Title
Ugandan Grandparents as Primary Caregivers for their Grandchildren.

Author
MATOVU, SCHOLA NAKACHWA

Publication Date
2017

Ugandan Grandparents as Primary Caregivers for their Grandchildren.

by

Schola N. Matovu

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

[redacted]

Dedication

This dissertation is dedicated to my guardian angel, my grandmother—Jajja Matilda Nabowa. Without her selflessness, courage, perseverance and love, I may not have survived my childhood years. In her memory, I will dedicate my professional life to advocating for the well-being of grandparent-caregivers for their grandchildren.

Acknowledgements

"When you learn, teach, when you get, give." —*Maya Angelou*

My academic journey would not have been the same without the support of my dissertation committee, faculty, sponsors, mentors, fellow students, family, friends, and study participants, who all deserve an honorable mention:

To my dissertation committee members, Drs. Sally Rankin and Carol Dawson-Rose, I am deeply grateful for your time, expertise, and insight and for enriching my research and academic experience. I give special thanks to my dissertation chair, Dr. Margaret Wallhagen, for the unwavering support, guidance, encouragement, and valuable feedback. To the esteemed UCSF faculty, especially Drs. Kit Chesla, Susan Kools, Carmen Portillo, Steve Paul, and many others; I thank you for modeling stellar professorship and leadership that I hope to emulate someday. Thank you for patiently listening to my academic woes and tolerating my relentless curiosity over the years.

My sincere gratitude to the SAMHSA MFP family for the moral, academic, and financial support. Ms. Janet Jackson, your warmth and kindness are immense. Dr. Outlaw, your leadership is exemplary! To Dr. Robert Pope, I blame you and sincerely thank you for introducing me to scientific inquiry.

To my 2011 cohort, thank you for your camaraderie. You made this PhD journey that much more fulling. Drs. Rafael Romo, Monica Eckfield, Elizabeth Halifax, Heather Leutwyler, Caroline Stephens, and participants of the gerontology writing seminar class, I thank you for all your valuable feedback and support. To Linda Gregory (Dr. G), my good friend and partner-in-crime, your professionalism and resilience are commendable. I am honored to call you "family" and to have shared this intellectual journey with you. I look forward to writing our next life chapters together. To the UCSF staff, especially the Parnassus Library and student affairs office personnel, I thank you for your competence and for the great work you do. I also wish to thank Dr. Rose Nabirye for facilitating the Makerere University School of Health Sciences Institutional Review Board process. Anne Becker and Bruce Smith, I am grateful for your editorial and professional support.

To my father, Mr. Godfrey Wavammuno Matovu, my deepest gratitude for all your love and unwavering vote of confidence. Thanks for always motivating me to aim for the sky and live to my fullest potential. I will always share my proudest accomplishments with you. To my best friend and husband, Tommy, your support through thick and thin and sense of humor is what has seen me through this strenuous doctoral journey. Your love, patience, attention to detail and realism inspires me every day. To our little precious daughter, Breana, thanks for enduring long days without “Mommy” as I pursued my academic dreams. I aim to make you proud.

To all my friends, near and far, I thank you for your support and well-wishes. And last, but certainly not least, am forever indebted to the unsung heroes, the invisible and unpaid grandparent-caregivers, who welcomed me into their homes and shared with me their personal stories of love, loss, courage, and perseverance. We laughed and cried together and I am honored to amplify your voice.

Abstract

Understanding the Experiences of Grandparents as Primary Caregivers for Grandchildren Affected by HIV/AIDS in Uganda

Schola N. Matovu

Purpose

The purpose of this dissertation grounded theory study is to gain understanding of the experiences and mental health of Ugandan grandparents 50 years of age and older who provide primary care for grandchildren affected by HIV/AIDS.

Background

Despite the overall global decrease in AIDS-related deaths and HIV infections, sub-Saharan Africa remains the region most affected by the epidemic. In 2015, 23.5 million people were living with HIV in sub-Saharan Africa while an average of 800,000 people have died of AIDS-related causes. Uganda was reported to have had an estimated 28,000 adult deaths due to AIDS by 2015 that rendered approximately 660,000 children orphans to date (UNAIDS, 2016). Despite broad acknowledgement that in this HIV/AIDS era older adult caregivers are the backbone and safety net of the African family, very little research has explored the impact of this grandparental burden on the physical and mental health of this vulnerable population.

Methods

Using a grounded theory approach, semi-structured qualitative interviews were conducted with 32 grandparents recruited from the general population impacted by the HIV/AIDS epidemic. The one-on-one interviews were audio-recorded, transcribed, and analyzed using open, axial, and selective coding as well as reflexive and analytic memoing congruent with the methodology.

Findings

Study participant narratives described the caregiving burden as being financial, emotional, and physical although a few rewards were reported. In addition, the current study highlighted other experiences such as the described dimensions of loss and characterized the psychosocial distress related the caregiving role and other socio-economic stressors and the associated coping strategies. The mental health implications and explanatory model of this experiences were also described.

Implications

The study's findings provide an extensive insight into the experiences of Ugandan grandparent–caregivers in the context of the HIV/AIDS epidemic. These insights can potentially inform clinicians, researchers, and policy makers who may seek explanatory models upon which to create care plans and design family-centered and community-based interventions such as childcare and respite care for these older grandparent–caregivers.

TABLE OF CONTENTS

List of Figures

CHAPTER 1:

Introduction

Background and Significance

The AIDS epidemic has placed tremendous demands on elderly caregivers in sub-Saharan Africa. In Uganda alone, approximately 660,000 children have been orphaned as a result of deaths due to AIDS as of 2015 (UNAIDS, 2016). As in the rest of sub-Saharan Africa, the burden of care for these Ugandan orphans has fallen on the shoulders of the children's grandparents. Indeed, in this HIV/AIDS era, these older adult caregivers have been recognized as the backbone and safety net of the African family. Remarkably, although grandparents have come to have such an important role in the Ugandan public health system and in sub-Saharan Africa, relatively little is known about the impact of caregiving on their health and personal wellbeing. To help rectify this critical knowledge deficit, this dissertation explores the range of factors that influence the experience of older Ugandan grandparent caregivers of grandchildren affected (directly or indirectly) by HIV/AIDS. In particular, this dissertation seeks to qualitatively explore the experiences of Ugandan grandparents in order to fill that gap in knowledge.

Problem Statement

Despite the overall global decrease in AIDS-related deaths and HIV infections, sub-Saharan Africa remains significantly affected by this condition with data supporting that it is the most impacted region worldwide. In 2016, the United Nations Programme on HIV and AIDS (UNAIDS; 2016) reported that the region had 23.5 million people living with HIV—out of 36.7 million people living with HIV globally. In 2015, approximately 800,000 individuals had died because of AIDS-related causes—out of 1.1 million AIDS-related deaths globally. Uganda was reported to have had an estimated 28,000 adult deaths due to AIDS, and these deaths orphaned the 660,000 children mentioned above (UNAIDS, 2016). The children themselves have not been impervious to the ravages of the disease. In 2015, the number of Ugandan children reported to be living with HIV who were14 years of age and younger was estimated to be 96,000; while that of adolescents (10–19 years) living with HIV was 79,000 (UNAIDS, 2016). It has been reported that regardless of the orphaned children's personal HIV status, their care has been taken on by grandparents who have very limited support. Several factors have been identified as impacting the lives of these grandparents and these range from micro to macro levels.

Social Factors

The burden of care imposed on grandparents caring for children infected with HIV, especially those dwelling in rural areas, is usually exacerbated by social factors that include poverty, poor infrastructure, and limited access to health care and other social services (Ice, Yogo, Heh & Juma, 2010; Kipp, Tindyebwa, Rubaale, Karamagi & Bajenja, 2007; Kamya & Poindexter, 2009; Ssengozi, 2009). The majority of older adults caring for their grandchildren reside in rural areas amidst extreme poverty and limited resources (Schatz, 2007; Shaibu, 2013). In addition, other older caregivers in northern Uganda have been impacted by over 20 years of civil war between the Lord's Resistance Army and the Ugandan government, causing subsequent displacements and severe disruption of households mostly headed by individuals 60 years of age and over (Bamuturaki, 2007).

The global community has attempted to respond to these social needs through non-governmental and multilateral organizational initiatives such as the Declaration of Alma Ata (WHO & UNICEF, 1978), and more recently, the United Nations (UN) Millennium Development Goals (MDGs) that were set in 2000 (UN, 2013) and now Sustainable

Development Goals (UN, 2016). Even though some of these MDGs, such as combating HIV/AIDS, could positively help support these older adults as the safety net of the African family in the era of this epidemic, the focus on this population has been minimal to non-existent (UN, 2013). Causes such as those pertaining to maternal health, malaria, and decreasing child mortality have higher priority and are the primary focus of global and national intervention—while older adults are left unsupported. Although a few non-governmental organizations, such as HelpAge International, have responded to the needs of these older adults and have advocated for the rights and health of these older populations in Africa, much work must be done to prioritize the needs of these older adults and to engage the national and international communities accordingly.

Cultural Factors

In African families and communities, older adults, especially older women, have been the traditional caregivers to sick family members and heads of households; yet despite this caregiver group's essential role, they remain understudied (MacNeil, 1996; Ntozi, Lubaale, & Nakanaabi, 1997; Schatz, Madhavan & Williams, 2011). Typically, patrilineal grandmothers are the families' preferred choice to assume the caregiving responsibilities, especially in the case of a death of an older child (Ismayilova, Ssewamala & Karimli, 2012; Oleke et al., 2005). Elsewhere in the world, similar expectations related to caregiving are evident in Cambodians (Knodel, Zimmer, Kim & Puch, 2006), Thai (Safman, 2004; Vithayachockitikhun, 2006), other diverse populations in the United States such as the Mexican (Goodman & Rao, 2007) and African American (Caliandro & Hughes, 1998). African Americans are also believed to have carried on this tradition of caregiving across generations in their families (Winston, 2003; del Bene, 2010). As will be demonstrated later, these cultural expectations can be both a detriment and a positive coping mechanism for these grandparents.

Relationships: Family Structure and Community Support

Several international researchers have analyzed the impact of the HIV/AIDS epidemic on the intergenerational relationships in African families of older adults. Socioeconomic changes caused by the epidemic are threatening to subvert and change the renowned cohesiveness of the African extended family and household composition. Driven by socioeconomic factors, older children are migrating to the cities in search of economic, educational, and other opportunities or because families' loss of agrarian land has led to intergenerational dissociation (Therborn, 2004; Zimmer and Dayton, 2007). These shifts have not only incapacitated the agricultural productivity upon which most of rural and urban economies rely (Haacker, 2002; Topouzis, 2003), but they have also resulted in grandparents' being left behind to care for the children with the expectation that their adult children would send financial support. Zimmer and Knodel (2010) examined the association between health of older parents and the return home of their previously dispersed older children. Their findings support the use of interventions that favor the return of adult children to locations that are close to their aging or ill parents as these could promote the health and wellbeing of these older adults. However, because of a dearth of knowledge, particularly research using qualitative methods, that would otherwise provide an in-depth account of the full effects of these social factors, the status of these older adults regarding their health and well-being remains poorly understood.

Caregiver Demographics and Health

In addition to cultural constraints, there are personal experiences, individual characteristics, and or physiological and psychosocial vulnerabilities that further compromise the older adults' health. Grandparental care of grandchildren is not a new phenomenon—African grandparents have cared for grandchildren for generations prior to the HIV epidemic era and yet little research has focused on this population. With or without the context of HIV/AIDS, further examination of the individual, social determinants and cultural dimensionality of older adults' well-being is imperative. Social factors and life adversities such as loss of spouses, parents, siblings; subsequent isolation; HIV stigma; and non-supportive or complicated polygamous marital status can affect the health of these older caregivers.

Also, links between poverty and HIV/AIDS and care of individuals affected by the epidemics in low-income countries have been identified in vulnerable groups such as the elderly and women (Oramasionwu, Daniels, Labreche & Frei, 2011; Zimmer, 2006). Accordingly, we can argue that for older adults directly impacted by the epidemic, the realities of aging in a poverty-stricken environment, combined with the experience of caring and grieving for dying children and grandchildren, can have long-term detrimental impact on these older adults' well-being. Therefore, the proposed qualitative study, informed by the theoretical perspectives described below, will explore the unique experiences of these grandparents and discuss the conceptual, individual, and environmental complexities and family dynamics of this phenomenon.

Theoretical Perspectives

This grounded theory study is underpinned by the social theory of symbolic interactionism (SI; Blumer, 1969). This theoretic perspective provides a basis for understanding human behavior as a product of an actors' self-interpretative process and formation of meanings of social interactions with symbols in their world. The term *symbolic interactionism* was coined by Blumer, an American sociologist, who believed that people create social reality through individual and shared interactions in relation to their environment in order to form meaning (White, Klein, & Martin, 2015). The three main premises of SI—meaning, language, and thought—help to formulate an individual's socialization in the larger community.

The first premise, regarding *meaning* proposes that "humans act toward things on the basis of the meanings they ascribe to those things." The second premise, regarding *language*, proposes that "the meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society." The third premise, regarding *thought*, proposes that "these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters" (Blumer, 1969, p. 2). The premises of SI lend themselves to the caregiving role among older adults. For example, when grandparents respond to a caregiving role on behalf of their older children, each caregiver interprets the crisis or situation and assign meaning to their new role. These meanings and perceptions elicit actions and mobilization towards a general collective response to achieve a desired goal of caring for the dependent children. These concepts offer both a philosophical worldview of social interactions and valuably inform research on the understanding of human behavior.

In addition, given the complexity and multifaceted nature of the caregiving experience among Ugandan grandparents, two other theories—the social ecological model (SEM; Bronfenbrenner, 1994) and the double ABC–X framework: family adjustment and adaptation response (FAAR) model (McCubbin & Paterson, 1982, 1983; Appendix C)—are used as frameworks that facilitate an understanding of the results of the study. The SEM particularly emphasizes the interplay between multiple levels of interaction in human development (i.e. macrosystems, microsystems, mesosystems, exosystems, and chronosystems) and how complex processes transpire among these systemic levels to the affect individuals' health and wellbeing (Bronfenbrenner, 1994; Stokols, 1992). Therefore, the SEM could lend itself to the understanding of interrelations among diverse personal and environmental factors—international, national, social, familial, and individual—that may affect the health and wellbeing of Ugandan older caregivers.

On the other hand, the FAAR framework informs the proposed study by highlighting the dynamic and continuously interactive nature of families, particularly when faced with stressful events that are a part of life (McCubbi & Paterson, 1983). The FAAR conceptual framework provides a rich and detailed approach to understanding the process of family adjustment from the pre- to post-crisis phases, with nuanced focus on the psychosocial component of coping and adaptation. For instance, if a surviving parent who is a family's sole support dies of HIV/AIDS, the FAAR may inform the design and execution of research and practice in reevaluating the new state of affairs in an attempt to re-establish optimal equilibrium or balance between demands and resources or capabilities (Paterson, 1988). It should be noted, however, that these western-based theories may not pertinently describe the experiences and behavior of populations within the culturally diverse sub-Saharan African region including Uganda.

Also, Glaser and Straus (1967) cautioned researchers to refrain from reviewing extant literature in constructing grounded theory studies, including literature that discusses pre-existing theories. This was based on the belief that such exposure would contaminate the emerging framework because researcher might be tempted to force their findings to fit pre-conceived concepts about a given phenomenon (Glaser & Straus, 1967). However, contemporary scientists such as Charmaz (2006) and Clarke (2005) have challenged this doctrine and instead support researchers' becoming informed beings who use their pre-conceived knowledge to critically analyze emerging data and explore alternative or confirmatory explanation of social phenomenon. Ultimately, all three theories—SI, SEM, and FAAR—will be used to elucidate the results of the proposed study. Fundamentally, these theories are based on social interaction, meaning, and subsequent behavior—all three elements that underpin symbolic interactionism and hence grounded theory. Accordingly, these theories facilitate development of a nuanced understanding of the caregiving experience of Ugandan grandparents' caring for grandchildren affected by HIV/AIDS; the ultimate aim of this nuanced understanding is to promote health and maximum functioning of these older caregivers.

Key Concepts and Terms

Age Parameters

In the United States, the age of 65 years or older is generally determined as retirement age and a time to receive pension benefits according to the national health insurance program-Medicare (Social Security, 2014). Conversely, no similar criterion currently exists in Africa, even though the UN has determined that age cutoff to be 60 or over (UNAIDS, 2003). Determining "old age" is further complicated by the ambiguity surrounding its definition in Africa, where the lack of birth records and informal celebrations of birthdays makes determining chronological age difficult. However, in the traditional African context, an elderly status is a hierarchical position of honor within the family and the community, characterized by knowledge and wisdom with trusted philosophical views and personal attributes such as grey hair or number of children (National Research Council, 2006). Based on this tradition and the low life expectancy in Africa, international organizations such as World Health organization (WHO) and HelpAge International have determined that 50 years is the ideal age cut off (Gorman, 1999;

Togunu-Bickersteth, 1987). Thus, for the purpose of this review, 50 years and older adults will be the unit of analysis and also terms "elderly" and "older adult" will be used interchangeably to describe them.

Grandparenting

In the African context, older adults caring for children may be either biological grandparents or other older relatives such as aunts, uncles, great-grandparents, and extended family members, or non-related individuals, such as neighbors and community members (Schatz, Madhavan and Williams, 2011; Zimmer, 2009). In fact, the traditional unisex term for ‘grandparent’ is "Jajja" (Kamya & Poindexter, 2009) in Luganda, which is the most dominantly spoken dialect in Uganda. This term is used not only by young people when addressing biological grandparents but also for any elders in the extended family or community. For the purposes of this paper, therefore, the terms "grandparents" or "older caregivers" will be used interchangeably to acknowledge the experiential aspects of this caregiving role, regardless of kinship to care receiver. Literature on paid caregivers will not be included in this review and the grandparent caregiver’s HIV status is not the focus of this paper. Similarly, children (those 18 years old or younger) receiving care may be biological grandchildren, children of other younger family members or any other minors under the care of an older adult. Additionally, these children may be affected by HIV/AIDS in one of several ways; they may be orphaned and have lost one or both of their parents, or their parents may be sick and or financially unable to care for them. These children may or may not also be HIV-infected.

Purpose and Specific Aims

The purpose of this grounded theory study is to seek an understanding of the experiences of Ugandan grandparents 50 years of age and older who provide primary care for grandchildren whose lives are affected by HIV/AIDS. For this dissertation, the research question: “What is the experience of the older grandparent-caregivers for grandchildren affected by HIV/AIDS in Uganda?” was posed. The specific aims of this dissertation study are to

1. explore the range of factors that influence the experience of older Ugandan grandparent caregivers of grandchildren affected (directly or indirectly) by HIV/AIDS.
2. describe the caregivers’ perceptions of how their decision to care for their grandchildren affects the caregivers’ health, quality of life, and relationship satisfaction with significant others;
3. explore the prevalence of mental health symptoms in this population using the Cultural Formulation Interview (CFI) of the DSM IV that will inform the interview guide.

Description of Dissertation Chapters

This dissertation has six chapters. Chapter 1 presented the dissertation’s problem statement, background and significance, theoretic perspective, definition of key terms and age parameters, study purpose, research question and specific aims. Chapter 2 will review and synthesize current literature and contextualize the phenomenon in the macro- and micro-discourse that shape the experiences of grandparent-caregivers of children affected by the HIV/AIDS epidemic in sub-Saharan Africa. Deficits in knowledge will be noted. Chapter 3 will describe the methods used in investigating the phenomenon and provide a brief overview of their philosophical underpinnings. Chapter 4 will explore the range of factors that influence the caregiving experience of older Ugandan grandparent-caregivers of children affected by HIV/AIDS. This chapter also addresses Aim 2 by describing the caregivers' perceptions of how their decision to care for their grandchildren affects their health, quality of life, and relationship satisfaction with significant others.

Chapter 5 will discuss the mental health implications of loss, caregiving, and coping as experienced by grandparent-caregivers who care for grandchildren affected by HIV in Uganda. This chapter will fulfill Aim 3 by exploring the prevalence of mental health symptoms in this population as identified using the Cultural Formulation Interview (CFI) and as they pertain to the phenomenon of interest. Chapter 6 will explore the current study's most salient theme, loss. Chapter 7 will synthesize the dissertation's findings and will identify research and practice recommendations for improving the psychosocial wellbeing of grandparents caring for grandchildren affected by the HIV/AIDS epidemic in Uganda. None of the chapters have been submitted to any journals for publication at this time. Each of the three chapters are linked to the specific aims and research question of this dissertation.

References

Bamuturaki, J. (2007). HIV and AIDS & internally displaced persons (IDPs): A background note on the current situation in conflict affected districts of northern Uganda. Retrieved from http://www.helpage.org/download/4c48a4e39b03e/

Blumer, H. (1969). *Symbolic interactionism, perspective and method.* Englewood Cliffs, NJ: Prentice-Hall.

Bronfenbrenner, U. (1994). Ecological Models of Human Development*. International Encyclopaedia of Education, 3,* Oxford, Elsevier.

Caliandro, G., & Hughes, C. (1998). The experience of being a grandmother who is the primary caregiver for her HIV-positive grandchild. *Nursing Research, 47*(2), 107–113.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn.* Thousand Oaks, CA: Sage.

Del Bene, S. B. (2010). African American grandmothers raising grandchildren: A phenomenological perspective of marginalized women. *Journal of Gerontological Nursing, 36*(8), 32–40.

Haacker, M. (2002). “The Economic Consequences of HIV/AIDS in Southern Africa.” IMF Working Paper No. 02/38, Washington, DC.

Ice, G. H., Yogo, J., Heh, V., & Juma, E. (2010). The impact of caregiving on the health and well-being of Kenyan Luo grandparents. *Research on Aging, 32*(1), 40–66.

Ismayilova, L., Ssewamala, F. M., & Karimli, L. (2012). Family support as a mediator of change in sexual risk-taking attitudes among orphaned adolescents in rural Uganda. *Journal of Adolescent Health, 50*(3), 228–235.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Goodman, M. R., & Rao, S. P. (2007). Grandparents raising grandchildren in a US–Mexico border community. *Qualitative Health Research 17*, 1117.

Gorman, M. (1999). Development and the rights of older people. In J. Randel et al., (Eds.), *The ageing and development report: Poverty, independence and the world's older people.* (pp. 3–21). London, Earthscan Publications Ltd.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2016, November). *Fact Sheet November 2016*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

Kamya, H., & Poindexter, C. C. (2009): Mama Jaja: The stress and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health, 24*(1), 4–21

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E. & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International, 28*(10), 856–871.

Knodel, J., Zimmer, Z., Kim, K. S., & Puch, S. (2006). The impact of AIDS on older-age parents in Cambodia. Phnom Penh, Cambodia: UNFPA, Royal University of Phnom Penh.

MacNeil, J. M. (1996). Use of culture care theory with Baganda women as AIDS caregivers. *Journal of Transcultural Nursing, 7*, 14. doi: 10.1177/104365969600700204

McCubbin, H. I. & Paterson, J. M. (1982). Family adaptation to crisis. In H. I. McCubbin and J. M. Paterson (Eds.), *Family stress, coping and social support* (pp. 26–47). Carbondale, IL: Thomas Publishers.

McCubbin, H. I. & Paterson, J. M. (1983). The family stress process: The double abc-x model of adjustment and adaptation. In H. I. McCubbin, J. M. Paterson, & M. Sussman (Eds.), *Advances and development in family stress theory and research* (pp. 1–26). New York.

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. B. Cohen & J. Menken (Eds.). Committee on Population, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

Ntozi, J. P. M., Lubaale, Y. M. A., & Nakanaabi, I. M. (1997). AIDS mortality in Uganda: Circumstances, factors and impact of death. *Health Transition Review, 7*(1), 207–224.

Oleke, C., Blystad, A., & Rekdal, O. B. (2005). When the obvious brother is not there: Political and cultural contexts of the orphan challenge in northern Uganda. *Social Science & Medicine, 61*, 2628–2638.

Oramasionwu, C. U., Daniels, K. D., Labreche, M., & Frei, C. R. (2011). The environmental and social influences of HIV/AIDS in sub-Saharan Africa: A focus on rural communities. *International Journal of Environmental Research and Public Health, 8*, 2967–2979.

Paterson, J. M. (1988). Families experience stress 1. The family response model ii applying the FAAR model to health-related issues for intervention and research. *Family Systematic Medicine, 6*(2) 202–237.

Safman, R. M. (2004). Assessing the impact of orphanhood on Thai children affected by AIDS and their caregivers. *AIDS Care 16*(1), pp. 11–19.

Schatz, E. J. (2007). "Taking care of my own blood": older women's relationships to their households in rural South Africa. *Scandinavian Journal of Public Health, 69*, 147–154.

Schatz, E, J., Madhavan, S., & Williams, J. (2011). Female-headed households contending with HIV/AIDS-related hardship in rural South Africa. *Health & Place, 17*, 598–605.

Seeley, J., Kajura, E., Bachengana, C., Okongo, M., Wagner, U., & Mulder, D. (1993). The extended family and support for people with AIDS in a rural population in south west Uganda: A safety net with holes? *AIDS Care, 5*(1), 117

Shaibu, S. (2013). Experiences of grandmothers caring for orphan grandchildren in Botswana. *Journal of Nursing Scholarship, 45*, 363–370.

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care, 21*(3), 309–314.

Stokols, D. (1992). Establishing and maintaining healthy environments: toward a social ecology of health promotion. *American Psychologist, 47*, 6–22.

Therborn, G. (2004). Between sex and power: Family in the world, 1900–2000. New York: Routledge.

Togunu-Bickersteth, F. (1987). Chronological definitions and expectations of old age among young adults in Nigeria. *Journal of Aging Studies, 1*(2), 113–24.

Topouzis, D. (2003). Addressing the Impact of HIV/AIDS on Ministries of Agriculture: Focus on eastern and southern Africa. Rome: Food and Agriculture Organization and Joint United Nations Programme on HIV/AIDS).

United Nations. (2013). The millennium development goals report. New York: UN. http://www.un.org/millenniumgoals/pdf/report-2013/mdg-report-2013-english.pdf

United Nations. (2016). Economic and Social Council: Progress towards the sustainable development goals—Report of the Secretary-General. Retrieved from http://www.un.org/ga/search/view_doc.asp?symbol=E/2016/75&Lang=E

United Nations Development Programme. (2003). *Human Development Report.* New York. Retrieved from http://www.unic.un.org.pl/hdr/hdr2003/hdr03_complete.pdf

United States Social Security Administration. (2014): *Understanding benefits.* Retrieved from http://www.ssa.gov/pubs/EN-05-10024.pdf

Vithayachockitikhun, N. (2006). Family caregiving of persons living with HIV/AIDS in Thailand: Caregiver burden, an outcome measure. *International Journal of Nursing Practice 12*, 123–128

White, J. M., Klein, D. M., & Martin, T. F. (2015). *Family theories An introduction* (4th ed.). Thousand Oaks, CA: Sage.

Winston, C. A. (2003). African American grandmothers parenting AIDS orphans: Concomitant grief and loss. *American Journal of Orthopsychiatry,1*, 91–100.

World Health Organization and United Nations Children's Fund. (1978). Declaration of Alma Ata: Report of the International Conference on Primary Health Care. Alma Ata, U.S.S.R.: World Health Organization and United Nations International Children's Emergency Fund

Zimmer, Z. (2006). Poverty, wealth inequality, and health among older adults in rural Cambodia. *Policy Research Division Working Paper* ISSN: 1554–8538, Population Council.

Zimmer, Z. (2009). Household composition among elders in Sub-Saharan Africa in the context of HIV/AIDS. *Journal of Marriage and the Family, 71*(4), 1086–1099.

Zimmer, Z., & Dayton, J. (2005). Older adults in sub-Saharan Africa living with children and grandchildren. *Population Studies, 59*(3), 295–312.

Zimmer, Z., & Knodel, J. E. (2010). Return migration and the health of older aged parents: Evidence from rural Thailand. *Journal of Aging and Health, 22*(7): 955–976.

CHAPTER 2:

Literature Review

Grandparents as Primary Caregivers for Grandchildren Affected by HIV/AIDS:

A Literature Review with a Sub-Saharan Perspective

Introduction

Despite the overall global decrease in AIDS-related deaths and HIV infections, United Nations Programme on HIV and AIDS (UNAIDS) reports that sub-Saharan Africa remains the most affected region worldwide. In 2015, 23.5 million people were living with HIV in sub-Saharan Africa (out of 36.7 million people with the infection globally), and an average of 800,000 people died of AIDS-related causes (out of 1.1 million deaths globally; UNAIDS, 2016). In 2015, Uganda reported that an estimated 28,000 adult deaths due to AIDS rendered approximately 660,000 children orphans (UNAIDS, 2016). In the same year, the number of Ugandan children 14 years of age and younger living with HIV was estimated to be 96,000; the number of adolescents 10–19 years of age living with HIV was 79,000 (UNAIDS, 2016). As HIV/AIDS continues to claim lives, the care of these orphaned children arrangements is usually assumed by surviving parents or other extended family members such as stepparents, older orphans, or uncles—and most often, by grandparents (Clark, 2006; Kamya & Poindexter, 2009; Ssengonzi, 2009). Indeed, in sub-Saharan Africa, the AIDS epidemic has placed tremendous demands on elderly grandparent–caregivers.

Although there have been a number of sociologic and demographic studies in parts of sub-Saharan Africa exploring the impact of HIV/AIDs on older adults, few have addressed the physiological and mental health impact of the grandparental caregiving burden on this vulnerable population. My research specifically addresses this underdeveloped area and explores the experiences of grandparents caring grandchildren affected by the HIV/AIDS epidemic in Uganda. This review analyzes the contextual and experiential empiric evidence of what is known about the grandparents' experience, identifies information deficits in the body of published research, and proposes recommendations for improving the lives of these older adults.

Review of the Literature

To inform the design and execution of the study described in this dissertation, a literature review examined articles relevant to the study's research question: "What is the experience of the elderly caregivers caring for HIV/AIDS affected grandchildren?" The first step in this review was a search that examined extant literature on the phenomenon of interest.

Literature Search

An article search used the PubMed, PyschINFO CINAHL, Google Scholar, and ProQuest Dissertation & Theses databases; to identify additional articles, the Web of Science citation indexing service was used to view abstracts and to critically analyze key references. Search terms, phrases, and MeSH terms included *older adults, elderly, caregivers, psychosocial, wellbeing, HIV/AIDS, Uganda,* and *sub-Saharan Africa*. Articles reviewed met all of the following inclusion criteria: (a) study participants were adults 50 years of age and older who were primary caregivers (studies with more than 50% of participants who were 50 years and older were included); (b) study participants were HIV/AIDS-affected or infected children as recipients of care; and (c) topics of interest included health of older caregivers (especially psychosocial or mental health). In addition, studies must have been conducted in sub-Saharan Africa and published not earlier than 2005. The search yielded 131 studies, 28 of which met criteria for inclusion.

Although in the selection of articles for review a greater diversity of sub-Saharan African research settings would have been preferable, the majority of published research on this phenomenon has been conducted in South Africa—in part because that country has the highest per capita proportion of older people in the region (Knodel, Watkins & VanLandingham, 2003).

Other factors in this literature review's preponderance of South African studies are South Africa's relatively advanced research capacity and associated NGO-generated research, and the research activities of South Africa's major institutes (e.g., the multidisciplinary Institute of Aging in Africa based in Cape Town). As a result of these factors, the search yielded more studies from South Africa than from any other sub-Saharan African country. A thematic analysis of the findings and methodologic review of the studies was performed to highlight key themes and methods and procedures with which researchers have arrived at the empirical evidence pertaining to this phenomenon. Therefore, reviewed studies fell under the following two categories: exploratory, confirmatory studies and interventional studies.

Exploratory Studies

Exploratory research on the multiple impacts of HIV/AIDS on older adults in the sub-Saharan region have provided insight in the experiences, responsibilities, and caregiver role's impact on this population's well-being. Although some studies have reported positive aspects of the caregiving role among grandparent–caregivers (Kamya & Poindexter, 2009; Kasedde, Doyle, Seeley & Ross, 2014; Ssengozi, 2009), an overwhelming number of negative outcomes on their health and well-being have been identified and collectively described as "caregiver burden." Chou (2000) has defined *caregiver burden* as an individual's subjective perception of overload in one or more of four dimensions: physical, psychological, social, and financial.

Physical Burden

In the selected studies, respondents—especially those caring for people living with HIV/AIDS—have been reported to contribute in multiple roles.   Typically, these caregivers have been found to not only care for those who were sick (e.g., changing wound dressings, toileting, bathing, feeding, and transportation to health centers or traditional healers), but also to make other contributions to their family's well-being, such as farming and meal preparation (Kamya & Poindexter, 2009; Muga & Onyango-Ouma, 2009; Schatz, 2007; Ssengozi, 2009; Schatz & Gilbert, 2014). Ssengozi (2009) reported that some respondents spent prolonged periods of time outside their home as they cared for their sick grandchildren in the hospital. These responsibilities have brought on chronic fatigue and damage to physical health and have been associated with numerous psychological complications.

Psychological Burden

The stress of daily living typically eventuates in psychological complications—especially for older adult caregivers. Consistent with the general caregiving literature findings, most of the studies discussed in this literature review have identified psychosocial complications, including increased emotional stress, burnout, fatigue, anger, resentment, guilt, anxiety, mental weariness, and isolation (Grobler and Roos, 2012; Littrell, Murphy, Kumwenda & Macintyre, 2012; Sefasi, 2010). Grobler and Roos (2012) reported that the parenting burden of raising and disciplining disobedient youth, for instance, elicits feelings of hopelessness and confusion as grandparents may constantly worry about their grandchildren's safety.

In addition, Ogunmefun, Gilbert, and Schatz (2010) investigated secondary stigmatization as a socioeconomic impact of HIV/AIDS among older caregivers. As reported by Schatz and Gilbert (2014), some of the grandparents related this psychological burden to their physical ailments (e.g., elevated blood pressure). In other instances, hopelessness can result from witnessing a grandchild's deteriorating health, despite all of the grandparent's care. Ssengozi (2009) reported that female respondents experienced frequent emotional episodes of crying, worrying, depression, and a sense of hopelessness, while some of their male counterparts resorted to alcohol in order to cope with stress.

Social, Cultural, and Gender Burdens

Most of the reviewed studies cited gender as a crucial factor in caregiving. Evidence from almost all studies reviewed suggested that older women comprised the majority of household heads and caregivers (Boon et al., 2010; Littrell, Murphy, Kumwenda & Macintyre, 2012; Muga & Onyango-Ouma, 2009; Nyasani, Sterberg & Smith, 2009; Schatz, 2007). Boon et al. (2010) reported that 85.8% of their participants were female, 52.6% were widowed, and 45.9% were between 60 and 69 years of age. Petros (2012) also reported that the majority of their participants were widowed, uneducated, and unemployed. Increase in household size as sick older children move their families back into the grandparents' homes has been reported as an additional social burden (Muga & Onyango-Ouma, 2009; Schatz, 2007). Boon et al. (2010) reported that 11.4% (46 of 409) the older adults in their study cared for multiple other family members such as adult relatives, and neighbors; 55.9% (224 of 409) cared for both grandchildren and adult children without much social support. In the absence of the necessary social support in assisting elderly caregivers, their perceptions of family functioning and self-efficacy were often compromised (Mhaka-Mutepfa, Cumming & Mpofu, 2014). In addition to social and gender factors, some studies have identified cultural expectations as the predominant factor influencing decisions by older adult caregivers to care for their grandchildren (Drah, 2014; Kasedde, Doyle, Seeley & Ross, 2014; Nyasani, Sterberg & Smith, 2009; Schatz & Gilbert, 2014).

Financial Burden

Primarily as a result of the HIV epidemic, grandparent–caregivers in Uganda and throughout sub-Saharan Africa struggle and are severely challenged by diminished income and standard of living (Seeley, Kajura, Bachengana, Okongo, Wagner & Mulder, 1993; Zimmer & Dayton, 2005). The majority of these caregivers reside in rural or peri-urban areas and have limited resources an education. In addition, many of the grandmother–caregivers are widowed and thus without a partner to share their financial burden (Casale, 2011; Drah, 2014; Grobler & Roos, 2012; Kipp et al., 2007; Schatz, 2007). On top of these financial challenges, the additional financial burden associated with caring for grandchildren—the costs of food, clothing, beds, shelter, school fees, after-school activities, medication and other health care, and household expenses—can be quite high, and this burden rests heavily on the shoulders of grandparent–caregivers who themselves were already struggling to make ends meet. Indeed, for some older adult grandparents in developing countries the scale and magnitude of financial destitution is great—even to the point of being overwhelming for these older adults (Casale, 2011; Kamya & Poindexter, 2009; Littrell, Murphy, Kumwenda & Macintyre, 2012; Muga & Onyango-Ouma, 2009; Mugisha, Schatz, Seeley & Kowal, 2015; Nyasani, Sterberg & Smith (2009); Schatz, 2007; Ssengozi, 2009; Sefasi, 2010).

In the studies conducted in Uganda and sub-Saharan Africa, the majority of the grandparent–caregivers had no formal employment, but instead depended upon subsistence income from selling their farmed crops or a traditional local brew (Drah, 2014; Shaibu, 2013). As a result of their financial constraints, the additional, often unanticipated costs of child care forced many of these grandparents to adapt to their financial burdens in a variety of ways. Some studies reported that a small fraction of grandparents reported receiving financial support from pensions and other government assistance (Boon et al., 2010; Grobler & Roos, 2012; Shaibu, 2013).

Coping Mechanisms

In addition to the financial strategies that grandparent–caregivers used to meet their challenges, the studies in this review also discovered that the grandparents used several types of non-financial coping strategies to manage the burden of caring for their grandchildren; such strategies included spiritual, social, and cultural strategies.

Spirituality. The majority of participants in the selected studies believed that God was a source of strength and hope throughout the process of caring for their ill adult children, grieving the loss of these children, and the subsequent shift to surrogate parenthood of their orphaned grandchildren (Caliandro & Hughes, 1998; Grobler & Roos, 2012; Kamya & Poindexter, 2009; Shaibu (2013)). Spiritual well-being, whether associated with a formal religion or with non-religious intangible elements—as in the case in most rural parts of Uganda—has been cited as a vital coping strategy for Ugandan caregivers (Kamya & Poindexter, 2009; Ssengozi, 2009).

Social support and action. Some studies indicated that respondents sought support from a small number of family members, neighbors, and acquaintances (del Bene, 2010; Grobler & Roos, 2012; Kipp et al., 2007) while other studies cited seared kinships that further weakened their support systems (Nyasani, Sterberg & Smith (2009); Muga & Onyango-Ouma, 2009). Other grandparents indicated that they coped best by taking action, by becoming resourceful in finding ways to help those in need, and by educating others with similar challenges (Kamya & Poindexter, 2009). Some grandparents benefited from a reciprocity of care from their grandchildren or other family members who assisted them with their household chores or rendered other types of support (Mugisha, Schatz, Seeley & Kowal, 2015). Other grandparents indicated that they drew upon inner strength by involvement in small income-generating projects to generate income and sustain the household (Ice et al., 2010; Kamya & Poindexter, 2009; Kipp et al., 2007; MacNeil, 1996; Ssengozi, 2009). Other grandparents were motivated by anticipated rewards such as assistance with chores or other future benefits of caring for their grandchildren (Kasedde, Doyle, Seeley & Ross, 2014). However, although these coping strategies were identified, no studies of grandparent–caregivers in Africa evaluated the strategies' effectiveness. Also, no studies evaluate the impact of cultural or religious influences in either alleviating or exacerbating the caregiving burden as experienced by these older caregivers.

Confirmatory Studies

Eight of the 27 studies reviewed in this paper examined, tested, or confirmed health hypotheses pertaining to the phenomenon of grandparents' functioning as primary caregivers for their grandchildren affected by HIV/AIDS. The confirmatory studies reviewed tested hypotheses related to physiological and or psychosocial (e.g., grief, depression, anxiety) health outcomes. Examples of investigated health outcomes in this category of studies have included general health (Ice et al., 2010; Muliira, 2011); cardiovascular disease (Horwitz, Yogo, Juma & Ice, 2009); personal, social, and environmental influences on mental health (Boon et al., 2010; Mhaka-Mutepfa, Cumming & Mpofu, 2014); depression (Kagotho & Ssewamala, 2012); nutritional status (Kruger, LekalakalaMokgela, & Wentzel-Viljoen, 2011). Others investigated concepts related to caregiving such as type of care provided and received by older caregivers (Mugisha, Schatz, Seeley & Kowal, 2015); and perceived ability to communicate with, care for, and provide for their grandchildren (Boon, et al., 2010).

Impact of Caregiving on Grandparents' Health

For example, to examine the impact of caregiving on the health of Kenyan grandparents, Ice et al. (2010) collected longitudinal data from 2005–2007. This study is one of the few longitudinal and comprehensive studies to examine health outcomes among African caregivers. Ice and colleagues used several health measures (e.g., body mass index, blood pressure, serum glucose, and hemoglobin) to compare Kenyan (Luo) grandparent caregivers with their non-caregiving counterparts. The researchers hypothesized that, on average, the health status of caregivers would be poorer than that of the non-caregivers. However, contrary to the findings of the majority of western and a few African qualitative studies that have also investigated this phenomenon, the study by Ice et al. found no significant impact of caregiving on the health of the caregiver grandparents. In fact, these authors found that the grandparent- caregivers reported better mental health as measured by psychosocial component of the MOS Short-Form 36 (SF-36).

Personal, Social, and Environmental Factors

A study by Mhaka-Mutepfa, Cumming, and Mpofu (2014) explored the influences of personal, social, and environmental factors that could prevent the development of psychological disorders. Their findings revealed that personal characteristics such as high self-esteem, strong internal locus of control, and greater problem-solving capabilities had positive impact on caregiving; this study also reported a strong association between social support and grandparent well-being. In the following year, another study by same authors found that both these personal factors and also social factors—such as social networks—were also associated with these grandparents' resilience (Mhaka-Mutepfa, Mpofu, and Cumming, 2015).

Grief Among Older Caregivers

Boon et al. (2010) investigated the range of caregiving activities and explored the concept and experience of grief among caregiving older adults who had experienced multiple losses.

Using quantitative methods, Boon and her colleagues interviewed 820 older adults who were 60 years of age or older. Moreover, Boon and her colleagues found that, as a result of caring for children and grandchildren dying of AIDS, more than 85% of the participants reported high levels of grief and pain. The grief was evidenced by reports of the correlates of grief: loneliness (85%), difficulty sleeping (85%), denial (80.8%), and feelings of unfairness about the death of their children (81.3%). An unexplained and contradicting finding was that higher levels of grief were related to higher self-efficacy, knowledge of care, and more access to care.

Depression Among Older Caregivers

A similar mental health study by Kagotho and Ssewamala (2012) examined factors that influenced perception of depression in Ugandan older caregivers who were caring for children orphaned by AIDS. In this 4-year longitudinal quantitative study, 80% of participants were female. In this study, the number of female caregivers who reported depressive symptoms was greater than that of male caregivers ($p = .009$). Participants—especially those with no savings or other assets—reported high rates of symptoms of irritability, poor appetite, sleep problems, low self-esteem, and loneliness. However, contrary to other researchers (Minkler & Fuller-Thompson, Miller, & Driver, 2007; Musil, 1998; Musil et al. 2009), Kagotho and Ssewamala reported that caregivers who received external funding and other social support were more likely to report higher depression than were caregivers who did not receive such funding or social support.

Nutritional Status of Older Caregivers

Nutritional status is another critical component in the well-being of older adults as substantiated in an investigation by Kruger, LekalakalaMokgela, and Wentzel-Viljoen (2011). In this cross-sectional descriptive study, Kruger and colleagues compared and described the nutritional status of 330 urban and rural older South African caregivers to HIV/AIDS orphans. Using anthropometry, biochemical analysis, HIV test results, and quantitative questionnaires, they found that rural caregivers had very low food intake and high alcohol intake, particularly among male participants. Kruker et al. also reported that uninfected participants had compromised immune system function. Conversely, urban participants were reported to have significantly higher intake of micronutrients and trace elements than did their rural counterparts. In comparison with their rural counterparts, urban participants also reported higher fat intake, and hence were more prone to cardiovascular and other illnesses (e.g., diabetes mellitus), that were evident in the sample. One of this study's strengths was the use of multiple sources of data on nutritional status, a research design feature that strengthened the findings' reliability. Kruger and her colleagues also used appropriate biochemical markers and measures that clearly identified areas of poor health. As a result, the findings of this study could be used to inform the design and execution of health and socioeconomic interventions to support older caregivers. The study's data revealed that, among participants in the study's urban group, urbanization itself was a cause for these health complications.

Caregivers' Health Outcomes and Health-promoting Practices

In a descriptive study, Muliira (2011), examined health outcomes and health-promoting practices of 204 caregivers for HIV/AIDS orphans in southern Uganda. Of the participants, 70% were female, 53% were grandparents, and 31% were above 50 years of age. Muliira reported that 61% of the participants reported poor health status, which the participants attributed to the demands of their caregiving role. These self-reported health problems included chronic illness (97%), social isolation (95%), and mental stress (92%). One of the study's strengths was its exploration of participants' perception of self-care and their social support-seeking practices: eating a balanced diet (67%), other self-care activities (44%), and seeking spiritual support from religious leaders (64%) or from family members (57%). Even though this study used a multifactorial approach in investigating different aspects of caregiving, the study was limited by a lack of focus on specific health outcome measures and failure to define "chronic illnesses" and "mental stress." To improve health interventions, practices, and supportive respite programs, researchers need a deeper understanding of these concepts.

Grandparental Ability to Provide Care

In 2010, Boon and colleagues also investigated grandparents' perceived ability to care for, provide for, communicate with their grandchildren. Their findings suggested that perceived grandparental ability to effectively care for their grandchildren was mostly predicated on both a personal inclination toward caring for others and more knowledge of how to access financial support. Also, a positive attitude toward communication and more negative attitude toward individuals living with HIV/AIDS predicated the perceived ability to communicate and provide financial support respectively. The care-related activities conducted by these older adults were consistent with those explored in many studies described above, such as that of Mugisha, Schatz, Seeley & Kowal (2015), who found that women were more likely to perform health or physical-related care while men were more likely to provide financial support.

Intervention-focused Studies

Out of the 27 reviewed studies, only 2 studies tested the effectiveness of interventions geared toward the well-being of older caregivers. For example, Boon et al. (2009) performed a study with older caregivers to test the effectiveness of a health education intervention, based on the needs of the population of older caregivers to children orphaned by AIDS-related causes in South Africa. As reported by Sefasi (2010), Boon and colleagues corroborated that this population lacked knowledge on HIV prevention. The intervention included HIV/AIDS education, an approach to improve intergenerational communication, and re-enforcement of home-based care skills for the sick. Although intergenerational communication did not change, the intervention's results were congruent with others' suggestions that educational efforts coupled with home-based services improved the caregiver's attitude toward people living with HIV/AIDS (p = .003), increased self-perceived control over nursing care activities (p = .003), and increased HIV/AIDS knowledge (p = .003). Littrell, Murphy, Kumwenda, and Macintyre (2012) also evaluated a program that provided support to community-based organizations in Malawi for income-generating projects to caregivers for orphans. This study indicated that although older caregivers reported poorer health, they experienced less emotional distress and higher levels of perceived trust than did younger counterparts. In fact, the study findings suggested that older caregivers were the more reliable cohort to care for orphans despite the carers' perceived challenges.

Recommendations for Research, Policy, and Public Health

The studies examined in this literature review offered recommendations regarding research, policy, and public health recommendations. The studies' investigators suggested that more research studies should investigate older adults' caregiver role in the contexts of other aging experience; family dynamics; positive accounts of caring for orphans; caregivers' social, cultural, and gender positions; and review of other cohorts (e.g., cohorts of younger caregivers and of non-caregiving older adults). Reviewed studies also highlighted the need for auxiliary research approaches that would identify additional causal pathways and deductively test hypothesis, concepts, and constructs—especially in relationship to the caregivers' health. A few studies also pointed out a need for both longitudinal and mixed-methods approaches to the investigation of the caregiving experience of grandparent-caregivers. In the majority of the reviewed study reports, the investigators made a resounding plea that policy and public health stakeholders implement interventions and comprehensive social protection and welfare programs.

Deficits in Research Evidence

Despite a surge of studies pertaining to the caregiving role as experienced by grandparents in sub-Saharan Africa, many deficits in our understanding of the phenomenon remain. First, and as noted in the review, few studies have focused on specific relevant health outcomes of these adults with or without caregiving responsibilities. To determine the impact of the caregiver role on the health and wellbeing of older caregivers, a few research teams have attempted to analyze biomarkers such as blood pressure, blood glucose, and nutritional enzymes (Ice et al., 2010). Unfortunately, there are not enough studies to corroborate some of these studies' findings. Also, the majority of the studies' discrepant findings on the phenomenon may be due to limitations in the studies' methodologies specifically those that hindered more conclusive investigation. A better understanding of the social health determinants and other negative health outcomes and their possibly unique symptom manifestations in different cultural settings is needed for design and development of relevant health, policy, and socioeconomic interventions to improve this population's well-being.

Second, to better identify effective areas of intervention, more studies are needed to assess and understand the complexity of extended family structures, family constellations, and the ways in which intergenerational relationships influence the family dynamics of these older adults. More studies that examine complex psychosocial constructs and family dynamics—such as household income, caregivers' perceived ability to provide nursing care, and intergenerational communication—are needed. A better understanding of these family dynamics and other phenomena, such as cultural interactions, norms, and external support systems, could be used to inform the development of effective recommendations for the provision of support to older caregivers.

Furthermore, as evident in the studies discussed in this review, the caregiving literature currently lacks definitions of key concepts. For instance, if caregiving as a concept is not viewed as a burden in a given culture, how can researchers best investigate the possible negative outcomes that may inevitably be associated with the caregiving role within that population? In the sub-Saharan Africa context, other concepts related to grandparent–caregiving could be further explored. Such concepts include empowerment, grandparenting, ambivalence, and resilience that have been studied more comprehensively in similar western literature.

Also noteworthy is the fact that, in the literature on sub-Saharan African populations, nursing research about the caregiving phenomenon as experienced by grandparents is very limited—and yet nurses constitute the predominant health professional workforce serving these populations. As with clinical practice, nursing research applies holistic perspectives to the conceptualization and implementation of interventions for studying and caring for individuals and families. This approach not only informs nursing practice, but also opens up opportunities for interprofessional collaborations and embraces the diversity of human experiences.

Last is the imperative for greater rigor in the methodologies used to explore this phenomenon in the African context. Application of interdisciplinary and cross-cultural approaches to scientific inquiry that is based upon sound philosophical and theoretic underpinnings is crucial to the progression of the research trajectory from exploratory to confirmatory and interventional studies. More mixed-method and longitudinal studies that use culturally appropriate tools to effectively investigate both the physiological and psychological cumulative impact of caring for and losing adult children and grandchildren by these older adults are needed.

Conclusion

The experiences of older adults caring for their grandchildren in the sub-Saharan African setting and the impact of HIV/AIDS on this role have been only minimally explored and today remain inadequately understood—in comparison with western studies on this phenomenon. Extant exploratory research has generally contributed to the identification of older adults as the safety net in the care of HIV/AIDS orphans and people living with HIV/AIDS in sub-Saharan Africa. As evidenced by the studies in this review, some studies have described the impact of HIV/AIDS on the health and wellbeing of older adults in the African setting. These studies have not only reported physical, psychosocial, and financial burden experienced by the caregiver, but have also identified some of the older caregivers' coping strategies, such as spiritual practice. Although the body of advocacy-oriented and academic research is growing—especially in areas of sociodemographic and economic research—health-related research remains inadequate.

To understand the nuanced experiences of caregiving grandparents in the context of the cultural diversity of the African continent and the dynamic nature of the African family structure, more rigorous studies must be conducted. The studies discussed in this literature review have highlighted the mostly negative impact of caregiving on the health and well-being of these older adults. However, these studies have also revealed the deficits in our understanding of (a) cultural and conceptual complexities, (b) the effectiveness of coping mechanism and potential interventions, and (c) the prevalence and severity of caregiving-related morbidity. Improved understanding of this phenomenon can lead to improvements in the design and testing of interventions tailored for these grandparents.

References

Boon, H., Ruiter, R. A., James, S., Borne, B. V., Williams, E., & Reddy, P. (2010). Correlates of grief among older adults caring for children and grandchildren as a consequence of HIV and AIDS in South Africa. *Journal of Aging and Health, 22*(1), 48–67

Boon, H., Ruiter, R. A., James, S., Borne, B. V., Williams, E., & Reddy, P. (2009) The impact of a community-based pilot health education intervention for older people as caregivers of orphaned and sick children as a result of HIV and AIDS in South Africa. *Journal of Cross-Cultural Gerontology. 24*, 373–389.

Caliandro, G., & Hughes, C. (1998). The experience of being a grandmother who is the primary caregiver for her HIV-positive grandchild. *Nursing Research, 47*(2), 107–113.

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. *Ageing and Society, 31*, 1265–1288

Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing, 15*(6), 398–407.

Clark, S. J. (2006). Demographic impacts of the HIV epidemic and consequences of population-wide treatment of HIV for the elderly: Results from microsimulation. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for furthering research,* (pp. 91 - 116). Washington: National Academies Press.

Del Bene, S. B. (2010). African American grandmothers raising grandchildren: A phenomenological perspective of marginalized women. *Journal of Gerontological*

Nursing, 36(8), 32–40.

Drah, B. B. (2014). Older women, customary obligations and orphan foster caregiving: The case of queen mothers in Manya Klo, Ghana. *Journal of Cross-Cultural Gerontology*, 29, 211.

Grobler, H., & Roos, V. (2012). Psychosocial experiences of coloured grandmothers who care for their grandchildren: Implications for intergenerational relations. 30th International Congress of Psychology, 22–27 July, Cape Town.

Horwitz, S., Yogo, J., Juma, E., & Ice, G. H. (2009). Care-giving and cardiovascular disease risk gactors in male and female Luo elders from Kenya. *Annals of Human Biology 36*(4), 400–410.

Ice, G. H., Yogo, J., Heh, V., & Juma, E. (2010). The impact of caregiving on the health and well-being of Kenyan Luo grandparents. *Research on Aging, 32*(1), 40–66.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2016, November). *Fact Sheet November 2016*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

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 stress and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health, 24*(1), 4–21

Kasedde S., Doyle A. M, Seeley J. A., & Ross, D. A. (2014). They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic. *Social Science*

Medicine, 113, 161– 168.

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E. & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International, 28*(10), 856–871.

Knodel, J., Watkins, S., & Van Landingham, M. (2003). AIDS and older persons: An international perspective. *Journal of Acquired Immune Deficiency Syndromes, 33*, 153–165.

Kruger, A., LekalakalaMokgela, S. E., & Wentzel-Viljoen, E. (2011). Rural and urban older African caregivers coping with HIV/AIDS are nutritionally compromised*. Journal of Nutrition in Gerontology and Geriatrics, 30*(3), 274–290.

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. [Forthcoming]. *Journal of Cross-Cultural Gerontology*

MacNeil, J. M. (1996). Use of culture care theory with Baganda women as AIDS caregivers. *Journal of Transcultural Nursing, 7*, 14. doi: 10.1177/104365969600700204

Mhaka-Mutepfa, M., Cumming, R., & Mpofu, E. (2014). Grandparents fostering orphans: Influences of protective factors on their health and well-being. *Health Care for Women International*, *35*, 7–9, 1022–1039, doi: 10.1080/07399332.2014.916294

Mhaka-Mutepfa, M., Mpofu, E., & Cumming, R. (2015). Impact of protective factors on resilience of grandparent carers fostering orphans and non-orphans in Zimbabwe. *Journal of Aging and Health*, *27*(3), 454–479, 10.1177/0898264314551333

Minkler, M., Fuller-Thompson, E., Miller, D., & Driver, D. (1997). Depression in grandparents raising grandchildren: Results of a national longitudinal study. *Archives of Family Medicine, 6*(5), 445–452.

Muga, G. O. & Onyango-Ouma, W. (2009). Changing household composition and food security among the elderly caretakers in rural western Kenya. *Journal of Cross-Cultural Gerontology, 24*(3), 259–72.

Mugisha J. O., Schatz E., Seeley J., & Kowal, P. (2015) Gender perspectives in care provision and care receipt among older people infected and affected by HIV in Uganda. *African Journal of AIDS Research, 14*(2): 159–167.

Muliira, R. S., & Muliira, J. K. (2011). Health-promoting practices and the factors associated with self-reported poor health in caregivers of children orphaned by AIDS in southwest Uganda. *African Journal of AIDS Research, 10*(4), 479–486

Musil C. M. (1998). Health, stress, coping, and social support in grandmother caregivers. *Health Care for Women International 19*, 441–455.

Musil, C. M., Warner, C. B., Zauszniewski, J., Wykle, M., & Standing, T. (2009). Grandmother caregiving, family stress and strain, and depressive symptoms. *Western Journal of Nursing Research, 31*, 389.

Nyasani, E., Sterberg, E., & Smith, H. (2009). Fostering children affected by AIDS in Richards Bay, South Africa: A qualitative study of grandparents' experiences. *African Journal of AIDS Research, 8*(2), 181 192.

Ogunmefun, C., Gilbert, L., & Schatz, E. (2011). Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of Cross-Cultural Gerontology, 26*(1): 85–102. DOI: 10.1007/s10823-010-9129-3.

Petros, S. G. (2011). Use of a mixed methods approach to investigate the support needs of older caregivers to family members affected by HIV and AIDS in South Africa. *Journal of Mixed Methods Research, 6*, 275. doi: 10.1177/1558689811425915

Schatz, E. J. (2007). "Taking care of my own blood": Older women's relationships to their households in rural South Africa. *Scandinavian Journal of Public Health, 69*, 147–154.

Schatz, E., & Gilbert, L. (2014). "My legs affect me a lot ... I can no longer walk to the forest to fetch firewood": Challenges related to health and the performance of daily tasks for older women in a high HIV context. *Health Care for Women International, 35*(7–9), 771–788. http://dx.doi.org/10.1080/07399332.2014.900064

Seeley, J., Kajura, E., Bachengana, C., Okongo, M., Wagner, U., & Mulder, D. (1993): The extended family and support for people with AIDS in a rural population in south west Uganda: A safety net with holes? *AIDS Care, 5* (1), 117

Sefasi, A. P. (2010). Impact of HIV and AIDS on the elderly: A case study of Chiladzulu district. *Malawi Medical Journal, 4*, 101–103.

Shaibu, S. (2013). Experiences of grandmothers caring for orphan grandchildren in Botswana.

Journal of Nursing Scholarship, *45*, 363–370.

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care, 21*(3), 309–314.

Zimmer, Z., & Dayton, J. (2005). Older adults in sub-Saharan Africa living with children and grandchildren. Population Studies, 59(3), 295-312.

CHAPTER 3:

Methodological Considerations

Introduction

The experiences of grandparents who care for their grandchildren affected by HIV/AIDS in the sub-Saharan African context are complex and multifaceted. This phenomenon could have been investigated using any approaches to social inquiry. However, in order to fully understand the contextual experiences and broader issues impacting their experiences, qualitative research was deemed more fitting than a quantitative approach. A review of extant literature described in Chapter 2 revealed that the impact of HIV/AIDS on the role of elderly caregivers had been explored to some extent, but remains superficially understood. The review revealed a great need for rigor in the methodologies used to explore this phenomenon, especially within the African context that is faced with socioeconomic and other environmental adversities. As such, scientific inquiry based upon sound philosophical and methodological underpinnings is crucial to the progression of the research trajectory of this phenomenon.

Philosophical Underpinnings of Scientific Inquiry

Different worldviews frame the philosophical lenses through which researchers see the world, and consequently influence the epistemological questions posed to explore and analyze social phenomena. Quantitative and qualitative methods of exploring and understanding social phenomena are anchored in the philosophical traditions of positivism and naturalism respectively (Denzin & Lincoln, 2005). Therefore, to argue any proposed research method over another, a brief description of these paradigmatic perspectives is noteworthy.

The positivist school of thought is based on the philosophical view that knowledge can only be sought by following objective, observable, deductive and measurable investigation methods, in order to understand a single reality (Guba & Lincon, 1994). This approach to scientific inquiry requires the researcher to start with a more abstract or general hypothesis and then deduce it to a more specific conclusion (Charmaz, 2006). This approach has been the basis of quantitative research methods, which entail the utilization of systematic data collection and analysis techniques and validated tools to minimize bias, maintain objectivity, and promote generalizability or applicability to similar populations (Coughian, Cronin, & Ryan, 2007). Arguably, positivistic approaches to research can also be used in qualitative research, as evidenced by objectivist grounded theorists who take on the role of an objective observer of social reality (Bryant & Charmaz, 2007). Glaser is one of such theorists (1992, 1998, 2001, 2002, 2004, 2005, 2011). However, a post-positivist paradigm shift has allowed researchers' acknowledgement of the impossibility of attaining the total objectivity of positivism while still adhering to its traditional tenets such as the rigorous codification of data and theory development (Charmaz, 2006).

A counter movement to positivism is the naturalistic approach to scientific research, which attempts to accommodate for the complexity and diversity of human experiences (Guba & Lincon, 1994). This approach challenges the conventional positivistic worldview, by acknowledging the dynamic multiple realities of a phenomenon that cannot be easily measured and require subjective involvement of the researcher (Lincoln & Guba, 1985). This approach has also been related to constructivism that assumes that both the researcher and the participants are active co-constructors of reality (Bryant & Charmaz, 2007). However, the naturalistic nature of knowledge acquisition has been adopted by qualitative methodologists who seek in-depth understanding of participants' experiences within the context of their worlds. This inductive approach involves extraction of meaningful categories from dense narrative data so as to further explore a new or poorly understood phenomenon (Charmaz, 2006).

Qualitative Approaches

Qualitative research is distinctively different from quantitative approaches due to its context-bound, person-oriented and non-hypothesis driven nature, which facilitate a holistic scientific inquiry into a phenomenon (Holloway & Wheeler, 2010). Guided by the positivist paradigm, quantitative researchers seek to confirm or reject a hypothesis by predicting and controlling for variables, and examining causal relationships as they perform objective inquiry. However, the inductive nature of qualitative approaches allows the researcher to explore a deeper understanding of participants' experiences from a shared human experience and epistemological point of view (Holloway & Wheeler, 2010). This exploration is conducted via multiple methodological approaches whose data collection and analysis techniques are dictated by the premises of their respective philosophical underpinnings.

Most qualitative methods utilize information-gathering tools such as observation techniques and semi-structured interview guides to elicit thick descriptions of participants' experiences in context of temporal, spatial, cultural, and interpersonal macro and micro dimensions (Bruner, 1986). Researchers immerse themselves in the data and engage in reflective exercises such as journaling, and writing field notes in attempt to capture the nuanced meanings embedded in participant narratives (Charmaz & Mitchell, 1996). Fundamentally, this research approach allows for active involvement and power sharing between the researcher and participant to explore a deeper understanding of the participants' internal worlds. Even though positivistic and quantitative scientists have criticized this co-constructive and subjective nature of the research process, many have argued that qualitative methods are the most effective in providing insight into complex social phenomena (Bruner, 1986). Ultimately, qualitative researchers seek to gain insight into a complex social phenomenon by exploring it in-depth and illuminating participant experiences.

Methodological Approach of Current Dissertation Study

This study was conducted using a qualitative research approach, specifically grounded theory methodology. The phenomenon of grandparents as primary caregivers for grandchildren affected by HIV/AIDS in Uganda and in the sub-Saharan region has been studied using mostly qualitative methods. However, most of the studies reviewed neither explained the appropriateness of adopting a qualitative approach, nor described how methodological rigor was achieved, especially during data collection and analytical processes. Although these studies have identified the general impact of HIV/AIDS on older caregivers, a deeper understanding of how and why is imperative to improving the wellbeing of these older adults. As I explored the epistemological question: "What do we know about the experience of the Ugandan elderly grandmothers caring for children affected by HIV/AIDS?" the complexity of this role called for an inductive mode of inquiry into this phenomenon. Therefore, grounded theory (GT) methodology was utilized in order to allow for a broader and deeper exploration; and analysis of qualitative data to arrive at a theoretic explanation of participants' experiences from a shared human experience and epistemological point of view of the researcher and participant (Holloway & Wheeler, 2010).

Grounded Theory

Unlike other qualitative approaches, grounded theory is a non-hypothesis-driven inductive methodology that follows a rigorous deconstruction and reconstruction of narratives during data collection and analysis to arrive at a theoretical explanation of a specific phenomenon (Bryant & Charmaz, 2007). Either in part or as a whole, grounded theory is the most frequently used qualitative method mainly due to its systematic approach to the analysis of data (Bryant & Charmaz, 2007). It has the advantage of taking findings beyond description to the level of explanation, which provides guidance for designing interventions. The current study was a hybrid of methodological approaches described by Charmaz (2006) and Strauss and Corbin (1990).

Grounded Theory Strategies

Data Collection

As is with all other qualitative research methods, the data collection process was initiated by identification of a specific social phenomenon of interest, followed by the development of a research question and identification of a population of interest. Additionally, specific research procedures were followed:

IRB approval. Research approval was obtained from the Institutional Review Board of the University of California, San Francisco Committee on Human Research and Makerere University College of Health Sciences. Also, the Uganda National Council for Science and Technology granted administrative clearance before data collection commenced. Potential participants provided informed consent and were reminded of the study purpose and assurance of confidentiality as part of ethical protocol as with any other research on human subjects (see Appendix A, Consent Form).

Sample, recruitment, and setting. Study participants were 32 Luganda-speaking grandparent–caregivers (ages 50 years and older) who had been providing care to children affected by HIV/AIDS for at least 6 months. Luganda, the primary researcher’s native language, is commonly spoken in Uganda. Table 1 further describes the characteristics of the current study participants. All participants were residing in Uganda at the time of the interviews. Inclusion criteria of participants required that grandparents would need to be physical functioning and able to perform activities of daily living such as cook, fetch water and firewood, etc. Grandmothers with obvious mental and cognitive disabilities, such as dementia or any form of psychosis were excluded. To select grandparents who could provide relevant responses to the research question, snowball and convenience-sampling techniques were used. In order to provide the study with richer narratives that could represent the diversified perspectives and experiences of grandparents, participants were recruited from both rural areas (i.e., Masaka and Luwero) and urban areas (i.e., Kampala and Busia). These settings included regions that, historically, have been the most affected by the HIV/AIDS epidemic.

Characteristics	**n (%)**
Gender:	
Women	27 (84.4)
Men	5 (15.6)
Age in years (mean: 63.13):	
50-59	14 (43.8)
60-69	9 (28.1)
70-79	5 (15.6)
80-89	3 (9.4)
90-99	1 (3.1)
Marital Status:	
Married	9 (28.1)
Monogamous	6 (66.7)
Polygamous	3 (33.3)
Divorced/Separated	5 (15.6)
Widowed	18 (56.3)
Level of education:	
Primary School	9 (28.1)
Secondary School	1 (3.1)
No education	22 (68.8)
Employment:	
Self employed	4 (12.5)
Day laborer	12 (37.5)
No employment	16 (50)
Setting:	
Rural	12 (37.5)
Urban	20 (23.44)

Table 1: Demographic characteristics of the grandparent-caregivers for children affected by HIVAIDS in Uganda (*N* = 32)

Interview guide and interviewing. For this dissertation study, I sought participants who initially informed the study with their insights on the phenomenon (Glaser & Strauss, 1967). In order to elicit 'thick' narratives (Denzin & Lincoln, 2006) or rich descriptive content from participants, I designed a purpose-guided, open-ended or unstructured interview guide, and used information gathering tools such as audio recorders and notebooks to capture participants' realities as reported (see Appendix B, Interview Guide). During these interviews, I also used participant observation techniques and photographs to further ascertain the details of the narratives. Participants were interviewed in their natural environment (homes or neighborhoods) to enhance the observation process (Bryant & Charmaz, 2007). The recorded interviews were then transcribed and observational field notes were gathered in preparation for the data analysis process, although as guided by Charmaz (2006), both the data collection and analysis process at times occurred simultaneously.

Research Team

The research team consisted of myself, as the primary researcher, the dissertation adviser and chair, Dr. Margaret Wallhagen, dissertation committee members—Drs. Sally Rankin, Carol Dawson-Rose—and mentor Dr. Frieda Outlaw, the Substance Abuse and Mental Health, Minority Fellowship Program executive program consultant. Although I performed the primary research activities such as data collection, analysis, and writing, I worked very closely with the dissertation chair and the rest of the committee to seek methodological and content expertise in aging, caregiving and mental health to further enhance the rigor of the study. I also worked with fellow doctoral students in a writing group that provided feedback on writing and analytic process.

Data Analysis

After transcribing data into Atlas-Ti software, a word processing program that manages the analysis of qualitative data, the data analysis process was performed using different techniques that are unique to grounded theory as a methodology.

Coding. Codes are descriptive words or short phrases that summarize the meanings of the participant narratives, and from which the researcher then builds themes and categories (Saldaña, 2009). As described by Charmaz, 2006, codes are the 'bones' that are then assembled to create a theoretical 'working skeleton' (p. 45). From the depth and thickness of participants' narratives, I used coding to deconstruct data to clusters or units (codes) of meaning that represent the participant's reality (Creswell, 1998). As codes accumulate between participants, their quantity and relationship between each other are tracked within Atlas-Ti. This process aids the researcher in identifying codes that are more salient by their frequency in the narratives and lead the researcher to develop data categories (Saldaña, 2009). However, the coding process was not performed in a linear fashion but rather through a constant comparative process of analyzing data during and throughout the duration of the research (Strauss & Corbin, 1990). As the primary researcher, I coded the data and frequently met with the research team review and discuss the codes and emerging concepts, subcategories and categories. Three major coding strategies were used: open coding, axial coding, and selective coding (Strauss & Corbin, 1990).

Open coding. Open coding, also referred to as 'initial coding' (Charmaz 2006, p. 47-55), is a data analysis process that involves identifying short descriptive summaries and direct salient participant quotes (in vivo codes) from participants' dense narratives, to capture the meanings embedded in the data. This may be done line-by-line, word-by-word, incident-by-incident and at times by full sentences from the narratives (Charmaz, 2006; Strauss & Corbin, 1990). Also, coding was performed using gerunds, such as "accepting loss" or "sacrificing self", in order to preserve actions reported in the narratives, detect emerging processes, and promote theoretic sensitivity. In the current study, the open coding produced a total of 728 codes.

Axial coding. This form of coding is analytic process in which the codes that were previously generated are reconsolidated into new categories according their logical connections to form broader concepts and themes (Glaser, 1992). Following Charmaz (2006)'s guidelines, I identified categories and subcategories and found the relationships between them in attempt to reform the puzzle from the pieces or codes of the narrative structure they were previously dismantled from. For instance, in response to an interview question regarding how grandparent-caregivers assist each other, participant 22_2016-Pa(2Mask) said, *"...If your friend is in the hospital, you have to get a little money and give her something...".* During open coding, meaning was derived from this line as 'social support'. This code was later modified to a category during axial coding as similar narratives pertaining to social support accumulated. In another quote, participant 4_2016-Pa(4Kit) said, *"... God blessed me and one of the oldest grandsons [orphan] grow up...".* This quote was coded as 'spirituality'.

As illustrated in Figure 1 below, the two of categories of *spirituality* and *social support* were related to the concept of caregiving, and their logical connections identified as coping strategies to the broader concept of caregiver burden.

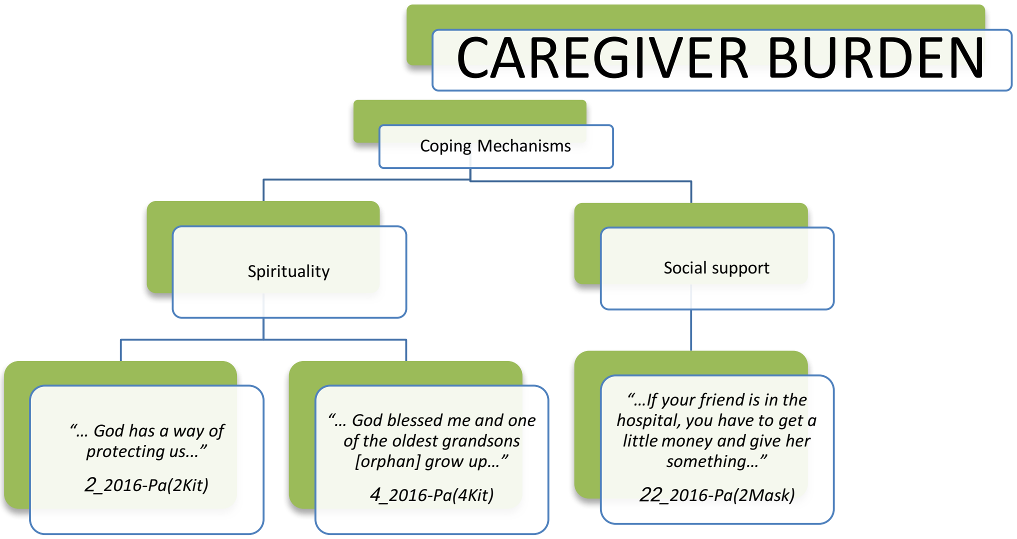
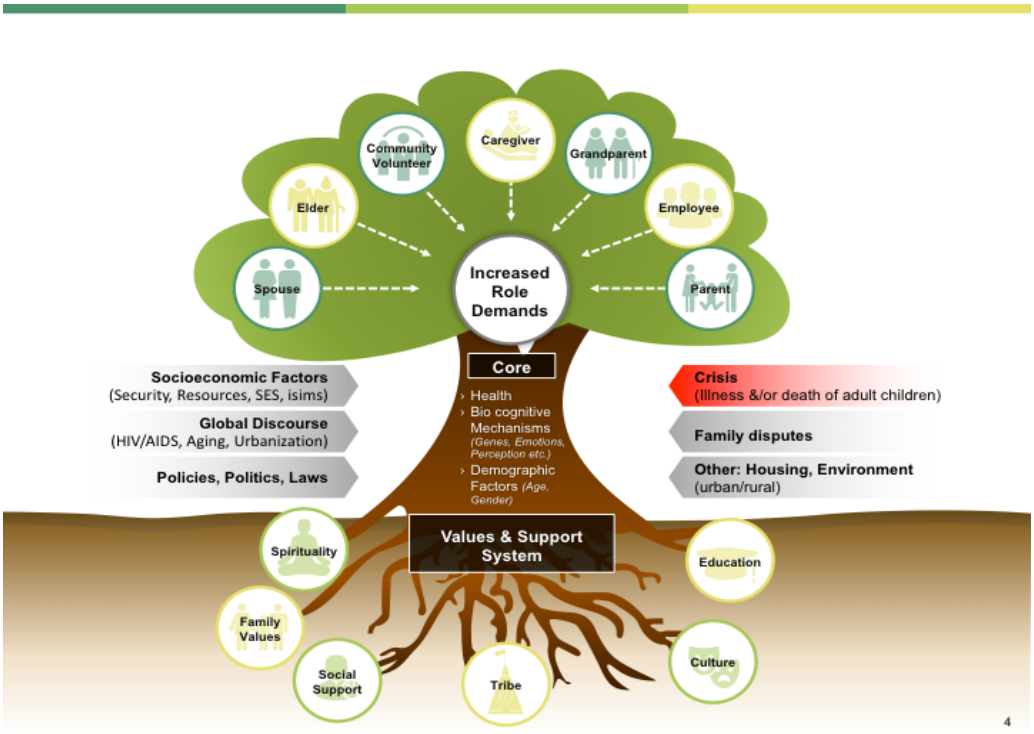


Figure 1: Illustration of data analysis inductive process.

Selective coding. This is another level of coding which is characterized by identification of emerging relationships between the core categories that are then analyzed and related back to the emerging conceptual framework (Strauss & Corbin, 1990). Charmaz (2006) describes this type of coding as "theoretical" (p. 63–66). Through this iterative process between and within new and old interviews, in a constant comparative method that includes the comparison of incidents that collectively define a category; integration of categories by finding similarities between them; and precisely highlighting the relationships between the categories in order to begin writing the theory (Glaser & Strauss, 1967). This strategy allows the researcher to seek out participants who will provide narratives to further confirm and strengthen the salient and emerging categories, a recruitment strategy referred to as theoretical sampling (Glaser & Strauss, 1967). According to these authors, this process would lead to theoretical saturation, a point at which no additional data can be found to contribute to existing or form new categories. For instance, when some of the participants in the urban settings reported their desire to have more land on which to cultivate crops or to expand their accommodations, I sought grandparent–caregivers from rural settings to investigate whether their access to more land improved their experiences. This investigation revealed that rural-dwelling grandparent–caregivers indeed wished they had less land to tend to even though this setting allowed them to, more readily, obtain food for their families for than their urban counterparts. Thus, theoretic sampling further enriched emerging categories and propositions that were then compared and contrasted to determine their salience to the overall evolving story line. Ultimately, this developing story line can be presented in narrative form, as a conceptual diagram, as a list of propositions, or an integration of all three (Charmaz, 2006).

Diagramming. Several grounded theorists believe that utilization of diagrams to illustrate "the relative, power, scope, and direction of the categories in the emerging theory is an integral element of analytic process" (Charmaz, 2006, p. 118). For instance, as part of the data analysis process of the current study, synthesis of emerging and dynamic relationships between the concepts, themes and categories inspired the conceptual tree in Figure 2 (below).



**Original design by Anthony Lagony©*

Figure 2: Conceptual tree illustrating the relationships among emerging themes.

Memoing. Alongside coding, memoing was used as a key methodological aspect of grounded theory. Charmaz (2006) describes memos as analytic locations where researchers are mostly fully present. This implies that the memoing exercise requires the researcher to be fully aware of the meanings emerging out of the data and reflect on them. During data collection and analysis processes, I paused frequently and intermittently to annotate thoughts and ideas about the emergent categories and general storyline (Charmaz, 2006). The two types of memoing used were reflexive and analytic memos (Bryant & Charmaz, 2007). Reflexive memos are the researcher's self-reflection on the data, participants and or their worlds. Analytic memos are 'questions, musings or speculations' (Creswell, 2007, p. 290) used to analyze developing and or complex concepts that seemed to be more salient than others during coding or other levels of analysis. A point in case, the concept of loss emerged as salient code and evolved into a category. In order to further examine this concept, I used analytic memos and feedback from the rest of the research team and writing group of doctoral students to further explore and refine the dimensions of loss that were reported in the narratives. Therefore, both coding and memoing follow an iterative process in which the former allows for the data to metaphorically speak to the researcher, and for the researcher to self-reflect on the data (Bryant & Charmaz, 2007).

Rigor in Grounded Theory

Researchers have grappled with the rigorous nature of qualitative research while some have criticized its analytic procedures. However, unlike quantitative research that demonstrates rigor through the objectivity of the researcher and validity and reliability of the design methods used, qualitative researchers demonstrate this rigor or trustworthiness through credibility or faithfulness to the research phenomenon; dependability or auditability, transferability or fittingness of study findings; confirmability; and goodness or authenticity of the research (Ryan, Coughlan & Cronin, 2007). Researchers have encouraged the utilization of tools or elements to aid their analytic process and ensure rigor in grounded theory. These elements include theoretical sensitivity and saturation, reflexivity and relationality (Charmaz, 2006; Hall & Callery, 2001).

Theoretical Sensitivity

As a means of ensuring rigor in this grounded theory, I practiced theoretical sensitivity (Glaser & Strauss, 1967). Glaser and Strauss define this as the researcher's ability to 'conceptualize and formulate a theory as it emerges from the data' (Glaser & Strauss, 1967, p. 46). The researcher's background and research experience allows them to be conversant of the meanings and relationships amongst the concepts of the emerging theory and storyline of the phenomenon. However, Glaser and Strauss warn against researchers entering the study setting with preconceived ideologies that may contaminate their judgment and conversance of the emerging theory. Therefore, using reflexive memos to acknowledge my own biases and preconceived ideas, I practiced heightened theoretical sensitivity to further enhance the rigor and hence the credibility of the study.

Reflexivity

According to Hertz (1997), reflexivity is a heightened awareness of the “self” in relation to the data. This exercise requires the researcher to detach from the data, internalize dialogue and intensively scrutinize one’s own ideologies and how they may inform the research process. Reinharz (1997) corroborates that the self could be in the form of the “research-based self,” who is informed by research knowledge and process to collect data, or a “brought self” or researcher’s role in the world, for instance mother or wife. Lastly, Reinharz (1997) describes another self as “*situationally created*” by being; for example, “being chronically exhausted” or “being a resident” (p. 5-6). I exercised this critical analysis using memoing to reflect on my own authentic self and the personal attributes that may influence the research findings. For instance, having been raised by my grandmother I reflected on my own upbringing and experiences that I then identified as a single reality separate from that narrated by those of the study participants. This acknowledgment of my positionality and constant interaction with the research team and peers who occasionally challenged my pre-perceived ideas allowed me to refine my analysis; prevented the imposition of my beliefs and assumptions on the emerging data (Charmaz, 2006); and further enhanced the dependability, trustworthiness and credibility and hence rigor of the study (Ryan et al., 2007).

Relationality

Underpinned by Symbolic interaction and pragmatism or openness to multiple interpretations of grounded theory (Bryant & Charmaz, 2007), relationality recognizes the connectedness between the investigator and the participant (Hall & Callery, 2001). Hall and Callery (2001) underscore the moral obligation of investigators to commit to the studied populations by developing relationships and community-based interventions with them. They also emphasize the need for researchers to use their study findings to advocate for the studied populations by seeking out opportunities to inform other disciplines such as those within policy or health sectors. In doing so, the research circle will be completed by initiation of social change to better the lives of the participants. It is with this same approach that I intend to use the preliminary qualitative data of the current study to advance my research trajectory in ways that will continue to advocate for grandparent–caregivers.

Discussion

The cultural diversity of the African continent, Uganda in particular, and the dynamic nature of the family structure as it pertains to the caring giving experiences of Ugandan grandparent-caregivers for grandchildren affected by HIV/AIDS warranted investigation of the phenomenon with methodological rigor. This chapter provided a detailed account of the philosophical and methodological underpinnings and of rationale for choosing a qualitative over quantitative approaches, particularly grounded theory to investigate the caregiving experiences of the grandparent-caregivers. In a diverse cultural setting that lacks key conceptual definitions in the extant body of literature on caregiving, utilization of grounded theory in the current study allowed for a broader exploration and analysis of emerging salient themes and thick description and explanation of these concepts and their relationships. Because I knew of no studies that used grounded theory to investigate caregiving as experienced by grandparent-caregivers, this gap was filled, particularly as it relates to the development of a theoretic framework that explains the conceptual or experiential complexities of this phenomenon (see the Matovu GRACE model presented on p. 148 of this dissertation). As I exercised reflexivity, relationality, and theoretical sensitivity, I hope to have been able to contribute to a better understanding of the experiences of caregiving among grandparents, with the intent to advance the knowledge base and contributing to the discourse surrounding this phenomenon from merely descriptive to explanatory theoretical framework development and eventually to interventional studies.

References

Bruner, J. (1986). *Actual minds: possible worlds.* Cambridge, MA: Harvard University Press.

Bryant, A., & Charmaz, K. (2007). Grounded theory research: Methods and practices. In A. Bryant & K. Charmaz (Eds.), *The sage handbook of grounded theory* (pp. 1-29). London: Sage Publications Limited.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Charmaz, K., & Mitchell, R. G. (1996). The myth of silent authorship: Self, substance, and style in ethnographic writing. *Symbolic Interaction*, *19*(4), 285-302.

Coughlan, M., Cronin, P., & Ryan, F. (2007). Step-by-step guide to critiquing research. Part 1: quantitative research. *British Journal of Nursing, 16*(11), 658-663.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage.

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 1–32). Thousand Oaks, CA: Sage.

Glaser, B. G. (1992). *Basics of grounded theory analysis.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussions.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2001). *The grounded theory perspective: Conceptualisation contrasted with* *description.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2002). *Constructivist grounded theory? Forum: Qualitative Social Research.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2004). *Naturalist inquiry and grounded theory. Forum: Qualitative Social Research.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2005). *The grounded theory perspective III: Theoretical coding.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2011). *Getting out of the data: Grounded theory conceptualisation.* Mill Vallye, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research: Theories and issues. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage.

Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research*, *11*, 257–272.

Hertz, R. (Ed.). (1997). *Reflexivity and Voice*. Thousand Oaks CA: Sage.

Holloway, I., & Wheeler, S. (2010). *Qualitative Research in Nursing and Healthcare*. Oxford: Blackwell.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Reinharz, S. (1997). Who Am I? The Need for a Variety of Selves in the Field. In R. Hertz (Ed.), *Reflexivity and Voice* (pp. 3–20). Thousand Oaks CA: Sage.

Ryan, F., Coughlan, M., & Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing, 16*(12), 738-744.

Saldaña, J. (2009). *The coding manual for qualitative researchers*. London: Sage.

Strauss, A., & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* Newbury Park, CA: Sage.

CHAPTER 4:

Understanding the Socioeconomic and Cultural Contexts of Caregiving by Ugandan Grandparents

Introduction

Research has shown that caring for ill loved ones can be stressful and can have adverse health outcomes for the caregiver. In sub-Saharan Africa, however, the HIV/AIDS pandemic substantially compounds this challenge in that older adults are caring for orphaned grandchildren, who themselves may be infected. According to a current United Nations report, sub-Saharan Africa remains the most affected region worldwide, with 23.5 million people living with HIV (out of 36.7 million globally), and having experienced an average of 800,000 AIDS-related deaths (out of 1.1 million globally) as of 2015 (UNAIDS, 2016). In that UNAIDS report, Uganda has had an estimated 28,000 deaths due to AIDS; these deaths created approximately 660,000 orphans (UNAIDS, 2016).

As HIV/AIDS has continued to claim the lives of adult children, surviving parents and other extended family members—such as stepparents, older orphans, and aunts and uncles—have stepped forward to care for the children orphaned by the disease. Chief among these caregivers are the orphaned children's grandparents, who in most commonly assume responsibility for the children's care, upbringing, and well-being (Clark, 2006; Kasedde, Doyle, Seeley & Ross, 2014; Merli & Palloni, 2006). These older adults take on this labor of love, whether by choice or because of various cultural and social circumstances, and usually with very limited resources (Kamya & Poindexter, 2009; Muga & Onyango-Ouma, 2009; Schatz, 2007; Ssengozi, 2009). Yet despite the acknowledgement that these grandparents serve as the safety net, they remain invisible, especially since multinational initiatives, similar to the United Nation's Sustainable Development Goals (SDGs-UN, 2016), continue to address overarching dimensions of vulnerability such as decreasing poverty or eliminating the HIV/AIDS epidemic.

Unfortunately, few researchers have examined the phenomenon of this grandparental caregiving beyond exploratory findings. There is need to get a deeper and broader understanding of the caregiving role's effects and ramifications, especially as they pertain to health of these grandparent-caregivers. Indeed, in some studies of the relevant body of literature, the grandparents themselves have remained an invisible generation. To better understand the experiences and mental health of the Ugandan grandparents who provide primary care for grandchildren affected by HIV/AIDS, we conducted a grounded theory study, the findings of which are presented in this dissertation.

Key Terms

The interviews were based on the study's aforementioned research question regarding the grandparents' experience in caring for orphaned grandchildren affected HIV/AIDS. From these interviews, several diverse concept of caregiving emerged from the grandparents' descriptions of their experience. Before discussing the current study's emergent themes and subcategories, we note that as a general concept, caregiving has been studied in numerous populations, either with regard to the formal care of individuals by others or with regard to informal care provided by family members to other family members (Brodaty & Donkin, 2009; Feaster, 2011). In some of these investigations, the term *caregiving* has been used with reference to grandparents providing care for their grandchildren, and hence often been used interchangeably with the term *grandparenting*. Given this semantic ambiguity, and the present study's objective of gaining a more accurate depiction of the grandparents' conceptions of caregiving, it was necessary to gain a clearer understanding of the distinctions between "caregiving" and "grandparenting" as described by the study's participants.

Grandparenting vs. Caregiving

As noted from the participant responses, the Luganda language has no linguistic concept that is equivalent to “grandparenting.” However, when the participants were prompted to define what being a grandparent meant, their descriptions were found to be based on both a biological relationship with grandchildren and the perceived roles and responsibilities they felt in relation to their grandchildren. In contrast, “caregiving” was described as acts of caring, helping, welcoming, nurturing, and attending to the needs of others. This definition of caregiving is synonymous to that of the *Oxford English Dictionary* (2014), which describes *caregiving* as a compound word composed of two words: *care*, "the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something" and *giving/give*, “cause someone to have, get, or experience something”, (p. 305). For the purpose of this paper, the term “caregiving” will be used to refer to the acts of providing care to others by these older adult grandparents.

Care Recipients

The grandparent–grandchildren relationships were complex. Some of the children under the care of these older adults were not the caregivers’ biological grandchildren, although the majority were. This finding is congruent with that of Boon et al. (2010) and others. Other care recipients included nieces, nephews, and in some instances non-relative children of friends or neighbors. The grandchildren’s ages ranged from a few days old to 30 years, and their needs varied accordingly. In the household, the grandparents also cared for their biological children, whose ages ranged from 10 to 65 years of age.

Typically, in a grandparent household, the number of orphaned and non-orphaned grandchildren exceeded the number of other family members. When participants were asked whether they considered themselves the primary caregivers to all members of their household, their affirmative response confirmed their perceived role and responsibility for providing for the care recipients. The findings indicate that the caregiving role was defined by both the hierarchical role of these elders as heads of the family its inherent responsibility to attend to the needs of their care recipients.

Characteristics	**n (%)**
Gender:	
Women	27 (84.4)
Men	5 (15.6)
Age in years (mean: 63.13):	
50-59	14 (43.8)
60-69	9 (28.1)
70-79	5 (15.6)
80-89	3 (9.4)
90-99	1 (3.1)
Marital Status:	
Married	9 (28.1)
Monogamous	6 (66.7)
Polygamous	3 (33.3)
Divorced/Separated	5 (15.6)
Widowed	18 (56.3)
Level of education:	
Primary School	9 (28.1)
Secondary School	1 (3.1)
No education	22 (68.8)
Employment:	
Self employed	4 (12.5)
Day laborer	12 (37.5)
No employment	16 (50)
Setting:	
Rural	12 (37.5)
Urban	20 (23.44)

Table 1: Demographic characteristics of the grandparent-caregivers for children affected by HIVAIDS in Uganda (*n* = 32).

Findings

Overall, the study findings revealed that the concept of caregiving as performed by these Uganda grandparents is contextualized by antecedents of caregiving, decision-making processes, and consequences (burdens, rewards, finding balance). Therefore, the current study's findings will be presented under those three categories that emerged from the analytic process described in chapter 3 of this dissertation.

Antecedents of Caregiving

The grandparent-caregiver narratives revealed two major reasons or factors that preceded the assumption of care for their grandchildren.

Poor health and/or death of children's parents. The majority of these grandchildren had been orphaned by HIV/AIDS or other illness that rendered them dependent on their grandparents:

10_2016-Pa-m(3Bus):

> Pa: . . . Both my boys' children are with me. He [adult son] decided to leave them with me because . . . and he had also contracted "this disease" [HIV] so when the situation got tough, he said, "Father, I can't manage." And so he decided to go away to try to make it somehow, so I remained with the children.

7_2016-Pa(7Kit):

> Pa: Three belong to my son that died of sugar [diabetes]. . . . One of the grandchildren belongs to my deceased daughter that died of "this disease" [HIV/AIDS]; she left just one child. Two belong to another son who was a builder but was pierced by a metal so is bedridden now. He fell from the house and fell on the metal that went through his foot.

Poor socioeconomic status. Secondly, and also relative to the impact of these illnesses, the present study's findings indicated that the role of caregiving was also assumed by these older adults as a result of their adult children's inability to care for their children—due to a lack of physical, financial, or other form of family stability. As noted,

9_2016-Pa(2Bus):

> Pa: . . . two of the [adult] children said to me, 'mom, keep the children and we will go and figure out [money] and if we get something, we will help you out.' And of course some go at times but things don't work out for them when things don't go well, or they don't get jobs. ...They get a little money for a while but then if they [lose jobs] and things get tough then they try to find other similar [odd] jobs or else I persevere with them [grandchildren]...

Also, the poor health, disability or other aging challenges faced by these older adults motivated them to seek out, or the adult children to offer, the grandchildren as caregivers to their grandparents (see grandparent characteristics in Table 1 above). This role reciprocity will be discussed later in this chapter.

However, equally important as the caregiving antecedents is the decision-making process, or lack of, culminating in the caregiving role and related responsibilities.

Decision-making Process

For the majority of these grandparents, the decision to take on the grandchildren care was made for them directly by others, by significant circumstances, or indirectly as predetermined by familial, gender, and/or sociocultural expectations. Therefore, these factors that influenced the decision-making process fell under the categories of *"Culture, gender and family expectations*," "*The default caregiver,"* and *"Negotiation*."

Culture, gender and family expectations. For example, in most of Ugandan tribes, the paternal family—the family to which the children were believed to belong—was predominant in determining where the orphans or other children were fostered after the death or inability of their parents to care for them (Kasedde, Doyle, Seeley & Ross, 2014). Thus, in the Baganda tribe, to which the majority of the participants belonged, paternal grandparents, particularly grandmothers, were the designated caregivers and homemakers of their families (MacNeil, 1996).

1_2016-Pa(1Kit): (Paternal grandmother)

> Pa: They go to visit [their maternal family] at times but since I am their father's mother, and am still alive, so they try hard to come back to me.

17_2016-Pa-m(10Bus): (Paternal grandmother)

> Pa: . . . And of course they may have two families; yours and their clan but yours is the biggest clan because they belong to you.

3_2016-Pa(3Kit): (Maternal grandmother)

> Pa: Yes, that is what we women do. Who are you going to throw them out to? When they grow up, they belong to the other clan [paternal side] but while young, they belong to us. They say, "Bring them, you stole our children."

13_2016-Pa-m(6Bus):

> Pa: . . . Remember as the saying goes, 'a woman is never done with being a parent.' So that is the case with us with grandchildren, ... when the adult children die at any time, that means that you have to immediately take over.

However, this study revealed that these pre-established cultural roles could be superseded, especially in the absence of anyone else to care for the children or other extenuating circumstances:

1_2016-Pa(1Kit):

> Pa: . . . [Y]ou see for the girl, her husband’s father had died and then the mother died too so they didn’t have anywhere else to go but to come to my side.

5_2016-Pa(5Kit):

> Pa: . . . See, the husband was an only child, poor man. So with the paternal grandmother away at the lake working, who would take care of them? So I had to be there for them. How can I turn away my child’s children? Besides, she hasn’t bought a plot of land to build her own house for the children so I have to live with them.

28_2016-Pa(2Luw)*:

> Pa: As for my son’s children, the paternal side was full of drunkards so I was forced to keep them with me instead of leaving them there.

With other family arrangements in which participants cared for relatives’ children (e.g., nieces or younger siblings), the grandparents’ normative beliefs, hierarchies, and practices as part of their cultural identity also played a big part in the decision of taking on the caregiving role. As the elders in the family, some of these participants bore the honor and burden of caring for their nieces and nephews because within their extended family, the study participants were the only surviving elders:

2_2016-Pa(2Kit):

> Pa: We were born only two of us in my family, my brother and I. I was the oldest. So when he got sick, I was all by myself since the children were all working in different districts far away from home. Since I didn’t want to be alone, and he was getting sick so we decided he comes live with me until he died and left the children with me.

Participants also reported that family members would request them to care for their children regardless of whether they were financially or otherwise capable of fulfilling this role:

30_2016-Pa(4Luw)*:

> Pa: As for my brother’s children, he asked me to promise him that I would raise his children until they were grown. When he died, his first daughter also got sick and I took care of her and nursed her until she died. I took her to [hospital] but it all failed. She too asked me to take care of her children. She said, “Auntie, I am going to die so please take care of my children.” I asked her, “How am I going to manage to take care of these children in my situation?” and she replied, “You will manage just like you did with me.”

In addition, some participants in the urban settings were perceived by their rural-dwelling extended family as more financially stable and hence more suitable to take in these children:

15_2016-Pa(8Bus):

> Pa: They are in the village. My mother and father are there but . . . the boys [brothers] were supposed to be there and help them but they are all dead and so they are on their own. My sisters are also married in the village but of course are all looking at me because I am in the city. When any problem arises, they say, “Call her, call her,” and yet I am also doing badly.

Frequently, however, these grandparents made a conscious decision to care for the children either to preserve the memory of their deceased loved ones or as a cultural obligation to take care of their own “blood” and keep the family unit intact:

8_2016-Pa-m(1Bus):

> Pa: They had to come live with me because all my siblings are long gone; including my sisters. So they had to live with me for me to protect them. I can’t keep them out; this is my blood [laugh].

9_2016-Pa(2Bus):

> Pa: . . . My situation is not very good but I persist with them because there is nothing else to . . . . [T]hey are mine and they are my blood so I don’t have anything to do about that. That is how I am surviving.

In fact, some participants took this role as earnestly as they would a primary parental role of caring for these children as their own—including having to breastfeed infant grandchildren.

As evidenced by the candid testament of 21_2016-Pa(1Mask) below, the duration of this caregiving relationship with the grandchildren and the age at which the care was initiated led some participants to perceive that their role was paramount to that of biological parents:

21_2016-Pa(1Mask):

> Pa: So your grandmother takes care of you like your mother would. In fact she may even do better than the mother in some cases. The mother can abandon the child but a grandmother can't do that, no. That can't happen, so one's grandparent is a very important person.

The default caregiver. As revealed by some of these grandparent–caregivers, the caregiving role defaulted to them because the grandchildren were already living in the grandparent-headed extended families during the parents' convalescence or at the times of death or disability:

2_2016-Pa(2Kit):

> Pa: See, I have always had the grandkids around, especially the one I picked up from their parents. But they are now more.

24_2016-Pa(4Mask)

> Pa: Their father was working [in a nearby town] and was planning to build a home for him and the children. So I kept the children until he would finish the house. But then he started getting sick and so I stayed with him and the children until he died.

The perception that no one else was available to care for the children after the death of their parents was a frequent theme in this study—a perception that caused these grandparents immense distress. It was a decision determined by fate. For some of these children, most of whom were orphaned, the grandparents were the only parents that the children had ever known; the children had no other family or relatives. Accordingly, without other potential caregivers, these older adults became the provisional parents:

23_2016-Pa (3 Mask):

> Pa: It means that you are the one that has to take care of them . . . [W]hat else can you do? You are the one left, after they all died . . . .[Y]ou are all that they see.

13_2016-Pa-m(6Bus):

> Pa: You see they were in [place] and this mother-in-law had lost a lot of children, and so I decided to bring the child because there was no one in particular taking care of this child.

Negotiation. Before commencement of the caregiving responsibility, some of the grandparents reported to have been involved in some form negotiation with their adult children or other relatives. For instance, some grandparents attempted to secure a promise of financial support from their adult children:

27_2016-Pa-m(1Luw)*:

> Pa: . . . I started with caring for my own children. The children then moved out and started their lives and found partners with home they had children. But due to their circumstances . . . you know . . . these young ladies, their wives, are very complicated. So they start fighting and becoming disruptive and my sons come to me and say, “Father, can I bring this child to you because this woman did this and that.” So I say, “Well, you know what my situation is like, I don’t have money. So how do you expect me to manage taking care of your child?” Then he says, “We will figure something out." But of course when they bring the child, they abandon them and take months before they return again.

Unfortunately, these adult children often failed to follow through with their promises—unintentionally or intentionally:

18_2016-Pa (11Bus):

> Pa: The biggest problem is that of not having anyone else to help me; I have to do it all by myself. Even when I try to ask for help from the girls [adult children], especially the mother to the children. ; I called her the other day all she said was, “Mother I will look for money and send you some soon.” But I have not seen anything since then. So I don’t know what to do at times.

This predicament of unmet promises was also perceived by the grandparent-caregivers as a deliberate abandonment and lack of accountability for these children by their parents:

14_2016-Pa(7Bus):

> Pa: Well the father [son-in-law] refused to take the children. He married another woman and she refused to keep another woman's children. The father lives close by but he refused.
>
> I: Wow! So was there any kind of discussion to have him take the children and he said, "No"?
>
> Pa: Yes we tried and in fact tried to take him to Probation [child support services] and he promised to take care of the children but he ultimately refused. So it is all on me. Even school. I try to ensure that they go to school but at times I fail and they stay home until I get money to take them back to school.

Thus, irrespective of physical and or financial capabilities, a cultural and gender expectation inherently predisposed these older adults to assume the caregiving role. And with that role came both negative and positive consequences.

Consequences of Caregiving

Caregiver Burden

Regardless of the reason for embarking on this caregiving responsibility, these older adults were forced by their unique circumstances to devise ways to fulfill it, even when they had barely any resources or external support. The grandparents described some of the component activities of caregiving as being positive and other components as being negative. The positive aspects of this role and responsibilities included loving, nurturing, protecting, assisting, providing, and attending to the care recipient. However, despite these positive attributes, participants reported overwhelming caregiver burden. According to Chou (2000) caregiver burden is defined as an individual's subjective perception of overload in one or more of four perspectives: physical, psychological, social, and financial.

Physical burden. The grandparent–caregivers in our study reported taking on a variety of responsibilities and engaging in often strenuous activities in order to provide for their grandchildren and general households. Although they would have engaged in some of these activities independent of the caregiving role, the grandparents' felt commitment to pursue and fulfill these endeavors with such exertion was made more urgent and inevitable by the additional caregiver burden. Participants' daily routines somewhat varied depending on whether they lived in urban or rural settings. For example, for most of the rural-dwelling participants and for a few of the urban-dwelling participants, this routine began at dawn with preparation of their grandchildren to go to school. The grandparents would then prepare breakfast for the grandchildren and for other family members who remained at home (e.g., elderly spouses and parents). The grandparents then set out to go to their gardens, where they grew produce either for their household consumption or to sell.

For some, their gardens were long distances from their residences. They spent an average of 5 hours daily tilling land, clearing bushes, weeding, and planting crops. Upon returning home from their gardens, the grandparents would prepare a single daily meal upon which most of these participants and their families often depended. Grandparents who cared for infant grandchildren had to provide even more hands-on care—such as breastfeeding, bathing, and washing clothes. For many of these caregivers, the care they provided was multigenerational: in addition to infant and child care, these grandparents provided care to their ailing adult children and to their own elderly parents.

For most of the urban cohort, the daily routine began as early as that of their rural counterparts as they set out to search for jobs as day laborers or temporary workers at construction sites, peddlers of produce or used clothing, household help, or workers in commercial places such as restaurants. At the end of their workday, they too would return home to prepare the evening meal for their families and attend to other household duties. For some of the participants, the routines of work within and outside of the home were similar regardless of gender. However, most of the two-grandparent households followed traditional norms: grandfathers worked outside of the homes to generate income for their families while the grandmothers stayed home to perform household chores. In those cases, neither the grandmothers nor the grandfathers viewed the homemaker role as a "job"—even though the homemaker role involved rigorous activities such as fetching firewood, carrying heavy cans of water from wells, or carrying loads of grass to feed their livestock.

When interviewed about their responsibilities and chores, the majority of the participants spoke candidly of the strenuous nature and conditions of their jobs. These grandparents were in constant pursuit of ways to sustain their large families by finding food—most often, through long hours of farming under the scorching sun or by peddling goods in the villages to earn money to support the family. Many participants described performing intense manual labor (e.g., digging trenches and pit latrines or carrying heavy loads) without a break for periods of several hours or working under extreme weather conditions:

10_2016-Pa-m(3Bus):

> Pa: …mostly I dig holes [in the ground] for a living, as you can see from my hands [shows palms]. I dig latrines, boreholes and ditches. … I usually wake up about 6am and I have to start work between 7am and 7:30pm if I have one. And you

> know when we dig, the stones at the bottom are usually very dusty which makes us cough a lot. We get off work about 6pm, by which time you can't really go anywhere since it is a very strenuous job. So after bathing, I sit down and finally rest.

23_2016-Pa(3Mask):

> Pa: I go to fetch the elephant grass that I grow and also find regular grass for [the cow]. And of course since the children are in school, I have to carry the heavy load on my head. And whenever I carry that on my head, I feel like my heart is swelling up and very painful. So most times I cut the grass and fetch a little bit of it at a time. And of course since my [elderly] husband doesn't have the energy to do that, he stays at home and chops up the grass and feeds the cows as I fetch more grass.

Given such responsibilities and chores, it is not surprising that almost all of the study participants reported several physical complaints and ailments such as chronic back, leg, and musculoskeletal pain and other complications potentially caused by these demands of manual labor:

26_2016-Pa(6Mask):

> Pa: The illnesses . . . . I started off with swelling of these muscles [neck]. . . I can barely bend to dig or wash clothes. After that, I started coughing a lot, without anything coming out, but eventually I started coughing them up [productive cough]. So I had [an X-ray] done and they told me that I had asthma... The next problem became my legs and my back. The illnesses were increasing, you see. Next, I started having chest pains. ... This causes me to feel very weak in the legs and all over my body. If it happens when I am walking or in the garden digging, I have to sit down right away. And once am down, at times I feel like I can't get up.

Financial burden. The majority of the chores and responsibilities described above were performed to meet household financial obligations. These participants described financial burdens of securing money for household basic needs such as food, soap, sugar, and clothing, as well as for medical costs, housing, and children's educational expenses. Although some grandparent–caregivers relied on their adult children and other family members and friends to provide minimal and sporadic financial support, some lacked such support—especially those who had lost multiple adult children or spouses. Furthermore, most of the married participants received little-to-no financial support from spouses, often as a result of the spouses' illnesses or polygamous lifestyles. Therefore, the grandparent–caregivers bore this individual financial burden in order to provide for their household—and they did so in the context of prevailing national socioeconomic challenges.

4_2016-Pa(4Kit):

> Pa: The house is Shs. 70,000. [approx . . . $21]. In fact as I speak, I owe them four months. Besides, I am very sickly which could be due to all the worrying. Because one of my children was shot too and the other two died of "this disease"[AIDS] and they all left me their children who in turn had children. So the job was left for me.

The odd jobs described above were typically the most viable sources of income, but many of these jobs were only temporary. The urban cohort reported having a greater variety of odd jobs than did their rural counterparts; for most of the latter, farming was the only source of income. Some grandparents supplemented household income and food with additional jobs such as raising a few livestock. Some older adults also described ageist discriminatory hiring practices that precluded their employment. This unwillingness of potential employers to hire a *'jajja'* [grandma/grandpa], since it would be considered disrespectful to give orders to an elder, further constrained the grandparents' job prospects as. For example,

6_2016-Pa(6Kit):

> Pa: So I just can't go to anyone and ask him or her to stay with them and work [as house help] because you wouldn't want to send jajja [grandma] around. So that is the problem we have as old people.

Therefore, as a result of these financial challenges, most of the grandparents were forced to persist in subsistence farming, despite its physical hardships and related food insecurity (mainly caused by pest infestations and droughts that were reported in all the study settings). A smaller percentage of the grandparents resorted to seeking assistance from family members and their community.

Emotional burden. In the present study, the physical burden of the grandparents' caregiving role was in many instances accompanied by a substantial emotional burden.

Emotional burden pertaining to orphan care. Many participants described great distress stemming from the normal but substantial requirements of childrearing: for example, the need to pay educational fees to put their grandchildren through school. However, in addition to these typical challenges, many of the study participants reported that their orphaned grandchildren were unusually difficult to care for—for example, exhibiting defiance and other problematic behaviors that may be less commonly encountered with non-orphaned children or children of earlier generations. Notably, the problematic behaviors described by grandparents in our present study were similar to those of children orphaned by HIV/AIDS who have been described in other studies (Hayslip, Shore, Henderson, & Lambert, 1998). Finally, the burden of caring for grandchildren who were themselves infected with HIV was particularly acute. In accordance with what was described by Vaz, Eng, Maman, Tshikandu & Behets, (2010), some participants in the present study reported the emotional challenge of having to disclose the HIV-status to their infected grandchildren.

In general, when asked to compare parenting of their biological children and that of their grandchildren, participants were unanimous in reporting that the grandchildren were more difficult. In this regard, participants referred to "changing times" as a dynamic and generational state of affairs that negatively affected their lives and undermined their parenting efforts. For example, they cited grandchildren as being more disobedient, despising and lazy as Participant 26_2016-Pa(6Mask) explained:

> Pa: [Grandchildren are not] as obedient as my children were. They [biological children] would tell me where they were going to play or who they were meeting up with and you would also tell them yes or no, ... but these ones just disappear and you have to look all over for . . . . You show them the truth and they don't accept it . . . [T]hey despise you. They don't want to work as hard as their parents did ... You may ask him to wash your clothes and he says, "I will wash them tomorrow," and of course he never does. So all that makes it harder on us.

In concert with this description by participant 26_2016-Pa(6Mask) above, most older adults reported that caring for these grandchildren adversely affected their health. The grandparents also said that these parenting challenges—encountered at a stage in their lives when they were supposed to be retired from an active parenting role—appeared to be a source of additional distress. Nonetheless, these grandparents also reported a few rewards and coping mechanisms that somewhat alleviated their caregiving burden.

Emotional burden pertaining to care of other family members. In addition to the distress associated with their care of orphaned grandchildren, participants in our study described three types of distress that were associated with their care of other family members. First was distress associated with the illnesses of multiple adult children, spouses, and other family members. Second was the still greater suffering that came from the eventual demise of these adult family members. Third and ultimately, the participants described having to cope with the aftermath stages of grief while simultaneously assuming the emotional burden related to caring for their adult children's orphans. Indeed, for many grandparent–caregivers who also lacked resources, the magnitude of their cumulative psychosocial distress was insurmountable.

24_2016-Pa(4Mask):

Pa: That one, she is five but she is very sickly [HIV- infected] as you can see with her legs . . . . I am really struggling with her. I don't know if she is going to be permanently crippled but [her legs] are getting more and more deformed every day . . . . [S]he complains of pain in the legs and get fevers after walking back from school.

Rewards

For the older adult caregivers in our study, the rewards of their efforts were threefold: in role reciprocity, in personal satisfaction, and in meaning.

Role reciprocity. The symbiotic relationship between grandparents and their grandchildren in the context of caregiving has been reported in earlier research (Mugisha, Schatz, Seeley & Kowal, 2015). For aging grandparents, the responsibility of caring for their grandchildren may be welcomed, partially because of the grandparents' need for assistance with chores and the companionship that was expected of and rendered by the grandchildren. Besides, some of the grandparents disclosed their HIV status as positive and hindering their physical functioning and performance of activities of daily living that the grandchildren assisted them with. Of course grandchildren who attended school did not frequently assist with chores. Researchers such as Skovdal (2010) have pointed to the importance of the orphans' contributions to the practical well-being of their fostering households. Indeed, the present study confirmed that grandchildren were able to assist their grandparents with household chores such as fetching firewood and water, cooking, and farming, among other activities:

30_2016-Pa(4Luw)*:

Pa: ... [Grandchildren] assist me with some chores like cooking food, making my bed, washing my clothes and fetching water, especially since the well is very far from here. Besides, being alone in the home is not good because when you are used to having people in the home, you don't want to stay alone.

Participant 30_2016-Pa(4Luw)* above concludes with a critical tension between burden and reward that will be discussed shortly.

Personal satisfaction. Furthermore, participants described their experience as one of pride, joy, and satisfaction in caring for the grandchildren in memory of their lost loved ones:

25_2016-Pa(5Mask):

> Pa: Being one's grandparent means that you have the responsibility to love your grandchildren as much as you loved your own child that birthed them. And so I tell myself, "Granted they [adult children] died but I can still see them [through the grandchildren]. That makes me very happy. They died, and that is the final destiny but when I look at my grandchildren, I see my own children in them."

Also, as elders in their families, the participants welcomed the honorable obligation of bestowing wisdom to their children and grandchildren to prepare them for a successful future. The advice they gave their grandchildren included gender expectations and role preparation, respect for elders, teaching cultural norms, and the value of education:

3_2016-Pa(3Kit):

> Pa: You have to tell them to wash their underwear. You have to teach them otherwise I may be here today and gone tomorrow. They will be lost if you don't teach them. . . . [O]ne of the girls is four years old, so I teach her to wash the dishes and… , "You need to also clean your underwear and clean yourself up as thoroughly as I clean you." Girls have to practice good hygiene and cleanliness. You have to prepare the children for the future.

5_2016-Pa(5Kit)

> Pa: You tell them, "This is what people do, when a visitor comes by, there is no road in the house, so prepare tea, and buy a snack for them. If a visitor comes home, you have to greet them."

9_2016-Pa(2Bus):

> Pa: When sitting around with them I say, “I don’t like such and such behavior from you.” For example the behavior of loitering around or stubbornness is not good. “When you are called by your elders, respond immediately. When you are sent on an errand, return promptly and don’t hesitate. You need to be respectful. Attain an education, however small it may be. If I fail to come up with tuition fees, then that will be unfortunate but at least you will have gotten somewhere.”

Meaning.

Sense of Family. Furthermore, participants appreciated the significance of the extended family structure and acknowledged this communal entity as a part of their cultural identity that they had to uphold:

8_2016-Pa-m(1Bus):

> Pa: You see, it is the people that make a home. Without people, you are not a person. But when other people are in a home, then that is a home. You may have to call this child, the other child and the other and you all sit down and discuss something and agree on one thing.

Also, the ultimate reward of this role, as reported by the participants, was the rejoicing and basking in the success of their children and grandchildren. This success was manifested in monumental events such as marriage and acquisition of a substantial job. The sense of satisfaction in the “job well done” was gauged by the successful growth of grandchildren into adults, a process that included the grandchildren’s being free of disease while under their care:

17_2016-Pa-m(10Bus):

> Pa: [Caring for grandchildren] has honored me. Now people say, “Wow, who knew that a man like him would be able to take care of his grandchildren?” I am honored to have my grandchildren love me as much as they do so much so that if am to die, I will still go on the record as, “Grandpa took care of us, he often would surprise us with passion fruits sometimes. He would work all day and come back dirty but he would still care for us.”

12_2016-Pa(5Bus):

Pa: Yes, when my grandchildren are well and healthy and playing around, that makes me happy. We may eat whatever I am able to get but we would be happy.

This reward was in part proof that their caregiving efforts had finally paid off. As such, most of the participants perceived their caregiving efforts as an investment in their own future:

17_2016-Pa-m(10Bus):

Pa: Being a grandparent means that those are the benefits I reaped from what I sowed.

I: Mmmm. Tell me more about that.

Pa: It is like having a capital, which in turn produces profits. So the grandchild is the profit. Even when the capital goes down [adult child dies], I remain with the profits [laughs].

Of course, this anticipated sense of accomplishment was seldom guaranteed but rather was viewed by participants as a hope that was subject to serendipity and to God's will. Unfortunately for many of the grandparents, their dream was denied when grandchildren were reclaimed by other family members who in most instances had never been involved in the task of raising the grandchildren. In other cases, grandchildren failed to fulfill their grandparents' expectations of taking care of them in their old age. For the present study's participants, such failures were a major concern, a disappointment that left these grandparents distressed and destitute:

14_2016-Pa(7Bus):

Pa: You may raise a child and they grow up to become good people however, they quickly begin realizing that the other [paternal] side is the main family and forget that you, the grandmother, are the one that raised them. That is a very big problem because they may then begin looking at you as a non-relative now that they have their other kin to go to so all your efforts go to waste.

I: Yes. And yet you expected that . . . .

> Pa: This child would grow up and take care of me but instead they just leave you alone. The paternal family then begins acknowledging the child as their own and yet they were nowhere to raise them.

Finding the Balance

Overall, the present study’s findings indicate that despite the grandparents’ immediate or long-term rewards of caring for their grandchildren, the inordinate caregiver burden borne by these older adults may have outweighed the benefits derived from their caregiving efforts. For these grandparent–caregivers, the tension between obligation, burden, and rewards of caregiving was unremitting:

26_2016-Pa(6Mask):

> Pa: They say, “Let’s take the children because you are sick and they are bothering you.” But in that case, I would wish for them to be with me. But the hardship with that is the lack of income because if you live with them, then you need to buy books, and before you know it, they have been sent back from school because of the school fees. And so the parents say, “No, I think I need to take them back home,” . . . but living alone is unbearable.

Conclusion

In the best of circumstances, caring for children is a complex undertaking. For older grandparents who lack resources, caring for children orphaned by HIV/AIDS is even more complex. Societal norms, cultural expectations, and life adversities compelled the grandparents in our study to assume caregiving roles that they reported to be a combination of perceived rewards and overwhelming physical and psychosocial distress. These older adult caregivers relied on extremely limited resources and sporadic support from a vitiated social network. In the context of inadequate social support and their own failing health, these grandparents constantly struggled with feelings of regret, worry, and inadequacy while attempting to fulfill their caregiving role. Ultimately, these participants demonstrated a human will to survive and to persevere, all for the wellbeing of their grandchildren and in memory of their departed children—but in many cases to the grandparents' own physical detriment.

Clearly, policy, research and public health innovations are needed to address the impact of caregiving on the health and well-being of grandparent-caregivers. For example, socioeconomic and mental health services are needed to improve the well-being of Uganda's caregiving grandparents. In addition, the government could implement laws that can ameliorate the caregiving burden borne by these older adults—for example, legislation to hold parents accountable for the care of their children or provide welfare services for orphan care. This study's findings uniquely provide a comprehensive report of the macro- and micro-contextual factors impacting the grandparents' caregiving role. To address this national crisis, multisector and interdisciplinary interventions, such as family-centered health care plans, childcare, and respite care for these older adults, must be implemented.

References

Blumer, H. (1969). *Symbolic interactionism, perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.

Boon, H., Ruiter, R. A., James, S., Borne, B. V., Williams, E., & Reddy, P. (2010). Correlates of grief among older adults caring for children and grandchildren as a consequence of HIV and AIDS in South Africa. *Journal of Aging and Health, 22*(1), 48–67

Brodaty, H., Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*;*11*(2):217–228.

Bronfenbrenner, U. (1994). Ecological models of human development. *International Encyclopaedia of Education, 3*, Oxford, Elsevier.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods for the twenty-first century, in J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. Clarke, *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.

Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing, 15*(6), 398–407.

Clark, S. J. (2006). Demographic impacts of the HIV epidemic and consequences of population-wide treatment of HIV for the elderly: Results from microsimulation. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for furthering research,* (pp. 91-116). Washington: National Academies Press.

Corbin, J., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.

Feaster, F. (2011). "What is the Caregivers' (Certified Nursing Assistant) Perception of their Role While Caring for a Patient in the Household Model?". *Nursing Theses and Capstone Projects.* Paper 155.

Hayslip, B., Shore, R. J., Henderson, C., & Lambert, P. (1998). Custodial grandparenting and grandchildren with problems: Their impact on role satisfaction and role meaning. *Journal of Gerontology: Social Sciences, 53B*, S164–S174.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2016, November). *Fact Sheet November 2016.* Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

Kamya, H., & Poindexter, C. C. (2009). Mama Jaja: The stress and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health, 24*(1), 4–21

Kasedde, S., Doyle, A. M., Seeley, J. A., & Ross, D. A. (2014). They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic. *Social Science & Medicine, 113*: 161– 168.

MacNeil, J. M. (1996). Use of culture care theory with Baganda women as AIDS caregivers. *Journal of Transcultural Nursing, 7*, 14. doi: 10.1177/104365969600700204

McCubbin, H. I. & Paterson, J. M. (1982). Family adaptation to crisis. In H. I. McCubbin and J. M. Paterson (Eds.), *Family stress, coping and social support* (pp. 26–47). Carbondale, IL: Thomas Publishers.

McCubbin, H. I., Sussman, M. B. & Patterson, J. (1983). Social stress and the family: Advances and developments in family stress theory and research. New York, NY: The Haworth Press.

Merli, M. G., & Palloni, A. (2006). The HIV/AIDS epidemic, kin relations, living arrangements and the African elderly in South Africa. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for Furthering Research* (pp. 4–1 – 4–50). Washington, DC: National Academies Press.

Muga, G. O. & Onyango-Ouma, W. (2009). Changing household composition and food security among the elderly caretakers in rural western Kenya. *Journal of Cross-Cultural Gerontology, 24*(3), 259–72.

Mugisha J. O., Schatz E., Seeley J., & Kowal P. (2015). Gender perspectives in care provision and care receipt among older people infected and affected by HIV in Uganda. *African Journal of AIDS Research 14*(2): 159–167.

Schatz, E. J. (2007). “Taking care of my own blood”: older women’s relationships to their households in rural South Africa. *Scandinavian Journal of Public Health, 69*, 147–154.

Skovdal, M. (2010). Children caring for their “caregivers”: Exploring the caring arrangements in households affected by AIDS in Western Kenya. *AIDS Care, 22*(1), 96–103. http://dx.doi. org/10.1080/09540120903016537

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care, 21*(3), 309–314.

Strauss, A., & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* Newbury Park, CA: Sage.

United Nations. (2016). Economic and Social Council: Progress towards the sustainable development goals—Report of the Secretary-General. Retrieved from http://www.un.org/ga/search/view_doc.asp?symbol=E/2016/75&Lang=E

Vaz L. M, Eng E., Maman S., Tshikandu T., Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care STDS, 24*(4):247–256.

CHAPTER 5:

Mental Health Implications of Loss, Caregiving, and Coping as Experienced by Grandparent–Caregivers for Grandchildren Affected by HIV in Uganda

“Thoughts can kill you,”

Background and Significance

Caring for a loved one is stressful and may have adverse health outcomes for the caregiver. Caregiving as a concept has been studied in many contexts, but primarily in relation to the strain experienced when care giver and care recipient are of the same generation or only a single generation apart (Chou, 2000; Davidhizar et al., 2000; DesRoches, Blendon, Grinstead, Young, Scoles, & Kim, 2002; Grinstead, Leder, Jensen, & Bond, 2003). A significant challenge arising from the HIV/AIDS pandemic is that grandparents are caring for orphaned grandchildren who themselves may be infected with HIV (Kamya & Poindexter, 2009; Ssengozi, 2009). Although in the HIV/AIDS era, the financial and physical burden of this caregiving has been moderately explored, health outcomes—particularly those related to mental health—remain understudied in sub-Saharan Africa.

In sub-Saharan Africa, mental disorders account for 10% of the assessed disease burden, and yet countries in this low-resourced region lack comprehensive legislation as well as the, financial capability and workforce capacity to promote the mental health of their vulnerable populations (World Health Organization [WHO], 2016). According to the 2006 *WHO Assessment Instrument for Mental Health Systems* (AIMS) report, Uganda's Ministry of Health allocated only 1% of its national health care expenditure to mental health, and most of this expenditure was for treatment of psychiatric disorders (WHO-AIMS, 2006). Consequently, the presumably less obvious and elusive symptomatology of other mental illnesses or subsyndromal conditions associated with the caregiving role, such as depression and anxiety, often go undetected. Additionally, the low expenditures allocated for mental health may compromise the assessment and case finding of particular mental health disorders.

The WHO (2014) defines *mental health* as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community ” (para. 1). As evidenced by the present study’s findings, the grandparent-caregivers’ health is affected by socioeconomic and environmental determinants that make them particularly vulnerable to mental illness and hinders the access to treatment of those negatively affected by these indispositions. This impact on health could potentially negatively influence all dimensions of the individuals’ well-being and quality of life that include psychological, social, physical (Dodge, Daly, Huyton & Sanders, 2012). Unfortunately, information about the prevention and prevalence of mental disorders or the promotion and treatment of these illnesses in the sub-Saharan African setting is lacking—particularly with regard to older grandparents who care for grandchildren affected by HIV/AIDS.

A search of literature on the psychosocial well-being of grandparent–caregivers yielded few studies on the mental health of this age group in the sub-Saharan African region. A few studies have investigated the mental health of adults younger than 50 years of age (Abasiubong, Emem, Olawale & Udobang, 2011; Skeen, Tomlinson, Macedo, Croome, & Sherr, 2014) and groups comprising both young and older caregivers (Kuo, Operario, & Cluver, 2012; Kagotho & Ssewamala, 2012). However, studies focusing exclusively on the mental health of older adults (50 years of age or older) are limited. The paucity of knowledge for this sub-Saharan African older adult age group contrasts markedly with the wealth of knowledge in western countries that have studied this population more comprehensively (Caliandro & Hughes, 1998; Hayslip & Kaminski, 2005; Kelley, Whitley, Sipe & Crofts Yorker, 2000; Musil, Warner, Zauszniewski, Wykle & Standing, 2009; Winston, 2003;). Also, some of these studies reported that HIV/AIDS generated intensified stigmatization, isolation, and shame among caregivers of people living with the disease (Caliandro & Hughes, 1998; Winston, 2003).

However, out of various debilitating mental disorders, depression in particular has been reported to cause a great burden on older adult populations, especially members of older populations who are caregivers to family members (McKinney, Oh & Sibille, 2012; Musil et al., 2009; Prina, Deeg, Brayne, Beekman & Huisman, 2012). The WHO reported depression as the leading cause of disability globally (WHO, 2016). A few Ugandan studies have investigated depression in the general populations (Johnson, Mayanja, Bangirana, & Kizito, 2009; Okello & Neema, 2007), but not specifically in grandparent–caregivers. Some theories have attributed prevalent mental illnesses, such as depression, to cognitive, biological, and environmental predispositions in the individual. Therefore, we can argue that symptoms exhibited by the study participants could be caused by an individual predisposition or by a combination of factors. Multiple factors—including the environmental and social stressors of various dimensions of loss and subsequent grief and bereavement, caregiving responsibilities and challenges, and other multifaceted socioeconomic factors—could explain the psychosocial distress symptoms reported by the study participants. Although the purpose of the present study was not focused on diagnosing mental illness, one of the study's specific aims was to qualitatively characterize symptoms of psychosocial distress as experienced by Ugandan grandparent-caregivers.

Findings

Psychosocial Distress

In oncology research, Holland and Gooen-Piels, (as cited in Kufe et al., 2003), defined *distress* as an unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer and its treatment. Participants in the current study reported similar experiences of distress. As evidenced by the study findings, participants' narratives revealed multiple types of psychosocial distress due to (1) losses such as death or disappearance of adult children, spouses and other family members and the depletion of tangible resources; (2) subsequent experiences of grief and bereavement; and (3) chronic social-economic challenges particularly as they relate to the perceived caregiver burden. As reported by the American Psychological Association Help Center, such cumulative and chronic stress, if not well-managed, can lead to mental illnesses such as depression and anxiety (APA, 2017). Therefore, an individual's position on this continuum of distress is determined not only by the magnitude of the cumulative stressors but her or his ability to cope effectively as described by participants in the present study.

Loss, grieving and bereavement. A normal reaction to loss is the grief and bereavement processes that follow. As described by Shives (2008), *grief* is "a normal, appropriate emotional response to an external and consciously recognized loss and bereavement a process of grief in which feelings of sadness, insomnia, poor appetite, deprivation and desolation are experienced" (p. 76). Among these grandparents, the type, stage, and intensity of the grief varied according to the amount of time between the perceived loss and time of the interviews. For example, the majority of the study participants had lost adult children or spouses in the distant past while others reported losses within months, weeks, and even days of the interview. However, despite the passage of time, these grandparents described both immediate and chronic responses to their grief, especially among those who had experienced multiple losses.

As expected, the grief process started with the anticipatory grief as the grandparents nursed their loved ones through often-extended periods of illnesses to the final stages of death. This finding supports those of Winston (2003) who reported on the experiences of anticipatory grief among grandmothers who had to cope with their adult children's illnesses and those who endured additional and similar experiences with their grandchildren infected with HIV. Participants in the current study reported experiences characterized by emotional strains due to worry of how life was to go on without their loved one's presence, love, companionship, and support. In particular, these older adults worried about the responsibility of taking care of grandchildren on their own and about who would in turn take care of them (the grandparents) in their old age.

Moreover, following the anticipatory grief came the actual grief after the death or departure of their loved ones or depletion of resources. Participants recounted visceral reactions of shock, disbelief, and mourning in vivid detail—a testament to the traumatic impact of these loses on their well-being:

7_2016-Pa(7Kit):

> Pa: And the day he died, it was late in the afternoon. I had cooked a lot of food to take to the hospital for us to eat. But he said to me, "Mom, I am very sick." He couldn't eat due to the wounds in his mouth. When I saw him licking his lips, . . . I gave him some water and I could still hear the sound in the back. When he finished drinking he gave me his hand and I said, "... is your hand hurting from the [IV lines] your hand?" He said no and little did I know that he was saying goodbye to me. I called his name, . . . but there was no response and so I suddenly realized that my child had died and I screamed out! They brought oxygen for him but I said, "It is too late; don't even bother." I cried so hard and they took him to the mortuary.

21_2016-Pa(1Mask):

> Pa: I took him [son] into the hospital myself . . . [O]ne hand was supporting him so he wouldn't fall and the other hand held my cane to support me. . . . [H]e abruptly popped up in bed and almost fell off the bed . . . I quickly grabbed him mid-air and he right away died in my arms. . . So I tried to call out for help and say, "please help me, my son has died." So the basawo [medical personnel] came in and helped me straighten him up in the bed and turned to me and asked, "so what can we wrap him in?" I took off my gomesi [traditional dress] and gave it to them.

> . . . So they wrapped him up. I walked home like a mad woman; I couldn’t even find my way back home. And when I finally did, I came and told them [family] the bad news and prepared to pick up his body the next day for burial. . . . He left four children: three boys and the fourth a girl. He was about 40 years old.

The majority of grandparents who had lost loved ones described chronic worrying and sadness that they described as “thinking a lot” or “having a lot of thoughts”:

8_2016-Pa-m(1Bus):

> Pa: I was very hurt! I felt very . . . like my heart . . . I was very hurt because losing that many children was such a tragedy! I still feel the same way today. It does not end at the funeral but the hurt continues and the thoughts are quite many!

To further unravel the meaning of “having a lot of thoughts,” I prompted these grandparents further to elucidate on the nature and impact of their “thoughts.” Participants then revealed their concerns and sadness about losing valuable relationships, worries about how they would continue supporting their families without resources, and disbelief at having lost almost all their children, which was described by some as losing their children “completely”:

14_2016-Pa(7Bus):

> I: But what were the thoughts mostly about?
>
> Pa: The thoughts were mainly about completely losing all my family. All my children that would have otherwise helped me out are completely gone! I remained with no one to help me or to run to. So those were the thoughts that consumed me.

21_2016-Pa(1Mask):

> Pa: You think of how they all went. . . all your children! You think about the diseases that took them and the way that they died. And so that is what you think about until you can’t think any more.

However, others seemed to be in a state of shock and numbness to the extent that they could not describe that feeling beyond “it feels so bad”:

14_2016-Pa(7Bus):

> Pa: It left me feeling so badly and I almost died but people tried so hard to console me and I realized that if I continued having those many thoughts, I would end up dead and leaving my children and grandchildren without anyone.

To seek a deeper understanding of what "feeling badly" meant, I modified the interview guide to enable participants to explain that experience more distinctively. This modification revealed more feelings related to grief such as doubt regarding their spirituality and other stages of grief as identified by Kübler-Ross (1969)-anger, denial, bargaining, and acceptance. Most anger was expressed as a reaction to having been left with the responsibility of caring for many grandchildren without any availability of resources. Some of these grandparents expressed anger toward their adult children for not having accepted their HIV status and for not seeking treatment that could have saved their lives. As a result, the older adult experienced guilt, regret, and anguish over the impact of HIV/AIDS epidemic:

28_2016-Pa(2Luw)*:

> Pa: . . . Of course I say, "If this disease hadn't come, maybe my children would still be alive."

For grandparents who had lost multiple children or family members, the recurring traumatic losses seemed to be much more detrimental, especially in cases in which these loses occurred in close proximity:

1b_2016-Pa(1Kit):

> Pa: It is very hard because you can't sleep. You think about the one that died first, the one that died second, and the third, up to the fifth. How can you sleep? Losing a child is the worst thing that could happen to you. Now I am left with that one [points at 65-year old son] He is my first child but. . . he looks at me for everything. But all of them are gone. So you stay up all night until dawn. . . You know how it is with us old people; we can't sleep anyway so all you do is think

about all those children that you have lost and stay in constant pain. You can’t forget the first one that died years ago just because it has been a while . . . . [Y]ou remember them as vividly, too.

14_2016-Pa(7Bus):

Pa: I had a lot of thoughts especially after losing five people in only one year! Three brothers, my daughter and my husband died, all in one year!

This recurrent grief and bereavement, if not managed well, could lead to unresolved grief and other subsequent disorders, such as persistent complex bereavement disorder—characterized by frequent experience of significantly severe grief that is unresolved at least 12 months after death of a loved one or beyond cultural norms of grief responses (APA, 2013). Customarily, the grief process is a shared experience among the Baganda that starts with days of mourning as family and neighbors view the deceased’s body and perform cultural and religious rituals such as choosing the heir to the lost loved one and pray (Seeley, 2014). With a decreased social network to provide such emotional and financial support to fulfil these culture ceremonies, unresolved grief may result.

As informed by the CFI, I probed these participants further to ascertain their cultural perspectives on meaning, cause, and symptoms of perceived loss-related and other cultural concepts of distress (APA, 2013). The majority of grandparents understood that the loss experience was a normal part of life, although they also emphasized that the most frequent cause of death was *“our disease”* (i.e., HIV/AIDS), which they now, unfortunately, considered an ordinary illness. However, some were further distressed by the belief that all their families’ misfortune, suffering, and loss was due to witchcraft that was cast onto them by disgruntled relatives or neighbors:

30_2016-Pa(4Luw)*:

Pa: He [son] was [bewitched] by his auntie who did something wrong to him and so he got really [mentally ill] although he would still support me.

I: Mmmm. Did you seek guidance and help from the traditional doctors?

Pa: We tried but. . . my husband was not as vigilant . . . I believe the sister took a cloth that belonged to this son of mine and did something with it that caused him to become [mentally ill]. I don't know what she did with the cloth but it looks like she took it to a gravesite. This problem [spell] is really in the family . . . my entire family is destroyed without any kind of progress. My [co-wife] also started bewitching me and so I was in a lot of pain and fear for my life.

In addition to distress caused by loss to death, grandparent–caregivers described distresses resulting non-death-related losses. These non-death-related distresses, which varied in magnitude, elicited feelings of regret, denial, anger, disappointment, among other responses; these feelings were similar to those associated with distress caused by loss to death. Among all causes of distress, loss to death seemed the most devastating. This type of distress was mostly related to the perceived caregiver burden.

Non-death-related distress. As revealed by the study findings, the psychological burden of caregiving was often related to the above-mentioned losses. Subsequent to these losses, however, grandparents had to take an active role in the physical, financial, and emotional well-being of their grandchildren. The majority of participants were most worried about how to cope with the burden of caring for grandchildren without the resources and social network necessary for fulfilling this duty. For many of these grandparents, emotional distress was magnified by multiple other factors, including (a) their orphaned grandchildren's being infected with HIV, (b) grandchildren's disrespectful or uncooperative behavior, (c) lack of financial resources to maintain a household and to provide for the family's basic needs (e.g., education and health care expenses), (d) disputes with family members, and (e) other socioeconomic stressors (e.g., unemployment, lack of education, exposure to traumatic civil wars, and displacement due to those wars). For example,

23_2016-Pa(3Mask):

> Pa: Problems . . . too much thinking due to the many problems. Worrying about what to eat, school fees, I worry about everything, from morning to morning. So you wonder what to do. . . . You think about the orphans they left you with; you don't have the school fees and yet you don't want them not to go to school, you see? I worry that if I also died today, how is their life going to be like, especially now that the Muzeyi [elder-husband] is now old.

4_2016-Pa(4Kit):

> Pa: The one I live with [adult daughter]. But the husband abandoned us while she was pregnant. So I started struggling then . . . my daughter, if you hear my story, you might think I am lying to you! Since my husband got shot ['80's], I started suffering until today! I rent my house and yet I can't find money. Sometimes I sell mats to get food for the children. My daughter tries to go to work but there are no jobs. We are all in a terrible state!

Characterization of Distress Symptoms

Given the grandparent–caregivers' stressful life circumstances, their reports of related symptoms of psychosocial distress were not surprising. Their chronic grief for lost family members, the subsequent fate of the orphans and caregiver burden manifested as expressions of anxiety- and depression-related emotional, physical and psychological symptoms:

Emotional Symptoms

As discussed above, participants reported emotional symptoms such as constant worrying or "having a lot of thoughts" described above and frequent crying. The emotional symptoms, if unmanaged, could lead to distortion of a person's thought process which has been believed to lead to depressive symptoms (Alloy, Abramson, Walshaw, Keyser & Gerstein, 2006; Beck, 1967; Beever, 2005; Ingram, 1984). In his seminal book, *Depression: Causes and Treatment*, Beck, 1967 proposed that chronic experiences of emotional stress due to a crisis or collective negative life experiences, negative schemata trigger cognitive distortions and perceptions of negative views of the world, self, future; which are collectively referred to as the *cognitive triad* (p. 255). McEwen (2003) examined the body's biologic response to environmental stress and allostasis, as manifested by physiological and behavioral responses to changing stress. This association between the physical environment and social environment has been attributed to physical illness such as arthritis, cardiovascular disease, and diabetes. And as found in the current study findings, grandparents perceived their emotional distress as causing other physiological ailments:

22_2016-Pa(2Mask):

> Pa: Actually, I do have a heart problem . . . especially after my child died. I was really affected and my heart started beating very fast. Say when the phone would ring, my heart would beat so fast.
>
> I: What do you think caused that problem?
>
> Pa: Having to worry too much. Yes, having to worry . . . I am constantly crying and worrying because of all the children that they left me with. I wish that the children would see their father again . . . I just cry until dawn.
>
> I: Mmmm. What do you remember about them?
>
> Pa: Musawo [nurse], it is your child with whom you spent time, talking and laughing; they may bring you something small for you to cook and eat and now, you don't see them anymore. Why wouldn't you cry? . . . [A]ll I hear [from grandchildren] is, "Daddy, Daddy, Daddy," which brings me even more sorrow, you see?

Physical Symptoms

In addition to the physical ailments described by participant 22_2016-Pa(2Mask), grandparent-caregivers, in general, experienced somatizations such as chills, general body weakness and aches, insomnia and loss of appetite. Additional physical symptoms described included heart palpitations, peptic ulcers, increased blood pressure, which could be directly related to either possible comorbidities or to psychological distress as reported in other studies

(Carels, Sherwood, & Blumenthal, 1998; Ewart, Taylor, Kraemer, & Agras, 1991; Glasser, Sheridan, Malarkey, MacCallum, & Kiecolt-Glaser, 2000).

Psychological Symptoms

While some participants described the above emotional and physiologic responses to stress, others recounted incidents of psychological distress. For example,

28_2016-Pa(2Luw)*:

> Pa: Mmmm. Well there was a year I got a lot of sadness. . . . [I]t must have been either 2003 or 2004. My heart started getting weak and I wanted to kill myself and get out of this world. I didn't have any one to assist me. There was no food at home, no money; I wanted the children to go to school . . . so many things. We all looked terrible in the home. I went to one of the ladies in the village crying and she got up and gave me a bar of soap and said, "You need to go home and clean up because you look so bad." I was tired of everything and all the heart was telling me was to die. I asked myself what I did in this world not to have anyone to help me out. [Silent].

Besides exhibiting suicidal thoughts, participant 28_2016-Pa(2Luw)* also revealed that two of her adult children and one of her grandchildren had cognitive disabilities. This evidence of genetic and possibly biologic and family history of mental illness supports the argument that in the presence of social, environmental or physiological stressors, grandparents could be at risk for mental disorders.

Although these participants did not explicitly refer to these mental symptoms as "illness" or "disease," they understood the impact of this type of distress on their health, as explained by participant 1b_2016-Pa(1Kit):

> Pa: . . . You have no peace left but are strengthened by those that are still with you. And if you don't have anyone, you die prematurely; the thoughts can kill you. You can see one losing weight and yet they deny being sick but those thoughts

> can kill you. Someone could worry so much and become as thin as a stick without any apparent problems but all due to that worry.

In light of the above-mentioned symptoms related to psychosocial distress, it is critical to analyze the nature of the coping strategies that these grandparents used to deal with their psychosocial distress.

Coping Behaviors

As defined by Folkman and Lazarus (1988), *coping* as constantly changing "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.310). Discovering the evidence of whether these older adults coped, well or poorly, with the various forms of psychosocial distress is a focus for another study. However, in the face of their extraordinarily stressful experiences, these grandparents described various ways in which they attempted to mitigate their losses and maintain a sense of normalcy and homeostasis.

Finding Comfort in Numbers

Some of these grandparents reported finding "comfort in numbers" through social interaction with others who had experienced similar losses. For example, participant 26_2016-Pa (6Mask) speaks of gaining solace in "not being alone" or not being the only one who endures the experiences of losing and grieving for loved ones. This attitude seemed to lessen these participants' own pain and allowed them to look beyond their own grief and empathize with others who are traversing similar experiences. These grandparents demonstrated an ability to overcome the natural instinct to withdraw both emotionally and physically and instead to look at the world with optimism and courage:

26_2016-Pa (6Mask):

> Pa: [You know] the saying that, “it doesn’t happen to only one of us” . . . I have to remember that I am not the only one going through this. I think of other people that have lost their loved ones and remind myself that I am not alone. And even when I have just lost a child, I cry but when I look over at their grave, I wipe my tears and ... wonder what can do I about it. . . nothing. . . [Y]ou can’t cry over spilt milk, so that thought strengthens you.

Escaping Grief

When prompted to describe how they cope with their grief, a few participants indicated that they had been advised by friends to use alcohol to numb their pain, but due to the poverty, most mentioned that they could not afford to sustain the habit:

21_2016-Pa(1Mask):

> Pa: Yes, [the alcohol] helps me a bit. I am able to forget and sleep better. But of course I drink very little since I don’t have too much money for it . . . but even that little helps. Otherwise if you think too much [about the deceased], you can fail to eat food.

Letting Go

Whether through a conscious decision to adapt to their new realities or out of sheer despair, the majority of grandparent–caregivers described coping by having to “let go” of their past and embrace the present circumstances as part of life. For instance, they let go of their hopes and dreams of having their children take care of them in old age and of having to constantly cry and worry since there was nothing that could reverse their loss.

6_2016-Pa(6Kit):

> Pa: . . . [S]o you forget about everything else. The others are dead and there is nothing you can do about that but take care of these young ones. Because if you don’t who is going to help you? But work hard and take care of the children. Forget about the tears . . . You have to decrease it [sadness] yourself.

Distracting Self

As demonstrated by these participants, some grandparent–caregivers accepted their reality and were further proactive at utilizing emotion-focused coping strategies to manage their stress. Folkman and Lazarus (1988) described this behavior as *emotion-focused coping*—a deliberate control of one's personal emotions in order to cope with stressors. Some participants achieved this control by engaging in various caregiving duties and by other activities with grandchildren and friends in order to distract themselves or to release negative emotions related to their psychosocial distress.

11_2016-Pa(4Bus):

> Pa: [Taking care of grandchildren] has changed my thoughts…you know, it keeps me busy. I might want to think but when I start playing or singing or joking with her, [laugh, points to granddaughter] . . . that takes the thoughts away and leaves me happy. . . just like that.

Spirituality

For the most part, participants believed that God had the ultimate power to control their circumstances. For example, as explained by the grandparents above, they held the biblical belief that God uses His sovereign prerogative to give and later take away their children, with the ability to provide them with emotional healing:

3_2016-Pa(3Kit):

> Pa: . . . [W]hen I go to sleep I wonder, "Why me, why me?" But if that is God's wish then I need to be strong. Because He brings the problems to try you.

As expressed by these participants, their faith in God was expressed as a rational interplay and justification for good or bad outcomes in their lives that allowed them to cope with their hardships. Accordingly, many coped through prayer, as described by participant 24_2016-Pa(4Mask):

> Pa: I grab my rosary when the sleep fails to come. The rosary is what I use to pray and ask the Lord to strengthen me until I fall asleep. Or if there is a program on the radio, I listen to the religious station and feel stronger. But no, I don't go out to drink to take the worries away . . . just my rosary is what takes the thoughts away.

Also notable is the significant role that traditional healers, as alternative mental health providers, play in the psychological well-being of these grandparents and society. Motivated by their indigenous beliefs in spirits and rituals, some of these participants consulted with traditional healers to treat illness and to resolve disputes, and to seek meaning of their misfortune and potentially put an end to or reverse their bad luck. Although a few made reference to engaging in these practices, the stigmatization—mostly created by the modern influences of Christianity—was evident among most:

25_2016-Pa(5Mask):

> I: Do you call upon those gods?
>
> Pa: How could I? Since I joined the born-again Christians, I burnt all of them [traditional ceremonial objects]. But occasionally I wonder if that was the cause of my sleep loss.
>
> I: Mmmm. Before you became born-again, what would you do or ask for?
>
> Pa: They would . . . you see, there were people that used to show us what to do. So, for instance, if you got sick, they would take you to a traditional healer who asks you to do such and such a thing. We would dress up in bark cloth when the moon came up or even in the dark. So we would wear that and also tie it on the head. But I gave all that up . . . I wondered if it helped at all . . . So I decided to pray to God instead which has helped me a lot. Before that, I really suffered with illness . . . you know the kind that others send to you [witchcraft]. I would be sick for three months straight. . . . I would lose all my fingernails from here to here. If those traditional healers really helped me. And those things [spirits] would say, "so and so sent me." So even when I pray, I still wonder about the power of the traditional practices. . . [T]hey really work. Since I don't go to the traditional

> healers anymore, I wonder if I would be able to handle one of those diseases if someone sent it my way. But I have to be strong. Besides, they [spirits] really didn't help me when my children got sick…they didn't help me when they died. So what kind of power is that? So I let that go.

Besides the spiritual conflict illustrated by participant 25_2016-Pa(5Mask) above, she explained the loss of social network as a result of denouncing the traditional religion which further impedes effective coping:

> Pa: But all my relatives disowned me after I burnt them [traditional ceremonial objects]. Even if they would have helped me with some of my household needs, now all they say is, "No, you are now a born-again Christian and we believe in the traditional spirits." So that is how we got the misunderstanding. . . . So I am all alone and am now worried about my son who is admitted at the hospital. I have never gone to see him since he was admitted.

Although for some grandparent–caregivers these beliefs exacerbated distress, these traditions practices also offered an alternative and causative explanation of illness and death—an explanation that allowed them to cope with their losses and other hardships. Also, engaging in these traditional practices by these older adults could promote social harmony among these grandparent–caregivers and their families and further alleviate emotional distress. As argued by Okello and Musisi (2006), this indigenous belief system could promote help-seeking behavior and offer culturally appropriate explanatory models of mental disorders otherwise described as *eByekika*—that is, clan illnesses—among the Baganda tribe to which the majority of the current study participants belonged. Also, according to Johnson et al., (2009), these clan illnesses have been conceptualized as psychotic depression and related "illnesses of thought" linked to unipolar depression.

Social Support

Most participants reported receiving some support—albeit minimal and often infrequent—from a surviving social network of adult children and grandchildren, spouses, extended family members, friends, neighbors, and community-based organizations. This support was in the form of loans, food, gift money, and other kinds of tangible and emotional support:

2_2016-Pa(2Kit)

> Pa: Yes, some of them [neighbors] are my friends. They at times help me with food, such as beans, flour and sometimes they give me money. And sometimes clan members help.

7_2016-Pa(7Kit):

> Pa: . . . In fact there is an old lady in the village that . . . I used to cry a whole lot. Every time I would quietly sit down, I would cry and so she advised me to be strong. She said, " you will not be able to make it if you are not strong." So she encouraged me like that. There is another one who lost a child to cancer of the leg and lost him. She also encouraged me to be strong.

3_2016-Pa(3Kit):

> Pa: When my child got sick a little while ago, I could not afford the hospital bill but the church paid for it, plus the food . . . here is money from Christian so and so for medicine." So the community's response is what saves you.

Finding Meaning

In addition to the above coping strategies part of grandparent–caregivers' adaptation and coping was motivated by the meaning drawn from their affliction. For example, some participants reported caring for the orphans in remembrance of their lost loved ones and maintaining a sense of kinship and family.

25_2016-Pa(5Mask):

> Pa: And so I tell myself, "Granted they [adult children] died but I can still see them [through the grandchildren]." That makes me very happy. They died, and that is the final destiny but when I look at my grandchildren, I see my own children in them.

While some rejoiced in caring for their children in order to please the spirits of their children, others hoped that the grandchildren would take care of them in the future, just as their adult children would have done:

17_2016-Pa(10Bus):

> Pa: . . . [L]ike I said, the capital is gone but you remain with the profits. If you escape death with a deformity, you thank God for it. So you have to look at it this way: you had one, but you've now been left with four. It's like this, wouldn't you be thankful if you reaped a cob of maize [corn] from just two seeds? Their fortune is in you and yours in them. You never know, they may grow up and save you more than the one that you lost. . . . So instead of mourning the dead, forget that and cry about how you are going to take care of these children so that they can survive as your profits.

Perseverance

For most of the grandparents in our study, a general sense of perseverance and coping skills of survival enabled them to convert their devastation into positivity. Whether this was a positive outcome from the use of all or some of the above coping strategies, the theme of perseverance seemed significant in strengthening their will to survive despite their immense adversity, loss, and grief:

5b_2016-Pa(5Kit):

> Pa: . . . [T]here is nothing that you can do about [the grief] so gradually . . . your heart has to calm down. Besides, you have to remember that you are not the first to lose children. You can hear someone say that they lost eight children; how do you think they survive that? But others end up losing their minds [mental illness], which at times is because of losing children. . . . [Y]ou have to be strong, otherwise where would you throw those children to? You have to be strong; share what you eat with them; use the same soap to wash their clothes like you do yours; and you have to take your cloth off at night and cover them with it. You have to do that until they grow up. . . . Find something to do [work] especially if you don't have any one to support you.

Conclusion

The dearth of knowledge on this phenomenon that was identified in this study's literature review and findings revealed that more research is needed to better understand the mental health and psychosocial implication of this experience in sub-Saharan Africa. Increased awareness of mental health and gerontology is also imperative. Studies such as this can be used to inform local community stakeholders, health sectors, national policy makers, and multilateral organizations to design multiple levels of interventions such as family-centered care plans, childcare and respite care, crisis interventions, and public health initiatives—among other social services needed to improve the mental health and psychosocial well-being of these older adults. The WHO's new comprehensive mental health action plan of 2013-2020 (WHO, 2013), with its objectives that include providing universal, integrative and responsive mental health and community-based social care services and increasing research in mental health, is a step in the right direction.

The above-mentioned psychosocial distress symptoms may not be individually classified as clinical psychiatric or mental health disorders. However, considering possible biological and genetic predispositions and vulnerabilities, coupled with a combination of accumulating stressful events and life adversities, these undiagnosed and untreated symptoms can trigger or constitute a myriad of physical, neurologic, and psychiatric disorders such as posttraumatic stress disorders, major depression, anxiety, persistent complex bereavement disorder, and other stressor-related disorders (APA, 2013). This risk is particularly high when the symptoms pertain to a general state of being rather than to one distinct incident, especially as the unresolved grief and/or recurrent forms of losses and daily stressors persist. Although the current study findings support the utilization of various coping strategies by the participants to manage their perceived psychosocial distress, more studies are needed to investigate the effectiveness of these strategies.

Where mental illness may be prevalent, caution should be exercised to avoid transplanting treatment modalities practiced in western culture, without the use of tools that are culturally sensitive and concordant. For instance, cultural relativism should be applied to (1) investigate normative ways in which loss and grieving are manifested, (2) identify effective coping strategies needed to deal with loss and caregiver burden; and (3) find an effective balance between formal and traditional religious practices as they relate to health. Therefore, the research community, public health, national and international policy makers, and other entities must advocate for this vulnerable population of grandparent–caregivers to improve their psychosocial well-being.

References

Abasiubong, F., Emem, A. B., Olawale, 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: *Psychological and Socio-medical Aspects of AIDS/HIV*, *23*(4), 494–500.

Alloy, L. B., Abramson, L. Y., Walshaw, P. D., Keyser, J., & Gerstein, R. K. (2006). A cognitive vulnerability-stress perspective on bipolar spectrum disorders in a normative adolescent brain, cognitive, and emotional development context. *Development and Psychopathology, 18*(4), 1055–103.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

American Psychological Association. (2017). Understanding chronic stress. Retrieved from http://www.apa.org/helpcenter/understanding-chronic-stress.aspx

Beck, A. T. (1967). *Depression: Clinical, experimental, and theoretical aspects.* New York: Hoeber.

Beever, C. G. (2005). Cognitive vulnerability to depression: A dual process model. *Clinical Psychology Review*, *25*, 975–1002.

Caliandro, G., & Hughes, C. (1998). The experience of being a grandmother who is the primary caregiver for her HIV-positive grandchild. *Nursing Research, 47*(2), 107–113.

Carels, R. A., Sherwood, A., & Blumenthal, J. A. (1998). Psychosocial influences on blood pressure during daily life. *International Journal of Psychophysiology*, *28*, 117–129.

Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods for the twenty-first Century, in J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. Clarke, *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press.

Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing, 15*(6), 398–407.

Creswell, J. W. (2007). *Qualitative inquiry & research design* (2nd ed.). Thousand Oaks, CA: Sage.

Davidhizar, R., Bechtel, G. A., & Woodring, B. C. (2000). The changing role of grandparenthood. *Journal of Gerontological Nursing*, 26(1), 24–29.

DesRoches, C., Blendon, R., Grinstead, L. N.,Young, J., Scoles, K. & Kim, M. (2002). Caregiving in the post-hospitalization period: Findings from a national survey. *Nursing Economics 20,* 5, 216–224.

Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing, 2*(3), 222–235. doi:10.5502/ijw.v2i3.4

Ewart C. K., Taylor C. B., Kraemer H. C., Agras W. S. (1991). High blood pressure and marital discord: Not being nasty matters more than being nice. *Health Psychology, 10*, 155–163. doi:10.1037/0278-6133.10.3.155

Folkman, S. & Lazarus, R.S. (1988). The relationship between coping and emotion: Implications for theory and research. *Social Science Medicine, 26(3),* 309–317

Glaser R., Sheridan J. F., Malarkey W. B., MacCallum, R. C., Kiecolt-Glaser, J. K. (2000). Chronic stress modulates the immune response to a pneumococcal pneumonia vaccine. *Psychosomatic Medicine, 62*:804–807.

Grinstead, L. N., Leder, S., Jensen, S., & Bond, L. (2003). Review of research on the health of caregiving grandparents. *Journal of Advanced Nursing, 44*, 318–326.

Hayslip, B., & Kaminski, P. L. (2005). Grandparents raising their grandchildren: A review of the literature and suggestions for practice. *The Gerontologist*, *45*, 262–269.

Holland, J. C., & Gooen-Piels, J. (2003). Guidelines for recognition of psychosocial distress. In Kufe, D. W, Pollock R. E., Weichselbaum, R. R., Bast, R. C., Gansler, T. S., Holland, J. F., Frei, E. 3rd (Eds.), *Cancer Medicine 6.* 6th ed. Hamilton (ON): Decker, B. C.Inc.

Ingram, R. E. (1984). Toward and information-processing analysis of depression. *Cognitive Therapy and Research*, 8, 443–447.

Johnson, L. R., Mayanja, M. K., Bangirana, P., & Kizito, S. (2009). Contrasting concepts of depression in Uganda: Implications for service delivery in a multicultural context. *American Journal of Orthopsychiatry, 44*(2): 275–289.

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 stress and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health, 24*(1), 4–21

Kelley, S., Whitley, D., Sipe, T., & Crofts Yorker, B. (2000). Psychological distress in grandmother kinship care providers: The role of resources, social support, and physical health. *Child Abuse & Neglect*, *24*, 311–321.

Kubler-Ross E. (1969). *On death and dying.* New York: Macmillan Publishing Company Inc.

Kuo, C., Operario, D., & Cluver, L. (2012). Depression amongst carers of AIDS-orphaned and other-orphaned children in Umlazi Township, South Africa. *Global Public Health*, *7*, 253–269.

McEwen, B. S. (2003). Introducing mediators of allostasis and allostatic load: Towards an understanding of resilience in aging. *Metabolism, 52*, 10–16.

McKinney, B. C., Oh, H., & Sibille, E. (2012). Depression has been reported to cause great disease burden to aging populations, especially those that are caregivers to other family members. *Frontiers in Genetics, 3*, 23.

Musil, C. M., Warner, C. B., Zauszniewski, J., Wykle, M., & Standing, T. (2009). Grandmother caregiving, family stress and strain, and depressive symptoms. *Western Journal of Nursing Research, 31*, 389.

Okello, E., & Musisi, S. (2006). Depression as a clan illness (eByekika): An indigenous model of psychotic depression among the Baganda of Uganda. *Journal World Cultural Psychiatry Research Review, 1*(2), 60–73.

Okello, E., & Neema, S. (2007). Explanatory models and help seeking behavior: pathways to psychiatric care among patients admitted for depression in Mulago hospital, Kampala, Uganda. *Journal of Qualitative Health Research, 17*, 14–25.

Prina, A. M., Deeg, D., Brayne, C., Beekman, A., & Huisman, M. (2012). The association between depressive symptoms and non-psychiatric hospitalization in older adults. *PLoS ONE*, 7(4).

Seeley, J. (2014). *HIV and East Africa: Thirty years in the shadow of an epidemic.* Routledge Skeen S, Tomlinson M., Macedo A., Croome N., & Sherr L. (2014). Mental health of carers of children affected by HIV attending community-based programmes in South Africa and Malawi. *AIDS care*, 26(sup1), S11–S20. doi: 10.1080/09540121.2014.906559

Shives, L. R. (2008). *Psychiatric–mental health nursing* (7th ed.). Philadelphia: Lippincott, Williams & Wilkins.

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS Care, 21*(3), 309–314.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Winston, C. A. (2003). African American grandmothers parenting AIDS orphans: Concomitant grief and loss. *American Journal of Orthopsychiatry,1*, 91–100.

World Health Organization-Assessment Instrument for Mental Health Systems (AIMS): *Report on Mental Health System in Uganda, WHO and Ministry of Health, Kampala, Uganda, 2006*. Retrieved from http://www.who.int/mental_health/uganda_who_aims_report.pdf

World Health Organization. (2013). Mental health action plan 2013-2020: Retrieved from http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf?ua=1

World Health Organization. (2014). Mental health: A state of well-being? Retrieved from http://www.who.int/features/factfiles/mental_health/en/

World Health Organization & Columbia University. (2016). *Group interpersonal therapy (IPT) for depression (WHO generic Field-trial version 1.0)*. Geneva, WHO, 2016.

CHAPTER 6:

Dimensions of Loss Experienced by Ugandan Grandparent Caregivers of Grandchildren Affected by HIV/AIDS

Introduction

During the literature search described earlier in chapter two of this dissertation, it became clear that published studies on this phenomenon have explored physical, psychosocial, and financial burdens experienced by the grandparent-caregivers and also discussed a few coping strategies reported by participants, including spirituality and social support. Although some studies also mention singular incidents of loss in relation to the caregiving experience in this population, studies examining the concept loss as it pertains to grandparent caregivers are woefully inadequate. However, a few researchers have attempted to address the general concept as experienced by this aging population.

For instance, Seeley (2014) recounts the impact of HIV/AIDS on Ugandan lives over the last three decades and provides anecdotes of grandparents' loss experiences that occurred as a result of HIV/AIDS-related deaths. Demmer also explored the impact of AIDS-related loss on the well-being of women and their subsequent attitudes and experiences of losing young children to AIDS (Demmer, 2010). Still, no studies were found that have examined dimensions of loss experienced by grandparent caregivers in the sub-Saharan setting. Western scientists such as Miltenberger, Hayslip, Harris & Kaminski (2004) have examined the societal perception of loss as a concept with regard to custodial grandparents, but not the grandparents' self-perception of their loss. Other studies have investigated loss as it pertains to overall mental health (Baker, Procter & Gibbons, 2009), Alzheimer's disease, and dementia (Collins, Liken, King, & Kokinakis, 1993; Sanders, Morano & Saltz, 2003). Findings from the present study help to address this deficit in the research evidence because a qualitative account of the nature, extent, and relationship between multiple types of losses emerged from the narratives obtained during the interviews. These accounts broaden our understanding of loss as experienced by Ugandan grandparent–caregivers in this era of HIV/AIDS.

Dimensions of Loss

After experiencing a crisis or a myriad of unfortunate occurrences, participants stated that they experienced the onset of a void—a sense of a missing element that impacted their lives at a physical, social, or emotional level. Although loss may often be associated with the death of a loved one, participants in the current study reported that they experienced a similar deprivation and emotional distress in relation to other types of losses. Although they may not have explicitly referred this deprivation or distress to as "loss," the researchers analytically inferred experience of missing possession, service, convenience, or other entity as a form of loss. In the present study, we used the descriptions of loss presented by Shives (2008): "an actual or potential situation in which a valued object, person or other aspect is inaccessible or changed so that it is no longer perceived as valuable" and "a condition whereby an individual experiences deprivation of, or complete lack of, something that was previously present" (p. 76).

All of the study's participants had experienced some form of loss—temporary or permanent, moderate or extraordinary, anticipatory or fait accompli. We identified relationships between these losses as being either *primary*-an initial inaccessibility or deprivation of a valued possession or person or other entity- or *secondary* – losses that came as a result of a cascading of events after the primary loss. Notably, the types of loss described by study participants were not mutually exclusive (i.e., any type of loss could co-occur with any other type of loss).

Primary Losses

Loss of self. Participants frequently referred to experiences that can be described as a "loss of self." Most grandparents, particularly grandmothers, described this experience of loss of self as (a) a decline in functional abilities, health, and/or quality of life, and/or (b) diminishing self-identity and self-image. These older adults attributed these declines to normal aging. Participants believed that this primary loss of their youth and vitality had led to other types of loss, such as loss of identity, independence, attractiveness, options, perceived control of body, and/or external function. Understandably, primary aging, determined by inherent or hereditary influences, is considered a normal process in any similar cohort (Shives, 2008). However, in the present study, many of the grandparent–caregivers were prematurely aged by the harsh, often traumatic and or unfortunate circumstances of their lives. This premature aging further inhibited their thriving or even their performance of the basic activities of daily life. For these older adults, the principal day-to-day objective was survival. In some instances, grandparents reported the loss of self as a decline in energy and an inability to perform daily activities or specific jobs that would more adequately support their families. For example,

26_2016-Pa(6Mask):

> Pa: Besides, [caregiving] is affecting me now because I am weaker . . . . If you send the child to do a chore that you would otherwise have done yourself and they don't, it saddens me to look at the [task] undone and yet I am too weak to do it myself. So that makes me feel sick inside. You may ask [a grandchild] to wash your clothes and he says, "I will wash them tomorrow," and of course he never does. So all that makes it harder on us.

Also, some participants described a loss of their youth that further hindered them from leaving abusive or unhappy marriages and seeking desirable companionships.

26_2016-Pa(6Mask):

> Pa: Let me tell you something, my child . . . . [finding another companion/spouse] can only be possible if you still look good and are still young.

Notably, the loss of self could also be considered secondary. For instance, loss of adult children or family members may lead to a qualitative diminishing of the grandparent–caregivers' view or recollection of their history. Ultimately, as they mourn the loss of their family members, some participants could not avoid reflecting on and worrying about the loss of their own lives or mortality and the impact of their eventual death on the lives of their grandchildren. For example, 2_2016-Pa(2Kit):

> Pa: I am pained by those children. If they don't get any schooling, how are they going to be in life? If I die, especially since my health worries me, what will happen to those children? They are still young.

Loss of adult children and grandchildren. Participants described unbearable experiences of loss of adult children as a result of death from any of multiple causes, but in most instances, death was due to HIV/AIDS. Although some grandparents reported having lost their children as toddlers or pre-adolescence, the majority lost adult children who were in the age range of 20–45 years. This age range corresponds to the age range of the most impacted demographic affected by the HIV/AIDS epidemic in Uganda, 15–49 years. (UNAIDS, 2016). Impacted participants described several sentiments related to this loss. In describing their experiences of burying their adult children, most of the grandparent–caregivers expressed the unbearable anguish endured by parents who bury their children in contravention of the perceived natural order—in which, normally, grandparents are buried by their adult children. For example, 1b_2016-Pa(1Kit):

> Pa: . . . as a parent and an elder, you would wish to die before your children. And if they die right after you, that is God's wish and you wouldn't know of it but it is so hard for them to die before you. It is so painful for a parent to bury one child after another. They go before you. I should have died first and left the children behind.

> Because it is better for the children to stay behind and bury you. See, I don't have many people [friends or family] to leave behind, but the children have many friends who can come and support them. But now we are left alone, what can we do?

This loss is particularly devastating to some, because it is not just a demise of immediate family members but of a lineage and heritage. For instance, as an only child who was orphaned as a child and who had to grow up with relatives who did not embrace her as kin, participant 25_2016-Pa(5Mask) lamented about what having had her children, and then losing them, meant to her:

25_2016-Pa(5Mask):

> Pa: . . . Having my own children made me so happy. One would be my brother, the other my father, my mother . . . it is like I created the [relationships] that I never had. But then I lost all of them and remained all alone as I was before. So you see, I have always had a tough life until my old age, but that is life.

In addition to this loss, participants reported the experience of losing children who had disappeared without a trace. For example,

6_2016-Pa(6Kit):

> Pa: Well yes, but he [one of the sons] also went off with soldiers [army] and I don't hear from him. He left when he was very young and we looked for him everywhere but couldn't find him. The next I heard was that he was seen in [town]. Since then, there was no trace of him. I haven't heard from him since. But I have heard that he went off with soldiers [army].

As reported by this grandmother, some adult children decided to migrate to other towns or countries, motivated mostly by a lack of financial stability and a desire to seek better opportunities elsewhere. As a result of these migrations, many of the adult children communicated with their families only sporadically or not at all. In many instances, grandparents lost all contact with their adult children. For adult children missing without a trace, affected grandparents lacked closure or finality and were instead chronically distressed by the mystery surrounding their children's disappearance. Not only did these grandparent–caregivers mourn the disappearance of their adult children, but also, at times, the grandparents perceived their children's sporadic communication or lack of communication as deliberate abandonment of the adult children's parenting responsibilities. For example,

10_2016-Pa-m(3Bus):

Pa: [My son] left. I hear he is in [place] now. It has been a very long time since he left. It has now been seven years without seeing him . . . . I don't know . . . and I have no way of finding him. . . . and he never calls up to this day. He doesn't even know what is happening with the children. The girl is in [place]. I do hear from her either . . . . She also just abandoned the child and left. So I asked a friend of hers, 'where is your friend; I don't see her anymore?' The friend told me that she is in [place]. And I thought, wow . . . well, what could I do? Her child is about four years now.

Some participants reported loss of their grandchildren in comparable circumstances. However, some participants also expressed anticipatory loss of grandchildren to the paternal family when they got older. For example,

14_2016-Pa(7Bus):

Pa: You may raise a child and they grow up to become good people however, they quickly begin realizing that the other [paternal] side is the main family and forget that you, the grandmother, are the one that raised them. That is a very big problem because they may then begin looking at you as a non-relative now that they have their other kin to go to so all your efforts go to waste.

I: Yes. And yet you expected that . . . .

Pa: . . . that this child would grow up and take care of me but instead they just leave you all alone. The paternal family then begins acknowledging the child as their own and yet they were nowhere to raise them . . . . Even when God blesses them [grandchildren] and gives them a good life, they don't look back and remember the grandmother that raised them.

Like 14_2016-Pa(7Bus) above, many grandparent–caregivers expressed that all of their efforts and sacrifices made to raise their grandchildren—in part, with the grandparents' hope and dream of being taken care of in return—could be lost when the adult grandchildren are later reclaimed by the grandchildren's "primary" family. Some of the participants had actually experienced this loss with older grandchildren. Therefore, this abandonment—whether potential (i.e., anticipatory) or fait accompli—was, for most of these older adults, intensely distressing and saddening.

Loss of spouses. In addition to the aforementioned losses, participants also reported losses of spouses as a result of death or other causes, such as separation, divorce, or the gradual emotional disconnection and dysfunction of their marriages. All participants interviewed were either widowed, separated, or in undesirable polygamous families.

9_2016-Pa(2Bus):

> Pa: I was married for about twelve years or so and had about seven children. [My] husband went into the army . . . he was convinced to go into the army to Somalia; and he died there. I never heard from him until I heard that he had died. I don't even know what year or when he died. So I [have] remained with the children then.

Because participant 9_2016-Pa(2Bus) was not certain that her husband had died, she was left in a state of unresolved grief. For some grandmothers, however, the loss of a spouse created a complex void. Some participants initially described themselves as married, but further prompting revealed that they were actually widowed:

12_2016-Pa(5Bus):

> I: Are you married?
>
> Pa: Yes I am.

I: How long have you been in this marriage?

Pa: I have been married for 23 years.

I: Oh, it has been a while, huh?

Pa: Yes.

I: With the same husband that you are with now?

Pa: Yes, with the same man who died.

I: Oh I am sorry. When did he die?

Pa: 1998.

As revealed by this participant, this status of widowhood, especially among the grandmothers (in contrast with the grandfathers), also created a prolonged or permanent void that resulted in a loss of option to remarry. For many of these grandmothers, remarriage would have been considered culturally abominable by their children, in-laws, or other extended family members. Some grandmothers were in fact interested in remarrying; however, their desire was superseded by their family's and/or community's expectation that, out of respect for the deceased spouse, these grandmothers would maintain their widowhood. For example,

30_2016-Pa(4Luw)*:

I: Can't you get another husband or companion now.

Pa: I could but . . . . My friend, I don't want to take that chance . . . . Things are complicated. Mmmm. But if I do, wouldn't the children be upset?

22_2016-Pa(2Mask):

Pa: I didn't want to get married again.

I: Oh why?

Pa: [Laughs] No, I just didn't want to. . . . First of all, my husband [ex-husband] is nearby and you can't get someone else in the home.

In addition to death as a cause of terminated marriage, some participants reported that spouses had overtly divorced or separated from them or had abandoned their marriages and disappeared without notice. For example,

26_2016-Pa(6Mask):

> Pa: The most painful thing is that the person you would have called your companion cannot even take you to the hospital when you are ill at night and yet he has the money. Through all the illness and lack of necessities in the household, he insists that he doesn't have the money. Even when I moan and cry in pain, he does not say, 'my dear, what is the problem? Let me take you for treatment,' or 'here is the money for your treatment.' I wonder how he can turn on me at this stage in my life when I need him to provide for the family. I am reminded of how far we have come together. . . . So I continue suffering with the illnesses, without food and without school fees for the children. He does not come back home at times and if he does, he comes in at 2am. He is enjoying his life and that hurts so much because there is nothing I can do.

Because of the marital problems that this participant experienced, she was emotionally disconnected from her husband, who had other wives and families. This loss of marital connection was frequently reported—particularly by grandmothers. As a result of their marital disconnection, most of these grandmothers had decided to never remarry.

Similar to participant 26_2016-Pa(6Mask) above, other participants expressed a loss of a partner and co-parent with whom they shared the caregiving responsibilities. This marriage dissolution often left these older adults disappointed, frustrated, and without support—after relying on their spouses for many years. For example,

11_2016-Pa(4Bus):

> Pa: The other problem is that of not having a man because if it is the two of you, you put your heads together and see what to do. But now, not having a man, not having a supporter, you don't have anything . . . [Y]ou see, [I am] just surviving.

For most of the grandmothers, this type of pragmatic loss—the loss of husband as partner—was particularly challenging and distressing, because in Ugandan households, husbands are typically solely responsible for the family's financial support while wives are the family's homemakers. Accordingly, for these grandmothers, the loss of her husband often necessitated a restructuring of family roles and the requirement that she partake in jobs outside the home—jobs that in many instances were viewed as untraditional and inappropriate for women. Considering that most of these women were married as young teenagers and throughout their adult life had depended on their husbands for support, the loss of their spouses was a devastating hardship. Moreover, for many of these grandmothers, the hardships of marital loss were exacerbated by other household stressors, waning health, and aging.

Secondary Losses

Loss of resources. In addition to primary losses, the large majority of our study participants were further distressed by the loss of resources—in the form of either property or financial savings. For the majority of both rural- and urban-dwelling participants, the most valuable form of resource or asset is land, from which they grow food, sell produce, raise animals, and construct homes without any restrictions from landlords. Other forms of resources may include small business assets, such as a retail shop. In the course of nursing their loved ones, usually over long periods of time, many of these older adults deplete all of the resources available to them. With the loss of spouses, this experience is further complicated by family disputes in which other extended family divide up, and or abrogate land ownership and take property belonging to the deceased husband, such as retail businesses or real estate, and leave the grandmothers without any assets.

21_2016-Pa(1Mask):

> Pa: My husband had left me in a good place, with my own plot. But my son, the heir [to the husband] sold it. . . . [H]e sold my land . . . and went on to buy his own. He called and said, “Mother, I am going to build you a house and give you the grandchildren to stay with you,” but he never did.

30_2016-Pa(4Luw)*:

> Pa: My father-in-law had given us a piece of land in 2010, he [deceased husband] started selling it off, claiming that he would use that money to start a business for us. Instead, he got another woman and spent all the land money on her [before he died].

Loss of the “Safety Net.” In addition to discrete losses created by a death or disappearance of a loved one, many grandparent–caregivers in the present study reported collective losses—that we referred to as the loss of a “safety net.” Safety net losses were losses of both physical assets and a social network of friends, relatives, and immediate family members. For most affected grandparents, such losses entailed dissolution of significant relationships that otherwise would have formed human capital and a safeguard against social destitution. For example,

6_2016-Pa(6Kit):

> Pa: . . . you think about your husband that you lost, you think about the children you lost, you don’t have anywhere you call your own, your current situation is not good. So of course you have to think.

For affected grandparents, the absence of adequate income or any human capital or social services was an impairment of the safety net that was detrimental to their personal well-being and that of their grandchildren. In the narratives of these older adults, being “the only one left to care for the grandchildren” was a recurrent theme—an expression of frustration and despair that was exacerbated by the vitiation of their social network. For example,

30_2016-Pa(4Luw)*:

Pa: What makes me sad is that most of my supportive people have died. At one point, before my husband died, I fell very ill and had to be taken to the hospital. But when I returned, my husband started falling sick; my [niece's] husband fell sick too . . . he eventually died in October 2012. He used to take care of me and would take us out to have a good time. And in December 2012, my husband died and thereafter, my son died in January 2013. Before I would heal from all that pain, I had to bury my niece in March 2013. That one was the hardest for me to take because she was my mother and my father.

I: Mmmm.

Pa: She is the one that bought everything for me that I needed. Even when she was sick, she would send me money... So when she died, I died too... She left me with a lot of sadness and poverty and I can barely take care of her children. Her family took all her belongings.

Also, this loss of the social network was partly created by the weakening or disintegration of intergenerational ties or lineage. Such losses of intergenerational ties and lineage left some grandparents without the safety net of their kin—especially if marriages had failed or other life circumstances occurred, such as with losses of employment or migration of relatives. In some instances, resultant factors such as intergenerational mobility or family disputes eventually hindered communication or other contact that would otherwise have facilitated the grandparents' support-seeking efforts.

Loss of "The Dream." One consequence of safety net and tangible resource losses was a gradual disintegration of ambitions—dreams of what life could have been. In their conditions of chronic poverty, our participants' unemployment and lack of government and other supportive social services eventuated in a lack of formal pension, retirement plan, and savings. Indeed, the only practicable investment for these older adults was in their children and grandchildren' education and success in life. Accordingly, if the grandparent–caregivers' surviving adult children and grandchildren failed to provide for these grandparents, the grandparents' dreams of security and of benefiting from their family were for naught. If the surviving adult children died, the grandparents' hope for security died with them. For example, participant 7_2016-Pa(7Kit) explained the dilemma and regret of loss after she had invested in her children's education: 7_2016-Pa(7Kit):

> Pa: . . . But when I think about my children that way, I fail to eat. I think about the one that was a teacher and say, I wouldn't be working today if it she was alive. The same with the doctor... even in his death bed, he would look around to make sure that his wife was not watching and he would give me the money and say, "here you go, mom, I know how much money you spend on household expenses." [silence]

Applications of Findings from the Present Study

The study's findings can potentially inform multiple entities. For instance, to provide the support—tangible and emotional—that is needed to deal with the losses and costs of daily living (e.g., increasing visitations to older caregivers), family members must understand the nature and magnitude of the experienced losses. As often is the case, family and friends rally around those that have lost their loved ones and may offer emotional and tangible support during those difficult circumstances. However, that might not be the case with other types of loss, such as those discussed below, that could potentially have the same or even worse impact on the affected individuals. Therefore, increasing the public awareness on the dimensions of loss is critical.

Also, emphasis of the nature and multitude of the loses experienced by grandparent-caregivers could increase awareness among policy, research, health, and other stakeholders which is crucial in facilitating availability of and access to social services, such as crisis interventions and counseling, to this population. Furthermore, an understanding of loss as experienced by grandparent–caregivers can broaden our knowledge of the cultural dimensions of loss—how loss is perceived, experienced, and dealt with by members of ethnic minority populations. Such scientific evidence could inform other studies investigating similar populations and help to improve the quality of care given to those individuals and or communities. Ultimately, a more comprehensive understanding of this phenomenon could result in an improved, more holistic approach to providing culturally sensitive care and services to grandparent–caregivers.

Conclusion

Whether a grandparent-caregiver's loss was isolated or collective, the repercussions of this deprivation are adverse, often extensive, and can potentially have psychosocial and mental health implications. In contrast with the death of a loved one, which may elicit an urgent and supportive response from others, other types of losses highlighted in this paper may not elicit as much attention and concern for the well-being of these older caregiving adults. Hence, the aim of the present study is to increase public awareness of the dimensions of loss as experienced and understood by these older grandparent–caregivers. The application of this increased awareness is in informing the design, implementation, and administration of policy, public health, and interventions for improving the wellbeing of these grandparents. More importantly, studies are needed to better understand how these dimensions may individually or collectively affect caregiver–grandparents' physical and mental health. Studies that investigate how others may perceive the losses experienced by these grandparents are also needed. Indeed, the ubiquity of these loss experiences calls for a global response for preventing or mitigating of their impact on the lives and health of this vulnerable population.

References

Allen, T., & Heald, S. (2004). HIV/AIDS policy in Africa: What has worked in Uganda and what has failed in Botswana? *Journal of International Development, 16*(8), 1141–1154. Retrieved October 2, 2006, from http://www3.interscience.wiley.com/cgi-bin/fulltext/109751930/PDFSTART

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Baker, A. E. Z., Procter, N., & Gibbons, T. (2009). Dimensions of loss from mental illness. *The Journal of Sociology & Social Welfare*, *36*(4), Article 4.

Blumer, H. (1969). *Symbolic Interactionism, perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.

Bronfenbrenner, U. (1994). Ecological models of human development. *International Encyclopaedia of Education, 3,* Oxford, Elsevier.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods for the twenty-first century, in J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. Clarke, *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn*. Thousand Oaks, CA: Sage.

Collins, C., Liken, S., King, S. and Kokinakis, C. (1993). Loss and grief among dementia caregivers. *Qualitative Health Research*. 3:236–253.

Creswell, J. W. (2007). *Qualitative inquiry & research design* (2nd ed.). Thousand Oaks, CA: Sage.

Demmer, C. (2010). Experiences of women who have lost young children to AIDS in KwaZulu-Natal, South Africa: a qualitative study. Journal of the International AIDS Society, 13:50

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2016). *Fact Sheet November 2016*. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf

McCubbin, H. I. & Paterson, J. M. (1982). Family adaptation to crisis. In H. I. McCubbin and J. M. Paterson (Eds.), *Family stress, coping and social support* (pp. 26–47). Carbondale, IL: Thomas Publishers.

McCubbin, H. I. & Paterson, J. M. (1983). The family stress process: The double abc–x model of adjustment and adaptation. In H. I. McCubbin, J. M. Paterson & M. Sussman (Eds.), *Advances and Development in Family Stress Theory and Research* (pp. 1–26). New York.

Miltenberger, P., Hayslip, B., Harris, B., & Kaminski, P. (2004). Perceptions of the losses experienced by custodial grandfathers. *Omega: Journal of Death and Dying*, *48*, 245–262.

Sanders S., Morano C. & Saltz C. (2003). The expression of loss and grief among male caregivers of individuals with Alzheimer disease. *Journal of Gerontological Social Work, 39*(4), 3–18.

Saldaña, J. (2009). *The coding manual for qualitative researchers*. London: Sage.

Seeley, J. (2014). *HIV and East Africa: Thirty years in the shadow of an epidemic.* Abingdon-on-Thomas, UK: Routledge

Shives, L. R. (2008). *Psychiatric–mental health nursing* (7th ed.). Philadelphia: Lippincott, Williams & Wilkins.

Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *American Psychologist, 47*, 6–22.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

CHAPTER 7:

Discussion

Introduction

My academic and personal PhD journey started as a quest to understand the experiences of grandparents who care for grandchildren in Uganda. On reviewing the body of literature, I discovered that the story of these grandparents was being told secondary to the discourse about the impact of HIV/AIDS, particularly in Uganda and the sub-Saharan Africa region. Although prior to the HIV epidemic era, grandparents, particularly older women, have cared for grandchildren for generations (Seeley, 1993), very little research has focused on this population. With the advent of the HIV/AIDS epidemic in the early 1980s, research started to focus on those who provide care to people infected with HIV. However, none of these early studies had examined older adult caregivers as the unit of analysis. I recognized that in the HIV/AIDS discourse, the phenomenon of older adult caregiving and its impact on Uganda families could not be ignored. Accordingly, I initiated my dissertation with the research question: “What is the experience of the older grandparent–caregivers who care for grandchildren affected by HIV/AIDS in Uganda?” Before addressing this issue, a review of the extant literature was conducted to clearly identify and document the gaps in our understandings of this phenomenon.

Literature Review

The literature search revealed that research performed within the first decade of the HIV/AIDS epidemic (the late 1980s to early 1990s) investigated the impact of HIV/AIDS on family carers, with very sporadic attention given to older adult caregivers. In some of these investigations, researchers’ predominant interest was the well-being of the orphans, to the extent that the vulnerable population of grandparent–caregivers remained relatively invisible to the larger community of researchers, to policymakers, and to health care providers. In the late 1990s to early 2000s, some researchers began to focus more on the older adult as the primary caregivers. On discovering this paucity of research on older adult caregivers, particularly in Uganda, I decided to review recent research (i.e., performed within the last decade) that exclusively focused on the experiences, health, and well-being of grandparents 55 years of age and older who were primary caregivers for children impacted by the HIV/AIDS epidemic in the sub-Saharan African region—that part of the world most affected by the epidemic.

This literature review revealed that the effects of caregiving on these grandparent–caregivers were physical, financial, and emotional. Moreover, the literature review's 27 selected studies indicated that these effects were primarily negative, with very few reciprocal benefits conferred to the older adults who provided this care. Most important, however, the review revealed a persistent lack of understanding of the complex cultural and other contextual factors that impacted the health and well-being of these grandparent–caregivers. These deficits in our understanding confirmed the need for studies that investigate the prevalence and severity of caregiving-related morbidities among these older adults, the nature and effectiveness of their coping mechanisms, and potential interventions needed to improve the grandparent-caregivers' well-being. In order to achieve a stronger and broader foundation upon which such interventions and additional studies can be designed, utilization of methodologically sound qualitative approaches for investigating the caregiving phenomenon as experienced by the grandparent-caregivers in were imperative.

Methods and Theoretical Perspective

Informed by the review of the literature, I designed a qualitative study that used grounded theory (Charmaz, 2009; Strauss & Corbin, 1990). Grounded theory is a methodology underpinned by the social theory of symbolic interactionism, which posits that human behavior is a product of the interactions, socialization, interpretation, and formation of meaning in an individual's social world (Blumer, 1969). The purpose of this grounded-theory study was to seek understanding of the experiences and mental health of Ugandan grandparents 50 years of age and older who provide primary care for their grandchildren affected by HIV/AIDS. In order to achieve that purpose, the following specific aims were proposed:

1) explore the range of factors that influence the experience of older Ugandan grandparent–caregivers of grandchildren affected (directly or indirectly) by HIV/AIDS.
2) describe the caregivers' perceptions of how their decision to care for their grandchildren affects their health, quality of life, and satisfaction with relationships to significant others;
3) explore the prevalence of mental health symptoms in this grandparental population using the Cultural Formulation Interview (CFI) of the DSM IV that will inform the interview guide.

In accordance with postmodern approaches to grounded theory (Charmaz, 2006), two theoretic approaches informed the proposed study: the social ecological model (SEM; Bronfenbrenner, 1994) and the family adjustment and adaptation response (FAAR) model (McCubbin & Paterson, 1982, 1983; see Appendix C). The complimentary application of these two theories together with the underpinning lens of symbolic interactionism was proposed to promote a nuanced understanding of the social interaction, meaning, and subsequent behavior pertaining to caregiving experiences of Ugandan grandparents caring for grandchildren affected by HIV/AIDS.

Equipped with these methodological and theoretic tools, I was ready to conduct the study.

After seeking and obtaining ethical approval and administrative clearance from the Institutional Review Board of the University of California, San Francisco Committee on Human Research, Makerere University College of Health Sciences and the Uganda National Council for Science and Technology, I commenced with data collection in Uganda. In order to provide the study with richer narratives that could represent the diversified perspectives and experiences of grandparents, purposive and snowball sampling techniques were used to recruit participants from both rural and urban areas of Uganda, particularly those that, historically, have been the most affected by the HIV/AIDS epidemic. Audio-recorded data were transcribed and analyzed using Atlas-Ti software (a word processing program that manages the analysis of qualitative data). Grounded theory procedures of coding, "memoing," and diagraming were used to analyze developing concepts and categories that later informed the write-up of the dissertation chapters.

Meaning of Findings in Relation to Research Questions and Specific Aims

Charmaz (2006) advises that, "Through writing and rewriting drafts, you can bring out implicit arguments, provide their context, make links with extant literatures, critically examine your categories, present your analysis, and provide data that support your analytic arguments" (p. 154). In following this advice, I aimed to fulfill my study purpose and its proposed specific aims by analyzing salient memos and categories and establishing the links between them (as illustrated in Figure 2, p.55 of this dissertation) in order to contribute to filling some of the gaps identified in the review of the literature. Specific Aim 1 was meant to drive the research process by keeping interview guide questions open-ended and by enabling the exploration of all factors that were perceived by these grandparents. For example, by asking interview questions such as "Tell me about how you started taking care of your grandchildren/child" quite early in the interview, the participants were given the opportunity to narrate any part of their caregiving experience that they perceived as being significant in their commencement of the role. Following such open-ended question with prompt questions such as, ‘Tell me more,” resulted in participants’ providing responses that enabled me to fulfil Specific Aim 1 and the other specific aims.

As a result of the open-ended and semi-structured interview questions, categories emerged that further enriched the concept of caregiving in Chapter 4 of this dissertation. In this chapter, pertinent terms such as *grandparenting* versus *caregiving* and *care receivers* were defined. Because these terms are frequently used in the extant literature, I sought to clearly understand how the grandparent–caregivers in the current study perceived these meanings as they pertain to their role. First, however, it became clear that the understanding of the role was influenced by the specific antecedents that precipitated these individuals taking on caregiving. The social factors that predisposed the grandparent–caregivers were identified as the grandparents’ and their adult children’s poor health as well as the poor socioeconomic status of the adult children.

A notable finding from the current study is the symbiotic relationship between grandparents and their grandchildren. This reciprocity in caregiving role has been reported by a few sub-Saharan studies (Kasedde, Doyle, Seeley & Ross, 2014; Mugisha, Schatz, Seeley & Kowal, 2015; Skovdal, 2010). Comparatively, this particular finding has not been reported in western literature on the caregiving phenomenon as experienced by grandparent-caregivers (Kelley, Whitley & Campos, 2010; Minkler, Fuller-Thompson, Miller, & Driver, 1997; Musil, Warner, Zauszniewski, Wykle & Standing, 2009). The interactive nature of this experience is created by cultural influences of family and the poor economy that forces these older adults to be more dependent on their extended family as opposed to formal social support services that are often available to their western counter parts. Therefore, the current study provides a better understanding of such antecedents to caregiving that can inform design of social support services needed to the grandparent caregivers.

Also, the grandparent–caregivers reported that, prior to assuming caregiving responsibilities, several factors had been crucial in the process by which the grandparents decided to assume those responsibilities. Those factors were "culture, gender, and family expectations," "the default caregiver," and "negotiation." Because of these intrafamilial dynamics, the older adults embarked on a journey of caregiving that was reported to bear rewards, but had mostly negative physical, financial, and emotional consequences that seemed to outweigh the benefits. With this comprehensive report of factors in both micro- and macro-levels pertaining to the caregiving role among grandparent–caregivers, Chapter 4 fulfilled Specific Aim 1.

Chapter 4 also fulfilled part of Specific Aim 2, specifically by exploring the impact of caregiving on the grandparents' health. The participants reported that they perceived their cumulative caregiver burden as contributing to their poor physical health and to diminished quality of life. Physical complaints such as chronic pain, cardiac symptoms, and musculoskeletal symptoms were reported. In addition, some of the grandmothers reported psychological complaints such as those related to abandonment by their significant others. These complaints were due in part to the increased household demands of caring for orphans; however, other marital factors such as polygamy were also reported.

Then, by describing a salient theme of loss that was reported by all participants in various dimensions, Chapter 5 provided additional insight that facilitated achievement of Specific Aim 2. In order to broaden our understanding of loss as experienced by Ugandan grandparent–caregivers in this era of HIV/AIDS, this chapter uniquely describes the various dimensions of their loss and the nature, extent, and interrelationships between these losses**.** The reported losses included those of a *primary* nature, such as loss of self; adult children, spouses, and other family members. Other losses—*secondary losses*—that came as a result of the primary losses included loss of resources, safety net, the dream. Although some of individual dimensions of loss may have been reported in other studies (Demmer, 2010; Seeley, 2014), the manner in which they are presented in this chapter is intended to emphasize the impact of all types of losses, whether death-related or not, on the well-being of the grandparent–caregivers. This analytic perspective uniquely contributes to a broader understanding of cumulative loss experienced by Ugandan grandparent-caregivers in a way that other studies have not. This chapter presented the participants' reflections on their lives and on their anguish. These reflections offer a glimpse into their mental health.

Informed by Chapter 4 and 6, Chapter 5, on mental health, aimed to fulfil Specific Aim 3 by providing an account of perceived psychosocial distress and the mental health implications of caregiving and loss. Chapter 5 was, in part, informed by Cultural Formulation Interview of the Diagnostic and Statistical Manual of Mental Disorders (CFI; APA, 2013) that is aimed to promote cultural humility in the mental health care of ethnic minority groups. Application of the CFI principles to research of ethnically diverse groups enables investigation of mental illness and associated symptoms in a culturally sensitive manner; also, this investigation uniquely highlights features and manifestations of symptoms of psychological distress. This symptomatology may be captured through meanings, communications, and presentations specific to a culture; these meanings, communications, and presentations further inform our understanding of these cultural dimensions and facilitate diagnosis and treatment of mental illness in similar ethnically diverse populations. As such, questions such as “What do you think caused ‘thinking a lot’?” or “What does ‘feeling bad’ mean to you?” further enabled participants to explain the meaning of their distress more in greater detail and more accurately. This approach also enabled me to investigate the participants’ support-seeking behavior, particularly as this behavior pertains to seeking treatment from traditional healers who are the provisional mental health providers accessible to most of the grandparent–caregivers.

Given the dearth of knowledge on the prevention, prevalence, and treatment of mental health in the Sub-Saharan Africa, and particularly in Uganda, Chapter 5 was intended to address the qualitative deficit in the research evidence pertaining to older grandparents who care for grandchildren affected by HIV/AIDS. Although the findings presented in this paper were not based on diagnostic data, they characterized the psychosocial distress symptoms reported by the participants and how these symptoms may suggest the prevalence or risk of mental disorders. Furthermore, this chapter presented various forms of coping that were used by the grandparent–caregivers in dealing with their multiple forms of psychosocial distress. The grandparent–caregivers coped by, in their terms, “finding comfort in numbers,” “escaping grief,” “letting go,” “distracting self,” “finding meaning,” and through “spirituality,” “social support,” and “perseverance.” Whether these forms of coping were effective or not is the subject of future studies that are needed to improve the mental health of these grandparent–caregivers.

Conceptualization and Theorization of the Caregiving Experience

Charmaz (2006) argues that “a contextualized grounded theory can start with sensitizing concepts that address such concepts as power, global reach, and difference and end with inductive analyses that theorize connections between local worlds and larger social structures" (p. 133). The review of pertinent literature and application of pre-existing theories (SEM and FAAR) was the starting point that provided me with the sensitizing concepts and highlighted deficits in our knowledge of the caregiving phenomenon as experienced by grandparent–caregivers in Uganda. Further exploration of this social phenomenon and a critical look at the unique macro and micro social contexts and the interplay between these levels of interaction led to my modification of Bronfenbrenner's social ecological model (see Figure 3) and further refined my understanding of grandparent–caregivers' caregiving experience.

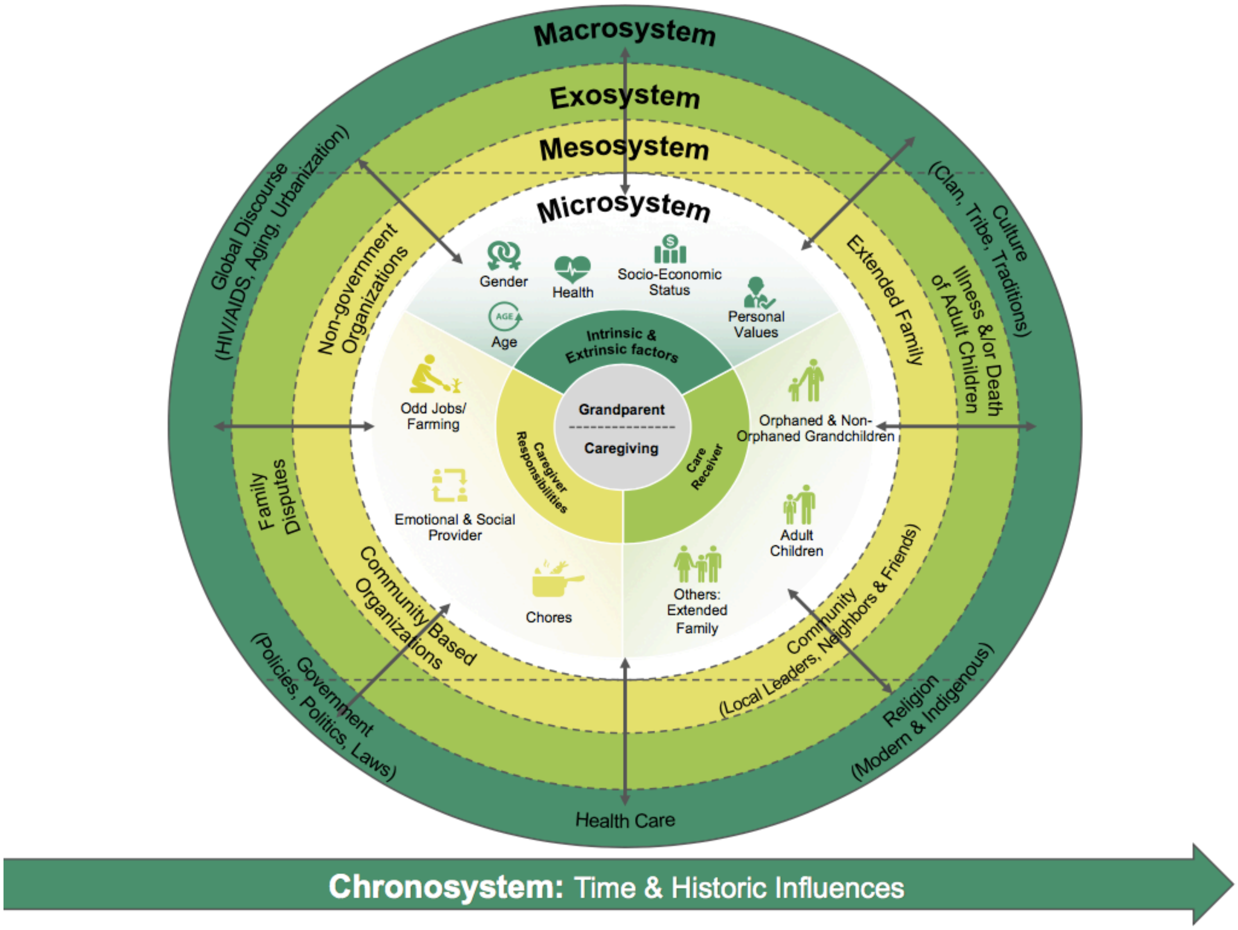


Figure 3: Matovu's modification of Bronfenbrenner's social ecological model.

During this study’s data analysis phase, salient categories and sub-categories were identified and links were made between them to make sense of the emerging theoretic explanation of the caregiving experiences. The developing theoretic framework was pieced together using conceptual diagraming as illustrated in Figure 2 (see p.55 of this dissertation). Several grounded theorists believe that the use of diagrams to illustrate “the relative, power, scope, and direction of the categories in the emerging theory” is essential in the analytic process (Charmaz, 2006, p. 118). However, we developed a more robust presentation of the key concepts and processes related to the caregiving role as experienced by Ugandan grandparent–caregivers as illustrated in Figure 4 below. This framework represents the key concepts and processes involved in the caregiving experience of participants in the current study: the antecedents of caregiving: decision-making processes; caregiving concept; balance between perceived rewards and burdens; adjustment (coping and adaptation); and grandparent–caregivers’ well-being (health and quality of life as related to the Maslow's hierarchy of needs):

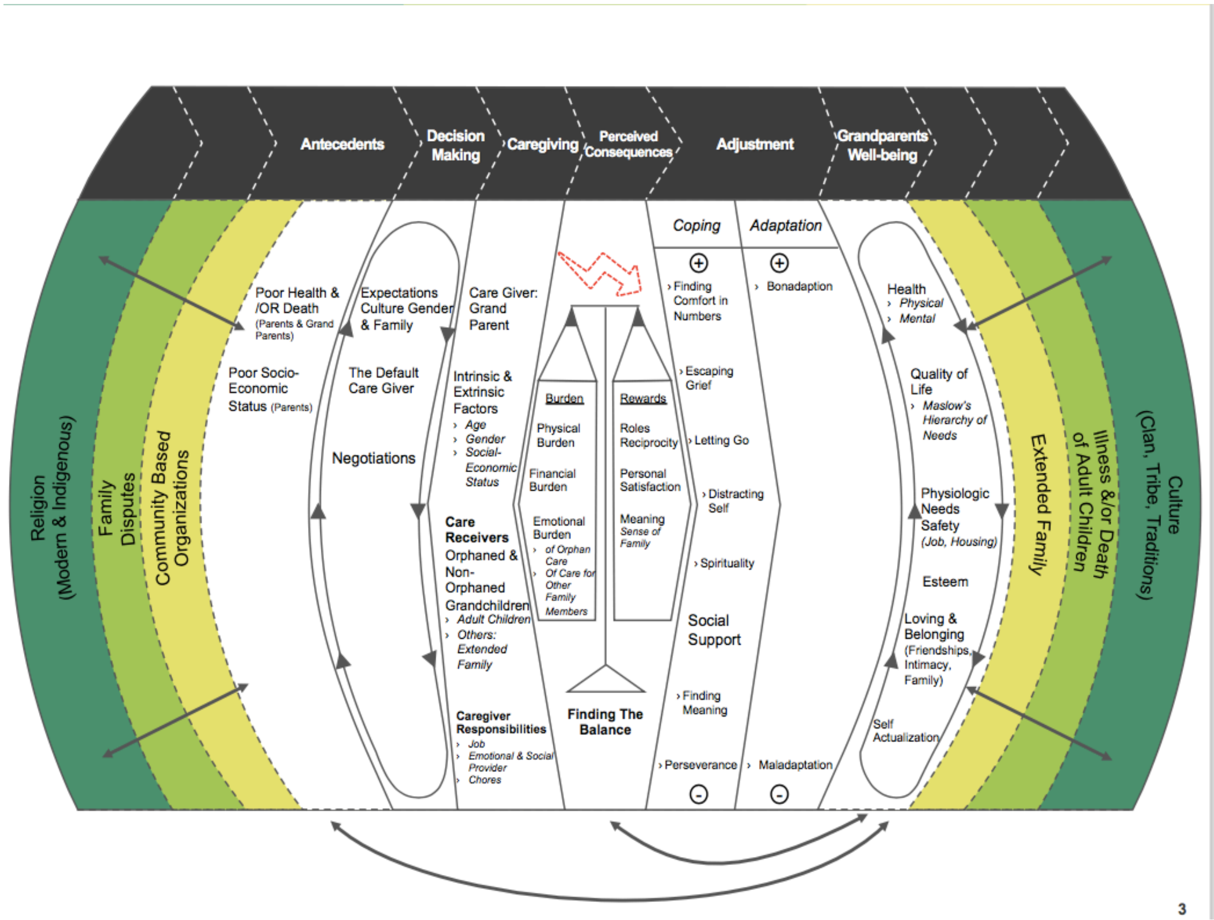


Figure 4: The Matovu GRAndparent CarEgiving (GRACE) model.

To achieve higher levels of abstraction and induction and develop a substantive theory, this process of broadening theoretical conceptualizations is ongoing. However, early hunches that supports this theoretic argument and propositions are emerging. For example, from Figure 2 (see p.55 of this dissertation), an overarching argument can be made that a strong cultural value and support system (represented by the roots of the tree)—that may include spiritual and or cultural beliefs—could provide a solid foundation to withstand any negative social factors (arrows towards stem) or competing role demands (represented by the tree's branches). The strong value and support system would in turn promote for grandparent–caregivers' positive coping and subsequent good health. In contrast, from the current study findings we can argue that increased role demands coupled with a weak family or cultural value and social support system could result in poor mental and physical health outcomes. These findings confirm findings that have been reported for similar populations (Kelley, Whitley & Campos (2010); Minkler, Fuller-Thompson, Miller, & Driver (1997); Musil, Warner, Zauszniewski, Wykle & Standing, 2009). Unfortunately, studies that examine these conceptual and theoretic explanations of the caregiving as experienced by grandparent-caregivers in the sub-Saharan region are very limited. Therefore, the current study uniquely contributes to this deficit in the knowledge.

Furthermore, the conceptual model also emphasizes the embeddedness of the caregiving experiences in the macro level of the sociocultural, national, and global contexts. Also, unlike the FAAR model and similar models that focus on the response of a family system in the face of a stressful event to adapt and adjust to, and cope with stressors and family demands over time, my GRACE model in Figure 4 (See p.148 of this dissertation) positions the grandparent–caregiver as central to this role. For instance, as depicted in Figure 4, the grandparent-caregiver's negative perception of the caregiving role and responsibilities could directly impact their well-being (health and overall quality of life), especially when faced with a crisis. The current findings provide an extensive and individualized qualitative account as experienced by the grandparent-caregivers. Ultimately, the GRACE model does not offer an autonomous and generalizable theory but rather an open model of a transferable substantive explanation of the caregiving experience of Ugandan grandparent–caregivers who care for grandchildren affected by the HIV/AIDS epidemic. To my knowledge, no study conducted in Uganda to date has provided such conceptualization and theorization of caregiving phenomenon as experienced by grandparent–caregivers who are caring for grandchildren affected by HIV/AIDS.

Limitations

The proposed study had several limitations. First, the restriction of participant recruitment to only four sites constrains the transferability or fittingness of findings' application to other populations in different parts of the country or continent of Africa. However, as informed by Denzin (1978) and Patton (1999), the study used triangulation of both rural and urban data sources to further examine consistency in different participants' points of view and to capture the variety of dimensions of the caregiving phenomenon. Also, theoretical sampling as described in chapter three enabled me to seek out participants who provided narratives that further confirmed and strengthened the emerging and salient categories (Glaser & Strauss, 1967).

Second, the proposed sample size of this dissertation study may be viewed as small in comparison with that of quantitative studies. However, because the intent of the sampling in qualitative research is not to generalize findings, but rather to describe the experiences of participants, the ultimate number of participants (32) was more than average to most qualitative studies (Charmaz, 2006). Third, contextual factors related to poverty—such as some participants' lack of telephones or other communication technologies—prevented me from contacting those participants for post-interview member checks that are essential for ensuring rigor. These hindering contextual factors may have decreased the confirmability of the study's findings (Ryan, Coughlan & Cronin, 2007).

Moreover, the brevity of the period during which the data were collected (3 months) may have may have hindered the practice of heightened theoretical sensitivity that otherwise could have enhanced the study's rigor and credibility. Glaser and Strauss (1967) have defined *theoretical sensitivity* as the researcher's ability to "conceptualize and formulate a theory as it emerges from the data" (p. 46). Ultimately, data collection was completed when theoretical saturation was reached, the study's purpose and specific aims were achieved, and no new data were being extracted from the interviews. The methodological rigor improved the study's overall credibility or faithfulness, goodness or authenticity, and dependability or auditability (Ryan et al., 2007).

Innovativeness in Addressing Gaps

As illustrated in the preceding chapters, the research purpose and all of the specific aims proposed at the beginning of the dissertation research were achieved. Considering that nurses constitute the predominant health professional workforce serving these populations, this study contributed to the nursing knowledge—knowledge that is desperately needed for providing holistic perspectives to conceptualization and investigation of the caregiving phenomenon as experienced by grandparent–caregivers. This approach not only informs nursing practice, but also opens up opportunities for interprofessional collaborations and embraces the diversity of human experiences.

As discussed in Chapter 2, the majority of published studies on failed to clearly identify an underlying conceptual or theoretical framework upon which the studies were based, or mention an attempt to develop a new model or test an existing model. The absence of culturally appropriate theories that could facilitate investigation of grandparental caregiving in sub-Saharan Africa has contributed to the deficits in our understanding of the phenomenon. These knowledge deficits pertain to the experiential and conceptual complexities of caregiving, the effectiveness of coping mechanisms, and the prevalence and severity of possible related morbidity. These gaps in research are substantial and consequential. Therefore, to support research that contributes to the development of the knowledge base pertaining to the caregiving phenomenon as experienced by grandparent-caregivers, this dissertation followed rigorous methodological tenets and practices congruent with and supported by sound philosophical and theoretical underpinnings.

The present study is one of a small number of studies that have qualitatively examined the impact of the HIV/AIDS epidemic on the well-being of grandparent–caregivers' in Uganda and their perceptions of the outcomes of their decision, or lack of decision, to care for their grandchildren, including its impacts on their health, quality of life and significant relationships. In addition, to my knowledge, this was the first study conducted in Uganda to use grounded theory in investigating the experience of grandparent–caregivers who are caring for grandchildren affected by HIV/AIDS. Grounded theory is inductive, context-bound, person-oriented, and non-hypothesis-driven. As such, the use of grounded theory conducive to holistic scientific inquiry into participants' social world and to the development of conceptual–theoretic explanations of the complexities of this phenomenon. This methodology enables broader exploration, deeper analysis, and a more comprehensive understanding of participants' experiences from a shared human experience and epistemological point of view of the research and the participant (Holloway & Wheeler, 2010). In seeking a better understanding of Ugandan grandparents' experiences of caregiving, I have understood, appreciated, and taken to heart the recommendations by Charmaz (2006) and others regarding the need for researchers to practice reflexivity, relationality, and theoretical sensitivity when conducting qualitative research. As the present study's primary researcher, I have attempted and I hopefully succeeded in applying these practices for the optimization of the research and, ultimately, to the benefit of the grandparent–caregivers who are so deserving of our support. To this end, this dissertation was intended to contribute to the existing knowledge base and to the discourse concerning the Ugandan grandparental caregiving phenomenon and to improve these older adults' health and well-being.

Summary and Implications for Nursing

The safety net that older adults provide as Uganda's primary caregivers is crucial not only to the individuals affected by the HIV/AIDS epidemic, but also to the national economy and public health system. Without this strong safety net, Uganda would face additional social distress from multiple causes, including increased orphan homelessness, increased incidence of HIV resulting from increased engagement in risk behaviors driven by survival needs; increased pressure on the public health system; and a general decline in the national economy as a result of a diminishing productive population. The findings of this study could inform health providers in their development of appropriate family-centered care plans, childcare, and respite care, among other social services. Furthermore, these study findings could usefully inform researchers who may seek explanatory models upon which to design or test interventions tailored for a grandparent who provides primary care for a grandchild with HIV infection. For instance, the findings of the current study will inform the design of a proposed intervention study outlined below:

Future Research

My future goals include building on the dissertational study findings and further developing knowledge to contribute to the mitigation of this financial, emotional and physical caregiver burden among Ugandan grandparents. I will aim to achieve this by, first, partaking a postdoctoral research project focused on identifying key community stakeholders needed to design a feasible intervention to promote financial empowerment and self-efficacy; improve physical and mental health outcomes; and strengthen the social network of caregiving Ugandan grandparents. The specific aims will include (a) identifying challenges faced by older Ugandan grandparent–caregivers of grandchildren affected by HIV/AIDS and highlight solutions they perceive as effective in improving their well-being; (b) engaging key stakeholders (e.g., nurses and social workers) and community-based organizations in identifying a feasible intervention needed to promote the well-being of Ugandan grandparents. This research will be informed by the fundamental premises of community-based participatory research (CBPR), which posits that genuine and long-term partnerships have to be fostered among key stakeholders in the design and implementation of research and capacity building tailored to address the needs of marginalized groups (Wallerstein & Duran, 2010).

Key stakeholders who were identified during the dissertation data collection phase and new stakeholders will be contacted to further achieve the research aims. I will travel to Uganda to convene focus groups of grandparents and other stakeholders and perform member checking to validate the findings of the preliminary data analysis and further broadly explore and elicit feedback on perceived interventions needed to improve these grandparents' well-being. Ultimately, the postdoctoral study findings will inform my long-term research agenda that will include the design of a multi-faceted and community-based intervention and test its effectiveness in promoting financial empowerment and self-efficacy; improving physical and mental health outcomes; and strengthening the social network of these Ugandan grandparents.

References

American Psychiatric Association.[APA]. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Blumer, H. (1969). *Symbolic Interactionism, perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.

Bronfenbrenner, U. (1994). *Ecological models of human development.* International Encyclopaedia of Education, 3, Oxford, Elsevier.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Charmaz, K. (2009) Shifting the grounds: Constructivist grounded theory methods for the twenty-first century, in J. Morse, P. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. Clarke, *Developing Grounded Theory: The Second Generation*. Walnut Creek, CA: Left Coast Press.

Denzin, N. K. (1978). *Sociological Methods*. New York: McGraw-Hill.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory.* Chicago: Aldine.

Grobler, H., & Roos, V. (2012). Psychosocial experiences of coloured grandmothers who care for their grandchildren: Implications for intergenerational relations. 30th International Congress of Psychology, 22–27 July, Cape Town.

Holloway, I., & Wheeler, S. (2010). *Qualitative Research in Nursing and Healthcare*. Oxford: Blackwell.

Kasedde S., Doyle A. M, Seeley J. A., & Ross, D. A. (2014). They are not always a burden: Older people and child fostering in Uganda during the HIV epidemic. *Social Science Medicine, 113*, 161– 168.

Kelley, S. J., Whitley, D. M., & Campos, P. E. (2010). Grandmothers raising grandchildren: Results of an intervention to improve health outcomes. *Journal of Nursing Scholarship*, *42*, 379–386.

McCubbin, H. I., & Paterson, J. M. (1982). Family adaptation to crisis. In H. I. McCubbin and J. M. Paterson (Eds.), *Family stress, Coping and social support* (pp. 26–47). Carbondale, IL: Thomas Publishers.

McCubbin, H. I., & Paterson, J. M. (1983). The family stress process: The double abc–x model of adjustment and adaptation. In H. I. McCubbin, J. M. Paterson & M. Sussman (Eds.), *Advances and Development in Family Stress Theory and Research* (pp. 1–26). New York.

Musil, C. M., Warner, C. B., Zauszniewski, J., Wykle, M., & Standing, T. (2009). Grandmother caregiving, family stress and strain, and depressive symptoms. *Western Journal of Nursing Research, 31*, 389.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *HSR: Health Services Research, 34*(5) Part II. pp. 1189–1208.

Ryan, F., Coughlan, M., & Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing, 16*(12), 738–744.

Seeley, J. (1993). *Searching for indicators of vulnerability: A study of household coping* *strategies in rural South West Uganda.* London: MRC/ODA.

Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques.* Newbury Park, CA: Sage.

Wallerstein, N., Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*, 100: S40–S46.

APPENDICES

Appendix A

Consent Form

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: *Understanding Experiences of 50-years and older Grandparents Caring for Grandchildren Affected by the HIV/AIDS Epidemic in Uganda.*

This is a research study focuses on seeking understanding of the experiences of the 50-years and older Ugandan Grandparent Caring for Grandchild/ren Affected by the HIV/AIDS Epidemic. The study researchers, Margaret I. Wallhagen, PhD, GNP-BC, AGSF, FAAN and Schola Matovu, RN, BSN, MSN from the UCSF Department of Physiological Nursing will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating, and discuss your decision with your family or friends if you wish. If you have any questions you may ask the researchers.

You are being asked to take part in this study because you are a 50-years and older Grandparent Caring for Grandchild/ren Affected by the HIV/AIDS Epidemic in Uganda.

Why is this study being done?

The purpose of this study is to better understand the experiences of the 50-years and older Grandparent Caring for Grandchild/ren Affected by the HIV/AIDS Epidemic in Uganda. The findings will be recommended as positive approaches to improve the psychosocial well-being of these grandparents.

How many people will take part in this study?

About 20-25 people will take part in this study.

What will happen if I take part in this study?

If you agree, the following procedures will occur:

- You will be asked to fill out a sheet about some personal and family information. Ms. Matovu will assist you where necessary.
- You will meet with Ms. Matovu at a location that will provide privacy and comfort and take part in an interview. You will be asked to describe your experience taking care your grandchild or grandchildren. This interview will take no longer then 90 minutes.
- If necessary, a second interview may be conducted to clarify information from the first interview. The second interview will take no longer than 90 minutes.

- Ms. Matovu will make a sound recording of your conversation. After the interview, someone will type into a computer a transcription of what's on the tape and will remove any mention of names. Once the transcription has been reviewed and compared to the audio recording, the recording will be destroyed.
- If necessary, you will be requested to have your photograph taken with or without your grandchild or children or even your home in order to better understand your experience as a caregiver. If any of your grandchildren is a minor, we will request that you grant us consent on their behalf to take their photograph. These photographs could be used in publications during dissemination of this study. The faces of all individuals taken will be obliterated in order to protect their anonymity. Therefore, you are at liberty to refuse to have your photograph or that of your grandchild or children and home taken during the study.
- **Study Location:** All these procedures will be done at a location that is mutually agreed upon between you and the researcher. The location will provide for privacy, comfort and safety for you and Ms. Matovu.

How long will I be in the study?

Participation in the study will take about 90 minutes per interview and a total of not more than 180 minutes for two interviews per participant if needed.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher right away that you wish to stop being in the study.

Also, the study researcher may stop you from taking part in this study at any time if she believes it is in your best interest, or if the study is stopped.

What side effects or risks can I expect from being in the study?

- Some of the interview questions may make you worried or upset. You are free to not answer any question. You are free to end the interview at any time.
- If you do not wish to continue an interview, you may request to reschedule at a later time.
- **Confidentiality:** Participation in research may involve a loss of privacy; however your records will be handled as confidentially as possible. Only Ms. Matovu, Dr. Wallhagen and those working on the research study will have access to your records. After the interview information has been transcribed from the audio recording and verified, the recording will be destroyed. Your name or other information that interviews you will not be used in any reports or publications that may result from this study.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However information that you provide may help health professionals better understand the experiences of 50-years and older Grandparents Caring for Grandchildren Affected by the HIV/AIDS Epidemic in Uganda.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in this study. If you decide not to take part in this study, there will be no penalty to you.

Will information about me be kept private?

- We will do our best to make sure that the personal information gathered for this study is kept private. However, we do not guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. If, during participation in this study, you report instances of child abuse or neglect, the researchers will report these events to the authorities as well as your contact information that you have provided. In addition if you report thoughts of self-harm, for your safety, the researchers may also take further action. Further explanation of these instances is given below:
    - Suspected child abuse or neglect: If during the interview process you reveal information that suggests that a child has been abused or neglected by you or anyone else, Ms. Matovu is required to report this to Child Protective Services for further investigation.
    - Caregiver or adult abuse: If during the interview process you reveal information that suggests caregiver or adult abuse, Ms. Matovu is required to report this to the authorities for further investigation.
    - Suspected self-harm or suicidal thoughts: If during the interview process you reveal information that suggests that you have thoughts of hurting yourself or share thoughts of suicide, Ms. Matovu may call 999 (Ugandan police) and emergency personnel if she feels you are in immediate danger. If you are not in immediate danger, yet may require further support and services, your contact information may be shared with the community organization or support group from which you were recruited.

Organizations that may look at and/or copy your research records for research, quality assurance, and data analysis include:

- UCSF's Committee on Human Research
- Makerere University IRB

What are the costs of taking part in this study?

You will not be charged for any of the study treatments or procedures.

Will I be paid for taking part in this study?

In return for your time, effort and travel expenses you will be compensated for your time with a gift of 10,000 Ugandan shillings per interview for taking part in this study, a maximum award of 20,000 if a second interview is needed. However you will be compensated with 10,000 Ugandan shillings immediately following the completion of each interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at anytime. No matter what decision you make, there will be no penalty to you in any way. You will not lose any of your regular benefits, and you can still get your care from this institution the way that you usually do.

Who can answer my questions about the study?

You can talk to the researchers about any questions, concerns, or complaints you may have about this study. Contact the researchers Schola N. Matovu at (+256) 783915149 or Dr. Rose Nabirye of Makerere University at (+256) 772592923 (cell), who is the local supervising researcher to Ms. Matovu and the study. You could also contact the study PI, Dr. Margaret I. Wallhagen at 415-476-4965.

If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the office of Dr. Rose Nabirye of Makerere University at (+256) 772592923 (cell), who is also the contact Makerere IRB committee member for this study. You could also contact the Chairperson, School of Health Sciences Institutional Review Board, Mr. Paul Kutyabami, at Tel: (+256) 772-404970.

CONSENT

You have been given a copy of this consent form to keep.
PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

____________	______________________________________
Date	Participant's Signature for Consent
____________	______________________________________
Date	Person Obtaining Consent

Appendix B

Interview Guide

Before we begin with the interview I just want to take this time to thank you for agreeing to participate in this study and to remind you about the purpose of the study. I am interested in knowing about your experience of being a caregiver for your grandchildren/child. Particularly, I want to learn what it has been like for you and so from time to time I will ask for examples to help me understand. I might also have to take a few notes during the interview to make sure that I don't miss any important points.

[Consent participant]

Individual	
1. Tell me a bit about yourself so I can get to know you better.	*Fill out demographics questionnaire.*
Role and responsibilities	
2. Tell me a little about what your daily schedule is like.	*House/Home chaos etc.*
3. Tell me about how you started taking care of your grandchildren/child.	▪ *How many grandchildren do you take care of?* ▪ *How long have you been taking care of them?* ▪ *What influenced your decision to assume care for your grandchildren/child* ▪ *What was the major consideration in these decisions?* ▪ *Were there any discussions on who should care for your grandchildren/child when you first took on that responsibility? Would you describe that for me?* ▪ *Who was involved in the decision-making?* *What would you say were the most influential factors related to the decisions to care for your*

Cultural identity	
4. What does it mean to you to be a grandmother/caregiver for your grandchildren/child in your clan/tribe?	*Prompt for cultural meanings of the grandparenting/caregiving role: which side of the family assumes care of grandchildren in the absence of the child's parents; Moral Traditions, Roles and responsibilities as elder and caregiver* *Tell me more…*
5. How do you think you are doing in fulfilling your responsibility as a caregiver?	*Tell me more…*
Experiences with caregiving/grandparenting and family relationships	
6. Tell me about your grandchildren/child. What is the nature of your relationship with your grandchildren?	*Grandchildren/child's behavior (respectful, hardworking, obedient, school performance)*
7. Tell me about your adult children/child (parents to children under your care). What is the nature of your relationship with your adult children/child?	*Do they live with you? If not, how often do you see them?* *Tell me more…*
8. What has been your experience dealing your family or community since you started taking care of your grandchildren/child?	*Please give me more examples.* *Elicit other family/community relationships.*
9. Is your experience any different from that before assuming care of your grandchildren/child?	*Tell me more…*
Stressors and Supports: (Social Network, Caregivers, Physical and psychosocial Stressors on health)	
10. Tell me about a particularly challenging event that has occurred when taking care of your grandchildren/child.	*Explore negative aspects of the participant's life.*

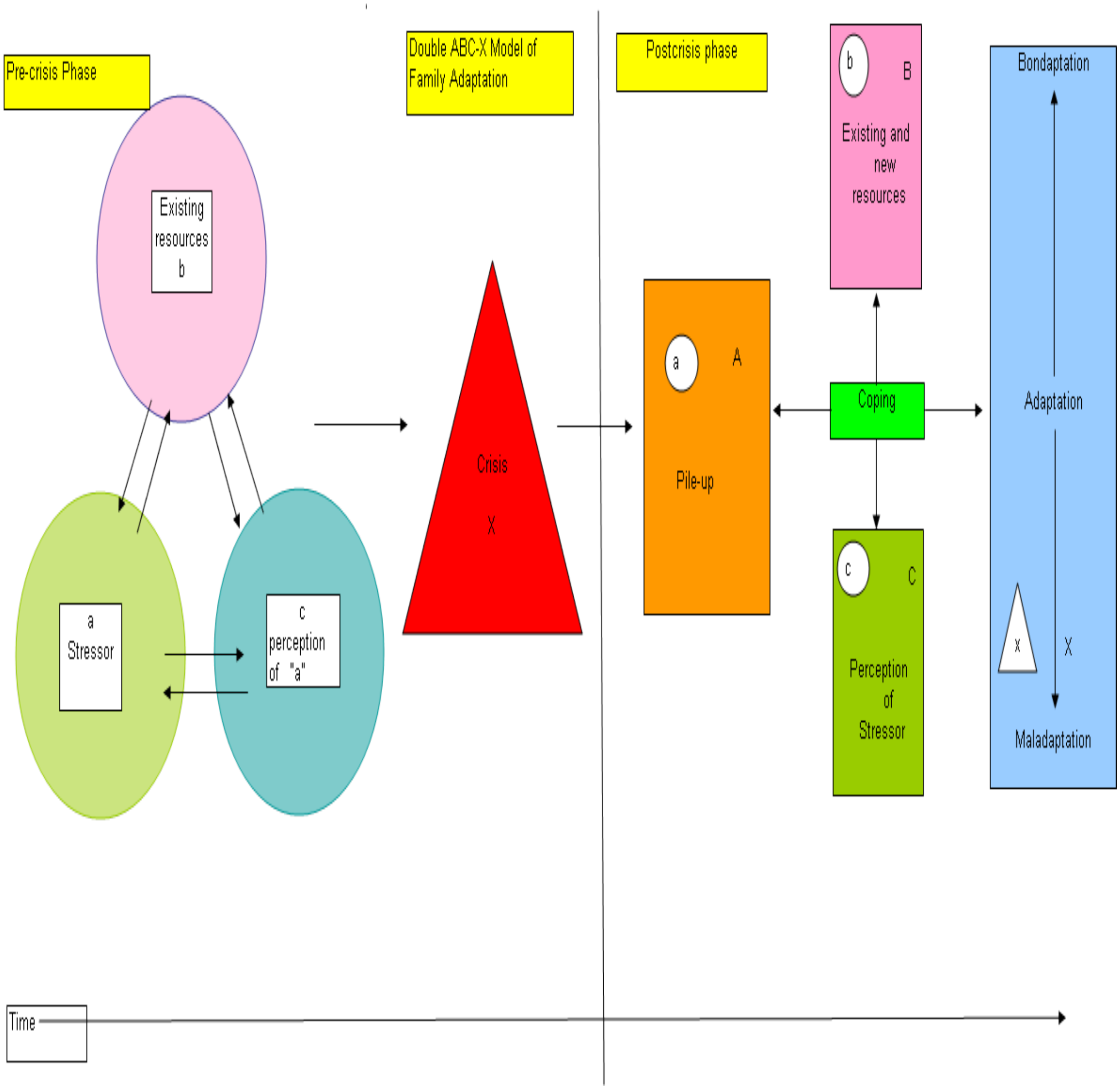
11. Tell me about your health.	*How you think caregiving has affected your overall health?* *How does your health now compare to before you assumed the caregiving role?* *Explore participant's perception of impact of caregiving on both their physical and mental aspects of their health.*
12. What kinds of support makes 'grandparenting' better, such as support from family, friends, or others?	*Please give me more examples.*
13. Tell me about particularly rewarding aspects of taking care of your grandchildren/child.	[Purpose of this question is to end on a positive note] *Explore positive aspects of the participant's life.*
14. Before we end today, is there anything else that you would like to share with me that I have not yet asked you about or that we haven't discussed?	*(Set up another time to meet for a second interview if needed).*

Thank you for taking the time to speak with me. Do you have any questions for me?

[End recording]

Appendix C

Double ABC–X **F**ramework: Family Adjustment and Adaptation Response Model (McCubbin & Paterson, 1982).



UCSF Library Release

Publishing Agreement

It is the policy of the University to encourage the distribution of all theses, dissertations, and manuscripts. Copies of all UCSF theses, dissertations, and manuscripts will be routed to the library via the Graduate Division. The library will make all theses, dissertations, and manuscripts accessible to the public and will preserve these to the best of their abilities, in perpetuity.

Please sign the following statement:

I hereby grant permission to the Graduate Division of the University of California, San Francisco to release copies of my thesis, dissertation, or manuscript to the Campus Library to provide access and preservation, in whole or in part, in perpetuity.

April 26th, 2017

Author Signature Date