothers 85.4%) caregivers as compared to the fewer (14.6%) male caregivers. In a typical African society such as this one, more often than not, women are expected to take the lead in caring for those who are sick and dying.

Consequently, caregiving responsibilities (such as those provided by the elderly grandparents to children infected and/or affected by HIV and AIDS) provided by women have become a norm in much of Africa (Akintola, 2004), where men in these communities are often viewed as unsupportive, uninvolved, and apathetic (Abasiubong et al., 2011).

Findings suggest and are consistent with findings of other studies that within the African context, grandmothers have increasingly become heads of households (Nyesigomwe, 2006) and have taken on the caregiving of those affected by the AIDS epidemic (Ardington et al., 2010; Nyambedha, Wandibba, & Aagaard-Hansen, 2003). The extended African family systems (i.e., including grandparents) are connected by reciprocal support obligations, especially among those living in rural areas (Fortes, 1969). Viewed as a form of familial social support, this kind of family safety net system is particularly prevalent during times of stress (Kayongo-Male & Onyango, 1984), such as during the HIV/AIDS epidemic. This finding was not surprising and may be explained by the cultural expectation among the Oshiwambo (who compose the majority of caregivers in this study's sample) that the elderly are obligated to raise and care for their own children, including their grandchildren and other children related to them, in a time of need. It is common practice within the Oshiwambo ethnic group for parents to invest in the education, health, and wellbeing of their children (Munthree & Maharaj, 2010) with the expectation that children will care for them in their later years (Ncube et al., 1997). In the Oshiwambo culture, which is governed by a matrilineal system, children essentially belong to the mother's side of the family (Brown, 2011). Consequently, in this era of high

prevalence of HIV/AIDS, caregivers, especially grandmothers, are compelled to assume the caregiving responsibility not only for their grandchildren but also for their sick and dying adult children (Munthree & Maharaj, 2010).

From the ecological systems theory perspective, the caregiver-child relationship represents the microsystem level, which consists of the immediate setting in which the individual is situated, such as the family environment (Bronfenbrenner, 1979). When AIDS-affected children lose their biological parents and are taken in by extended family (i.e., grandparents), elderly caregivers help raise these children and continue to maintain relationships and ties with other extended family, develop cultural identity, and enter into the home of a known person, thereby making the transition less traumatic and disruptive (Schwartz, 2002). However, it is suggested by this study that many kinship caregivers raising children orphaned by AIDS are more likely to live in poverty and have poorer health and fewer economic resources that may directly affect children's physical, emotional, and mental well-being. This precarious scenario has the potential to create distress and depressive symptoms for elderly caregivers, for the children in care, and for society that will experience the negative effects of children whose well-being has been compromised.

Furthermore, the findings reveal that elderly caregivers were experiencing financial hardship or were financially unable to meet the needs of OVC primarily due to a lack of financial resources. In the current sample, findings show that 97.8% caregivers relied heavily on their old-age pension and foster care grants as their main sources of income. These results are consistent with studies conducted in South Africa (Reddy;

Schatz, & Ogunmefun, 2007), Kenya (Nyambedha et al., 2003), Togo (Moore, 2007-2008), and Uganda (Kagotho & Ssewamala, 2012; Kanya & Poindexter, 2009).

Consistent with existing literature (Moore, 2007-2008; Schatz & Ogunmefun, 2007), data from the present study showed that caregivers were struggling financially with the upkeep of OVC in their care. Over one-third (31.5%) of respondents were not receiving government foster grant(s) even though they were raising OVC, while 47.2% of the caregivers reported that they found it very difficult to cope financially in their caregiving role. In addition, 37 (41.6%) caregivers reported being frequently worried about the financial challenges in meeting the needs of household members. Similar to previous work (Booyesen, 2004; Naidu & Harris, 2005; Schatz & Ogunmefun, 2007), findings reveal that well over half (57%) of caregivers reported that they often had used the government monthly pension money to cover household costs in order to meet the needs of OVC, subsequently risking their own physical health and mental well-being.

From an ecological perspective, child foster care grants and old-age pensions represent the exosystem level, which consists of interactions or settings in which the caregiver is not directly involved; events and changes within these systems, however, may affect the individual in some way (Bronfenbrenner, 1979). Findings from this study point to the critical role of foster care grants and pensions in HIV/AIDS caregiving, especially in households headed by grandmothers. Results suggest that elderly caregivers who were receiving child grants and/or old-age pensions were using these funds to care for AIDS-affected children, which may thereby have helped to alleviate somewhat the caregiver burden and consequently decrease the levels of distress or depressive symptoms

among caregivers. Thus, social grants from the government may be helping to provide an economic safety net for many households affected by the AIDS epidemic. This finding is consistent with other studies, particularly in South Africa (Casle, 2011; Ogunmefun & Schatz, 2009; Reddy, 2005; Schatz et al., 2010; Schatz & Ogunmefun, 2007).

Furthermore, 37 (41.6%) of the caregivers reported needing to sell their household assets (e.g., goats, sheep, cows, *manhangu* millet, chickens, etc.) to meet the needs of orphans. In addition, 49 caregivers (55.1%) had to utilize their savings to meet needs such as food, clothing, funeral costs, school fees, school uniforms, health care, and transport. It was unfortunate to find that, contrary to other studies (Tsiwo-Chigubu, 2000), the majority of caregivers (80.9%), including other family members in their households, were not involved in any income-generating projects (e.g., selling goods at the local market) as a means of supplementing their family income. The literature is replete with studies that have shown how income-generating projects, microfinance, and cash transfers (Adato & Bassett, 2009; Cluver & Gardner, 2007; Sswamala et al., 2012) projects may buffer the economic shocks of households affected by HIV and AIDS in developing countries. Researchers have found that cash transfers show the strongest evidence, particularly in programs in Latin America and Asia (Adato & Bassett, 2009).

### **Research Question 1**

This section includes discussion of results for Research Question 1: Do elderly caregivers who care for an HIV-infected child/ren experience financial stability, informational support, social support, and depression differently than caregivers who do not care for a non HIV-infected child/ren? This study examined whether caring for an

HIV-infected child/ren was associated with depression among elderly caregivers. It was hypothesized that caregivers caring for an HIV-infected child/ren will report more symptoms of depression than caregivers who were not caring for an HIV-infected child/ren. This hypothesis was not supported. In fact there was a negative association between caring for an HIV-infected child/ren and depression (-.32). Surprisingly, findings of this study were contrary to previous studies on caring for an HIV-infected child in KwaZulu Natal, South Africa (Demmer, 2011) and in Burkina Faso (Hejoaka, 2009), in which caregivers who were caring for an HIV-infected child/ren expressed HIV/AIDS related stigma and were more likely to have high levels of psychological distress compared to those who were not caring for an HIV-infected child/ren. Findings showed that the average depression score for caregivers caring for an HIV-infected child/ren was lower ( $M=44.6$ ) compared to caregivers who were not caring for an HIV-infected child/ren ( $M=54.8$ ). The difference between the two groups was statistically significant. Thus, caring for a HIV-infected child/ren was not a predictor of depression in this sample. These results were unexpected and reveal the complexity of HIV/AIDS caregiving in this population, and there could be all sorts of explanations.

It could be that caregivers who are less depressed are more likely to care for HIV-infected child/ren. Alternatively, other extended family members, friends, neighbors, local churches, and/or local community members could step up to provide social, instrumental, material, and/or spiritual support to caregivers. It is generally known that Africans are reluctant to seek professional mental health services; instead, they have developed and rely heavily on cultural beliefs and attitudes on how to handle emotional

or psychological problems that reflect a tradition of serenity, perseverance, and religious faith (Neighbors & Jackson, 1984). Another explanation could be that grandparents may feel some sort of increased self-worth that fights against depression or helps them find positive meaning in their caregiving role. Contemporary theorists on coping have shown that HIV/AIDS caregivers are able to apply positive coping mechanisms such as positive reappraisal, goal-directed, problem-focused coping, and spiritual beliefs and practices while facing the reality of the death of their family members (Folkman, 1997). These

### **Research Question 2**

This section includes discussion of results for Research Question 2: Does caring for an HIV-infected child/ren relate to elderly caregivers' financial stability, informational supports, social supports, and depression? In trying to examine whether financial stability was associated with depression in this study, it is hypothesized that there is a negative or inverse association (or relationship) between financial stability and symptoms of depression. This means caregivers with a higher score on financial stability would be more likely to show lower levels of depression than those with a lower score on financial stability. This hypothesis was supported. Thus, caregivers who reported higher financial stability were negatively associated with higher levels of depressive symptoms. The multiple regression analysis showed that financial stability was the strongest predictor in the model. These socioeconomic findings raise concerns about how well elderly caregivers are financially able to raise children affected by AIDS. Findings showed that overall, elderly caregivers in this sample were struggling financially as they were raising children affected by HIV and AIDS. Researchers have argued that taking in

children such as OVC has the potential to exacerbate household poverty (Hodge, 2008).

In turn, poverty has a profound impact on adherence to drug regimens among HIV-infected children in Uganda (Bikaako-Kajura et al., 2006).

Although it was not the focus of the study, poverty was rife in this region.

According to the Population Housing Census of 2011, this area was among the regions with populations in a rural area that is severely poor (NPC, 2011). Moreover, child poverty in this area was found to be severe among thousands of OVC (NSA, 2012). The majority of caregivers (97.8%) reported that they were pensioners, and more than two-thirds (68.5%) stated that their monthly household income was N\$500 (Namibian dollars). Poverty is disproportionately prevalent among pensioners, and many of the pensioners were raising OVC (NSA, 2012). It is reasonable to argue that preexisting challenges of poverty have the potential to create depressive symptoms in caregivers of children affected by HIV and AIDS. Further, the financial difficulty experienced by elderly caregivers may be attributed to various factors, including, among others, the cumbersome process of administering welfare grants, lack of appropriate information concerning access of social grants, lack of correct documentation (e.g., identification documents of birth certificates), insufficient number of social work practitioners as well as insufficient data on service provision and outcome (USAID, 2011).

Applying Bronfenbrenner's (1979) ecological theory, poverty experienced by grandmothers, which is compounded by a lack of financial resources or supports, is part of the macrosystem. The macrosystem is generally considered to encompass broad societal, political, legal, economic, and cultural values guiding society. As stated earlier,

women in much of Africa are culturally viewed as caretakers of those who are vulnerable and sick, including children infected or affected by HIV and AIDS. In addition, scholars have contended that kin caregivers are more often than not adults aged 50 and older (Ardington et al., 2010; Boon et al., 2010a; Nyambedha et al., 2003) living in dire poverty or below the poverty line (George et al., 2011; Hlabyago & Ogunbanjo, 2009; Lindsey et al., 2003; Orner, 2006) and are often faced with myriad of challenges, such as lack of basic resources, insufficient support, high demand of caregiving responsibilities, anxious feelings about their future health and well-being, isolation, and stigma (Moore, 2007-2008; Orner, 2006; Ssengonzi, 2007). Taken together, these factors have the potential to negatively affect the mental well-being of elderly caregivers, thereby elevating levels of distress and depression in this population.

### **Informational Supports**

The study examined whether informational supports were associated with depression. In this study, it was hypothesized that there is a negative association (or relationship) between informational supports and symptoms of depression. This means that caregivers with a lower score on informational supports would be more likely to show higher symptoms of depression than those who have a higher score on informational supports. This hypothesis was not supported, because the correlation was positive and not significant. Thus, informational supports were not a predictor of depression in this sample. Results show that 32% of caregivers had a high score on the informational supports measure. By and large, respondents in this study had knowledge about essential informational supports in their caregiving role. This finding departs from

the results found by Boon et al. (2009) and Lindsey et al. (2003), in which informational supports was a predictor of negative mental health outcomes for HIV/AIDS caregivers.

### **Social Supports**

The study also examined the association between social supports and depression among caregivers raising children orphaned by AIDS. In this study it was hypothesized that there is a negative association (or relationship) between social supports and symptoms of depression. This means caregivers who had a lower score on social supports would be more likely to show higher symptoms of depression than those who had a higher score on social supports. This hypothesis was not supported. Thus, there was not a clear relationship between social supports and depression in this sample. In this current study all caregivers reported depression scores above the cut-off point of 16 (Radloff, 1977). Since none fell into the non-depressed range, it was not possible to fully explore the relationship between social supports and depression. Findings show that caregivers had a mean score of ( $M= 5.31, SD=0.73$ ) indicating that the majority of elderly caregivers scored high on the social supports measure. Contrary to other studies (Kuo, Operario, & Casle, 2012) in which social supports was a significant predictor of depression, in the current sample no relationship was found between social supports and depression among caregivers raising children orphaned by AIDS in this region.

It was surprising to find that social supports were not associated with depression in this sample. In this study, social supports were generally high among elderly caregivers, although these supports were unrelated to depression, suggesting that they were not used to maintain mental well-being in this population. A possible explanation is

that Oshiwambo caregivers may be reluctant to disclose their struggles about caregiving to family, friends, neighbors, and the larger community. Also, disclosing their challenges may contradict the moral obligations and cultural expectations for elders to provide care to their adult child and grandchildren in a time of need (Fortes, 1969; Kayongo-Male & Onyango, 1984).

This study examined whether caring for an HIV-infected child/ren was associated with depression among elderly caregivers. It was hypothesized that caregivers caring for an HIV-infected child/ren will report more symptoms of depression than caregivers who were not caring for an HIV-infected child/ren. In this study, this hypothesis was not supported. In fact there was a negative association between caring for an HIV-infected child/ren and depression (-.32). Surprisingly, findings of this study were contrary to previous studies on caring for an HIV-infected child in KwaZulu Natal, South Africa (Demmer, 2011) and in Burkina Faso (Hejoaka, 2009), in which caregivers who were caring for an HIV-infected child/ren expressed HIV/AIDS related stigma and were more likely to have high levels of psychological distress compared to those who were not caring for an HIV-infected child/ren. In the current study, findings show that the average depression score for caregivers caring for an HIV-infected child/ren was lower ( $M=44.6$ ) compared to caregivers who were not caring for an HIV-infected child/ren ( $M=54.8$ ). The difference between the two groups was statistically significant. Thus, caring for a HIV-infected child/ren was not a predictor of depression in this sample. These results were unexpected and reveal the complexity of HIV/AIDS caregiving in this population, and there could be all sorts of explanations.

It could be that caregivers who are less depressed are more likely to care for HIV-infected child/ren. Alternatively, other extended family members, friends, neighbors, local churches, and/or local community members could step up to provide social, instrumental, material, and/or spiritual support to caregivers. It is generally known that Africans are reluctant to seek professional mental health services; instead, they have developed and rely heavily on cultural beliefs and attitudes on how to handle emotional or psychological problems that reflect a tradition of serenity, perseverance, and religious faith (Neighbors & Jackson, 1984). Another explanation could be that grandparents may feel some sort of increased self-worth that fights against depression or helps them find positive meaning in their caregiving role. Contemporary theorists on coping have shown that HIV/AIDS caregivers are able to apply positive coping mechanisms such as positive reappraisal, goal-directed, problem-focused coping, and spiritual beliefs and practices while facing the reality of the death of their family members (Folkman, 1997). These positive psychological ways of coping have demonstrated a buffer against intense distress and depressive symptoms among family caregivers (Folkman, 1997).

### **Research Question 3**

This section includes discussion of results for Research Question 3: Does the age of elderly caregivers relate to their self-reported financial stability, informational supports, social supports, and depression? The study examined whether age was related to financial stability, informational supports, social supports, and depression. It was hypothesized that there was a significant association between age and financial stability, informational supports, social supports, and depression. This hypothesis was partially

supported. Only informational support was related to age in the current study. Findings showed that younger caregivers were more likely to have informational support than older caregivers. Thus, one could argue that because younger caregivers were more likely to have essentially information about raising children orphaned by AIDS, they were more to access in the needed services for children in their care.

#### **Research Question 4**

This section includes discussion of results for Research Question 4: To what extent do financial stability, informational supports and social supports predict elderly caregivers' levels of depression above and beyond caring for an HIV-infected child and age? The study examined also how well financial stability, informational supports, and social supports were able to predict symptoms of depression among elderly caregivers after controlling for age and caring for a HIV-infected child/ren. It was hypothesized that among caregiver's greater informational supports, greater social supports, and greater financial stability will be associated with fewer symptoms of depression after controlling for age and whether caregivers are caring for an HIV-infected child/ren. Findings from the current study showed that financial stability was the strongest predictor, followed by caregivers who were caring for children who were not HIV-infected. Results in this study show that the majority of caregivers faced financial challenges. Thus, many grandmothers were struggling financially as they raise their grandchildren and other children infected and/or affected by HIV and AIDS.

### **Depression Among Elderly Caregivers**

Findings from this study revealed an elevated level of depressive symptoms, with all caregivers in this sample scoring above the threshold criteria for elevated depression (CES-D score  $\geq 24$  points). These findings are consistent with the results of previous studies on the higher presence of depressive symptoms among elderly female caregivers of adults and children infected and/or affected by HIV/AIDS in southern Africa (Lindsey et al., 2003; Lv et al., 2012; Ssengonzi, 2009). A possible reason for such a high level of depressive symptoms among the study sample might be attributed by both the high rates of HIV/AIDS and high poverty in this region.

Other possible reasons why grandparent caregivers in this study had high levels of depression could be attributed to factors that predispose such individuals (e.g., facing the challenges of a chronic illness and or HIV/AIDS stigmatization). Research is replete with evidence of how the elderly are at risk for multiple chronic illnesses such as arthritis, cardiovascular and respiratory conditions, diabetes, and high blood pressure as they age. Moreover, if these health conditions are neglected or go untreated, then they may have the potential to impact mental health negatively (Joslin & Harrison, 1998; Minkler & Fuller-Thomas, 1999). In this study, more than half of caregivers revealed they had a chronic illness that prevented them from working for more than 3 months. Thus, chronic illness that is prevalent in this sample may have potential to elevate symptoms of depression in this population (Van Dyk, 2005).

In addition, Demmer (2011), Lindsey et al. (2003), and Ogunmefun et al. (2011) have found that HIV and AIDS are stigmatized illnesses. Studies have shown the

pervasive effects of stigmatization on the lives of those caring for family members infected with the HIV/AIDS virus (Hejoaka, 2009; Moore & Williamson, 2011). From the above, it can be argued that caregivers who face stigmatization because they are either raising children orphaned by AIDS or caring for an HIV-positive child/ren may experience distress that can lead to elevated levels of depression.

In sum, clearly, there is a compelling need to recognize the severe impact of the HIV/AIDS epidemic on caregivers who are, for the most part, elderly women. Results from this study clearly point to the plethora of personal challenges that elderly caregivers face in their caregiving role. Findings from the present study suggested stressors of a lack of financial resources and caring for HIV/AIDS orphans posed particular struggles for many caregivers in general. These challenges were associated with most elevated levels of depression among elderly caregivers. It is known that in much of sub-Saharan Africa, females had a history of being disadvantaged long before the HIV/AIDS epidemic and were frequently further burdened with the responsibility of caring for those sick and dying of AIDS. Kinship caregivers have long been perceived as a viable option for children affected by HIV and AIDS. However, as identified in this sample, elderly caregivers face a heavy financial/economic burden as they risk their own physical and mental well-being in raising AIDS-affected children. Since the child welfare system depends heavily on this population as a means to provide familiar continuity for children in need of care, it is imperative for practitioners and policy-makers to actively redress the needs of caregivers in order to safeguard their service needs. The findings of the study have implications for social work practice, policy, and research that will be discussed in the next chapter.

### **Limitations of the Study**

There are several limitations in the current study, as discussed in this section.

#### **Sampling Limitations**

A cross-sectional, correctional survey design was used for this study. In general, survey research is strong on reliability and weak on validity (Nardi, 2003). Therefore, survey research is limited in its ability to show causality (Dillman, Smyth, & Christian, 2009). In this study the aim was to examine the predictive relationships between independent variables (i.e., caring for a HIV-infected child/ren, financial stability, informational support, and social support) and the dependent variable (i.e., depression). However, this examination does not necessarily indicate a causal relationship. That is, determining that one independent variable is associated with depression does not necessarily mean that that variable caused the depression. There may be other confounding variables unaccounted for within this statistical modeling as well. Thus, correlational studies are unable to control for threats to the internal validity of the findings.

Another limitation is that the sample was not a random sample because participants volunteered and because participants were selected by CAA according to their accessibility to tarred roads. . In addition, it is possible that there were elderly caregivers who were raising OVC but who were not affiliated to CAA and, thus, were excluded from the study. Consequently, findings of this study may not be applicable to more urban samples, more racially and tribally diverse populations, or even to other rural regions of the country. However, even if findings may be specific to the Omusati Region,

they may reflect some of the dynamics of other HIV/AIDS caregiving and resource-limited communities within Namibia. Finally, this study was limited in that it was cross-sectional study and not longitudinal. Data collected from one time point can provide a good view of supports of caregivers raising children orphaned by AIDS; however, these data present only a single, static picture of events.

### **Instrument Limitations**

One other limitation specific to this study to recognize was the administration of the questionnaires. In this study, questionnaires were administered orally to ensure that the elderly caregivers understood each item. However, this approach may cause validity issues when the original measures (i.e., the CES-D and Perceived Social Support measures) were designed for self-administration. In addition, although these measures have been used in many cultures in southern Africa, they have not been used in Namibia or with the unique population and local language. Also, there could be cultural differences in the meaning of the terms used in the instruments. Further, the financial stability and informational support measures used in this study have not been validated for a rural Namibian population, although the development of such a score followed general recommendations in the global literature on assessing financial and informational supports for caregivers raising children orphaned by AIDS (Bell, 1990; Lindsey et al., 2003; Olenja, 1999; Rioio et al., 2005). For example, items on the financial and informational measure have not been tested elsewhere. Therefore, these items may not conform to established psychometric standards.

An additional limitation in this study is that data were self-reports of caregivers' depressive symptoms, which may be less reliable than clinician-based assessments of mental health. Additionally, the data focused exclusively on elderly caregivers and cannot depict family or household dynamics associated with depression. For example, additional data on family members such as children's general health status and the relationship of the caregiver to the child may have shown a relationship between these family factors and the caregiver's mental health. Capturing the relationship of the caregiver to the child was particularly challenging in the analysis because a caregiver was often related to different children in the family in different ways: One caregiver could be caring for her or his own children as well as her or his nieces, nephews, and grandchildren. It is common practice among many ethnic groups in Namibia and South Africa that families live in mixed-generation, extended-family households due to dislocation from apartheid and migratory work. This trend may be particularly common in HIV-endemic communities where households often experience multiple deaths of family members (Madhavan, 2004).

Finally, although the purpose of this study was to examine the relationships between depressive symptoms and supports of caregivers raising children orphaned, this focus may be viewed as only emphasizing negative aspects of caregiving. Thus, it is important to acknowledge that future research examines the complexity of caregiving in a way that also explores the strengths of this caregiving.

## CHAPTER 7: STUDY IMPLICATIONS

The findings of this study, despite the limitations, have a number of implications for social work. This chapter discusses implications for social work practice, policy, and research applying ecologically grounded strategies.

### **Implications for Social Work Practice**

Family-focused interventions are congruent with social work and offer a framework through which to improve the overall efficiency of elderly caregivers raising children orphaned by HIV and AIDS. By family-focused, I mean interventions that target caregivers and the children in their care as well as other household members. Social work practitioners are trained to intervene at the micro, meso, and macro levels with individuals, families, groups, and communities. From this study, elderly caregivers of OVC show unique needs that may be presented to social workers across the social services delivery system.

#### **Microsystem**

At a microsystem level, there is a need for clinical therapeutic intervention to address issues such as caregiver-child relationships, especially for caregivers who were raising non-HIV-infected child/ren and who showed elevated levels of depression. The results from this study clearly point to the plethora of personal accounts about the many ways in which elderly caregivers are affected by the various social systems that impinge on their caregiving role. Findings from the present study suggest that many of the stressors centered on caregivers' lack of financial supports and most commonly were manifested in emotional distress, worry, and in pervasive senses of uncertainty about the

future and of helplessness about caregiving demands. A direct implication of the study is to promote mental health interventions for these elderly caregivers. At the core of the social work profession is the enhancement of resilience, human strength, and assets (Saleebey, 1996). For practitioners to strengthen the psychological well-being of caregivers, it is imperative that human service practitioners identify and focus on the strengths, assets, and coping skills of caregivers (Cowger, 1994; Saleebey, 1996).

Furthermore, there is a need for interventions that provide psychosocial care directly to elderly caregivers. This care may include grief and bereavement counseling, age- and gender-specific educational campaigns on the prevention of HIV/AIDS and the role elders play in fighting the epidemic, support groups, and psycho-education groups. For example, short-term psycho-educational groups (i.e., 6 to 8 sessions) can be cost-effective and useful interventions that equip caregivers with essential survival skills for coping with the effects of the disease, including those who face mental health challenges (Marshall et al., 1998). Interventions of that nature have the potential to broaden family, professional, and social support, increasing caregivers' knowledge of caregiving responsibilities and ultimately decreasing their loneliness and social isolation (Butler, 2005). In addition, at the core of African caregiving, traditional and cultural norms compel women, especially grandparents, to step in to care for children orphaned by HIV and AIDS even at caregivers' personal cost. Thus, practitioners and social service agencies, NGOs, and churches that provide assistance to AIDS-affected families will need to develop programs that are culturally sensitive and accessible to this population.

**Mesosystem**

Additionally, at the mesosystem level, there is a need for community development practitioners to initiate culturally appropriate economic empowerment interventions that can act as safety nets and improve the economic circumstances of families affected by HIV/AIDS for HIV/AIDS-affected households. These may include, among others, community-based capital cash transfers (Skovdal, Mwasiagi, Webale, & Tomkins, 2011) and child support grants and youth saving accounts (Ssewamala, 2007). Further, home-based care initiatives seek to provide both emotional and tangible support to caregivers. For example, they should offer advice, positive ways of coping with grief and bereavement counseling, encouragement, and comfort as well as practical assistance in caregiving tasks, health care, respite care, prevention, and transportation to health facilities. Programs such as these have the potential to drastically and rapidly improve outcomes of children and families in poverty stricken and AIDS-endemic communities (Irwin, Admas, & Winter, 2009; Plagerson et al., 2011).

**Implications for Social Work Policy****Exosystem**

At the exosystem level, there is a major need for practitioners and stakeholders to review the existing policies in the areas of mental health services, food security, welfare grants, economic opportunities, caregiver policy, and education and training in the area of mental health education as they impact elderly caregivers raising OVC. These policy revisions will be briefly explained.

**Expand mental health services.** It is evident from the research findings that there is need for mental health services for elderly caregivers raising OVC. Policy-makers need to prioritize strategies to address the mental health needs of caregivers in high HIV-prevalence settings and socioeconomically deprived communities such as rural areas in Namibia. A clear argument has emerged for more comprehensive policies and interventions that are sustainable and enabling and that promote the physical and psychological wellbeing of caregivers. These policies need to focus on the capacity and stability of families. They need to address resilience by focusing on caregivers' external vulnerabilities and by alleviating stressors threatening households (Drimie & Casale, 2009).

An emerging literature suggests that mental health needs in developing countries are under resourced compared to those in high-income countries. For example, studies in the global south have found that countries in this region spend less than 1% of their total health budgets on mental health, and mental health professionals in these areas are inadequate for service needs (WHO, 2005). However, recent studies have demonstrated the efficacy of low-cost, community-based interventions that can be affordable and feasible even in human- and resource-poor environments (Bass, Neugebauer, & Clougherty, 2006). For example, a community-based randomized trial study in Uganda showed that group therapy for men and woman diagnosed with depression yielded positive outcomes and was feasible and affordable. After the intervention, 6.5% of the participants who received group therapy showed symptoms of depression compared to half in the control group, and this effect was sustained 6 months later (Bass et al., 2006).

Thus, this kind of intervention also has implications for expanding social work and other mental health education in Namibia.

**Increase food security.** Findings from this study revealed that HIV/AIDS-affected households experienced a great challenge with food security because caregivers lacked sufficient financial supports to provide the needed nutrition for children in their care. Researchers have found that the majority of elderly caregivers are often too physically weak to engage in active food production (Nhongo, 2004; Smith, 2007). Therefore, it is critical for the Namibian government, nongovernmental organizations, and civic organizations to focus on increasing food security in elderly headed-households, particularly those raising OVC. Alleviating food security in HIV/AIDS-affected households will go a long way in decreasing the psychological stress of caregivers.

**Expand welfare grants.** As HIV/AIDS continues to strip away remittance from family members, the elderly caregiver's pension and foster care grants for OVC were found to be the main sources of income for the majority of families in this study. The pension that was supposed to support the elderly caregiver may well be insufficient to meet the needs of caregivers and the numerous household members, many of whom are still of school-going age. The evidence of the importance of pensions, foster care, and disability grants speaks to the need for the expansion of these welfare grants. In addition, it would be helpful for the Namibian government to partner with the private sector (i.e., private-owned business) so as to provide supplementary resources to the most vulnerable groups, especially grandparents raising children affected by HIV and AIDS. Because of

the age of many caregivers, they are less likely to qualify for other sources such as loans and grants that could alleviate their financial instability (Ferreira, 2004). To this end, it seems that when the meager resources that elderly caregivers rely on heavily do not come through (e.g., when there are delays in social grants), that deprivation plunges them into a state of crisis. This scenario creates opportunities for government and nongovernmental agencies to respond in various ways to mitigate such crises, for example, through emergency support and self-help initiatives (CINDI, 2007).

**Expand economic opportunities.** The financial challenge associated with providing care to additional children affected by HIV/AIDS is hardly debatable in much of southern Africa (Freeman & Nkomo, 2006a). There is a need to enhance the economic opportunities of families affected by HIV and AIDS. Policies focused on strategies to address the economic deprivation families are needed. Economic strengthening is defined as “approaches to strengthen the capacity of caregivers and communities to address the financial issues to ensure vulnerable children are able to access essential services, including safety, healthcare, education, and other basic needs” (USAID, 2008, p. 11).

There is a need to develop various economic opportunities for caregivers raising children who are infected with AIDS. Studies have shown how income-generating projects, microfinance, and cash transfer projects (Adato & Bassett, 2009; Cluver & Gardner, 2007; Sswamala et al., 2012) may buffer the economic shocks of households affected by HIV and AIDS in developing countries. Researchers have found that cash transfers show the strongest evidence, particularly in programs in Latin America and Asia

(Adato & Bassett, 2009). Consequently, there is a need for expanding economic opportunities for households affected by HIV and AIDS.

**Caregiver policy.** There is a compelling need to put in place a caregiver policy directed to elderly caregivers that is similar to the OVC Policy (GRN/MGECW, 2004). For example, such a policy should address antipoverty strategies and viable economic opportunities (e.g., cash transfers) and improve the well-being of families by way of initiatives such as providing access to social welfare grants and family counseling; establishment of food gardens; assistance for the elderly to have better relationships with the children in their care special help for HIV/AIDS orphans; incentives for other family members in HIV-affected households; and welfare initiatives that will improve the quality of life of elderly caregivers raising children orphaned by AIDS (CINDI, 2007). Moreover, the policy should focus on raising more awareness among the general public about the pivotal role of the elderly in HIV/AIDS caregiving. Community-level care should garner greater community/village involvement and support from local churches and faith-based organizations, nongovernmental organizations and the private sector to help the elderly as they care for OVC. Such policy initiatives have the potential to significantly alter the impact of poverty and vulnerability of poor households affected by the AIDS epidemic (Ferreira, 2004), thereby decreasing depressive symptoms in this population.

**Education and training.** With the overwhelmingly high number of elderly caregivers who experienced elevated depressive symptoms in this sample, it is evident that there is a high need for education and training for practitioners and social service

providers in areas of mental health and HIV and AIDS. Findings from this study point to the need for mental health providers to gain understanding of the impact of culture, caregiving, and the grieving processes of this population in order to provide culturally sensitive services to caregivers and their children.

### **Macrosystem**

At a macrosystem level, there is a need for more concerted efforts to be made in involving all stakeholders. The focus should be on integrating a gender perspective in community-based care and support. There is a need to increase the role of men and boys in caregiving beyond what they are currently doing. In addition, although the government of Namibia can be applauded for putting in place social protection measures by way of old age pensions, social welfare grants, and the OVC Policy (GRN/MGECW, 2004), there is a need for the government to partner with NGOs, civic society, and community agencies to provide supplementary financial supports to the most vulnerable families, especially grandparents who may not qualify for other sources such as loans and grants.

### **Areas for Future Research**

The Namibian society in general should critically consider cost-effective ways and/or put in place resources to alleviate the economic burden shouldered by elderly caregivers raising children orphaned by AIDS, especially those who find themselves in resource-poor environments. Few studies have been conducted investigating the variables examined on the population of elderly caregivers in rural areas. Numerous questions for further study could be explored that shed more light on the role of different supports in HIV/AIDS caregiving. Further research is needed to explore best practices in which the

elderly can continue to play a pivotal role in HIV/AIDS caregiving, especially by taking care of OVC without compromising their own health and mental well-being.

Further research needs to undertake to explore why caring for a HIV-infected child/ren was related to lower levels of depression. For example, exploring the lived experiences of grandparents raising HIV-infected child/ren could help researchers identify insights into the everyday life of caregivers; or grandparents could be asked what strategies they employ in coping with child/ren infected by HIV virus. In addition, qualitative studies could also explore the mental health of caregivers in HIV/AIDS-endemic communities raising HIV-infected child/ren. Opportunities exist for studies to examine why social supports do not matter in this population. Future potential longitudinal studies will be important to fully understand the development of support trajectories for caregivers.

Since all the elderly caregivers who participated in the present study lived in a rural setting, no rural-urban comparisons were possible. Thus, it is essential for future studies to explore this difference to better understand the mental health of caregivers. Furthermore, there is a paucity of epidemiological mental health studies in Namibia, a situation that poses multiple challenges to policy development, planning, and service delivery (Ruiz-Casares, Thombs, & Rossseau, 2009). More studies on the psychosocial needs of elderly caregivers as well as on cultural beliefs, norms, values, and attitudes towards mental health disorders and treatments across the diverse ethnic groups in the country are critical.

In sum, findings from this study make an important contribution to the body of knowledge on aging and HIV/AIDS caregiving in southern Africa. This is the first study to my knowledge to examine the relationship among supports and depression among caregivers of AIDS-orphaned children in Namibia. This study demonstrates the heightened lack of financial stability and that may exacerbate the vulnerability of and limit ability of caregivers to cope with the myriad challenges associated with caring for children in today's HIV epidemic communities. Moreover, this study has shown that there is a difference between caregivers raising an HIV-infected child and those who were not raising an HIV-infected child. Finally, findings from this study have demonstrated the urgent need for mental health services for elderly caregivers raising children orphaned by AIDS in Namibia.

## References

- Abasiubong, F., Bassey, E. A., Ogunsemi, O. O., & Udobang, J. A. (2011). Assessing the psychological well-being of caregivers of people living with HIV/AIDS in Niger Delta region, Nigeria. *AIDS Care*, 23(4), 494-500.
- Adato, M., & Bassett, L. (2009). Social protection to support vulnerable children and families: The potential of cash transfers to protect, health and nutrition. *AIDS Care*, 21(1), 60-75.
- Ankrah, E.M. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care*, 5(10), 5-22.
- Ardington, C. A., Case, A., Islam, M., Lam, D., Leibbrandt, M., Menendez, A., & Olgiati, A. (2010). The impact of AIDS on intergenerational support in South Africa: Evidence from the Cape Area Panel Study. *Research on Aging*, 32(1), 91-121.
- Bachman, H. J., & Chase-Lansadle, P. L. (2005). Custodial grandmothers' physical, mental and economic well-being: Comparisons of primary caregivers from low-income neighborhoods. *Family Relations*, 54(4), 475-487.
- Bass, J., Neugebauer, R., & Clougherty, K. (2006). Group interpersonal psychotherapy for depression in rural Uganda: 6-month outcomes: Randomized controlled trial. *British Journal of Psychiatry*, 188, 567-573.
- Bedard, M., Pedlar, D., Martin, N. J., Malott, O., & Stones, M.J. (2000). Burden in caregivers of cognitively impaired older adults living in the community: Methodological issues and determinants. *International Psychogeriatrics*, 12(3), 307-332.
- Beegle, K., Filmer, D., Strokes, A., & Tiererova, L. (2008). *Orphanhood and living arrangements of children in sub-Saharan Africa*. New York, NY: World Bank.
- Bell, D. (1990). Poverty and mental health. *American Psychologist*, 45, 385-389.
- Belue, R., Schreiner, A. S., Taylor-Richardson, K., Murray-Kolb, L. E., & Beard, J. L. (2008). What matters most: An investigation of predictors of perceived stress among young mothers in Khayelitsha. *Health Care for Women International*, 29, 638-648
- Bhana et al., (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: A qualitative investigation. *AIDS Care*, (iFirst)1-9.

- Bikaako-Kajura, W, Luyirika, E., Purcell, D.W., Downing, J., Kaharuza, F., & Mermin., J., et al., (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV infected children in Uganda. *AIDS and Behaviour*, 10, s85-s93
- Blustein, J., Cham, S., & Guanais, F.C. (2004). Elevated depressive symptoms among caregiving grandparents. *Health Services Research*, 39, 1671-1689.
- Boon, H., James, S., Ruiter, R. A. C., van den Borne, B., Williams, E., & Reddy, P. (2010). Explaining the perceived ability among older people to provide care as a result of HIV and AIDS in South Africa. *AIDS Care*, 22(4), 399-408.
- Boon, H., Ruiter, R. A. C., James, S., van Den Borne, B., Williams, E., & Reddy, P. (2009). The impact of a community-based pilot health intervention for older people as caregivers of orphaned children and sick children as a result of HIV/AIDS in South Africa. *Journal of Cross-Cultural Gerontology*, 24, 373-389.
- Booyesen, F. (2004). Social grants as safety net for HIV/AIDS-affected households in South Africa. *Journal of Social Aspects of HIV/AIDS Research Alliance*, 1(1), 45-56.
- Boston University, Pharm Access Foundation. (2009). *Namibia research situation analysis on orphans and vulnerable children country brief*. Boston, MA: Boston University.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiences by nature and design*. Cambridge, MA: Harvard University Press.
- Brown, J. (2011). Child fostering chains among Ovambo families in Namibia, southern Africa. *Journal of Southern Africa Studies*, 37(1), 155-176.
- Brown, L., Thurman, T., & Snider, L. (2005). *Strengthening the psychological well-being of youth-headed households in Rwanda: Baseline findings from an intervention trial*. Horizon Research Update. Washington, DC: Population Council.
- Butler, S.S., Turner, W., Kaye, L.W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work*, 46 (1) 46-59.
- Campanelli, P. (1997). Testing survey questions: New directions in cognitive interviewing. *Bulletin de Methodologie*, 55,5-17.
- Campbell, C., & Foulis, C. (2004). Creating contexts for effective home-based care of people living with HIV/AIDS. *Curations*, 27(3), 5-14.

- Casale, M. (2011). "I am living a peaceful life with my grandchildren. Nothing else": Stories of adversity and resilience of older women caring for children in the context of HIV/AIDS and other stressors. *Aging & Society*, *13*, 1265-1288.
- Cattell, M. (1993). Caring for the elderly in sub-Saharan Africa. *Aging International*, *20*(3), 13-19.
- Chazan, M. (2008). Seven 'deadly' assumptions: Unraveling implications of HIV/AIDS among grandmothers in South Africa and beyond. *Aging & Society*, *28*, 935-958.
- Chepngeno-Langat, G., Falkingham, J., Madise, N. J., & Evandrou, M. (2010). Socioeconomic differentials between HIV caregivers and non-caregivers: Is there a selection effect? A case of older people living in Nairobi city slums. *Research on Aging*, *32*(1), 67-96.
- Chirwa, W. (2002). Social exclusion and inclusion: Challenges to orphan care in Malawi. *Nordic Journal of African Studies*, *11*(1), 93-113.
- Clinton, H. (1996). *It takes a village: And other lessons children teach us*. New York, NY: Simon & Schuster.
- Children in Distress [CINDI]. (2007). Networking for children affected by AIDS. Retrieved from <http://www.cindi.org.za/>
- Cluver, L., & Gardner, F. (2007). The mental health of children orphaned by AIDS: A review of international and southern African research. *Journal of Child Adolescent Mental Health*, *19*(1), 1-17.
- Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Psychiatry and Psychology and Allied Disciplines*, *48*(8), 755-763.
- Cohen, S., & Wills, T. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310-357.
- Cole, S. A., & Eamon, M. K. (2007). Predictors of depressive symptoms among foster caregivers. *Child Abuse & Neglect*, *31*, 295-310.
- Costello, E. J., Compton, S. N., Keeler, G., & Angold, A. (2003). Relationships between poverty and psychopathology: A natural experiment. *JAMA*, 290-2023.
- Cowger, C. A. (1994). Assessing client strengths: Clinical assessment for client empowerment. *Social Work*, *39*(3), 262-268.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. Los Angeles, CA: SAGE.

- Cutrona, C., Wallace, G., & Wesner, K. (2006). Neighborhood characteristics and depression. *Current Directions in Psychological Science, 15*(4), 188-192.
- Dageid, W., & Duckert, F. (2008). Balancing between normality and social death: Black, rural, South African women coping with HIV/AIDS. *Qualitative Health Research, 18*(2), 182-195.
- Dayton, J., & Ainsworth, M. (2002). *The elderly and AIDS: Coping strategies and health consequences in rural Tanzania*. New York: Policy Research Division Working Paper 160, Population Council.
- Dayton, J., & Ainsworth, M. (2004). The elderly and AIDS: Coping with the impact of adult death in Tanzania. *Social Science Medicine, 59*, 2161-2172.
- Deininger, K., Garcia, M., & Subbarao, K. (2003). AIDS-induced orphanhood as a systemic shock: Magnitude, impact, and program interventions in Africa. *World Development, 31*, 1201-1220.
- Demmer, C. (2011). Experiences of families caring for HIV-infected child in KwaZulu-Natal, South Africa. *AIDS Care, 23*(7), 873-879.
- Dillman, D., Smyth, J. D., & Christian, L. M. (2009). *Internet, mail, and mixed-mode surveys: The tailored design method*. Hoboken, NY: Wiley.
- Drimie, S., & Casale, M. (2009). Multiple stressors in Southern Africa: The link between HIV/AIDS, food insecurity, poverty and children's vulnerability now and in the future. *AIDS Care, 21*(1), 28-33.
- Everson, S., Maty, S., Lynch, J., & Kaplan, G. (2002). Epidemiologic evidence for the relation between socioeconomic status and depression, obesity, and diabetes. *Journal of Psychosomatic Research, 53*, 891-895.
- Fengler, A. P., & Goodrich, N. (1979). Wives of elderly disabled men: The hidden patient. *Gerontologist, 19*, 175-183.
- Ferreira, M. (2004, January). HIV/AIDS and family well-being in southern Africa: Towards an analysis of policies and responsiveness. A brief synthesis paper prepared for a United Nations Department of Economic and Social Affairs Division for Social Policy and Development Policy Workshop. Windhoek, Namibia.
- Fortes, M. (1969). *Kinship and social order*. Chicago, IL: Aldine Press.
- Foster, G. (2000). The capacity of the extended family safety net for orphans in Africa. *Psychology, Health & Medicine, 51*, 55-62.

- Fredriksen-Goldsen, K. (2007). HIV/AIDS caregiving. *Journal of Gay & Lesbian Social Services, 18*(3), 53-73.
- Freeman, M. (2004). HIV/AIDS in developing countries: Heading towards a mental health and consequent social disaster. *Southern African Journal of Psychology, 34* (1), 139-159.
- Freeman, M., & Nkomo, N. (2006a). Guardianship of orphans and vulnerable children: A survey of current and prospective South African caregivers. *AIDS Care, 18*(4), 302-310.
- Govender, K., Penning, S., George, G., & Quinlan, T. (2011). Weighing up the burden of care on caregivers of orphan children: The Amajuma District Child Health and Wellbeing Project, South Africa. *AIDS Care, 1-10*, iFirst.
- Government of the Republic of Namibia/Ministry of Gender Equality and Child Welfare [GRN/MGECW]. (2012). *The effectiveness of child welfare grants in Namibia*. Windhoek, Namibia. Directorate of Child Welfare Services.
- Government of the Republic of Namibia/Ministry of Gender Equality and Child Welfare [GRN/MGECW]. (2004). *Orphans and vulnerable children policy*. Windhoek, Namibia.
- Government of the Republic of Namibia/Ministry of Gender Equality and Child Welfare [GRN/MGECW]. (2008). *National plan of action 2006-2010 for orphans and vulnerable children in Namibia: Annual progress and monitoring report*. Windhoek, Namibia.
- Government of the Republic of Namibia/National Planning Commission [GRN/NPC]. (2006). *Namibia Household Income & Expenditure Survey 2003/2004. Main Report*. Windhoek Namibia, NPC and Central Bureau Statistics.
- Government of the Republic of Namibia/National Planning Commission [GRN/NPC]. (2012). *Namibia 2011 Population and Housing Census Preliminary Results*. Windhoek, Namibia.
- Haihambo, C., Hayden, J., Otaala, B., & Zimba, R. (2004). Young children affected or infected by HIV/AIDS: A comparison of the living situations for children aged 0-8 years in Windhoek, Namibia. *Journal of Early Childhood Development, 2*, 50-68.
- Haihambo, C., Kalomo, E. N., & Ashton, D. (2006). *Namibia Global Fund Programme Evaluation Report: The comprehensive care and support of orphans and vulnerable children*. Windhoek, Namibia: University of Namibia Consultancy Bureau.

- Hamad, R., Fernald, L., Karlan, D., & Zinman, J. (2008). Social and economic correlates of depressive symptoms and perceived stress in South African adults. *Journal of Epidemiology and Community Health, 62*, 538-544.
- Hamra, M., Ross, M. W., Karuri, K., Orrs, M., & D'Agostino, A. (2005). The relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV-infected children in Kenya. *AIDS Care, 17*(7), 911-922.
- Hayden, J., & Otaala, B. (2005). Very young children affected and infected by HIV/AIDS: How are they living? A case from Namibia. *International Journal of Early Childhood, 37*(2), 11-19.
- Help Age International [HAI]. (2003). *Forgotten families: Older people as carers of orphans and vulnerable children*. London: Help Age International.
- Hejoaka, D. (2009). Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine, 69*, 869-876.
- Heymann, J., & Kidman, R. (2009). HIV/AIDS, declining family resources and community safety net. *AIDS Care, 12*(1), 34-42.
- Hlabyago, K. E., & Ogunbanjo, G. A. (2009). The experiences of family caregivers concerning their care of HIV/AIDS orphans. *South Africa (SA) Family Practice, 51*(6), 506-511.
- Ice, G. H., Zidron, A., & Juma, E. (2008). Health and health perceptions among Kenyan grandmothers. *Journal of Cross Cultural Gerontology, 23*, 111-129.
- Irwin, A., Admas, A., & Winter, A. (2009). Home truths: Facing the facts on children, AIDS, and poverty: Final report of the Joint Learning Initiative on Children and HIV/AIDS. Boston, MA: Joint Learning Initiative on Children and HIV/AIDS (JLICA).
- Irwin, M., Artin, K. H., & Oxman, M. N. (1999). Screening for depression in older adults. Criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D).
- Isiugo-Abanihe, U. (1985). Child fosterage in West Africa. *Aging and Development, 53*-73.
- Joslin, D., & Harrison, R. (1998). "The hidden patient": Older relatives raising children orphaned by AIDS. *American Journal of Women's Medical Association, 53*, 65-71.

- Kagotho, N., & Ssewamala, F.M. (2012). Correlates of depression among caregivers of children affected by HIV/AIDS in Uganda: Findings from the Suubi-Maka family study. *AIDS Care, 24*(10), 1226-1232.
- Kamya, H., & Poindexter, C.C. (2009). Mama Jaja: The stresses and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health, 24*, 4-21.
- Kautz, T. et al. (2010). AIDS and declining support for dependent elderly people in Africa: Retrospective analysis using demographic and health surveys. *BMJ, 340*, 1-6.
- Kayono-Male, H., & Onyango, P. (1984). *The sociology of the African family*. London: Longman.
- Kidman, R., & Heymann, S. (2009). The extent of community and public support available to families caring for orphans in Malawi. *AIDS Care, 21*(4), 439-447.
- Kim, D. (2008). Blues from the neighborhood? Neighborhood characteristics and depression. *Epidemiology Review, 30*(1), 101-117.
- Kim, S., Lee, Y., Kim, H., Cho, I., Lee, J., & Cho, S. (2009). Age as a moderator of the association between depressive symptoms and morninigness-eveningness. *Journal of Psychosomatic Research, 58*(2), 159-164.
- Kimuna, S. R., & Makiwane, M. (2007). Older people as resources in South Africa: Mpumalanga Households. *Journal of Aging & Social Policy, 19*(1), 97-115.
- Kipp, W., Matukala, T., Laing, L., & Jhangri, G. S. (2006). Care burden and self-reported health status of informal women caregivers of HIV/AIDS patients in Kinshasa, Democratic Republic of Congo. *AIDS Care, 18*(7), 694-697.
- Kipp, W., Tindyebwa, D., Karamagi, E., & Rubaale, G. (2006). Family caregiver to AIDS patients: The role of gender in caregiver burden in Uganda. *Health Care for Women International Studies, 7*, 1-13.
- Kruger, A., & Wentzel-Viljeon, E. (2011). Rural and urban older African caregivers coping with HIV/AIDS are nutritionally compromised. *Journal of Nutrition in Gerontology, 30*, 274-290.
- Kuehner, C. (2003). Gender differences in unipolar depression: an update of epidemiologic findings and possible explanations. *Acta Psychiatrica Scandinavica, 108*(3), 163-174.
- Kuhanen, J., Shemeikka, R., Notkola, V., & Nghixulifwa, M. (2008). Junior-headed households as a possible strategy for coping with the growing orphan crisis in northern Namibia. *African Journal of AIDS Research, 7*(1), 123-132.

- Kumakech, E., Cantor-Graae, E., Maling, S., & Bajunirwe, F. (2009). Peer-group support intervention improves the psychosocial well-being of AIDS orphans: Cluster randomized trial. *Social Science & Medicine*, *68*, 1043-1048.
- Kuo, C., & Operario, D. (2011). Health of adults caring for orphaned children in an HIV-endemic community in South Africa. *AIDS Care*, *23*(9), 1128-1135.
- Kuo, C., Fitzgerald, J., Operario, D., & Casle, M. (2012). Social support disparities for caregivers of AIDS-orphaned children in South Africa. *Journal of Community Psychology*, *40*(6), 631-644.
- Kuo, C., Operario, D., & Cluver, L. (2012). Depression amongst carers of AIDS-orphaned and other-orphaned children in Umazi Township, South Africa. *Global Public Health*, *7*(3), 253-269.
- Kuyini, A. B., Alhassan, A. R., Tollerud, I., Weld, H., & Haruna, I. (2009). Traditional experiences and views of children and carers and adults in Tamle. *Child and Family Social Work*, *14*, 440-449.
- Kyobutungi, C. et al. (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*, 153-161.
- Landman-Peeters, K. M. C., Hartman, C. A., van der Pompe, G., den Boer, J. A., Minderaa, R. B., & Ormel, J. (2005). Gender difference in the relation between social support, problems in parent-offspring communication, and depression and anxiety. *Social Science & Medicine*, *60*, 2549-2559.
- Leech, N. L., Barrett, K. C., & Morgan, G. A. (2011). *IBM. SPSS for intermediate statistics. Use and interpretation* (4<sup>th</sup> Ed.). New York, NY: Routledge/Taylor & Francis.
- 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. *Health South Africa [SA] Gesondheid*, *16*(1), 1-6.
- Lewis, S. (2006). *Grandmothers to grandmothers campaign*. Toronto, Ontario, Canada: Media press clippings, Stephan Lewis Foundation.
- Lightfoot, E., & Kalomo, E. (2010). The interplay of population aging and HIV/AIDS on social development. *Social Development Issues*, *32*(1), 1-15.
- Lindsey, E., Hirschfeld, M., Tlou, S., & Ncube, M. (2003). Home-based care in Botswana: Experiences of older women and young girls. *Health Care for Women International*, *24*, 486-501.

- Linn, M., Sandifer, R., & Stein, S. (1985). Effects of unemployment on mental and physical health. *American Journal of Public Health, 75*, 502-506.
- Lippmann, S., & James, W. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African family clan revisited. *AIDS Care, 5*, 71-88.
- Littrell, M., Murphy, L., Kumwenda, M., & Macintyre, K. (2012). Gogo Care and protection of vulnerable children in rural Malawi: Changing responsibilities, capacity to provide, and implications for well-being in the era of HIV and AIDS. *Journal of Cross Cultural Gerontology, 27*(4), 335-355.
- Lv. et al. (2010). Depression symptoms among caregivers of children in HIV-affected families in rural China, *AIDS Care: Psychological and Socio-medical aspects of HIV/AIDS, 22*(6), 669-676.
- Madhavan, S. (2004). Fosterage patterns in the age of AIDS: Continuity and change. *Science & Medicine, 58*, 1443-1454.
- Makoni, S. (2008). Aging in Africa. A critical review. *Journal of Cross-Cultural Gerontology, 23*, 199-209.
- Marais, H. (2005). *Buckling: The impact of AIDS in South Africa*. Pretoria, South Africa: University of Pretoria Press.
- Marshall, A., & Batten, S. (2003). Ethical issues in cross-cultural research. In W.-M. Roth (Ed.), *Connections '03* (pp. 139–151). Victoria, Canada: University of British Columbia
- Marshall, E., Roberts, T. L., Barton, B., Stephany, C., & Lighty, B. (1998). Ecological approach to families living with HIV disease. In I. R. (Eds.), *Serving diverse constituencies. Applying the ecological perspective* (pp. 325-358). New York, NY: Aldine De Gruyter.
- Mathambo, V., & Gibbs, A. (2009). Extended family childcare arrangements in a context of AIDS: Collapse or adaptations. *AIDS Care, 21*(1), 22-27.
- Mbonu, N. C., van den Borne, B., & De Vries, N. K. (2009). Stigma of people with HIV/AIDS in sub-Saharan Africa: A literature review. *Journal of Tropical Medicine, 1-14*.
- Minkler, M., & Fuller-Thomson, E. (1999). The health of grandparents raising grandchildren: Results of a national survey. *American Journal of Public Health, 89*(9), 1384-1389.
- Moore, A. (2007-2008). Older parents who lost an adult child in AIDS in Togo, West Africa: A qualitative study. *Omega, 56*(3), 289-302.

- Moore, A. R., & Henry, D. (2005). Experiences of older informal caregivers to people with HIV/AIDS in Lome, Togo. *Aging International*, 30(2), 147-166.
- Moore, A. R., & Williamson, D. (2011). Disclosure of children's positive serostatus to the family and non-family members: Informal caregivers in Togo, West Africa. *AIDS Research and Treatment*, 1-8.
- Mudavanhu, D., Segalo, P., & Fourie, E. (2006). *Grandmothers caring for their grandchildren orphaned by HIV and AIDS*. Pretoria, South Africa: University of South Africa.
- Munthree, C., & Maharaj, P. (2012). 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.
- Musil, C. M., Youngblut, J. M., Ahn, S., & Curry, V. L. (2002). Parenting stress: a comparison of grandmother caretakers and mothers, *Journal of Mental Health and Aging*, 8, 197-210.
- Myint, T., & Mash, B. (2008). Coping strategies and social support after receiving HIV-positive results at a South African district hospital. *South African Medical Journal*, 98, 276-278.
- Namibia Statistics Agency [NSA]. (2012). *Poverty dynamics in Namibia: A comparative study using the 1993/94, 2003/04 and the 2009/10 NHIES surveys*. Windhoek, Namibia.
- Namibia Statistics Agency [NSA]. (2012). *Child poverty in Namibia: A child-centered analysis of the NHIES 2009/10*. Windhoek, Namibia.
- Namibia Statistics Agency [NSA]. (2012). *Namibia Household Income & Expenditure Survey 2009/2010*. Windhoek, Namibia.
- National Research Council. (2006). Aging in Sub-Saharan Africa: Recommendations for furthering research. Panel on policy \research and data needs to meet the challenge of aging in Africa. In B. Cohen and J. Menken (Eds.), *Committee on population, division of behavioural and social sciences*. Washington, DC: The National Academics Press.
- Nashimiyimana, B. (2008). *Perception of support provided to orphan children in foster care placement in an urban setting of Windhoek, Namibia*. Unpublished master's thesis. Sweden: Linkoping Univeristy.
- Ncube, W., Stewart, J. E., Kazembe, J. L., Donzwa, B. R., Gwaunza, E. C., Nzira, T. G., & Dengu-Zvobogo, K. (1997). *Continuity and change: The family in Zimbabwe. Harare: Women and the Law in Southern African Project*. Zimbabwe: Longman.

- Nekundi, L. (2007). *A comparative study of orphans and vulnerable children support in Oshakati District, Oshana Region, Namibia*. Unpublished master's thesis. Free State, South Africa: University of Free State.
- Nhongo, T. M. (2004). The changing role of older people in African households and the impact of aging on African family structures. Paper presented at The Ageing in Africa Conference, Johannesburg, South Africa.
- Nkosi, B., & Daniels, P. (2007). Family strenghtens. *Marriage & Family Review*, 41(1-2), 11-26.
- Nkosi, B. (2005). *Household food security and health behaviours in rural communities of Kwazulu Natal, South Africa*. St. Paul, Minnesota: University of Minnesota: Unpublished doctoral dissertation.
- 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, 33-52.
- Njororai, F., & Njororai, W. W. S. (2012). Older adult caregivers to people with HIV/AIDS in sub-Saharan Africa: A review of literature and policy implications for change. *International Journal of Health Promotion and Education*. iFirst Article, 1-19.
- Oburu, P. O., & Palmerus, K. (2005). Stress related factors among primary and part time caregiving grandmothers of Kenyan grandchildren. *International Journal of Aging and Human Development*, 65(4), 273-282.
- Ogunmefun, C., Gilbert, L., & Schatz, E. (26, 85-102). Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of Cross Cultural Gerontology, Journal of Cross-Cultural Gerontology*, 27(1), 85-102.
- Okawa, S., Yasuoka, J., Ishikawa, N., Poudel, K. C., Ragi, A., & Jimba, M. (2011). Perceived social support and the psychological well-being of AIDS orphans in urban Kenya, *AIDS Care*, 23(9), 1177-1185.
- Olenja, J. (1999). Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya, *Journal of Community Health*, 24(3), 187-199.
- Olley, B. (2008). Health and behavioural problems of children orphaned by AIDS as reported by their caregivers in Abuja, Nigeria. *Nigerian Journal of Psychiatry*, 6(2), 70-75.
- Oluwagbemiga, A. (2007). HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State. *Journal of Social Aspects of HIV/AIDS*, 4(3), 668-677.

- Orner, P. (2006). Psychosocial impact on caregivers of people living with AIDS. *AIDS Care, 18*(3), 236-240.
- Piccinelli, M., & Wilkinson, G. (2000). Gender differences in depression. *The British Journal of Psychiatry, 177*, 486-492.
- Plagerson, S., Patel, V., Harpham, T., Kielmann, K., & Mathee, A. (2011). Does money matter for mental health? Evidence from the child support grants in Johannesburg. *Global Public Health: An International Journal for Research, Policy and Practice, 6*(7), 760-776.
- Project Hope. (2006). *Sustainable strengthening of families of orphans and vulnerable children in Mozambique and Namibia. Baseline Survey Report*. Namibia.
- Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*(3), 385-401.
- Reddy, P. (2005). "Inkala ixinge Etyeni: [Trapped in a difficult situation] " *The burden of care on the elderly in Eastern Cape, South Africa*. Johannesburg, South Africa: South African Population Council/Horizon Update.
- Rioio, S. A., Nguyen, T. A., Greden, J. F., & King, C. A. (2005). Prevalence of depression by race/ethnicity: Findings from the national Health and Nutrition Examination Survey III. *American Journal of Public Health, 95*, 998-1000.
- Ross, C.E., & Mirowski, J. (1989). Explaining the social patterns of depression: Control and problem solving-or support and talking? *Journal of Health and Social Behavior, 30*, 206-219.
- Ruiz-Casares, M. (2009). Between adversity and agency. Child and youth-headed households in Namibia. *Vulnerable Children and Youth Studies, 4*(3), 238-248.
- Ruiz-Casares, M., Thombs, B. D., & Rossseau, C. (2009). The association of single and double orphanhood with symptoms of depression among children and adolescents in Namibia. *European Child & Adolescent Psychiatry, 18*(6), 369-376.
- Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social Work, 41*(3), 296-305.
- Schatz, E., & Gilbert, L. (2012). " My heart is very painful": Physical, mental and social well-being of older women at the times of HIV/AIDS in rural South Africa. *Journal of Aging Studies, 26*, 16-25.
- Schatz, E. & Ogunmefun, C. (2007). Caring and contributing: The role of older women in rural South Africa multi-generational households in the HIV/AIDS era. *World Development, 35*(8),1390-1403.

- Schatz, E. (2007). "Taking care of my own blood": Older women's relationships to their households in rural South Africa. *Scandinavian Journal of Public Health*, 35(69), 147-154.
- Schatz, E., Madhavan, S., & Williams, J. (2011). Female-headed households contending with AIDS-related hardships in rural South Africa, *Health & Place*, 17, 598-605.
- Schmidt, M. (2009). *Poverty and inequality in Namibia. An overview*. Windhoek, Namibia: IPPR, 2009.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*, 282(23), 2215-2219.
- Seely, J., & Kajura, E. (1993). The extended family and support for people with AIDS in rural populations in southwest Uganda. A safety net with holes? *AIDS Care*, 5, 17-23.
- Sheppard, M. (2002). Mental health and social justice: Gender, race, and psychological consequences of unfairness. *British Journal of Social Work*, 32, 779-797.
- Sherraden, M. (1990). Stakeholding: Notes on a theory of welfare based on assets. *Social Service Review*, 64, 580-601.
- Skovdal, M., Mwasiaji, W., Webale, A., & Tomkins, A. (2011). Building orphan competent communities: Experiences from a community-based capital cash transfer initiative in Kenya. *Health Policy and Planning*, 16, 233-241.
- Smith, R. (2007). Living in an age of HIV and AIDS: Implications for families in South Africa. *Nordic Journal of African Studies*, 16(2), 161-178.
- Social Impact Assessment and Policy Analysis Corporation [SIAPAC]. (2002). *Situational analysis of orphan children in Namibia*. Windhoek, Namibia: Ministry of Health and Social Services.
- Ssengonzi, R. (2007). The plight of older persons as caregivers to people infected/affected by HIV/AIDS: Evidence from Uganda. *Journal of Cross Cultural Gerontology*, 22, 339-353.
- Ssengonzi, R. (2009). The impact of HIV and AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care*, 21(3), 309-314.
- Ssewamala, F. M., Neilands, T. B., Waldfogel, J., & Ismayilova, L. (2012). The impact of a comprehensive microfinance intervention on depression levels of AIDS-orphaned children in Uganda. *Journal of Adolescent Health*, 50, 346-352.

- Stein, D., Seedat, S., Emsley, S., & Olley, B. O. (2005). HIV/AIDS in Africa a role for the mental health practitioner, *South African Medical Journal*, 95, 167-168.
- Steintz, L. (1998). *More than the loss of a parent. Namibia's first study of orphan children*. Windhoek, Namibia: Ministry of Health and Social Services.
- Strawbridge, W., Deleger, S., Roberts, R., & Kaplan, G. (2002). Physical activity reduces the subsequent depression for older adults. *American Journal of Epidemiology*, 38(2), 73-92.
- Tanga, P. (2008). The impact of old age pension on households and social relationships in Lesotho. *Journal of the Institute of Southern African Studies*, 12(1-2), 184-215.
- Thomas, F. (2006). Stigma, fatigue and social breakdown: Exploring the impact of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia. *Social Science Medicine*, 63, 3174-3187.
- Thupayagale-Tshweneagae, G. (2008). Psychological effects experienced by grandmothers as primary caregivers in rural Botswana. *Journal of Psychiatric and Mental Health Nursing*, 15, 351-356.
- Tsiwo-Chigubu, M. (2000). *Exploring self-esteem of orphans whose parents died of HIV/AIDS: Examined through the extended family/kinship caregivers' well-being, social support networks, and child rearing practices*. Thesis of Philosophy in Family and Child Ecology. Michigan: Michigan State University.
- United Nations. (2005). *Living arrangements of older persons around the world*. Population Studies No. 240. New York: United Nations.
- United Nations Children's Fund [UNICEF]. (2008). *Children and HIV/AIDS*. Retrieved from [http://www.unicef.org/aids/index\\_documents.html](http://www.unicef.org/aids/index_documents.html)
- United Nations Children's Fund [UNICEF] (2002). *Psychosocial well-being for children and adolescents*. Windhoek, Namibia.
- United Nations Children's Fund [UNICEF]. (2011). *Statistics by area HIV/AIDS*. Retrieved from [http://www.childinfo.org/hiv\\_aids.html](http://www.childinfo.org/hiv_aids.html)
- United Nations Joint Program on HIV/AIDS [UNAIDS]. (2008). *Report on the global AIDS Epidemic*. Geneva: UNAIDS.
- United Nations Joint Program on HIV/AIDS [UNAIDS]. (2011). *Global HIV/AIDS progress report: AIDS epidemic update [online]*. Geneva, Switzerland: UNAIDS.

- United Nations Joint Program on HIV/AIDS [UNAIDS]. (2006). *2006 report on the global AIDS epidemic: A UNAIDS 19<sup>th</sup> anniversary special edition*. Geneva: United Nations.
- United States Agency for International Development [UNAIDS]. (2008). *Third annual report on orphans and vulnerable children in developing countries*. Washington, DC: USAID. Retrieved from <http://www.healthpolicyinitiative.com/Publications/Documents/1346>
- United States Agency for International Development [UNAIDS]. (2012). *Report on the global AIDS epidemic*. Retrieved from <http://www.unaids.org/en/media/unaids/contentassets/documents/epidemioly/201>
- Van Dyk, A. (2005). *HIV/AIDS Care and Counseling. A Multidisciplinary Approach* (3<sup>rd</sup> ed.). Cape Town: Pearson Education.
- William, A., & Tumwekwase, G. (2001). Multiple impacts of the HIV/AIDS epidemic on the aged in rural Uganda. *Journal of Cross-Cultural Gerontology*, 16, 221-236.
- World Health Organization [WHO]. (2012). *Progress report 2011: Global HIV/AIDS response*. Retrieved from <http://www.who.int/trade/glossary/story028/en/>
- World Health Organization [WHO]. (2005). *Mental health atlas*. Geneva: World Health Organization.
- World Health Organization [WHO]. (2000). *Community home based care: Family caregiving. Caring for family members with HIV/AIDS and other chronic illnesses: The impact of older women and girls. A Botswana case study*. Geneva: WHO.
- Yamano, T., & Jayne, T. (2004). Measuring the impact of working-adult mortality on small scale farm households in Kenya. *World Development*, 32.
- Zimet, G., Dahlem, N., Zimet, S., & Farley, G. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assessment*, 52, 30-41.
- Zimmer, Z., & Dayton, J. (2005). Older adults in sub-Saharan Africa living with children and grandchildren. *Population Studies*, 59(3), 295-312.

**Appendix A: Survey Instrument (English Version)**

Survey of Caregivers “*Omufilishisho*”  
Raising AIDS-Orphaned Children in Omusati Region, Namibia  
June 2013

Conducted By: Eveline Ndi Kalomo, PhD. Candidate, School of Social Work

Introduction

Hello. My name is ..... Thank you so much for agreeing to meet with us. Talking with caregivers is really the best way for us to understand the needs of AIDS-affected caregivers. I am going to ask you some questions about you, as the primary caregiver of orphans in your care and your family. It may seem like I am asking you the same questions a couple different times, but each question is different and helps me to get all the information I need.

Tell me what you think. This is not a test, and there is no right or wrong answer. All you have to do is answer what is true for **you**. Also, please stop me at any time if the questions are confusing or you have concerns or need a break. Before we begin, we need to review the consent form for the interview. The University of Minnesota in research always uses consent forms. The consent form is important so that you know what your rights are in this interview. What you say will be treated in confidence.

INTERVIEWER REVIEWS CONSENT FORM WITH CAREGIVER.





A12. Overall, how satisfied or dissatisfied are you with the **amount** of help the government gives you?

1.  Very satisfied
2.  Somewhat satisfied
3.  Somewhat dissatisfied
4.  Very dissatisfied

A13. How often do you need to borrow money to provide for the orphans and vulnerable children in your care?

1.  Always
2.  Usually
3.  Rarely
4.  Never

A14. How often do you have problems with a lack of money to buy food or clothing or to pay for health or schooling?

1.  Always
2.  Usually
3.  Rarely
4.  Never

A15. Was there ever a time that you could not pay school fees for your grandchildren in your care?

1.  Always
2.  Usually
3.  Rarely
4.  Never

A16. Was there ever a time that you could not purchase a school uniform for your grandchildren in your care?

1.  Always
2.  Usually
3.  Rarely
4.  Never

**Section B: Informational Supports**

B1. The next questions are about informational supports. Tell me if you have any knowledge about essential informational supports that caregivers like you ought to have. As I read each statement, I would like you to tell me if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with each of the following statements.

|  | Strongly<br>agree        | Somewhat<br>agree        | Somewhat<br>disagree     | Strongly<br>disagree     |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| <b>a.</b> Are you a caregiver who has knowledge/information about how to HIV/AIDS is transmitted?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>b.</b> Are you a caregiver who has knowledge/information about how to access government welfare grants for children affected by HIV/AIDS?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>c.</b> Are you a caregiver who has knowledge/information about how to provide psychosocial support to AIDS-affected individuals including children?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>d.</b> Are you a caregiver who has knowledge/information about how to Information on how to access grants for AIDS-affected children?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>e.</b> Are you a caregiver who has knowledge/information about caregiver supports (e.g. financial, informational or social support) in your community/village (specifically those raising children affected by HIV/AIDS)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>f.</b> Are you a caregiver who has knowledge/information about how to administer medication and provide care to an HIV positive person (including a child)?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Section C: MSPSS- Perceived Social Support Scale

C1. Now, I am going to ask you some questions about the people who may or may not be helping you and your family in your caregiving role. I am going to read you several statements, and I am going to ask how much you disagree with them.

| MSPSS Items   | Very<br>strongly<br>disagree | Strongly<br>disagree | Mildly<br>disagree | Neutral | Mildly<br>agree | Strongly<br>agree | Very<br>strongly<br>agree |
|---|------------------------------|----------------------|--------------------|---------|-----------------|-------------------|---------------------------|
| 1. There is a special person who is around when I am in need.           |                              |                      |                    |         |                 |                   |                           |
| 2. There is a special person with whom I can share my joys and sorrows. |                              |                      |                    |         |                 |                   |                           |
| 3. My family really tries to help me.                                   |                              |                      |                    |         |                 |                   |                           |
| 4. I get the emotional help and support I need from my family.          |                              |                      |                    |         |                 |                   |                           |
| 5. I have a special person.   |                              |                      |                    |         |                 |                   |                           |
| 6. My friends really try to help me.                                    |                              |                      |                    |         |                 |                   |                           |
| 7. I can count on my friends when things go wrong.                      |                              |                      |                    |         |                 |                   |                           |
| 8. I can talk about my problems with my family.                         |                              |                      |                    |         |                 |                   |                           |
| 9. I have friends with whom I can share my joys and sorrows.            |                              |                      |                    |         |                 |                   |                           |
| 10. There is a special person in my life that cares about my feelings.  |                              |                      |                    |         |                 |                   |                           |
| 11. My family is willing to help me make decisions.                     |                              |                      |                    |         |                 |                   |                           |
| 12. I can talk about my problems with my friends.                       |                              |                      |                    |         |                 |                   |                           |

Section D: Depression Scale (CES-D)

D1. Below is a list of ways that describe how you may have felt during the past week. Please tell me how often you have felt this way during the past week.

|  | Rarely or none<br>of the time<br>(Less than 1 day) | Some or<br>little of the<br>time<br>(1-2 days) | Occasionally<br>or moderate<br>amount of the<br>time<br>(3-4 days) | Most or all<br>of the time<br>(5-7 days) |
|--|--|--|--|--|
| 1. I was bothered by things that usually don't bother me.                                | 1  | 2  | 3  | 4  |
| 2. I did not feel like eating; my appetite was poor.                                     | 1  | 2  | 3  | 4  |
| 3. I felt that I could not shake off the blues even with help from my family or friends. | 1  | 2  | 3  | 4  |
| 4. I felt that I was just as good as other people.                                       | 1  | 2  | 3  | 4  |
| 5. I had trouble keeping my mind on what I was doing.                                    | 1  | 2  | 3  | 4  |
| 6. I felt depressed.   | 1  | 2  | 3  | 4  |
| 7. I felt that everything I did was an effort.   | 1  | 2  | 3  | 4  |
| 8. I felt hopeful about the future.  | 1  | 2  | 3  | 4  |
| 9. I thought my life had been a failure.   | 1  | 2  | 3  | 4  |
| 10. I felt fearful.  | 1  | 2  | 3  | 4  |
| 11. My sleep was restless.   | 1  | 2  | 3  | 4  |
| 12. I was happy.   | 1  | 2  | 3  | 4  |
| 13. I talked less than usual.  | 1  | 2  | 3  | 4  |
| 14. I felt lonely.   | 1  | 2  | 3  | 4  |
| 15. People were unfriendly.  | 1  | 2  | 3  | 4  |
| 16. I enjoyed life.  | 1  | 2  | 3  | 4  |
| 17. I had crying spells.   | 1  | 2  | 3  | 4  |
| 18. I felt sad.  | 1  | 2  | 3  | 4  |
| 19. I felt that people dislike me.   | 1  | 2  | 3  | 4  |
| 20. I could not get "going."   | 1  | 2  | 3  | 4  |

Section E: Demographics

For this last part of the interview, I am going to ask basic questions about you and your family.

E1. What is your gender?

- Female  Male

E2. What is your current relationship status?

1.  Single
2.  Married
3.  Widowed
4.  Divorced/separated
5.  Cohabit
6.  Engaged

E3. What is your age?

- Years

E4. What is the highest grade or year of school you have completed?

1.  No schooling
2.  Some primary
3.  Completed primary
4.  Some secondary
5.  Completed secondary
6.  Tertiary

E5. What is the number of adults (that is everyone older than 18 years) in the household?

- Number of people

E6. How many children are living with you in this household (that is everyone 18 years and younger)?

Number of children

E7. Are you caring and raising a HIV-infected or HIV-positive child or children?

1.  Yes 2.  No

E8. What is your length of time of being a caregiver?

1.  Since birth
2.  1 year
3.  2-5 years
4.  6-10 years

E9. What is your main source of income? Please tick **ALL** that apply.

1.  Pension
2.  Salary and wages
3.  Own Business or household business
4.  Child Grant (foster care, disability, and /or maintenance grant)
5.  Micro-lending (bank or any other)
6.  Veterans grant
7.  Remittance/payments (from family)

E10. Is your monthly household income higher than N\$500?

1.  Yes
2.  No

E11. Do you have chronic illness (any illness that prevented you from working for 3 months or more)?

1.  Yes
2.  No

E12. Are you a pensioner?

1.  Yes
2.  No

E13. As a caregiver do you receive financial support from the government (i.e., child maintenance/foster care grants or disability grant special maintenance grant) from the Ministry of Gender Equality and Child Welfare on behalf of the children your care?

1.  Yes
2.  No

Thank you for participating in the study.

**Appendix B: Consent Form**  
HIV/AIDS Caregivers Raising Orphans and Vulnerable Children

You are invited to part of a study being done by Eveline Ndinela Kalomo, a researcher at the University of Minnesota, School of Social Work. The study will look at the supports of HIV/AIDS caregivers raising children affected by AIDS. You are being asked to participate in this study because you are a caregiver looking after/raising a child or children orphaned by AIDS. Please listen as I read the background of the study, and feel free to ask any questions you may have before agreeing to be in the study.

Background Information

The purpose of this study is to learn more about support needs of caregivers raising AIDS-affected orphans. In the study, I will ask about what supports or services you need to parent your grandchildren or other children in your care as well as the types of supports or services you have received. Also, I would like to know how, if at all, the lack of these supports affects you emotionally, psychologically, or physically.

Procedures

If you agree to be in the study, we will ask you to participate in a face-face interview with an interviewer. The interview will last approximately 45 minutes. During the interview, the interviewer will ask you questions like:

- How dependent are you on the government grant for meeting the financial needs of the OVCs in your care?
- Overall, how easy or difficult is it for you to meet the financial costs of raising orphaned children in your care?

You do not need to respond to any specific question if it makes you uncomfortable.

Risks and Benefits of Being in the Study

There are no benefits to being in the study. The only risk to participating in this study is that you may be talking about private or personal information.

Confidentiality

The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify you. The records of the interview will be kept in a locked file.

Voluntary Nature of Study

Your decision of whether or not to participate in this study will not affect your current or future relations with any community organization that is assisting me in this study, or the University of Minnesota. If you decide to stop being in the study at any time, you can do so without affecting your relationships with the agencies listed above.

Contacts and Questions

The researcher conducting this research is Eveline Ndinela Kalomo. If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Research Subjects' Advocate Line, D-528 Mayo, 420 Delaware Street S.E., Minneapolis, Minnesota, 55455; telephone 001-612-625-1650; email: [irb@umn.edu](mailto:irb@umn.edu)

If you have any other questions or concerns regarding this study and would like to talk to someone other than the researcher(s), you may also contact Mr. Efraim at Catholic AIDS Action.

You will be given a copy of this form to keep for your records. Do you understand the consent form that we just went through? Do you have any questions about the consent process?

Statement of Consent

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

**Appendix C: Survey Instrument (Oshiwambo Version)**

Omapekapeko gomusilishipwiyu “*Omufilishisho*”

Okuputudha Oothigwa dhoAIDS mOmusati Region, Namibia

Ga Ningwa ku:

Eveline Kalomo, Ph.D. Candidate

University of Minnesota, School of Social Work

## Introduction

Ekundo. Edhina lyandje ongame ..... Tangi sho wa zimine opo tu tsakanene. Okukundathana naatekuli yoothigwa oko naana kwa opalela opo tu uveko oompumbwe dhaatekuli yaanona ya gumwa ko HIV no AIDS. Otandi ke ku pula omapulo gopaumwene onga omutekuli nomuputudhi goothigwa mofamily yeni. Otashi vulika toka mona sha fa tandi ku pula omapulo taga iendulula ihe epulo kehe olya yooloka nota li ka kwathelandje opo ndi mone omauyelele ngoka nda pumbwa.

Ndika kalishi ekonakono nokaku na omayamukulo ga puka nenge ge li mondjila. Shoka wu na okuninga, okuyamukula shoka sho shili kungweye. Niishewe, oto vulu okulombwelandje ndi mwene ethimbo kehe ngele omapulo otaga lyalyakanitha, nenge owu na omalimbililo nenge wa pumbwa okafudhepo. Manga inatu tameka otatu ka kundathana omukanda tsokumwe gomapekapeko ngaka nangoye. Oshiputudhilo (University) ya Minnesota ohashi pula aluhe opo pu kale omukanda-tsokumwe ngele taku ningwa omapekapeko. Omukanda-tsokumwe nguka ogwa simana oshoka mugo oto tseyu uuthemba woye momapulapulo ngaka. Shoka to ka popya otashi ka dhigininwa onga oshiholekwa shetu.

Omupekapeki ta kunda thana omkanda uvathano nomutekuli

Section A: Eyambidhidho Pashimaliwa

Omapulo gotango otaga ka tala kombinga yomakwatho nomayambidhidho ga longekidhwa ngoka hamu pewa, ngoye mwene, oothigwa naanegumbo wo yalwe yaandjeni ndele inamu ga futila. Omakwatho nomayambidhidho ga longekidhwa otashi ti omakwatho haga zi kaa /komuniilonga moprograma yontumba nenge lyongandi. Oprogram yatya ngaaka otashivulika yi kale yepangelo yopaumwene, yongeleka, yaagandji yeeshali nenge yaakwashigwana. Otandi ka tameka okulesha omapulo kombinga nkene ho shi enditha okugwanithapo oompumbe dhopashimaliwa dhoothigwa naanona yalwe oshowo aanegumbo mboka ho sile oshimpwiyu.

A1. Oshi dhigu shithike peni okugwanithapo oompumbwe dhopashimaliwa?

1.  Uudhigu uunene
2.  Oshidhigu
3.  Oshidhigu ngaa kashona
4.  Ka shishi oshidhigu nande

A2. Onga omutekuli, oho kala walimbililwa shithike peni molwa onkalo yoshimaliwa okutsakanitha oompumbwe dhaanegumbo lyoye?

1.  Nande nande
2.  Kashona ngaa
3.  Olundji
4.  Ethimbo alihe

A3. Olungapi ho longithapo iimaliwa yoye yopenzela mokufutula oompumbwe dhaanegumbo lyoye ngaashika iikulya, oshipangelo, elongo, iizalomwa, omafumbiko nomalweendo.

1.  Aluhe
2.  Olundji
3.  Kashona kowala
4.  Nande nande

A4. Muule woomwedhi 12 dha piti, olungapi wa landithapo omaliko goye (iikombo, oonzi, oongombe, iilya, oondjuhwa, iiyenditho, iikutu nenge iilongitho yomegumbo) opo wu gwanithapo oompumbwe dhoothigwa dhi li mesiloshimpwiyu lyoye?

1.  Nande nande
2.  Lwaali
3.  Lutatu nenge lune
4.  Lutano nenge shi vulepo

A5. Ope na gumwe / yamwe yomaanegumbo lyoye ye na / ye li moprojeka yoku imonena iimaliwa ngaashi okulanditha iinima komalandithilo opo ya yambidhidhe iiyemo yomegumbo?

1.  Aluhe
2.  Olundji
3.  Kashona kowala
4.  Nande nande

A6. Muule woomwedhi 12 dha piti, owa longithapo iipungulwa yoye (iimaliwa wa li weyi pungula) opo wu gwanithapo oompumbwe dhoothigwa dhoka ho sile oshimpwiyu wu lande iikulya, iikutu, epango nenge iifuta nomizalo dhoskola?

1.  Nande nande
2.  Lumwe
3.  Lutatu nenge lune
4.  Lutano nge shi vulepo

A7. Pakuyelekanitha, oshipu / oshidhigu ngiini kungoye okugwanithapo oompumbwe dhoshimaliwa dhoothigwa dhoka to tekula?

1.  Oshipu unene
2.  Oshipu ngaa
3.  Oshidhigu
4.  Oshidhigu unene

A8. Owa ikolelela shithike peni kiimaliwa mbyoka hayi zi kepangelo moku gwanithapo oompumbwe dhopashimaliwa dhoothigwa dhoka ho sile oshimpwiyu?

1.  Oyo ike nda itula
2.  Onde yi pumbwa ngaa
3.  Hayo ngaa unene
4.  Hayo nda itula

A9. Iimaliwa mbyoka hayi pewa aanona kepangelo otayi kwatha ngiini mokugwanithapo oompumbwe dhopashimaliwa dhoothigwa dhoka to sile oshimpwiyu?

1.  Itayi kwatha
2.  Otayi kwatha kashona
3.  Ohayi kwatha
4.  Ohayi kwatha unene

A10. Owa nyanyudhwa nenge owa uvithwa nayi shithike peni komwaalu gwiimaliwa mbyoka hokwathwa kepangelo?

1.  Onda pandula unene
2.  Onda pandula ngaa
3.  Inandi pandula nawa
4.  Ondi uvite nayi unene

A11. Oho pumbwa okulya oonkuma shithike peni opo wu gwanithepo oompumbwe dhaanona mboka ho sile oshimpwiyu?

1.  Aluhe
2.  Olundji
3.  Omapita ngaa
4.  Nande nande

A12. Omapita gethike peni ho kala ku na oshimaliwa shokulanda iikulya, iikutu nenge okufutula oshipangelo noskola ?

1.  Aluhe
2.  Olundji
3.  Omapita ngaa
4.  Nande nande

A13. Ope na oompito dhimwe wa li ino vula okufuta iifuta yoskola yaatekulu yoye mboka to sile oshimpwiyu?

1.  Aluhe
2.  Olundji
3.  Omapita ngaa
4.  Nande nande

A14. Ope na oompito dhimwe wa li ito vulu okulandela aatekulu yoye mboka to sile oshimpwiyu omizalo dhoskola?

1.  Aluhe
2.  Olundji
3.  Omapita ngaa
4.  Nande nande

Section B: MSPSS- Perceived Social Support Scale

B1. Ngashingeyi otandi ke ku pula omapulo kombinga yaantu mboka tashivulika nenge itashivulika yeke ku pe ekwatho onga omutekuli opamwe naanegumbo lyoye. Otandi ka lesha amatumbulo gamwe notandi tegelele u holole nkene wu uvite ku shoka nda ti.

- 1~ Hasho nande nande (Itandi tsu nande nande kumwe nasho)  
 2~ Hasho (Itandi tsu kumwe nasho)  
 3~ Hasho ngaa (Itandi tsu ngaa kumwe nasho)  
 4~ Kandi na shoka te ti (Ondi li pokati)  
 5~ Osho ngaa (Otandi tsu kumwe nasho)  
 6~ Osho lela (Otandi tsu lele kumwe nasho)  
 7~ Osho lela lela (Oshi li mondjila noshuuka).

| MSPSS Items   | Hasho nande nande | Hasho | Hasho ngaa | Kandi na sho teti | Osho ngaa | Osho lela | Osho lela lela |
|---|-------------------|-------|------------|-------------------|-----------|-----------|----------------|
| 13. Ope na aluhe omuntu nde mu inekela shampa ndi li mompumbwe                        |                   |       |            |                   |           |           | SO             |
| 14. Ope na omuntu ngoka nda inekela tandi vulu okuhokololela enyanyu nuupongo wandje. |                   |       |            |                   |           |           | SO             |
| 15. Aakwazimo yandje aluhe ohaya kambadhala ya kwathelendje.                          |                   |       |            |                   |           |           | Fam            |
| 16. Aakwazimo yandje ohaya kwathelendje ngele nda uvithwa nayi.                       |                   |       |            |                   |           |           | Fam            |
| 17. Ondi na omuntu nde mu inekela.  |                   |       |            |                   |           |           | SO             |
| 18. Ookuume kandje ohaya kambadhala ya kwathelendje.                                  |                   |       |            |                   |           |           | Fri            |
| 19. Ohandi inekele ookuume kandje ngele iinima oya ende nayi.                         |                   |       |            |                   |           |           | Fri            |
| 20. Otashivulika ndi popje naakwanezimo yandje kombinga yuupyakadhi wandje.           |                   |       |            |                   |           |           | Fam            |
| 21. Ondi na ookuume mboka tandi vulu okuhokololela enyanyu nenge uupongo wandje.      |                   |       |            |                   |           |           | Fri            |

22. Ondi na omuntu  
omwiinekelwa ngoka e nako  
nasha nomaiuvo gandje.

23. Aakwanezimo yandje oye na  
ehalo okukwatha ndi ninge  
omatokolo.

24. Otandi vulu okupopya  
uupyakadhi wandje nookuume  
kandje.

Dhidhilika: Omapulo oga hala oku yoolola oongundu nkoka ha ku ziilile omakwatho nenge omayambidhidho ngele okaakwazimo nenge okookuume nenge opalwe.

Section D: Depression Scale (CES-D)

F1. Omapulo taga landula otwa hala oku nongela nkene wa kala wu uvite muule woshiwike sha ziko. Tomona uuna wa kala wu uvite ngaashika tashi landula moshiwike sha piti:

|   | Kashona lela<br>(kashithike<br>pesiku 1) | Omathambo<br>gamwe-gamwe<br>(esiku 1-2) | Omapita ngaa<br>(Omasiku 3 -4) | Iikando oyindji<br>lela<br>(omasiku 5-7) |
|---|--|---|--------------------------------|--|
| 1. Onda kala tandi piyaganekwa kiinima ihandi yi tsakaneke shito.                     | 1  | 2                                       | 3                              | 4  |
| 2. Kanda li nda hala okulya . Ehalo lyiikulya olya li enkundi.                        | 1  | 2                                       | 3                              | 4  |
| 3. Kanda li tandi vulu okusinda uudhigu nonando ookuume naakwanezimo ya kwathelendje. | 1  | 2                                       | 3                              | 4  |
| 4. Onda li ndi uuvite nawa ndafa aantu ooyakwetu.                                     | 1  | 2                                       | 3                              | 4  |
| 5. Onda li ndi na uudhigu okukaleka omadhiladhilo gandje ku shoka kwa li tandi longo. | 1  | 2                                       | 3                              | 4  |
| 6. Onda li nda lulilwa.   | 1  | 2                                       | 3                              | 4  |
| 7. Onda li ndi uvite kutya kehe shoka nda longo oshomupondo.                          | 1  | 2                                       | 3                              | 4  |
| 8. Ondakala ndi uvite ndi na etegameno lyonakwiiwa.                                   | 1  | 2                                       | 3                              | 4  |
| 9. Ondi li te dhiladhila kutya onkalamwenyo yandje oya ndopa.                         | 1  | 2                                       | 3                              | 4  |
| 10. Onda li nda tila.   | 1  | 2                                       | 3                              | 4  |
| 11. Kanda li he kotha nawa.   | 1  | 2                                       | 3                              | 4  |
| 12. Onda li nda nyanyukwa   | 1  | 2                                       | 3                              | 4  |

|   | Kashona lela<br>(kashithike<br>pesiku 1) | Omathimbo<br>gamwe-gamwe<br>(esiku 1-2) | Omapita ngaa<br>(Omasiku 3 -4) | Iikando oyindji<br>lela<br>(omasiku 5-7) |
|---|--|---|--------------------------------|--|
| 13. Onda li omumweni ite<br>popi ngaashika shito. | 1  | 2                                       | 3                              | 4  |
| 14. Ondali ndi li<br>muuwike.                     | 1  | 2                                       | 3                              | 4  |
| 15. Aantu kaya li ye na<br>ombili nangame.        | 1  | 2                                       | 3                              | 4  |
| 16. Onda tyapula<br>onkalamwenyo.                 | 1  | 2                                       | 3                              | 4  |
| 17. Ondali handi adhika<br>komayeme noondila.     | 1  | 2                                       | 3                              | 4  |
| 18. Onda li ndi uvite nayi<br>/ uupongo.          | 1  | 2                                       | 3                              | 4  |
| 19. Onda li ndi uvite aantu<br>kaye holendje..    | 1  | 2                                       | 3                              | 4  |
| 20. Ka nda li ndi shi shoka<br>ndi na okuninga.   | 1  | 2                                       | 3                              | 4  |

Section G: Demographics

Moshitopolwa shika otandi ke ku pula omapulo gen a sha nangoye nofamily yoye.

G1. Ngoye omushike?

Omukiintu

Omulumentu

G2. Owa hokanwa nenge owa hokana?

1.  Omwiikaleli
2.  Nda hokanwa/na
3.  Omuselekadhi
4.  Omuhengwa / mwa topoka
5.  Owa otekwa
6.  Owa yalekwa

G3. Owu na omivo ngapi?

Omivo

G4. Owa hulila mongapi moskola ?

1.  Inandi hita oskola
2.  Onda hulila moondondo dhopevi lela
3.  Onda mana oongundu thopevi
4.  Onda ya sigo osekundoskola
5.  Onda mana osekundosikola
6.  Onda mana eithanolongo lyandje

G5. Megumbo lyoye omu na aantu yangapi?

Aantu

G6. Megumbo lyoye omu na aanona yangapi?

Aanona

G7. Megumbo lyoye omu na aa/omunona e na ombuto yoHIV?

1. Eeno

2. Ahawe

G8. Owa ninga ethimbo lyi thike peni to tekula aatekulu yoye mboka?

1.  Okuza sho ya valwa
2.  Omuvo gumwe
3.  Omivo 2 -5
4.  Omivo 6 – 10

G9. Oho mono iiyemo (iimaliwa) tayi zi peni momuvo ngoka gwa ziko?

1.  Openzela
2.  Ondjambi yokiilonga
3.  Ongeshefa yopaumwene
4.  Iimaliwa yaanona okuza kepangelo
5.  Omikuli okuza koombaanga / kulwe
6.  Iimaliwa yoonakulwa aakulu
7.  Oonzo dhofamily

G10. Megumbo lyeni ohamu ya iimaliwa ingapi komwedhi?

1.  N\$ 500
2.  N\$ 500-1000
3.  N\$ 1000- 1500
4.  N\$ 1500-3000
5.  N\$ 3000- 4500
6.  N\$ 5000 and above

G11. Owu na omukithi ngoka gwe ku imba opo wu longe oomwedhi 3 nenge dhi vulepo dha ziko)?

1. Eeno
2. Aawe

G12. Oho kwata openzela?

1. Eeno
2. Aawe

G13. Oho kwata iimaliwa okuza kepangelo molwashoka oto tekula nokuputudha oothigwa naanona yalwe ngaashika, iimaliwa yomutekuli, nenge yuulema nenge yilwe okuza kuuMinisteri Wuukakwashike Kookantu?

1. Eeno
2. Aawe

Tangi sho wa kutha ombinga momapulapulo ngaka.2

## Appendix D: Letter of Approval by Catholic AIDS Action



**Catholic AIDS Action**

Tel: (061) 276 350 Fax: (061) 276 364 PO BOX 159, Windhoek, Namibia  
E-mail: [godwin@caa.org.na](mailto:godwin@caa.org.na) website: [www.caa.org.na](http://www.caa.org.na)

27 April 2013

To Whom It May Concern

Dear University of Minnesota,

I am writing to indicate approval for Ms. Eveline Ndinela Kalomo's study on HIV/AIDS Caregivers' "Omufilishiso" Support Systems: Raising Orphans and Vulnerable Children in Sub-Saharan Africa which she will be conducting here in Namibia. I have reviewed her materials and deem them appropriate for research in Omusati Region, northern Namibia.

We are aware that Ms. Kalomo is a lecturer at the University of Namibia (UNAM), currently pursuing postgraduate studies (Ph.D. in Social Work) for the purpose of UNAM's capacity building at the University of Minnesota, School of Social Work. We value her contribution to our country in area of HIV/AIDS and caregiving. In addition, we are aware that Ms. Kalomo is Namibian, and is acquainted with southern African norms and values regarding research, including the consent process. We are confident, therefore, that any research she undertakes in Namibia will be thoughtful and considerate to research subjects.

On behalf of Catholic AIDS Action, I am approving MS. Kalomo's research project which will be valuable in the fight against HIV/AIDS in Namibia, and I have full confidence it will be successfully executed.

Yours faithfully,

G Chisenga  
Executive Director

"With the courage to fight and the strength to care for the benefit of all"  
Registered Welfare Organisation # 189