

Post-Caregiving Transition in African American Caregivers

by

Ebere Peace Ume

A Dissertation Presented in Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Philosophy

Approved July 2013 by the  
Graduate Supervisory Committee:

Bronwynne C. Evans, Co-Chair  
David W. Coon, Co-Chair  
Colleen S. Keller

ARIZONA STATE UNIVERSITY

August 2013

## ABSTRACT

Caregiving studies generally do not focus on the post-caregiving phase of care, or African Americans post-caregivers (AAPCGs). This mixed-methods study guided by the Transitions Theory, explored the experiences of 40 AAPCGs residing in Los Angeles, California and Phoenix, Arizona, whose loved ones died within the last 10 years. Data collection tools included individual interviews, demographic questionnaire, CES-D, Brief Cope, and Social Support.

Findings present the specific aims of the study. Aim 1 dealt with the types, patterns and properties of post-caregiving transitions (PCT). Many AAPCGs experienced multiple, simultaneous transitions that continued to impact their lives many years after caregiving ends.

Aim 2 dealt with factors that facilitate or inhibit healthy PCT. Facilitators include: Being satisfied with care provided; fulfilling death-bed promises; living out the legacy of the deceased; deep spiritual beliefs in God and support of family, friends and church. Inhibitors include: Experiencing a deep sense of loss, confusion, depression, loneliness, and guilt; physical challenges such as fatigue and exhaustion, breathing problems, dizziness, fainting, cognitive difficulties, pain, headaches, hypertension and insomnia; family conflicts, job or home loss that linger long after PCT.

Aim 3 involves process indicators including: connectedness with family, friends, co-workers, church and God; returning to work or school. Coping strategies that helped AAPCGs include: productive ventures, family mementoes, reminiscing, new baby, or visiting cemetery. Appropriate coping led to outcome indicators of mastery such as new environment; making decisions; taking actions; readying oneself for another caregiving

role; preparing for one's own life and death; or caring for self. Fluid integrative identities include: Sense of balance, peacefulness and joy, fulfillment, compassion; remembering without pain; or new identity.

Implications for practice, policy, education and research include: Care providers and policy makers must ensure that AA caregivers receive adequate EOL and hospice information and support for adequate preparation of loved one's death. Geriatric educators must design and implement curricular programming that includes the post-caregiving phase as a very important phase of caregiving. Researchers should design culturally-congruent assessment tools or improve the checklist developed in this study to appropriately measure PCT; and also develop culturally-relevant interventions to facilitate healthy PCT.

## DEDICATION

I dedicate this PhD degree to my three wonderful children: Ivy, Nony and Ike, Jr. who have been my motivating force. Thank you for your strong, unwavering support and love. I could not have done this without you. We went through a lot, but God has shown us his manifold blessings. I love you so much and God bless you forever.

I also dedicate this dissertation and my PhD degree to my late brother Akachi Ume who pushed, prodded and encouraged me to pursue this dream but was not able to stay to see me complete the assignment. You are sorely missed.

## ACKNOWLEDGMENTS

I wish to thank my primary mentor and co-chair of my dissertation committee, Dr. Bronwynne Evans who has been my solid rock of support and challenge throughout this program. Thank you for: believing in me when I did not believe much in myself; pushing me beyond my personally-known limits; holding my hands as I walked the difficult, often arduous terrains of doctoral education; and being right there to catch me when I thought I was crashing.

I also wish to acknowledge my co-mentor and co-chair of my dissertation committee, Dr. David Coon. Thank you for: Supporting, guiding me through “that” difficult subject that I dreaded so much; getting me to see that it’s not as bad as I thought it would be; and for gently directing me to “consider” diverse possibilities even more than I was willing to allow myself to imagine.

I also acknowledge Dr. Colleen Keller, a member of my dissertation committee who was always very encouraging and supportive of my academic pursuits. I wish to also thank my Los Angeles mentors Dr. Linda Phillip and Ms. Loretta Jones (Healthy

I also acknowledge my siblings – Obioma, Ndy, Okey, their spouses, my nieces, nephews and cousins. A special “thank you,” to Chinyelu, for helping to edit and format this dissertation. I wish to express a profound, heartfelt gratitude to my cousin and “sister” Tina Ezumah. I acknowledge my wonderful pastors – Bright and Hannah Meretighan; Harry and Angela Nze. Thank you for standing with our family through the darkest stages of our lives. God bless you all.

I also acknowledge the assistance, support and encouragement of all the Momento Crucial staff (Ed Larosa, Christine Wheless; Lorena, Kevin, Mary, Anique, and Bertha);

the CONHI HCGNE and PhD office staff especially Shannon Hodge, Christina Peete and Levi Colton; CONHI ORS and business office staff (Audrey Brockhaus, Deb Fisher, Kristina Winterstein, and Sally Balanon); and Dr. Pauline Kommenich for always being kind, caring and supportive. I appreciate you all.

I thank Dr. Vanessa Miller for hours of statistical support, and I acknowledge Dr. Shirley Evers-Manly, Dr. Lisa Jones, Dr. Patricia Humbles, and Sylvia Jones of Charles Drew University for your support. You are great role models. I also thank Ms Bettye Randle and Yolanda Bozant for assisting with recruitment and emotional support.

I also acknowledge the staff and funding organizations that supported my doctoral education. Dr. David Banks and the National Institutes of Health/National Institute of Nursing Research (NIH/NINR) for the following awards: 2009-2011 - RO1 Research Supplement to Promote Diversity in Health-Related Research; and 2011-2013 – F31 National Research Service Award (NRSA). I also thank Dr. J. Taylor Hayden and Penny of the Hartford Foundation for my 2011-2013 - Building Academic Geriatric Nursing Capacity (BAGNC) pre-doctoral scholar award. I also acknowledge Mr. and Mrs. Jonas, Darlene Curley, and the JONAS Foundation for my 2010-2012 - Jonas-Hartford Pre-Doctoral Scholar award. I thank the Hartford and Evercare Foundations for multiple pre-doctoral fellowship awards; and CONHI for providing excellent environment and great faculty to cultivate and water my passion for geriatric nursing care. I thank Dr. Afaf I. Meleis, Dean, University of Pennsylvania School of Nursing and Co-author of the Transition Theory for personally meeting with me twice and giving great input as I crafted this dissertation study.

## TABLE OF CONTENTS

	Page
CHAPTER 1: INTRODUCTION .....	1
Caregiving in Ethnic Minorities .....	4
Statement of the Problem .....	6
Recruitment of Minorities in Research .....	8
Philosophical Foundation for Mixed Methods Research Design.....	11
Relevance of This Research Study to the Discipline of Nursing .....	13
Research Question .....	14
CHAPTER 2: REVIEW OF LITERATURE.....	15
AA Caregivers .....	15
Theoretical Framework.....	18
The PCT: Transitions Theory.....	18
Application of Transitions Theory to This Study .....	19
Transition Types .....	19
Transition Patterns .....	20
Transition Properties.....	21
Transition Conditions. ....	22
Healthy Transition in AAPCGs.....	23
Process Indicators .....	23
Outcome Indicators.....	24
Bereavement, Depression, and PCT .....	25
Relational and gender experiences in PCT. ....	28

Relief for PCGs.....	28
The Healthy PCT .....	29
Achieving Healthy PCT .....	32
Gaps in Literature .....	34
Instruments for PCT investigation. ....	34
Summary .....	34
CHAPTER 3: METHODOLOGY .....	36
Introduction.....	36
Philosophical Foundation .....	36
Research Question .....	37
Theoretical Framework.....	37
Specific Aims.....	37
Preliminary Study .....	38
Specific Aims of the Preliminary Study.....	39
Design of the Preliminary Study .....	40
Recruitment.....	40
Inclusion and Exclusion Criteria .....	41
Procedures .....	42
Data Collection Devices .....	42
Standardized Measures .....	44
Conclusions.....	45
Relevance of Preliminary Study to the Dissertation Study .....	47
Design of the Dissertation Study .....	48



Sample and Setting .....	49
Inclusion and Exclusion Criteria .....	52
Data Collection Devices .....	57
Screening/Demographic Questionnaire .....	57
Interview Protocol.....	57
Standardized Measures .....	59
Data Collection Procedures .....	61
Screening and Informed Consent .....	61
Data Collection .....	62
Procedures for Monitoring Data Quality and Managing Data .....	64
Data Preparation.....	66
Coding.....	66
Case-Oriented Analysis .....	68
Other Bases of Analyses .....	68
Socio-Demographic Comparisons .....	68
Case- and Variable-Oriented Analytic Strategies .....	71
Re-Presentation of Data to Add to the Scientific Body of Nursing Knowledge .....	77
Strengths and Limitations of This Study.....	78
The Timetable .....	80
<i>Figure 2. Research Timetable</i> .....	81
The Feasibility .....	81
CHAPTER 4: FINDINGS AND DISCUSSION .....	82
Demographics .....	82

<i>Figure 3. Work outside home during caregiving</i> .....	84
<i>Figure 4. Return to work post-caregiving</i> .....	84
Considerations of Study Aims in Relation to the Transition Theory.....	87
Aim 1. Describe the types, patterns, and properties of the PCT in AAPCGs.....	88
Nature of Transitions .....	88
Types of Transitions .....	88
Patterns of Transitions .....	94
Properties of Transition .....	97
Aim 2. Explore the facilitators and inhibitors of PCT in AAPCGs.....	101
Transition Facilitators: Personal, Community, and Societal .....	101
Meanings.....	101
Cultural Beliefs and Attitudes .....	110
Nigerian-born versus US-born AAPCGs.....	114
Socioeconomic Status.....	117
Preparation and Knowledge .....	118
Transition Inhibitors: Personal, Community, and Societal.....	119
Meanings.....	119
Cultural Beliefs and Attitudes .....	140
Socioeconomic Status.....	148
Lack of Knowledge and Preparation.....	152
Summary of Inhibitors.....	154
Aim 3. Describe the process and outcome indicators of the PCT in AAPCGs.....	155
Patterns of Response .....	155

Process Indicators .....	155
Social Support.....	166
Outcome Indicators.....	191
Summary .....	198
CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS.....	200
Summary of Transitions Domains and Specific Aims .....	200
Aim 1. “Describe the types, patterns, and properties of the PCT in AAPCGs.” .....	200
Aim 2. “Explore the facilitators and inhibitors of progress through the PCT in AAPCGs.” .....	203
Aim 3. “Describe the process and outcome indicators of the PCT in AAPCGs.” .....	206
Limitations of this Study.....	209
Implications of the Study.....	211
Implications for Practice and Policy .....	211
Implications for Research.....	218
Contributions to Science.....	219
Future Research.....	220
Recommendations.....	223
REFERENCES .....	225
APPENDIX A .....	242
Figure 1. Transitions: A middle range theory .....	243
APPENDIX B .....	244
SAMPLE OF STRATIFIED SAMPLING PLAN: PCT IN AAPCGS .....	244
APPENDIX C .....	246

DATA COLLECTION PLAN .....	246
APPENDIX D .....	248
TELEPHONE SCREENING FORM/DEMOGRAPHIC QUESTIONNAIRE .....	248
APPENDIX E .....	253
INTERVIEW PROTOCOL.....	253
APPENDIX F.....	256
SAMPLE CES-D .....	256
APPENDIX G .....	259
SAMPLE BRIEF COPE.....	259
SAMPLE SOCIAL SUPPORT INSTRUMENT.....	262
APPENDIX I.....	266
INFORMATION LETTER .....	266
APPENDIX J .....	269
TYPES AND PATTERNS OF TRANSITIONS.....	269
APPENDIX K.....	272
IRB APPROVAL LETTER .....	272
APPENDIX L: TABLE 1 .....	274
DEMOGRAPHIC DESCRIPTION OF AAPCGS AND CARE RECIPIENTS (CR) .....	274
APPENDIX M: TABLE 2.....	277
INTER-RELATIONSHIP OF LIFESTYLE VARIABLES.....	277
APPENDIX N: TABLE 3.....	279
TOTAL CES-D SCORES FREQUENCY DISTRIBUTION.....	279
APPENDIX O .....	281

<i>Figure 5. Total CES-D scores</i> .....	282
APPENDIX P: TABLE 4 .....	283
MEASURES OF WELL-BEING ACCORDING TO CES-D ITEMS.....	283
APPENDIX Q: TABLE 5.....	285
MEANS TABLE FOR RELATIONSHIP WITH SOCIAL SUPPORT DOMAINS .....	285
APPENDIX R: TABLE 6.....	287
SAMPLE OF CHECKLIST TO MEASURE HEALTHY POST-CAREGIVING TRANSITION.....	287
APPENDIX S: TABLE 7 .....	292
MEASURES OF COPING ACCORDING TO THE BRIEF COPE ITEMS .....	292
APPENDIX T: TABLE 8 .....	295
MEASURES OF COPING ACCORDING TO BRIEF COPE DOMAINS .....	295
APPENDIX U: TABLE 9.....	297
SIGNIFICANT INTER-RELATIONSHIPS OF COPING PER THE BRIEF COPE .....	297
APPENDIX V, TABLE 10.....	299
MEANS TABLE FOR RELATIONSHIP OF CES-D AND BRIEF COPE DOMAINS..	299
SELF –PERCEPTION OF ADJUSTMENT TO PCT .....	301
APPENDIX X: .....	303
BIOGRAPHICAL SKETCH.....	303

## CHAPTER 1: INTRODUCTION

The prevalence of United States (U.S.) adults who need ongoing care services, more than half of whom are elderly, will increase by more than 100% between 2000 and 2050 (U.S. Department of Health and Human Services, 2003; U.S. Department of Labor, 2003). Although nine out of 10 of these older adults have at least one chronic health condition and 77% have multiple chronic conditions (Family Caregiver Alliance, 2010), most will remain at home with family caregivers (FCGs). The National Alliance for Caregiving (NAC), in a collaborative study with American Association of Retired Persons (AARP) Foundation and Metlife Foundation (2009), reported that there are 48.9 million adults in the U.S. who serve as FCGs to adult care recipients (CRs). In fact, the number of FCGs might be as high as 52 million when those who provide care only at some point during the year are considered (AARP, 2009; Family Caregiver Alliance, 2010; NAC, 2009). These informal FCGs are often unpaid for the invaluable care services they render to their loved ones. The value of the FCGs' tremendous economic contribution is estimated at approximately \$450 billion dollars (Feinberg, Reinhard, Houser, & Choula, 2011).

The majority of FCGs are females, with an average age of 48 years, and they provide an average of 20.4 hours of caregiving per week (NAC, AARP & Metlife, 2009). FCGs provide care on a long-term basis to their loved ones, averaging about 4.6 years (NAC et al., 2009). Most FCGs take care of a relative, usually a parent who requires care due to old age, chronic illness, or disability (NAC et al., 2009). The most prevalent reason for caregiving in old age is Alzheimer's disease (NAC et al., 2009), but other conditions include cancer, mental and emotional illness, heart disease, stroke, diabetes,

etc. FCGs providing care for family members with these debilitating cognitive, physical, and/or emotional conditions often provide assistance with tasks involving activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Female FCGs provide more ADLs such as bathing, toileting and dressing; while male FCGs provide more IADL assistance such as help with finances or coordinating care.

Selection into informal family caregiving roles often does not offer FCGs a choice in whether or not to take on the responsibility (Lyonette & Yardley, 2003). They assume the responsibilities when their loved ones become ill and are unable to care for themselves. They undertake informal family caregiving responsibilities with both positive and negative motivations, justifying caregiving as an expression of love and devotion (Gerdner, Tripp-Reimer, & Simpson, 2007), or accepting informal family caregiving roles out of guilt, responsibility, duty, and to avoid a perceived disapproval by others (Lyonette & Yardley). This sense of guilt may impact caregiving by producing undue stress, which may lead to other challenges in the process of informal caregiving.

Informal family caregiving brings with it challenges which impact FCGs' overall lives and wellbeing such as physical, emotional and financial challenges. These challenges are aggravated by increased stress, burden and role strain and result in diminished health status of FCGs. Stress is considered as the nonspecific response a person's body reacts to any demand (Selye, 1976). Stress is the most pervasive health problem for FCGs (NAC & Evercare, 2006) and leads to physical and emotional health impediments. Burden is the caregiver's subjective appraisal, and is defined as the "physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired adults" (George & Gwyther, 1986, p.

253), and how much that burden affects the subjective self-assessment of the caregivers (Zarit, Reever, & Bach-Peterson, 1980). Role strain is the difficulty that a FCG feels in carrying out the duties of their caregiving role (Archbold, Stewart, Greenlick, & Harvath, 1990).

Some of the common physical health issues suffered by FCGs include hypertension, insomnia, low energy level, poor nutrition or lack of exercise, headaches, or weight gain/loss (Stajduhar, Martin, & Cairns, 2010). These conditions are further exacerbated by poor FCG self-care behaviors in areas of nutrition, rest, sleep, exercise, and attending to preventative health care such as dental cleaning, eye exam, or physical exam by a physician or nurse practitioner (NAC & Evercare, 2006). These poor self-care behaviors are often attributable to lack of time, and energy to engage in those activities.

The perceived lack of time reported by FCGs also contributes to feelings of isolation because they are unable to participate in activities with their family and friends (NAC & Evercare, 2006). Isolation increases stress and burden, which leads to emotional issues such as anxiety, panic attacks, pain, or depression. In fact, depression affects 90% of FCGs who report a decline in health (NAC & Evercare, 2006).

The time constraints of caregiving also affect the employability of many FCGs, thus adding to the severity of both the physical and emotional impacts of caregiving through, and worsening the financial costs. Many FCGs experience financial difficulties because they quit their jobs, reduce their work hours, or change their job roles in some way to accommodate the increasing time and demand of their caregiving role (AARP, 2008). The length of time spent and the tasks involved in caregiving lead to the emergence and/or exacerbation of both physical and emotional issues. FCGs who provide



more than 40 hours of caregiving each week report health problems due to their caregiving responsibilities (NAC & Evercare, 2006). These FCGs provide more intensive care for their loved ones more than FCGs who provide less than 40 hours of care per week, performing at least three or more ADLs for their loved ones (NAC & Evercare, 2006).

### **Caregiving in Ethnic Minorities**

The composition and expectations of caregiving may demonstrate ethnic differences. Caregiver demographics, caregiver experiences or expressions of burden, depression, well-being, and cultural expectations differ by ethnic configurations. According to Family Caregiver Alliance (FCA; 2011), about one-fifth (21%) of Anglo and African American (AA) populations are informal FCGs; while 16% of Hispanic Americans and 18% of Asians provide informal family caregiving services to their loved ones. Minority FCGs are more likely to be adult children compared to Anglos who are more likely to be spousal FCGs (Pinquart & Sörensen, 2005), and they are more likely to be females who are expected to take up the mantle of caregiving despite other responsibilities (NAC, AARP, & Metlife2009).

The expectation to care for a CR is higher among ethnic minorities such as AAs (Williams & Dilworth-Anderson, 2002). This expectation supports the idea that adult children or even fictive kin will provide care to an elderly relative. Fictive kin are family friends, neighbors, or God-children not related by blood who participate in caregiving as if they were biological or marital relatives (Williams & Dilworth-Anderson, 2002).

According to NAC and Evercare (2006), 85% of AA family caregivers (AAFCGs) in the

35 to 44 year age group feel they had no choice about becoming FCGs. For an expanded discussion of AAFCGs, see Chapter 2.

In the Hispanic population, older adults are to be treated with respect (Cox & Monk, 1996), and family members are expected to care for them (Evans, Coon, & Crogan, 2007; Evans, Crogan, Belyea, & Coon, 2009). Hispanic parents expect care from their adult children and the adult children believe that their parents have the right to expect them to provide that care (Cox & Monk, 1996). Thus, in Hispanic communities, adult children provide most of the care required by older adults (Evans et al., 2009). This care system stems from a strong sense of filial responsibility, closely related to familism, where family needs and obligations override personal interests. Familism is noted to provide possible protection against negative caregiving (Coon et al., 2004), where CRs are treated poorly or neglected by caregivers. Most Hispanics often believe caregiving to be reciprocal for the care they received from their parents when they were children (Evans et al., 2009). They learn such long term caregiving patterns through observation of their parents' ongoing care of older family members (Evans, Coon, & Ume, 2011a; Evans, Belyea, & Ume, 2011b).

Gender roles differ amongst Hispanic caregivers, with female caregivers acting as primary caregivers and doing most of the personal care assistance (Evans et al., 2007). Male caregivers are primary decision makers (Evans et al., 2009) and usually engage in non-personal care activities such as yard work, helping with medications, driving the CR to doctor's appointments, or financial management (Evans et al., 2009). However, when necessary, Hispanic male caregivers go "against taboo" by providing personal care to their elderly mothers (Evans et al., 2011a; Evans et al., 2011b).

Hispanic FCGs prefer informal support assistance from other family members or friends. They often believe that using formal assistance means that they are abdicating their role as FCG, and are not doing a good job taking care of their loved ones (Cox & Monk, 1990).

Asian caregivers also value caregiving of their older adults. Chinese families raise their children to expect to care for their elders in their old age. Just as in Hispanic culture, filial piety is also very strong amongst Chinese caregivers (Pang et al., 2002; Patterson et al., 1998), who believe in the tenets of *hsiao ching*, which means a deep sense of obligation to care for, and respect one's elders (Chow, Ross, Fox, Cummings, & Lin, 2000). Unfortunately, this belief can be problematic because it leads to unwillingness to report cognitive or other emotional changes, such as in Alzheimer's disease, because it is perceived as mental illness in Asian cultures, against which there remains a strong stigma. Therefore, caregivers would rather continue to provide care at home without reporting changes in behavior or seeking outside help for fear of showing their CR in a negative light (Chow et al., 2000).

In spite of the difficulties and challenges of caregiving, minority caregivers tend to tackle it with temerity and strong cultural justification for care. Such caregivers often continue caregiving even against their own personal interests and abilities. When caregiving ends, it also creates major disruptions in the caregivers' lives.

### **Statement of the Problem**

The informal caregiving continuum involves three distinct phases: pre-caregiving, active caregiving and post-caregiving. Pre-caregiving precedes active caregiving, occurring when family members provide minimal, infrequent care or support for an older

loved one, referred to in this study as the CR. During pre-caregiving, the FCG may occasionally check on a fairly independent or moderately well-functioning older adult CR by phone or in person or help with transportation to physicians' appointments or grocery-shopping. This pre-caregiving phase may continue for years until the CR deteriorates physically, emotionally or mentally and needs more active caregiving.

The active caregiving phase begins when the CR's dwindling health and self-care abilities require increased and direct caregiving. In this phase, FCGs may provide assistance with ADLs such as bathing, hygiene, grooming, feeding, and elimination or with IADLs such as medication management, shopping, cooking, driving and phone calls. FCGs also provide social support to their CRs through necessary companionship until care is no longer necessary or possible.

The last phase is post-caregiving, which occurs when active caregiving ends due to a CR's nursing home placement or death. It is termed the "ignored phase of caregiving" (Pearlin & Zarit, 1993, p. 156) and, to date, even longitudinal caregiving studies tend to ignore the period between CR's death and reintegration of FCGs into new social, occupational, and personal interests and relationships.

Difficulties with every phase of caregiving are well-documented and continue even through the termination of the active caregiving period. When caregiving ends, FCGs often experience chaos and uncertainty (Bridges & Bridges, 2009; Orzeck & Silverman, 2008), leading to emotional, physical, social or spiritual difficulties (Aneshensel, Botticello, & Yamamoto-Mitani, 2004) that may continue to affect their lives and well-being.

In general, the post-caregiving period, also called the Post-caregiving Transition (PCT), has three phases and begins with the "post-caring void," a period of emptiness and chaos, characterized by loneliness and loss of hope, purpose, and balance (Bridges & Bridges, 2009; Larkin, 2009). A second phase is "closing down," which involves routine activities of closure such as packing up personal belongings of the CR (Larkin, 2009). The final phase is "constructing life post-caring" which involves a new beginning and includes hope, confidence, a new identity, reconnections with old friends and family, and engaging in previously enjoyed or new activities of leisure and/or employment (Bridges & Bridges, 2009; Larkin, 2009).

There is sparse research available on the PCT, even in Anglo families, and, although there is a substantial literature on both the Anglo and the AAFCG experience (explored in detail in Chapter 2), virtually nothing is known about what happens in such families during post-caregiving. Because the PCT is unexplored, there is little basis for timely or effective intervention with AAFCG families who are unable to move forward with their lives. The purpose of this study was to explore the experience of post-caregiving in AA caregivers, a largely unexamined area, as a foundational step for future intervention.

### **Recruitment of Minorities in Research**

The topic of PCT in African American family caregivers (AAFCGs) is critically important to nursing research, the AA community, and personally to this researcher. The National Institute of Health (NIH) Revitalization Act known as the Public Law 103-43 of 1993 requires the inclusion of women and minorities in clinical research studies (National Institute of Health, 2001; Williams & Corbie-Smith, 2006). A 14-year minority trend

summary showed that in 1995, all minority subjects enrolled in U.S. research studies represented only 26.9%. In 2008, the number increased only to 34.2%. AAs in 2008 represented only 18.4% of all subjects in Phase III clinical trials, but accounted for 12.6% of the U.S. population, as opposed to Anglos 50.2% who comprise 72.4% of the U.S. population (U.S. Census Bureau, 2011). Other ethnic groups represented include Asians (17.0%), Hispanics (11.5%), American Indians or Alaskan Natives (2.7%), and Hawaiian or Pacific Islanders (0.1%) (National Institute of Health [NIH], 2001). By focusing on a specific minority population, this study ensures compliance with this NIH minority inclusion directive by recruiting African American post-caregivers (AAPCGs) as participants.

Recruitment and retention of minority participants is universally perceived as a problematic, "alarming challenge" in clinical research (Godden, Ambler, & Pollock, 2010; Ntiri & Stewart, 2010; Paskett et al., 2008). Various social, economic, language and cultural challenges contribute to the difficulty in recruiting minorities into clinical research (Knobf et al., 2007), including lack of awareness of on-going clinical studies and lack of education to understand the reasons for the studies. There is also a lack of communication between researchers and members of the minority group about what research is being done, why the research is important and how the study would affect the community or the participants specifically. In addition, there also may be a lack of genuine concern or involvement in the community by research staff. Furthermore, there are also financial or economic reasons that impact participation of minorities in research (Dilworth-Anderson, 2011; Williams & Corbie-Smith, 2006).

Other barriers and concerns include researchers' attitudes toward, or the values that the researcher places on the minorities who participate in their research (Sheikh et al., 2009). Another major barrier is language or cultural differences between researcher and participants (Sheikh et al., 2009; Williams & Corbie-Smith, 2006). There are stereotypes or prejudices such as the belief that minorities would not participate in research (Evans et al., 2007) and the potential difficulties in engaging minorities (Sheikh et al., 2009). These stereotypes lead to perceptions of non-compliance of minorities in research protocols, and the purported lack of interest of minorities in research (Williams & Corbie-Smith, 2006). Some of the difficulties stem from language and cultural differences that make communication between the researcher and participants difficult (Evans et al., 2007). The researcher would need to employ cultural brokers that understand the language and culture of that community of people to ensure more effective recruitment (Sheikh et al., 2009; Williams & Corbie-Smith, 2006).

Community-based barriers (barriers that are due to a collective need or issue for the members of an ethnic group) indicate that AAs may not participate in research because of negative past experiences, fear of exploitation, fear of being harmed or distrust of researchers and research institutions (Ejiogu et al., 2011). Historically, the distrust of minorities towards research can be traced to the use of slaves for medical experimentation, or the Tuskegee Syphilis Experiment (Dilworth-Anderson, 2011). Thus, the issue of trust building between researchers and minorities remains a challenge (Dilworth-Anderson, 2011). Fears that informed consent forms have some hidden agendas, or a reluctance to participate in the study because of an attitude that, "we are not signing our life away" permeate the thoughts and mindsets of certain minority groups.

Researchers have not convinced minorities that research will be fair or that it has shared risks and benefits (Stahl & Vasquez, 2004). This study with AAPCGs was designed to mitigate these barriers through leadership of an AA researcher. It is believed that AA participants felt safer participating in a research study that was primarily conducted by someone of their own racial or cultural group. It is believed that trust was facilitated by a more informed understanding of the AAPCGs experience, set within the context of the AA community, and exemplified by the researcher.

Another important aspect of this study is the researcher's own personal experience with caregiving and post-caregiving of her aged mother and brother. This disclosure is important to provide a clear, view of the deep-rooted personal interest of the researcher for this topic (Creswell, 2009), and to acknowledge the potential for coloring the study in terms of research design, sampling, data collection or data analysis. Such disclosures are common in the naturalistic paradigm and set forth the researcher's interpretive lens for the reader. Attention to such issues of credibility was explored extensively in Chapter 3. Familiarity with the caregiving process enabled the researcher to display an empathetic approach (Fontana & Frey, 1998), more easily build trusting relationships, and engage more fully in interactions with the participants, thereby increasing data quality (Miles & Huberman, 1994) and effectively acting as a cultural broker for the study (Williams & Corbie-Smith, 2006).

### **Philosophical Foundation for Mixed Methods Research Design**

This study utilized a mixed methods design combining elements of qualitative and quantitative research approaches (Creswell, 2009; Tashakkori & Teddlie, 2010), as set forth in Chapter 3. This study used a pragmatic worldview, a leading philosophical



foundation for mixed methods design (Creswell; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2010). Pragmatism is useful as a philosophical foundation for mixed methods studies (Evans et al., 2011), and suggests that researchers may use any research method that best answers their research question (Creswell, 2009; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2010).

Pragmatism is an ideology put forth in 1878 by C.S. Peirce, but later expanded and brought to the limelight by William James in 1898 (James, 1907). Other proponents and champions of early pragmatism include John Dewey, Oliver Wendell Holmes, and Schiller (James, 1907; James, 1975; James, 1981). Pragmatism flourished in the early 1900s and retreated to the mainstream in early 1940s, but was again resurrected in the 1980s by Richard Rorty (Leary, 2009; McCready, 2010).

James (1907) notes that, “A pragmatist turns his back resolutely and once for all ... from abstraction and insufficiency, from verbal solutions, from bad a priori reasons, from fixed principles, closed systems, and pretended absolutes and origins...he turns towards concreteness and adequacy, towards facts, towards action, and towards power” (pp. 49-50). He goes on to suggest that a pragmatic orientation looks at outcomes, consequences, and facts, suggesting that multiple relevant forms of data collection and data analytic formats could be utilized to answer a research question (Creswell, 2009; Evans et al., 2011). The pragmatic foundation is not reliant on any set of beliefs or a prior theories, or research methods however, it tends to focus on the “low, swampy grounds” (Schon, 1983) of dealing with the difficult and confusing research problem or question (Evans et al., 2011), and using whatever possible appropriate, complementary and rigorous methods to resolve the problem or answer the question (Evans et al., 2011).

Therefore, the use of a mixed methods approach in this study was to gain "breadth and depth of understanding and corroboration" on the phenomenon of PCT in AAPCGs (Johnson, Onwuegbuzie, & Turner, 2007).

Case-oriented and variable-oriented approaches were used concurrently and merged at data analysis and interpretation processes (Sandelowski, 2000). The descriptive nature of this study seeks to gain in-depth knowledge about PCT in AAPCGs, an area where little research is available. Thus, it was important to utilize diverse modes of data collection tools and data analytic methods to explore PCT in the AA population (Creswell, 2009; Tashakkori & Teddlie, 2010).

In this study, the use of a semi-structured in-depth interview protocol provided insights and expands the knowledge of the PCT in AAPCGs. At the same time, a demographic questionnaire and standardized instruments (Center for Epidemiological Studies-Depression Scale [CES-D], Social Support Instrument [SSI], and Brief Cope [BC]) were used to measure such critical issues in AAPCGs as depression, social support and coping to provide fuller description of the PCT in AAPCGs (Sandelowski, 2000).

### **Relevance of This Research Study to the Discipline of Nursing**

A study on the PCT is important for nurses, allied health care clinicians, nurse educators and researchers who are interested in end-of-life care to better understand how to provide culturally-sensitive, end-of-life care and post-caregiving support for AAPCGs. The majority of formal support for caregivers usually terminate as soon as the CR dies. This is very distressing for PCGs because they often feel inadequately prepared for life after caregiving. The lack of social support may affect their coping with PCT and may lead to complicated grieving (unrelenting and severe grieving that significantly impairs

the quality of the PCG's life) (Bonanno, Wortman, & Nesse, 2004; Ellifritt, 2003). This study addressed both social support and coping, in an effort to explore how AAPCGs ultimately achieve healthy PCT.

Another outcome of this study was to provide a foundation for PCGs in their quest to achieve healthy transition. To achieve this outcome, this study defined and fully described PCT in AAPCGs, along with essential characteristics of healthy transition. Findings of this study can have a significant impact on AAPCGs who sacrifice so much to provide care for their loved ones.

### **Research Question**

The gaps in the literature are fully described in Chapter 2. To address the paucity of research on the PCT, particularly in AA caregiving literature, and to fill the gaps identified in Chapter 2, this study was guided by this research question: "How does the PCT evolve for AAPCGs?"

## **CHAPTER 2: REVIEW OF LITERATURE**

This chapter presents an in-depth discussion, derived from the available sparse literature, concerning the PCT in both the general population and in AAPCGs. Literature reflecting what is known about the PCT in the general population provides the scaffold for the discussion, with specific AA attributes incorporated when available. A detailed discussion on the selection and application of the theoretical framework for this study; Transitions Theory by Meleis, Sawyer, Im, Hilfinger Messias, and Schumacher (2000); is also presented.

### **AA Caregivers**

Fifty-nine percent of AAFCGs live on less than \$50,000/year, a much lower income than most Anglo or Asian FCGs (FCA, 2010; NAC, 2009). AAFCGs spend an average of 24 hours each week on caregiving. Sixty-three percent assist family members with ADLs such as transfers, dressing, bathing, elimination, or feeding, while 99% assist with IADLs such as shopping, transportation, meal preparation, housework, and financial management (NAC et al., 2009).

AAFCGs endure much sacrifice to provide informal elder care. They often combine such care with childcare, giving rise to a “sandwich generation” effect that increases role strain and burden (Pierret, 2006; Williams, Dilworth-Anderson, & Goodwin, 2003). Additionally, 68 percent put their lives on hold due to the excessive amount of time and effort required for caregiving (NAC et al., 2009). Caregivers may decrease their social contacts, family activities, or other previously enjoyable activities in order to care for older family members. Many caregivers give up their jobs or reduce work hours, resulting in loss or reduction of family income, shouldering an additional

financial burden that contributes to increased stress and emotional difficulties (Bullock, Crawford, & Tennstedt, 2003; Gerdner et al., 2007; NAC et al., 2009).

Although some researchers suggest that AAFCGs report little depression, burden, and stress (Haley et al., 2005), others note the emotional cost of caregiving: 24% of AAFCGs rate the emotional cost as high, 39% provide care in high burden situations, and those who experience depressive symptoms also show increased role strain (Dilworth-Anderson, Williams, & Cooper, 1999; NAC et al., 2009; Williams et al., 2003). Despite these difficulties, most AAFCGs accept their role as inevitable due to cultural expectations, with 43% reporting that they had no choice (NAC et al., 2009). They often see caregiving as paying a debt for previous care by family members (McCallum, Longmire, & Knight, 2007; NAC et al., 2009).

AAFCGs rely a great deal on informal social support networks such as family, friends, co-workers and church members for help in their caregiving role. AAFCGs view their role as a team effort with other adult family members coming together to ensure care is provided (Turner, Wallace, Anderson, & Bird, 2004). Turner et al. (2004) reported that AAFCGs bring to caregiving four cultural resources – respect for elders, value for children, extended family ties, and a strong religious orientation. These resources aid in caregiving and help to mitigate caregiving strain. Spirituality plays an important role in defining caregiving in AA (AA) families (Dilworth-Anderson et al., 2002), by providing support for active FCGs and providing comfort and strength during the post-caregiving phase.

**PCT in AAFCGs due to nursing homes (NH) placement.** AAFCGs generally eschew institutionalization, resulting in a greater likelihood of informal care for frail,

dependent elders than their Anglo counterparts. Consequently, AA CRs are less likely to die in a NH (Owen et al., 2001). AAFCGs generally choose to continue care for loved ones at home, despite limited access to or utilization of formal care support, suggesting that their CGs are at risk for increased burden and strain (Dilworth-Anderson et al., 1999; Scharlach et al., 2006; Williams et al., 2003). Placement of loved ones in NHs is often preceded by worsening CR behavior problems but AAFCGs tend to continue giving care until they are unable to physically maintain the necessary effort (Gaugler, Pearlin, Leitsch, & Davey, 2001). Generally, AAFCGs express a distrust of nursing homes (Turner et al., 2004) and, because of this distrust, they tend to continue care even after placement in the NH through monitoring, supervision of care and daily visits.

AAFCGs who relinquish care of loved ones to nursing homes often feel guilty, because placement is seen within the AA community as abandonment, abdication of duty, lack of love or disrespect, or disowning of the CR (Gonyea, Paris, & Zerden, 2008; Guberman & Maheu, 1999; Sanders, Ott, Kelber, & Noonan, 2008; Turner et al., 2004). Many FCGs continue to experience guilt long after placement because they feel that they let their loved ones down, or failed in their promise not to place the CRs in NHs. Others may believe that placement led to premature death of the CR (Bern-Klug, 2008; Guberman & Maheu; Ryan & Scullion, 2000; Sanders et al.; Schulz et al., 2004).

**PCT in AAFCGs due to death.** Although little is known about the PCT in AAFCGs, they are less likely to accept CRs' deaths, or consider them a relief, but instead perceive death as a greater loss than Anglo FCGs (Owen et al., 2001). Family relationship is important in AA caregiving families, because it forms the foundation for the reciprocal caring and support of one another that is valued in AA communities.

## **Theoretical Framework**

Theory helps researchers focus their studies, select their techniques, and manage data collection, analysis and interpretation (Charmaz, 1990; Sandelowski, 1993).

Although Transitions Theory is well-developed (Meleis et al., 2000), there is little research directly addressing the PCT. Presented in this section is a synthesis of Meleis' Transitions Theory, the current state of the science, including what is known about the dynamic process and the hallmarks of PCT, identified gaps in the literature, and application of the theory to this research study. Transitions Theory was central to the design, conduct, and dissemination of this study (Sandelowski, 1993).

### **The PCT: Transitions Theory**

Following cessation of caregiving of CR due to death, NH placement or transfer to other relatives, there is an inevitable sense of loss from disruption in day-to-day routine of caregiving responsibilities, in addition to the challenge of dealing with its aftermath. PCGs experience grief involving unresolved health, financial, and social issues (Aneshensel, 2000; Davis & Nolan, 2006; Dellasega, Mastrian, & Weinert, 1995), feelings of chaos and uncertainty, and a series of transitions that must be endured (Bridges & Bridges, 2009; Brown & Powell-Cope, 1991; Davis & Nolan, 2003; Orzeck & Silverman, 2008). Such transitions were addressed by the theoretical background for this study, Transitions Theory (Meleis et al., 2000).

Transition is defined as a, "passage from one life phase, condition, or status to another" (Chick & Meleis, 1986, p. 239) and transitions are viewed as chaotic periods of disruption from normalcy among otherwise stable periods of AAPCGs' lives. Transitions result in, and are the result of, changes in daily life, health status, relationships, and the

environment in which one lives - all of which are adversely affected by the death of the CR. According to Bridges and Bridges (2009), transitions are requisite to a new life, which begin, oddly enough, with an ending. When this ending can be acknowledged, the PCG begins to exhibit a decrease of distress, renew social ties, and reintegrate occupational, personal interests and relationships into a new life (Pearlin & Zarit, 1993).

### **Application of Transitions Theory to This Study**

The theoretical framework (Appendix A, Figure 1) will provide an intricate guide for all aspects of this research study. For example, Transitions Theory will inform the design of the study, including the selection of standardized instruments and the development of the interview protocol questions (Sandelowski, 1993), and guide the analysis and interpretations. The following explication of Transitions Theory identifies the various constructs of the theory and specifically relates them to this project.

Discussion of design, data collection tools and analytical processes are discussed more fully in Chapter Three. The complex and multidimensional transition experience is characterized by types, patterns, and properties of transition (Appendix A, Figure 1).

#### **Transition Types**

Types of transitions include developmental, such as moving from childhood to adolescence or situational, such as death of the loved one; health/illness, such as a terminal diagnosis. A third type of transition is organizational, such as changes in leadership changes in a hospice facility that affects the ability of family caregivers to continue providing care to their loved ones by limiting visiting hours. Transnational transition, a fourth transitional type, involves moving from one country to another (Meleis et al., 2000), a transition in which many PCGs of African descent who reside in



the US are engaged. The PCT usually includes at least two or three types of transitions that may be related to one another, such as death of the CR and loss of home which belonged to the CR, or unrelated, as in the death of the CR along with loss of the CG's job.

### **Transition Patterns**

Patterns of transitions (consistent, recurring characteristics of the transition experience) vary, but they may be single, where the individual experiences only one type of transition, such as the death of a CR, or multiple, in which transitions occur simultaneously and may have a devastating effect. Multiple transitions occur when grief associated with the loss of a CR is compounded by concomitant problems surrounding the death. For example, cultural death beliefs of FCGs, such as the need to return the dead body of the CR to their home country or home state and prescribed burial rites, can be complicated by the need to search for gainful employment, manage the financial and legal responsibilities of the dead person's estate and deal with the loss of home and livelihood because caregivers quit their jobs during active caregiving (Larkin, 2009).

Transitions can be positive or negative and are experienced differently by each individual depending on the circumstances, environment, meaning and cultural beliefs attached to the situation (Brammer & Abrego, 1981; Chick & Meleis, 1986; Meleis et al., 2000). Even when the circumstance of loss is the same such as the death of the CR, meaning of the loss for each caregiver may differ due to his or her personal relationship with the deceased. For example, the death of a father who was very close to his first daughter-caregiver might produce more difficult transition than the death of that same

father is to his second daughter who is a secondary caregiver, but never got along with the father.

### **Transition Properties**

Properties of transition involve the levels of PCG awareness of being in, and engaging in PCT. Individual FCGs display various levels of awareness in regard to their transition experience. The complex and multidimensional properties of the PCT include awareness, engagement, change and difference, transition time span, and critical points and events.

**Awareness.** This suggests that an individual may be in transition even if he or she does not recognize it as such. For example, caregivers for terminal elderly loved ones may experience all the burdens and strains of caregiving and the pre-bereavement role strain which characterizes post-caregiving transitions, without recognizing that they are in transition (Meleis et al., 2000).

**Engagement.** This refers to the degree of involvement in moving through the process, such as active information-seeking and participation in behavior changes and skill acquisition necessary for healthy transition (Meleis et al., 2000). For example, a nurse who previously cared for her mother at home for three years may have given up her hospital nursing position (Larkin, 2009). She must be able to recognize that her nursing license has expired and that she will need to renew it in order to return to work after her family caregiving career ends.

**Change and difference.** Meleis et al. (2000) believe that, "All transitions involve change, whereas not all change is related to transition" (p. 19). For example, the death of a CR may mean a change in role for the caregiver involving more free time, but would

still not make a difference in the emotional state of the CG. They would argue for example, that a change of physician due to insurance requirements may not produce any transitional issue for a healthy adult who seldom sees the physician anyway. Practically, however, Bridges and Bridges (2009), disagree, suggesting that transition must occur and be well-managed for change to be successful. They would argue that unless one adjusts psychologically to the loss of a physician who met your needs, however minimally, one may never move forward to a therapeutic relationship with his or her replacement.

**Time span.** Another important property of transition, time span varies widely across individual experiences; it is marked by the beginning and end of each stage of the transition. According to Chick and Meleis (1986), healthy transition might be facilitated if nurses spend time educating clients on the phases and progression of the transition. This strategy would enhance each individual's ability to monitor his or her own progress and mark the successful completion of each phase.

**Critical points.** The last property focuses on the critical points and events associated with the time span of the transition. Significant (critical) events such as receiving a terminal diagnosis, the final stages of terminal illness, long-term care placement, or death may characterize the post-care phase of caregiving (Orzeck & Silverman, 2008).

### **Transition Conditions.**

Transition conditions facilitate or inhibit progress toward desired outcomes (Meleis et al., 2000). Components of personal conditions include the meaning attributed to transition events, cultural beliefs affecting meaning, socioeconomic status, and knowledge of what to expect during transition. Community and societal conditions

include social support, advice from respected resources, gender equality/inequality or marginalization.

### **Healthy Transition in AAPCGs**

Individuals move through the PCT in an effort to achieve a state of positive resolution. If this effort is successful, it is marked by several process and outcome indicators (Meleis et al., 2000).

#### **Process Indicators**

**Connectedness.** Achievement of a sense of connectedness (Meleis et al., 2000), is demonstrated by being a part of relationships which provide a sense of belonging. AAPCGs must be able to continue previously important relationships or form new and meaningful relationships that help them move on with their life or adjust to life after caregiving. Connectedness may involve re-engaging with family, friends, neighbors and co-workers. The construct of connectedness is measured in this study with the Social Support Scale (Roff et al., 2004), using questions such as "How many relatives, friends, neighbors do you see or hear from at least once a month?" or "How many relatives, friends, neighbors, do you feel close to? That is, how many do you feel at ease with, can talk to about private matters, or can call on for help?" Connectedness was also measured through qualitative interviews with the AAPCGs.

**Interaction.** This is the ability to relate and socialize with other people (Meleis et al., 2000). Interaction was also measured by the Social Support Instrument (Roff et al., 2004), which specifically also measured negative interactions with questions such as "How often have others made too many demands on you?" or "How often have others been critical of you?"

**Feeling situated.** This process indicator emphasizes feelings of being included in a group (Meleis, 2000). AAs pride themselves in being part of groups such as their families, churches or community organizations. Questions on the Interview Protocol were crafted to help explore this concept. For example, "How did being African-American influence your decision to become a caregiver and how you dealt with the loss after care ended?" encouraged participants to reflect on what aspect of group or cultural belonging was most helpful in their decision to engage in caregiving and ways in which they coped with the loss of caregiving.

**Developing confidence or coping.** This process indicator demonstrated whether or not individuals move forward effectively with minimal anxiety (Meleis et al., 2000). The coping instrument selected for this study was the Brief Cope Inventory (Carver, 1997). Questions such as, "I've been concentrating my efforts on doing something about the situation I'm in," examined a proactive pattern by the individual to improve life rather than passively playing or accepting a victim role. A further evaluation of coping strategies that provided the individual with the confidence to deal with the loss was provided by the Interview Protocol: "What strategies worked for you as you tried to adjust to life after caregiving?" Religious coping used by AAPCGs to deal with loss of their CR and loss of their caregiving role was explored by a question on the Interview Protocol, for example, "How did spirituality help you as you worked to adapt to life after caregiving?".

### **Outcome Indicators**

**Mastery of new skills.** Individuals who achieve positive adjustment to the post-caregiving phase also exhibit (Meleis et al., 2000) mastery of new skills which may

involve, for example, re-entering an old career or beginning a new one, learning a new hobby, returning to school, or starting a new relationship. Although mastery indicated that the PCG is on a positive course to healthy transition, each individual may define mastery differently. To determine what “healthy transition” really means to each AAPCG, they were asked, “Please tell me what you believe adjustment to life after caregiving or life after the loss of your CR should look like.” Questions exploring achievement of self-perceived “healthy” transition will include, “What strategies worked for you as you tried to adjust to life after caregiving?,” and “What kind of support (from your family, friends or others) was most meaningful to you after caregiving ended and your loved one died?”

**Integrative fluid identity.** A second outcome indicator of healthy PCT is *Integrative fluid identity* (Meleis et al., 2000). Fluid integrative identities allow PCGs to remember their time as caregivers, while being able to discuss or deal with the PCT without distortion, emotional challenge, or chaos (Meleis, A. I., Personal Communication 9/2/2010). PCGs must learn to re-identify themselves as separate from their former caregiving role, adjust to life without the CR, and manage the accompanying challenges (Meleis et al., 2000; Pearlin & Zarit, 1993). To assess AAPCGs’ ability to identify both the positive and/or negative aspects of caregiving even in the midst of the chaos and uncertainty of PCT, the Interview Protocol included the following question, “What were the positive or negative aspects of your caregiving experience?”

### **Bereavement, Depression, and PCT**

Unfortunately, the dearth of PCT literature, especially in the AA population, necessitated examination of bereavement literature in order to gather information about

post-caregiving which may be extrapolated to the PCT. A complicating issue in PCT research is, that although the PCT itself has certain hallmarks, it can be easily conflated with a variety of associated variables (Ume & Evans, 2011). Associated variables such as bereavement may mirror or parallel a portion of the PCT passage through chaos and uncertainty, but are not components of the PCT itself (Ume & Evans, 2011).

Bereavement is considered a major transition in caregiving that may present challenges for the PCG, in health effects or relational experiences (Aneshensel et al., 2004). Much bereavement literature associated with PCT focus on complicated grief (Schulz, Boerner, Shear, Zhang & Gitlin, 2006; Schulz, Herbert, & Boerner, 2008) and depression (Aneshensel et al., 2004; Taylor et al., 2000). Complicated grieving is an enduring emotional difficulty experienced by bereaved individuals, and it is characterized by feelings of disbelief, anger, bitterness, pain about the loss of the loved one, and preoccupation with constant thoughts of the deceased (Horowitz et al., 2003; Schulz et al., 2006). There may be conflicting emotions in complicated grief such as delayed reaction to grief or absence of guilt and remorse (Schulz et al., 2006; Schulz et al., 2008; Koop & Strang, 2003; Ume & Evans, 2011). Complicated grief may negatively affect the lives of PCGs physically, emotionally, socially or financially, resulting in a very difficult PCT (Horowitz et al., 2003; Schulz et al., 2008).

The PCT may mark the end of a relentless period of active caregiving, often leaving the PCG with varying degrees of physical, emotional, and social challenges that go unacknowledged, adequately recognized, or managed. Physical consequences of the PCT can include hypertension, weight loss, insomnia and other stress-related illnesses (Carter, Mikan, & Simpson, 2009; Stajduhar et al., 2010). This may be related to the

lingering stress from the caregiving period. Sleep disturbances and insomnia are said to continue even up to five years beyond caregiving and may lead to increased depression in PCGs (Carter et al., 2009).

Depression is one of the prevailing emotional consequences of post-caregiving, occurring equally in both males and females (Taylor, Kuchibhatla, Østbye, Plassman, & Clipp, 2008). Researchers believe that emotional states such as depression and anxiety of the FCGs prior to PCT may continue and may predict their emotional state post-caregiving (Aneshensel et al., 2004). Depression, role strain or anxiety experienced by the PCG prior to the death of the CR, might remain or even worsen after the death (Bernard & Guarnaccia, 2003). Depression is said to be the highest before the death of the CR, continued at about the same level up to six months, and improved by one year after the death of the CR (Grant et al., 2002; Schulz et al., 2003; Schulz et al., 2006). Interestingly, research showed that PCGs who exhibited adverse health behaviors such as smoking, skipping meals, and lack of exercise, were at higher risk for depression in post-loss (Zhang, Mitchell, Bambauer, Jones, & Prigerson, 2008).

Continued negative emotional impact of the PCT may pervade other aspects of the PCG's life (Aneshensel et al., 2004; Orzeck & Silverman, 2008), affect roles such as employment. It was noted that caregivers who experienced role strain and isolation and who gave up employment, community involvement and socialization during their active caregiving role may often find it difficult to return to work or resume participation in social activity negatively impacted subsequent PCT (Aneshensel et al., 2004).

The combination of severe physical and emotional impacts of PCT may lead to decreased well-being and increased risk of mortality, especially in strained elderly,



debilitated Post-caregivers (PCGs) following the death of their CR (Richardson, 2010; Schulz & Beach, 1999). This may be the ultimate price of caregiving paid by PCGs, thus suggesting a need for further evaluation of this phase of care to fill the gap and prevent such fatalities.

**Relational and gender experiences in PCT.** Caregivers are usually spouses and adult children of both genders. The effect of death of the CR and the loss of caregiving in PCT can be vastly different. Spousal PCGs may experience more emotional strain than adult children (Bernard & Guarnaccia, 2003; Li, 2005). Adult children may experience guilt, remorse, and fear on realization of their own poor health or eventual death (Aneshensel et al., 2004; Koop & Strang, 2003). Although during active caregiving daughters may experience more depression than husband caregivers (Bernard & Guarnaccia, 2003), wives may experience a quicker reduction in depression levels post-bereavement than daughters (Li, 2005).

**Relief for PCGs.** Death of the CR may ultimately offer relief to caregivers who are otherwise strained and burdened by the intensive nature of caregiving, leading to marked improvements in quality of life, physical and emotional health (Bond, Clark, & Davies, 2003). Strained caregivers show improvement in health risk behaviors after the death of their CR (Koop & Strang, 2003) and depressive symptoms may decrease over time, stabilizing by the third year post-bereavement (Aneshensel et al., 2004). Relief from caregiving may be seen as liberating from constant worry posed by the emotional and physical demands of the caregiving experience (Grant et al., 2002; Li, 2005; Rubio, Berg-Weger, Tebb, & Parnell, 2001). Relief, however, may create feelings of guilt in caregivers who may view it as negative.

**Guilt.** Guilt in caregivers is common and tend to remain pervasive even post-termination of caregiving due to death of the CR (Schulz et al., 2004). Guilt can result in frustration, anger, decreased energy level and greater sense of burden for the caregiver (Gonyea et al., 2008). The emotional burden of guilt sometimes outweighs the physical burden of providing actual care. Thus, in post-caregiving, guilt can be exacerbated by feelings of relief, thus worsening feelings of depression and anxiety in the PCG. The support, positive validation and encouragement by family and friends will help to lessen the sense of guilt in PCGs.

### **The Healthy PCT**

Several constructs have been helpful in attempting to understand coping and adjustment to life after caregiving. These constructs include social support, religious coping, and positive or negative appraisals of caregiving.

**Social support.** Social support is an important aspect of healthy adjustment to PCT. Social support may be informal (family, friends, and neighbors); formal with professionals, healthcare workers such as home health nurses; or church support or other religious affiliations (Williams & Dilworth-Anderson, 2002). Social support can be positive or negative, and is highly instrumental in an individual's ability to cope during the PCT.

Positive social support provides desired companionship and instrumental support (assistance with day-to-day, practical matters) for PCGs in the immediate onset of PCT. Instrumental support may include such assistance as packing the CR's personal belongings, making phone calls to notify other family members of CR's death, making funeral arrangements, and bringing food (Almberg, Grafstrom, & Winblad, 2000; Schulz

et al., 2001). Positive support is very helpful in bringing hope and comfort in times of chaos and uncertainty.

On the other hand, negative social support may result from family and friends pushing the PCG to rush through the process of grieving and move on with life (Almberg et al., 2000; Schulz et al., 2001; Ume & Evans, 2011). Relatives may expect the PCG to begin participating fully in family activities and functions too soon after the death of the CR. Family members may not understand why the PCG still feels a lack of energy, is unmotivated or isolated, and seems unable to rapidly jump back into social or occupational activities. This may become a source of conflict in the family and a major source of stress for the PCG. Data from the preliminary study demonstrated that such PCGs may feel misunderstood or may worry that there is something wrong with the way they are experiencing the PCT. Therefore, negative social support may in fact hinder adjustment to healthy transition.

AAFPGs depend a great deal on informal social support of family members, fictive kin, and church members to help them with their physical, emotional and spiritual needs after loss of their CR (Dilworth-Anderson et al., 1999; Fox, Hinton & Levkoff, 1999; Scharlach et al., 2006; Ume & Evans, 2011). Fictive kin are friends, neighbors or "God"-families who provide emotional, physical, and spiritual support necessary to buffer stressors and mitigate the negative consequences of the PCT (Sharma & Romas, 2008). "God"-families are individuals who are related as spiritual families in AA churches through "God"-parents who accept the responsibility for a child at baptism. These "God"-parents support the spiritual development of that young person, thus making them a "family."

AAPCGs frequently underutilize formal support, which may increase stress (Williams & Dilworth-Anderson, 2002). Although AAPCGs may express the need or desire for support groups to help them cope with the loss of their loved ones (Turner et al., 2004), they are less likely to attend bereavement support groups (Owen et al., 2001; Turner et al., 2004). Interestingly, AAPCGs who participate in research focus groups may attempt to use those focus groups as regular bereavement support groups (Turner et al., 2004). This may be because the focus groups are usually organized through churches and the AAPCGs may feel more comfortable with a program sponsored by their church than those in other formal settings.

**Religious coping.** Much is written about the dependence of AAs on their churches as a major source of support (Turner et al., 2004; Ume & Evans, 2011). The church provides emotional support, usually in the form of prayers, encouragement and visits (Williams & Dilworth-Anderson, 2002), especially in the immediate aftermath of bereavement, and validates the use of religious coping by AAPCGs as a basis of managing difficult situations. AAPCGs may utilize religious coping more than Anglo PCGs to manage their losses (Janevic, 2001; Turner et al., 2004). For them, religious coping includes belief in God and participation in prayers. It serves as a source of strength, helping caregivers deal with the difficulties of life and articulate the positive aspects of caregiving such as strength, duty and reciprocity (Dilworth-Anderson, Boswell, & Cohen, 2007). AAPCGs depend on prayer and their faith in God to mitigate their stress, burden, fear, anxiety and uncertainty of the loss of their CR, and to provide relief from the impact of caregiving and the ensuing loss of their CR and the caregiving role (Gerdner et al., 2007; Turner et al., 2004).

**Positive aspects of caregiving.** Most AAPCGs express personal fulfillment and joy, knowing that they did all they could to express their love and devotion, and that they were there for their loved ones till the very end (Gerdner et al., 2007; Scharlach et al., 2006; Turner et al., 2004). AAPCGs may fulfill multiple (caring for more than one family member at the same caregiving period), or serial caregiving roles (caring for one family member after another), which, although it creates a sense of satisfaction for a job well done, may fail to provide time to adequately grieve, resulting in a difficult adjustment to the loss of a CR and the associated caregiving role.

### **Achieving Healthy PCT**

Realistically, “healthy transition” is a state of affairs not yet fully described, especially in AA literature. However, one can synthesize available reports to suggest a picture of healthy transition based on Transitions Theory. According to Meleis et al. (2000), healthy transition involves process indicators such as achieving a sense of connectedness, interaction and feeling situated (described earlier in Chapter 2). These constructs speak to the basic challenges of social isolation and feelings of being trapped or imprisoned that many caregivers suffer and continue to deal with even past the termination of their caregiving roles (Gonyea et al., 2008; Morse & Messimeri-Kianidis, 2002).

**Interactions.** Thus, an important beginning point in achieving healthy transition will entail the re-engagement and reconnection of the PCG with a social network of friends, family and neighbors. This re-engagement might also include resuming social activities such as parties, or interesting pastimes and occupational interests such as returning to work or school, and reorganizing home life.

**Feeling included in a group.** PCGs attempting to knit their family together again may attend and support their children or grandchildren's extra-curricular activities. They may also participate in other previously shared enterprises that they gave up during active caregiving.

**Confidence and coping.** Another consideration for achieving healthy transition is the developing of confidence or coping. A PCG who has adjusted to the death of the CR and the ensuing loss of his/her caregiving role should show utilization of adaptive coping behaviors to deal with difficult, challenging or traumatic events in their lives. For AAs, coping is based on strategies that facilitate healing and restoration such as prayers and hope (Holtslander & Duggleby, 2009). They define hope as a "gradual process of regaining inner strength and building self-confidence to make sense of their completely changed situations" (p. 391).

Achieving confidence might involve finding balance in various aspects of the PCGs' lives (Holtslander & Bally, 2009). Key suggestions for achieving balance include focusing on positive thoughts, making plans, getting involved, and supporting other peoples' experiences in difficult times.

Finally, Transitions Theory suggests mastery of new skills as an outcome indicator manifesting healthy transition (Meleis et al., 2000). Gaining new meaning concerning what life represents at this time without the CR may be difficult for PCGs to articulate or achieve, but is very important to their healthy transition (Cadell & Marshall, 2007). The PCG manifesting healthy transition would exhibit skills such as creating a new life that does not revolve around caregiving, returning to school or training for a new hobby or occupational skill, or starting another caregiving situation (Meleis et al., 2000).

## **Gaps in Literature**

**PCT literature.** There is a significant gap in general caregiving literature in regard to the actual experience of the general population of FCGs in PCT (Koop & Strang, 2003; Larkin, 2009; Orzeck & Silverman, 2008). A recent detailed search of AA caregiving literature revealed no studies addressing post-caregiving specifically. A few studies focused on active AAFCGs, but only parenthetically addressed post-caregiving if these FCGs became bereaved during the study period (Burton, Haley, & Small, 2006; Herbert, Dang, & Schulz, 2006; Owen et al., 2001; Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Schulz et al., 2003). Some studies included AAFCGs, but with such small samples that racial and cultural effects could not be separated out in their analyses (Burton et al., 2006; Herbert, Schulz, Copeland, & Arnold, 2009). Other studies focused on associative variables such as social support (Herbert et al., 2006). Consequently, the PCT is generally not well understood, and particularly not in AAPCGs. Further investigation as a basis for effective intervention is critical.

**Instruments for PCT investigation.** A major gap in post caregiving research is the lack of a standardized instrument that directly measures healthy, effective, or successful transition. Because no such instrument exists, other associated constructs are measured instead, such as depression, social support, and coping, selected for assessment in this study. These instruments provided supportive variable-oriented data for the primary qualitative study findings.

## **Summary**

To address the paucity of research and to fill the gaps of knowledge regarding manifestation of PCT, particularly in AAPCGs, this study will explore the course of th

PCT. It also will provide the groundwork necessary for planning appropriate PCT intervention studies to further investigate the AAPCG experience and development of an instrument to measure healthy transition.



## **CHAPTER 3: METHODOLOGY**

### **Introduction**

This mixed methods dissertation study (Creswell & Plano-Clark, 2007) expands the body of knowledge about African American post-caregivers (AAPCGs), first explored in a preliminary qualitative descriptive study (Sandelowski, 2010) triangulated by the results from three standardized instruments, described later in this chapter. The dissertation combined a predominantly qualitative design with a supplementary, variable-oriented component which used the same standardized instruments to determine levels of depression, social support and coping. Variable-oriented analysis was used for purposes of fuller description, rather than to draw statistical inferences, highlighting the richness of experience from the perspectives of PCGs (Sandelowski, 1995). Case- and variable-oriented data were integrated at the level of interpretation, comparing data within and across cases and contributing to nursing science through increased understanding of the PCT in AAPCGs.

### **Philosophical Foundation**

This study used mixed methodology with both case-and variable-oriented approaches to intensively explore the natural course of the PCT in AAPCGs. The pragmatic worldview (see expanded discussion in Chapter One) is recommended as the best foundation for mixed method research design (Creswell, 2009), because it allows multiple modalities of data collection and data analytical view-points that are uniquely suited to the case in hand, and that can assist in answering the research question.

## **Research Question**

The research question for this study was, "How does the PCT evolve for AAPCGs?"

## **Theoretical Framework**

To realize this question, Transitions Theory was utilized (described in Chapter 2) as a theoretical framework to guide research design and implementation (Meleis et al., 2000). Transitions Theory (Appendix A, Figure 1) provides the guidance for the development and selection of data collection tools and data analytic methods, and assists in generating logical conclusions grounded in the data (Creswell, 2000).

## **Specific Aims**

**Aim 1.** Describe the types, patterns, and properties of the PCT in AAPCGs.

- a. What are the various types and patterns of PCT responses and how do they differ from one another, as identified by the PCG Interview Protocol?
- b. What are the properties of each type and pattern of PCT response, as identified by the PCG Interview Protocol?

**Aim 2.** Explore the facilitators and inhibitors of progress through the PCT in AAPCGs.

- a. What are the personal conditions that facilitate or inhibit progress through the PCT, as identified by the PCG Interview Protocol, and measured by the BC, CES-D, and SS?
- b. What are the community and societal conditions that facilitate or inhibit progress through the PCT, as identified by the PCG Interview Protocol, and measured by the BC, CES-D, and SS?

- Aim 3.** Describe the process and outcome indicators of the PCT in AAPCGs.
- a. How do the process indicators of connectedness, interaction, feelings of inclusion, and confidence/coping manifest themselves in the PCT, as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?
  - b. Is there a difference in levels of depression, coping and social support between AAPCGs who demonstrate mastery of new skills in the PCT and those who do not as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?
  - c. Is there a difference in levels of depression, coping and social support between AAPCGs who demonstrate separation from the caregiving role and adjustment to life without the CR in the PCT and those who do not, as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?

### **Preliminary Study**

The preliminary study explored perspectives of PCT in AAPCGs and determined AAPCGs' willingness to participate in a research study that asks them to share their caregiving and post-caregiving experiences in a group setting. The preliminary study also substantiated recruitment procedures and access to AAPCGs through community agencies. It supported the need for this current study of the AA population in the PCT, about which little is known. This study provided the foundational work necessary to progressively develop and implement culturally relevant interventions.

### **Specific Aims of the Preliminary Study**

The dearth of research on PCT supported the need for the preliminary study, which utilized Transitions Theory (Meleis et al., 2000). The purpose of this project was to conduct a descriptive study identifying characteristics of PCT expressed by former caregivers of AA older adults in the home. The following three aims were addressed:

**Aim 1.** Explore the PCT in African American caregivers.

- a. How do PCT caregivers perceive the role of social support in achieving healthy transition at the end of their caregiving roles?
- b. How do they begin to re-organize and restart their own lives after their loved one is gone?

**Aim 2.** Explore the determinants of both effective and ineffective PCT in African American CGs.

- a. What constitutes effective PCT?
- b. What constitutes ineffective PCT?
- c. What factors are antecedents of effective PCT?
- d. What factors are antecedents of ineffective PCT?

**Aim 3.** Determine the types and characteristics of effective PCTs in the African American caregivers.

- a. What are the various types of PCT responses noted in the AA population?
- b. How do these types differ from one another?
- c. What are the characteristics of each type of PCT?

## **Design of the Preliminary Study**

The preliminary study utilized a descriptive research design with both quantitative and qualitative components. The core component of the preliminary study was one focus group, an intensive, qualitatively-driven, examination of a group of individuals sharing the life event of PCT (Morgan, 1997). Triangulation was sought through the use of standardized instruments, Social Support Questionnaire – Short Form (SSQSR) and CES-D to enable conditional insights into social support and depression in these AAPCGs (Roberts, 1980; Sandelowski 2000; Saranson, Levine, Basham, & Saranson, 1983; Saranson, Saranson, Shearin, & Pierce, 1987). The preliminary study provided much needed guidance for this dissertation study and added significantly to the science in the area of PCT in AAPCGs by identifying types, characteristics of, and adjustment to transitions after the CR died or was transferred to the NH.

### **Recruitment**

Participants were recruited through the leadership/caregiving ministry of Church One, a medium-sized AA church in the metropolitan LA area. A copy of the IRB-approved flyer was emailed to the leader of the caregiving ministry who then forwarded it to known PCGs in the area. A date for the focus group was set in collaboration with the church leader who arranged for the church fellowship hall to be used on a Friday evening that was suitable for most church members. The preliminary study took place in LA where this dissertation study was also partially based, promoting transferability of lessons learned.

## **Inclusion and Exclusion Criteria**

**Inclusion criteria.** Interested individuals were AAPCGs who cared for an older adult 50 years or older, and whose caregiving career lasted at least three months. Initially, the research team decided that care was to have terminated within the last three years due to death or transfer of the CR to NH. However, many individuals whose loved ones died up to 10 years earlier indicated serious interest in participating in the study. Therefore, a modification was requested and approved through the IRB to accept individuals whose loved ones died within the last 10 years. The period of loss was found to be very legitimate, still painful, and significant to the AAPCGs. The decision to extend the time since end of caregiving was very important for the AAPCGs who participated in the study. Other inclusion criteria were that the PCGs must be of African American or African descent, either male or female, 18 years and older, English speaking and willing to participate.

Although multigenerational households may exist in AA families, resulting in care by younger members for older ones, caregivers who were 18 years of age or older were selected to ensure adult intellectual processing of the caregiving experience. The inclusion of CRs who were 50 or older was in response to the fact that AAs may be disabled sooner than Anglos, due to health disparities which could result in adolescents caring for aging parents (Aranda & Knight, 1997).

**Exclusion criteria.** Any racial or ethnic groups other than African Americans were excluded because the study hoped to ascertain the particular transitional issues of AAPCGs, in order to design culturally-sensitive interventions for them to achieve healthy post-caregiving transitions.

## **Procedures**

**Screening and informed consent.** Interested individuals were told about the research study including the purpose and modes of gathering data (focus group session, demographic questionnaire, SSQSR and CES-D scale). They were then screened to ensure that they met inclusion criteria and to assist in contextualizing data. Before the focus group session started, the researcher guided participants to read and sign the information letter granting consent to participate in the preliminary study.

**Setting and sample.** The location of the preliminary study was Los Angeles, California. There were 12 AAPCG participants including 2 males and 10 females, 11 participants were adult children and 1 was a spouse. The participants ranged in age between 30 and 55 years old, and cared for adult CRs 50 years and older. These AAPCGs provided care at home until their caregiving role terminated. Seven PCGs terminated caregiving due to the death of the CR and five PCGs had their caregiving roles terminate when CR was placed in a NH. Out of those five CRs, two died during placement. One CR wished to be moved back to her family in Louisiana to die, was moved, care was transferred to other relatives, and she died soon after. Two CRs who were placed in the NH are still alive. One CR continues to live at the NH while the other one went back home to live with a spouse.

## **Data Collection Devices**

**Focus groups.** Focus groups provided a data-rich source of data collection and an important ethnographic tool for gathering data from several individuals from the same racial and cultural background who had experienced the same phenomenon. Thus, the choice of focus group in the preliminary study, enabled access to the rich cultural and

personal components of experience from each AA participant who was experiencing PCT. The focus group was moderated using the "funnel" approach method described by Morgan (1997) that starts with more general questions. Such questions allow participants to begin discussion of non-threatening items of their choice, such as their experience during caregiving, and are followed by more specific semi-structured interview questions. A Focus Group Protocol was developed for the preliminary study and began with the question, "Let us talk a little bit about your experience of caregiving," and proceeded to other questions aimed at eliciting perspectives directly relating to PCT experiences of the participants.

**Focus group protocol.** Interview questions were derived from interdisciplinary caregiving literature, including nursing, anthropology, and the socio-behavioral sciences. Open-ended questions such as, "What types of adjustments, changes or challenges did you go through after caregiving ended?" helped to ascertain the types, characteristics of transitions that PCGs experienced. Another question, "Where do you think you got the most social support?" helped elicit information about social support and provided information as to how helpful the social support was in moving the PCG forward to healthy transition. The researcher also inquired about PCGs' spiritual and cultural bases of behavior, so as to elicit beliefs affecting caregiving and PCTs. Such beliefs are important, regardless of researcher labels, because if the beliefs are "true" within the context of the AA family, they direct and structure individual behavior (Dilworth-Anderson et al., 2005).



## **Standardized Measures**

**CES-D Scale.** The CES-D Scale, a self-administered scale with 13 numbered and sub-numbered questions, was chosen to measure current depression in PCGs. A score of 15 on the CES-D scale was considered indicative of depressive symptomatology and was to be reported to the PI, and a referral given to the participant for follow-up with a mental health provider. None of the participants scored more than 15 on the CES-D. The CES-D has been tested in various studies for validity and reliability in general population (Roberts, 1980). It also has been tested and analyzed using AA populations and shown to be an appropriate measure for depression (Conerly et al., 2002).

**SSQSR.** The SSQSR is a self-administered scale with 12 numbered questions chosen to measure both the perceived level of social support and how satisfying the social support is to the individual (Saranson et al., 1983). Lack of social support was shown in other studies to increase anxiety, difficulties and risks for illness and death which could be prevalent in PCT (Saranson et al., 1987). Social support in the preliminary study was a very important component of PCT that affected AAPCGs.

**Data collection.** The preliminary study explored PCT among AA families using focus group discussions, in combination with a demographic questionnaire and scores from standardized measures, to investigate the PCT, social support and depression.

A semi-structured Focus Group Protocol was used to guide the moderation of the focus group, to support participants to retrospectively discuss their progression through the PCT. Although retrospective approaches may not result in completely accurate reports, what matters is the socio-cultural meaning of the post-caregiving experience as viewed and remembered by the post-caregivers. The focus group discussion lasted over

two hours, was audio-recorded to fully capture participants' view points and participants were eager, energetic and enthusiastic for the duration of the entire focus group.

**Data analyses.** The focus group interview recording was transcribed verbatim and reviewed to ensure accuracy. A Coding Manual (CM) was initially developed to assist with the data reduction. Data reduction was done using start codes developed from the conceptual framework of Transitions Theory, which formed the initial domains (major categories for the study). After reading the focus group transcripts a number of times, the team identified codes emerging from the data. Both the researcher and her mentor reviewed the codes, refining and updating them according to data from the preliminary study. This process involved naming the codes, defining and describing the codes, and finding exemplars from the data that captured the essence of meaning of each code. The CM continued to undergo frequent reviews, revisions and refinements by collapsing (merging two or more like codes), adding (new codes) or revising previous codes as ongoing data analysis continued.

Frequently appearing codes forming a *leitmotiv* dealing with similar, recurring concepts or events were designated as themes (Miles & Huberman, 1994). Those themes were further grouped into categories to aid in analysis and interpretation of data.

## **Conclusions**

Preliminary analysis reveals that AAPCGs expressed a deep sense of loneliness and loss which remained for many years after the death of their loved ones. This continued sense of loneliness and loss was expressed even by those PCGs whose family members died four to nine years earlier. This refutes general beliefs that caregivers whose loved ones died more than two to three years earlier may no longer have a residual sense

of loss. Therefore nurses and healthcare workers need to be alert for emotional concerns in AAPCGs.

Depression was not reported in this group of participants. However stress and burden of the AAPCG was expressed in relation to the PCGs feeling bound by "death bed promises" to continue care of other relatives after the death of the current CR. AAPCGs reported caring for relative after relative in their homes (serial caregiving) and caring for several relatives at once (multiple caregiving).

Serial and multiple caregiving resulted in "a different kind of grieving," which was private, may not have followed expected norms of grieving such as crying or frequently visiting the cemetery, and appeared to prolong fully grieving and resolving the loss of the loved one. The "different kind of grieving" was described as constant, pervasive, and sometimes delayed, thus, creating family and inner conflicts for PCGs. However, some PCGs describe using this grieving pattern as a coping strategy, for example, not crying publicly or showing apparent emotional distraught, in order to be able to rapidly continue their other family or occupational roles. This may also have included pushing away their deep emotional responses about the loss of their loved ones in order to be able to continue or start another caregiving situation with other needy family member. Coping was based on the AAPCGs' reliance on God for spiritual strength, informal social support networks for instrumental and emotional support, and recognition of one's own inner strength.

Understanding AAPCGs' perspectives of issues and challenges of caregiving is critical for support in the post-caregiving phase. Although preliminary, this study provides timely and relevant information for nurses and healthcare workers about PCT.

### **Relevance of Preliminary Study to the Dissertation Study**

The preliminary study provided information that AAPCGs could be recruited to participate in research studies of this kind, and were willing to discuss their losses, challenges, coping, and adjustment strategies. It provided information about productive strategies for recruitment, such as making contact with a church leader who headed the caregiving ministry. This leader had great influence on, and shared mutual respect with, many of the caregivers in her church community, and she encouraged them to participate in the focus group.

The preliminary study also provided information about data collection tools. It was noted that the interview protocol was too long for a focus group of 12 vibrant AAPCGs who were more than willing to share their own experiences, thus making the scheduled 2-hour focus group last over three hours. It became apparent that managing 12 participants made it very difficult to provide equitable time for all participants to fully engage in the focus group discussions.

The data analysis of the focus group study provided the realization that individual semi-structured interviews were necessary to gain more in-depth, richer data from study participants and enable a more intensive exploration of PCT. Thus, the choice was made to use individual interviews in the dissertation study.

The preliminary study also revealed that PCGs who had lost their CR up to 10 years ago may still be affected by that loss. These PCGs were grateful to be given the opportunity to participate and share their story. Thus, the dissertation study also looked at individuals not only in the beginning but also in a long-term stage of PCT, up to 10 years since the death of the CR.

Sharing their stories in the focus group provided the participants an opportunity to explore sadness, loneliness, frustration, and fear associated with the loss of their loved ones. Participation also provided the benefit of a supportive environment with others AAPCGs who were going through the same situation and allowed the participants to provide emotional support for each other.

### **Design of the Dissertation Study**

This mixed methods study expands the body of knowledge about the PCT in AAPCGs, first explored by the preliminary study. A convergent triangulation design (Creswell & Plano-Clark, 2007) provided the opportunity for the researcher to collect and analyze both case- and variable-oriented data separately, merging the findings and results during interpretation. Data were collected concurrently from AAPCGs and selected case-oriented data were quantized, that is, converted to numerical data (Miles & Huberman, 1994) to facilitate integration and comparison with variable-oriented data.

Convergent triangulation is an efficient design that, when properly accomplished, results in “valid and well-substantiated conclusions” (Creswell & Plano-Clark, 2007, p.65). Appropriate to such a design, both case- and variable-oriented data were obtained at the same time from the same sample of AAPCG’s, and demographic information was collected. The study was weighted toward case-oriented findings, based on the aims, purpose, and research questions (Creswell & Plano-Clark, 2007) of the study.

. In combination with this predominantly qualitative (case-oriented) design (Creswell, 2009; Creswell & Plano-Clark, 2007; Sandelowski, 2000), a supplementary variable-oriented component using standardized instruments (CES-D, SS [a different instrument from that used for the preliminary study, Belle et al, 2006]and the Brief Cope

[Carver, 1997]) determined levels of caregiver support, depression, and adjustment to the PCT. Variable-oriented analyses were used for purposes of fuller description, rather than to draw statistical inferences (Sandelowski, 1995).

A case-oriented approach involves "an intensive study of a single unit for the purpose of understanding a larger class of similar units" (Gerring, 2004, p. 341). In this study, a case was defined as one AAPCG who met the criteria for inclusion, described further under sample and setting. The case-oriented method was appropriate for this study because case-oriented data can be evaluated and analyzed both qualitatively and quantitatively, thus supporting the mixed methods design (Gerring, 2004). Furthermore, the case-oriented approach is useful to study a phenomenon about which little is known, such as the types of PCT and how PCT is manifested in AAPCGs (Gerring, 2004). This approach allowed us to conduct an in-depth descriptive study that sought to explore and provide a deep understanding of PCT as a homogenous unit of analysis (Gerring, 2004) in terms of English-speaking informal caregivers of similar racial and cultural backgrounds, and loss of a loved one to death.

### **Sample and Setting**

Forty cases ensured that the sampling frame (Appendix C) were filled and allowed us to reach data saturation (the point at which no new data emerged from the analysis (Miles & Huberman, 1994; Sandelowski, 1995). The AAPCGs served as the data source. As previously noted data from standardized instruments such as CES-D, SS, and BC were used to ensure a fuller description of the concepts of depression, social support and coping, rather than to draw statistical conclusions (Sandelowski, 1995).

AAPCGs were defined as family members or fictive kin (individuals considered relatives but not related by blood or marriage) of African or AA descent, 18 years of age or older, of either gender, who provided prior informal family caregiving for an AA CR. AAPCGs were individuals who, within the last 10 years, provided continuous or intermittent assistance with most, if not all of the CR's ADLS and IADLs, and whose caregiving relationship culminated with the death of the CR. CRs were to have been 50 years or older, of either gender, and with various types of diagnoses.

The researcher included primary and secondary AAPCGs, co-resident AAPCGs, or distant AAPCGs in the study. Primary CGs were individuals who were directly responsible for the heavy day-to-day care of the CR including ADLs or IADL, whereas secondary CGs only provided a portion of the care such as financial management of the CR, driving to health care providers' appointments or buying food or medications. Secondary CGs may or may not have lived in the same home as the CR and only occasionally relieved the primary CG. Co-resident CGs lived in the same household with the CR while providing care. On the other hand, distant CGs did not live in the same city, but provided close care, supervision, and monitoring of the CR on a routine basis. Distant CGs monitored CRs via routine phone calls, emails, or other technology-based modalities (such as Skype and conference calls) to direct the care of the CR, and sent regular financial, medical and household material support. It is believed that each of these caregiving situations was unique and that each participant brought their own specific meanings to the study within the context of their particular care experiences (Evans et al., 2011; Gerring, 2004; Sandelowski, 2006).

. A stratified purposeful sampling plan (Appendix B) ensured case variation on the pre-selected parameters. The researcher explored specific variations in cases, including time since the death of the CR, relationship to the CR (spouses and others including siblings, nieces/nephews, daughters/sons, neighbors or friends), and gender (male or female) of PCGs. The spouse/other designation is commonly used in caregiving research, as demonstrated by the recent report of the national REACH study (Belle et al., 2006). The researcher attempted to fill each sampling cell with two or more cases that exemplified the kinds of variation relevant to understanding the post-caregiving phenomenon in AA families, enrolling cases that varied on those pre-selected parameters (Sandelowski, 2000).

The primary variable for stratification was the elapsed time since termination of the intense, continuous caregiving for each case due to death of CR (Appendix B). Participants whose family member died while in their care, who placed their CR in NHs, or transferred care of their CR to other relatives before the CR died were enrolled. Although most literature examines the active caregiving period and the immediate bereavement period that usually represents the first three years after death of the CR, this study examined the post-caregiving period up to 10 years after the death of the CR. This extension enabled a fuller examination of the differences and/or similarities in adjustment and progression through PCT.

The study enrolled cases into one of three groups. The first group included PCGs in which 0-3 years had passed since the death of the CR, to examine the beginning aspects of coping and adjustment of PCT. The second group consisted of AAPCGs whose loved ones died 4-6 years prior to this study and examined the continued evolution of



PCT, coping with challenges, and achieving adjustment. The final group had AAPCGs who lost their loved ones 7-10 years prior to the study. This group helped the researcher to examine long-term coping, and adjustment in transition because the preliminary study for this dissertation revealed that individuals in this stage of PCT continued to experience and express adjustment and coping challenges, the PCT period of examination was extended to 10 years to provide greater insight into the exploration of PCT. The inclusion of the three groups allowed examination of early to late transitions, including challenges, coping and adjustments strategies that helped AAPCGs achieve healthy transition. Finally, this study explored long-term PCT on individuals who were expected by society to be completely adjusted to their loss and to have moved on with life after loss of their CR and loss of their caregiving role.

### **Inclusion and Exclusion Criteria**

**Inclusion criteria.** AAPCGs who were accepted into the study met the following criteria: they had to be willing to participate, fluent in English, and have telephone service for setting the appointment and other possible contacts.

Participants were at least 18 years of age, and had cared informally for a CR who was at least 50 years of age or older, at home for at least three months before the CR died. The CR must have died within the last 10 years. All study materials, recruitment script, information letter, interview protocol and standardized instruments were in English. All participants were interviewed face-to-face.

**Exclusion criteria.** Non-English-speaking AAPCGs or those whose CRs were still alive at home, in the NH, or with other relatives were excluded from this study. AAPCGs who lived within Phoenix and the Los Angeles metropolis who were not able to

be present for face-to-face interviews and who did not have access to a computer with Internet were excluded because of the inability to contact them via the selected modality of face-to-face or Skype interviews. However, no one utilized the Skype modality for this study.

**Sample size.** The mixed methods approach for this study was supported by a purposeful sampling plan for intense, in-depth, case-oriented, descriptive analyses and a complementary variable-oriented analysis. Extant literature revealed that 40 cases are an adequate sample size for case-oriented analyses. Many qualitative studies used even smaller sample sizes. For example, Bentelspacher et al. (2006) used 10 cases; Gerdner et al. (2007) used 15 participants; Poindexter, Linsk, and Warner (1999) had 20 participants; and Anderson and Turner (2010) utilized 24 cases. A sample of 40 cases was adequate for data saturation, a point in the data collection and data analytical process when no new codes or themes appear (Lincoln & Guba, 1985; Onwuegbuzie & Leech, 2007). This study generated 40 AAPCG interviews, each about two hours in length, comprising about 80 hours of data collection based on in-depth semi-structured interviewing.

Although it was difficult to calculate appropriate gender representation of the sample prior to data collection because the literature on AAPCGs is so sparse, the preliminary study provided data concerning availability. In that study, 10 females (83.3%) and 2 males (16.6%) were enrolled. Based on that data, 34 females and 6 males were enrolled for this dissertation study. Although male AAPCGs were expected to be in the minority, they were actively sought out, their involvement solicited, and they were over-sampled in order to examine gender differences in the PCT.

**Power.** For the variable-oriented analyses, the sample of 40 participants was adequate to add "fuller description" to complement the predominantly qualitative design (Sandelowski, 1995). As previously noted, although a sample size of 40 is not adequate for inferential statistics, the intent of this primarily case-oriented study is rich description. Power is not a consideration for case-oriented data because such data are used to create logical generalizations which provide theoretical understanding of a similar class of phenomena rather than probabilistic or statistical generalizations to a population (Popay, Rogers, & Williams 1998, p.348). The researcher used descriptive statistics to further clarify the case-oriented portion of the study.

**Settings.** The settings for this study were the metropolitan areas of Phoenix, Arizona and Los Angeles, California. The AA researcher recruited AAPCGs through churches, community organizations, beauty shops, or schools where large numbers of such individuals might be found. The researcher personally completed data collection at locations of these participants' choice, preferably in their homes or workplaces within Los Angeles or Maricopa counties. This ensured a comfortable environment which promoted feelings of safety in sharing information.

**Recruitment.** Participants were recruited simultaneously in metro Phoenix and Los Angeles. Use of both metropolitan areas via personal interviews allowed access to established families and their networks of support. It is estimated that 4.1% of households in metro Phoenix and 6.2% of households in Los Angeles are AAs, for a total of 114, 551 AAs in Maricopa County and 930,957 AAs in Los Angeles County (U.S. Census Bureau, 2011). The researcher was easily able to draw 40 AAPCG participants from a pool of over one million AAs. Access was through relationships already developed by the

researcher with stakeholder organizations such as churches serving AA families via a grass-root network and word-of-mouth strategies to enhance recruitment. As recommended by Dilworth-Anderson, Thaker, & Burke (2005), “best practices” in recruitment were used by proactively determining that research on post-caregiving in AA families was of interest to AA organizations, churches and post-caregiving families. Finally, recruitment also occurred through relationships built with other researchers reaching out into diverse communities of AA families coordinating outreach efforts at local health and other community events.

Based on successful recruitment during the preliminary study, recruitment flyers with pictures of AA individuals portrayed as FCGs, including older adults and young adults, were utilized in this study. The use of pictorial flyers and making phone contacts were recommended as one of several “best practices” for enhancing recruitment of AA families (Dilworth-Anderson et al., 2005). Because data collection was completed at one time point, there were no attrition issues. The researcher’s preliminary focus group study, community activities, long-term participation in, and support for AA organizations and churches in the Phoenix and LA areas helped to draw participants. These strategies have been found to enhance recruitment in other studies (Moreno-John et al., 2004).

The principal investigator (PI) who was culturally and linguistically matched to the community acted as the cultural broker to provide access to the system, interpret culturally and ethnically-laden perspectives, and provide a conduit to family acceptance. Use of the cultural broker provided additional insight into cultural issues and increased data quality and validity (Dilworth-Anderson et al., 2005).

Additionally, the AA researcher agreed to disseminate the outcomes of the study to the AA community. For example, an abstract submitted to the 2013 Association of Black Nurse Faculty (ABNF) Scientific Conference has been accepted.

The researcher made telephone contacts to set up appointments for data collection with participants identified by agency, church or organization representatives and reminder calls were made the day prior to visits. The researcher continued to enroll all eligible participants identified during the study period until the final sample of 40 cases was reached. Also, there were attempts to maintain interest in the study through weekly phone calls by researcher to church and organization leaders (Walsh et al., 2004) and a monetary incentive of \$20 was given at the time of the interview with enrolled participants.

Personal, warm conversations focusing on family and pets at the beginning of the telephone, face-to-face contact were used to build a trusting rapport with participants (Evans et al., 2007). Generally, to limit each participant's burden from lengthy study questions, the researcher was flexible in data collection, stopping intermittently for rest periods or rescheduling, as needed. Participants were offered the option to complete the instruments over the phone after the interview visit, if fatigue or time constraint were reported or noted. Two participants had to leave before fully completing all the instruments to pick up children after school and to attend to personal appointments respectively, however, efforts to reschedule the appointments for a phone conference were unsuccessful. That portion of the data was treated as missing data.

## **Data Collection Devices**

A number of data collection devices were used to answer the research questions, including interviewing, a demographic questionnaire and standardized measures.

Interview questions and questionnaires were read to participating AAPCGs to avoid literacy and visual problems. Data collection devices, concepts/variables, and data sources are portrayed in Appendix C.

### **Screening/Demographic Questionnaire**

**Screening.** Screening ensured that participants met inclusion criteria and assisted in contextualizing the data. Questions 5-7 on the screening/Demographic Questionnaire form (Appendix D) determined eligibility for the study. These questions include the age of CR, length of caregiving, and time since caregiving ended. AAPCGs were screened to ensure that they were eligible for participation according to the inclusion and exclusion criteria previously discussed.

**Demographic questionnaire.** This form contained demographic questions concerning the PCG's age, gender, relationship to the CR, the types of caregiving tasks provided (such as bathing dressing, grooming, shopping, driving etc.). The questionnaire (Appendix D) also ascertained whether the AAPCG was involved in multiple caregiving (caring for more than one person at the same period of time) or serial caregiving (caring for one person after another).

### **Interview Protocol**

Interview protocol questions (Appendix E) were derived from interdisciplinary caregiving literature, including nursing and the socio-behavioral sciences, and from the theoretical framework of the study (Transitions Theory). Questions took 90-120 minutes

to administer. Open-ended questions followed by probes were used when participants needed additional guidance to answer questions. Questions helped to ascertain the types, patterns, and properties of PCT and adjustment strategies used by the AAPCGs. The following is an example of a theory-derived question from the interview protocol: "Tell me the strategies you used as you were trying to adjust to life after caregiving ended, both those that worked and those that did not?" Another question was "What influence did being AA or the influence of culture have on your caregiving?", with probes such as "...your decision to become a caregiver?" or "...how you dealt with the loss of your loved one?"

Protocol questions were designed to elicit both positive and negative statements about caregiving and post-caregiving experiences. The researcher examined interviews carefully for such utterances which emerged from the data (Miles & Huberman, 1994).

Immediately after each interview, the researcher recorded field notes, making short condensed notations about observations of major events and/or key phrases from participants' comments, including her opinions and any interruptions during the visit (Spradley & Baker, 1980). Soon after the visit, the field notes expanded into detailed description of the events (Spradley & Baker, 1980). The researcher also completed contact summaries which included important nonverbal data, paraverbal data, and observations of the researcher based on interactions with the participant (Miles & Huberman, 1994; Spradley & Baker, 1980). The contact summary sheets allowed the researcher to reflect on the interactions, noting similarities and differences in the narratives, and recording themes that emerged from the interviews. The researcher recorded any experiences that significantly shaped the PCT experiences for the AAPCGs,

such as migration, culture, religion/spirituality, coping, social support, marriage, births or deaths (Uhlenberg, 1996), along with the explanations of the meaning and occurrence of such event. The contact summary sheet acted as the first level of data reduction, was used to suggest additional codes, acted as an adjunct to data analysis (Miles & Huberman, 1994), and recorded generalizations, cultural meanings, interpretations and insights (Spradley & Baker, 1980).

### **Standardized Measures**

This study used three standardized measures. As in the preliminary study, AAPCGs' depression was measured using the CES-D scale, a Social Support Instrument (SS). Additionally, the AAPCGs' coping abilities were measured using the Brief Cope (BC). The reliability and validity of the instruments reported by previous studies are discussed below.

**CES-D.** This is a scale (Appendix F) with 13 numbered and sub-numbered questions, and provides a reliable and valid measure of depressive symptoms in both general populations and AA caregivers (Clay, Roth, Wadley & Haley, 2008; Gary & Berry, 1985; Haley et al., 2004; Radloff, 1977; Roberts, 1980). It displays a coefficient alpha of .90, well above the accepted range of .70–.80 (Conerly, Baker, Dye, Douglas, & Zabora, 2002; Nunnally & Bernstein, 1994). Participants who received a score of 15 or above, which is indicative of depression, were referred for follow-up with a mental health provider.

**Brief Cope (BC).** This instrument (Appendix G) was originally a 28-item instrument with 14 scales (with two questions each). Reliability and validity were tested in a sample of 34 percent AAs and 66 percent females from a study on the recovery after



Hurricane Andrew and included 118 participants (Carver, 1997). The reliability showed a Cronbach's alpha on each question of more than .60 except on venting, denial and acceptance (examples include: religion = .82, using emotional support = .71). These alphas exceeded the minimally acceptable norm of 0.50 (Carver, 1997; Nunnally, 1978).

The instrument has been used in various studies (Cooper, Kationa, & Livingston, 2008) with good internal consistency in the following subscales: emotion-focused = .72, problem-focused = .84, and dysfunction = .75. The BC is researcher-friendly because it is not meant to be an "all or none" instrument (Carver, 1997, p.98), that is, researchers are encouraged to choose questions that best address their intended aims and the Brief Cope may be used in a retrospective, situational manner (Carver, 1997).

For this study, we used an adapted 22-item BC (Appendix G) with 11-scales of two questions each, adapted and used by the REACH Project. The following scales were part of this adapted BC instrument: Active coping, items 1 and 2; Planning items 3 and 4; Positive reframing, items 5 and 6; Acceptance, items 7 and 8; Use of emotional support, items 9 and 10; Use of instrumental support, items 11 and 12; Self- distraction, items 13 and 14; Denial, items 15 and 16; Venting, items 17 and 18; Behavior disengagement, items 19 and 20 and Self-blame, items 21 and 22. Three scales from the original BC instrument - humor, religion and substance use - were not part of this adapted scale.

Each question was scored on a Likert-type scale of 0-3 with 0= "I haven't been doing this at all;" 1 = "I have been doing this a little bit;" 2 = "I have been doing this a medium amount" and 3 = "I have been doing this a lot" (See Chapter 3 for description of data collection instruments).

**Social Support.** The 17-item SS instrument (Appendix H) is a composite measure developed from several instruments (Barrera, Sandler, & Ramsay, 1981; Krause & Markides, 1990; Krause, 1995; Lubben, 1988), and used in the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) project – a multi-site intervention study (Belle et al., 2006; Wisniewski et al., 2003). The total sample for that particular study (n = 642) included 211 AA caregivers (Wisniewski et al., 2003). The scale measured multiple domains of social support including received support, satisfaction with support, social network, and negative interactions or negative support that negatively impacted health of caregivers (Belle et al., 2006). The measures for negative interactions were reverse-coded and included questions such as “How often have other people taken advantage of you?” The total scores of all items were summed for a total social support score ranging from 0-30. A higher score on the instrument indicates increased social support (Belle et al., 2006).

### **Data Collection Procedures**

#### **Screening and Informed Consent**

Organization and church leadership staff identified and contacted potential participants and forwarded their contact information to the researcher in-person, by phone or via email if participants were willing to become part of the study. After obtaining verbal consent, the researcher screened each potential participant’s suitability for participation in the study according to the inclusion and exclusion criteria discussed earlier in this chapter. The researcher explained the study and obtained informed consent from eligible AAPCGs. The information letter (Appendix I) served as the consent form, and accompanying explanations of its contents outlined the project’s procedures, benefits,

risks, and emphasized the voluntary nature of participation. The PI provided opportunities for questions. If consent was not obtainable, the individual was not enrolled. However, all potential participants who showed interest in the study and who met the criteria gave verbal and/or signed consent. Similar to other recent national studies such as REACH II, if the PCG was unable or unwilling to provide written consent, verbal consent was obtained and audio-recorded so the individual could participate in the study. Completion of the data collection devices, including the interview, was also accepted as implied consent. The researcher read the information letter to the participant to avoid literacy and visual difficulties and to facilitate understanding.

### **Data Collection**

The case-oriented approach used in this study elucidated a topic not well explored and facilitated the conceptualization of new research domains (Gerring, 2004) through interviewing, which is considered “one of the most common and most powerful ways to understand our fellow human beings” (Fontana & Frey, 1998, p. 47). Interviewing has long been the gold standard for naturalistic data collection and is widely used in the health sciences. The purpose of the semi-structured interviews was to furnish in-depth data about the PCT experience of AAPCGs.

During the visit, using the participant’s answers, the researcher completed the Demographic Questionnaire (Appendix D), and used the semi-structured PCG Interview Protocol (Appendix E) as a guide for interviewing AAPCGs retrospectively (eliciting memory recall of the AAPCG’s past or ongoing experience of PCT). Retrospective data collection may have certain challenges such as recall-bias, which are research errors that result from differences in what each participant remembered about a particular

experience (Hassan, 2006). The difference in AAPCGs recall over time may lead to concern about the reliability and validity of the data collected (Fowler, Coppola, & Teno, 1999; Martyn & Belli, 2002). However, retrospective data collection (Lowey, 2008) appeared to be a realistic method of gathering data in end of life situations because it provides the AAPCG's perspective and personal meaning of the caregiving and post-caregiving experience, which may not be available while they were dealing with their dying loved ones. The creation of the story and the telling and retelling of their experiences, helped the AAPCGs to formulate the individual meaning of each care experience which then became their reality and their truth (Ayres, 2000). Elicitation or augmentation or clarification of information was garnered using probes such as, "Tell me more about..." or "How did that happen?"(Sandelowski, Davis, & Harris, 1989).

Interviews were audio-recorded.

As in the preliminary study, most PCGs were between the ages of 30-55 years old, therefore, fatigue was not a serious concern. They were encouraged to complete both the interview and standardized portions of the study in one session. However, in the unlikely event that they became fatigued, they were offered the opportunity to reschedule a phone or Skype contact to complete the second phase of data collection which involved answering questions from the three standardized instruments (CES-D, SS and BC) over the phone or Skype. As previously noted, only two people took advantage of that offer, but they were not able to complete that portion of the standardized instrument. Each question on the standardized instruments was read to the participants to avoid literacy concerns or visual challenges and the participant's answers were marked on the form by the researcher. Marking the answers on the instrument by the researcher helped to

facilitate full completion of the instruments to avoid or reduce the issue of missing data, that is, questions that are left blank or unanswered by study participants.

Prior to data collection, the researcher maintained confidentiality of project materials by assigning each participant a unique project I.D. number and pseudonym. At the beginning of the audio-recording of each AAPCG interview, the researcher prefaced the interview with an introduction identifying the AAPCG only with the assigned ID number and pseudonym.

At no time were AAPCGs coerced to participate in this study. Participants were reminded that they could refuse to participate in any aspect of the project. The risks to participants were minimal in comparison to the benefits of generation of new knowledge about the PCT in AAPCGs.

Participants were pleased that they were part of a study that would add to the science, and which might lead to an intervention to improve the lives of other AAPCGs and families. They felt empowered that their stories were considered significant and important enough to be requested, and that their caregiving roles were acknowledged. Telling their stories also provided participants the much needed exploration of the PCT, as noted in the preliminary study.

### **Procedures for Monitoring Data Quality and Managing Data**

A protocol book containing coding decisions, naming conventions for the pseudonyms, and data collection procedures was developed to guide this study. Pseudonyms were assigned by changing the first letter of the participant's first name to the next letter in the alphabet, then designating an appropriately-gendered name beginning with that letter. For example, a participant named "Alisha" would be given the

pseudonym “Bashira.” The researcher selected pseudonyms from a list of online-generated AA names. Data collection packets and audio-recordings were marked with the pseudonym and ID number. Data collection packets were prefaced by cover sheets with checklists for each procedural step. A research assistant who was added to the team during this project received one-on-one orientation by the researcher, and completed the National Institutes of Health (NIH) training on protection of human subjects in research.

All interview transcripts were transcribed verbatim and were checked for accuracy by the researcher using the audio-recorded MP3 file and the hard-copy of the transcript. The researcher met regularly with Drs. Evans and Coon to improve understanding of her role, review her progress in the study, promote consistent administration of study instruments, and develop analytical codes to aid in analysis and interpretation of the data. The team established 90% inter-rater agreement (Miles & Huberman, 1984) on coding of interview data.

The researcher or the supporting research assistant cleaned (removing all identifying information such as name of participants or family members from the transcribed interview document) and imported transcribed interview data into ATLAS.ti Version 5.2 (Scientific Software Development, 2006) for coding and analysis. Results of all data from demographic questionnaires and standardized instruments were entered by the researcher or the trained research assistant (RA) into the Statistical Package for Social Sciences (SPSS), version 19, a computer database (Fahy, 2003). Accuracy of data entry was checked and verified by the researcher, using a double entry procedure (acceptable accuracy 100%; Fahy, 2003). All data were confidential and were reported only in the aggregate or using pseudonyms.

## **Data Preparation**

### **Coding**

As previously described, a Coding Manual developed from the literature and Transitions Theory during the preliminary study formed the foundation for the Coding Manual used in this study. The Coding Manual was refined and updated with emerging data from the study, collapsing (merging two or more like codes), adding (new codes) or revising previous codes (Spradley, 1980).

Each of the 40 AAPCGs was systematically examined as an individual case using “within-case” analyses (examining important issues or themes or patterns of like data that emerged within the same case), and compared with every other participant in a “cross-case” analysis (which compared the emerging themes or categories from all the cases, noting similarities and differences [Miles & Huberman, 1994; Gerring 2004]). Inductive research methods (Miles & Huberman, 1994) guided analysis of interview data in an effort to increase understanding of naturally occurring PCT events. Viewing the interviews as narratives, the researcher identified relationships among social, cultural, and spiritual phenomena that exerted strong influences over AAPCGs because they were construed in common ways (Patton, 2002).

In order to establish inter-rater agreement (reliability), the researcher and mentor, Dr. Evans, or a RA separately coded one interview using previously established decision rules (in the Coding Manual as previously discussed), compared results, and repeated this process until an inter-rater agreement of 90% was achieved (Miles & Huberman, 1994). They separately examined and coded successive interviews to see if they included codes found in the first interview. Each coder then presented her/his coding decisions to the

other investigator to cross-check findings and weighed the evidence for indications of stronger data such as volunteer statements. If the coding investigators disagreed on interpretation, the researcher applied decision rules from the Coding Manual, and revised, collapsed, or unpacked codes/themes as needed (Spradley, 1980).

Following procedures as outlined in Miles & Huberman (1994) for case-oriented analyses, all data collected from each of the 40 cases were read and coded. The researcher read the transcripts, and wrote marginal remarks (notations made on margins of the transcript by the researcher as the transcripts are read). The marginal remarks denoted ideas of possible interpretations, leads, and connections to other parts of the data, questions or other things to explore during subsequent data collection or interviews (Miles and Huberman, 1994). These remarks were useful for noting possible codes and themes emerging from the data (Sandelowski et al., 1989).

Analytic memos (notations of a researcher's reflective thoughts and theories about the data) helped the researcher to document the ongoing changes in her perspectives, thoughts and theorizing about the data and the conduct of the study (Sandelowski et al., 1989). Constant comparisons were utilized (which involves reading and reviewing each data multiple times, moving back and forth between the data), to investigate variations in data, to integrate codes and themes, and analytic memos (Sandelowski et al., 1989). Pattern coding (which pulls together all emerging themes that group together codes with like terms, concepts and constructs), were used to categorize information which helped in cross-case analysis from all interviews. Case-oriented data were quantitized (converting qualitative data to numerical values for purposes of descriptive statistical analysis;



Sandelowski, Voils, & Knafl, 2009) by dichotomizing data or using frequencies of occurrence of concepts or variables where appropriate.

### **Case-Oriented Analysis**

Case-oriented analysis emphasized the qualitative descriptive phase of inquiry, identified types, patterns, and properties of transitions, and searched for personal, community and societal meanings and conditions underlying transition events, as well as process and outcome indicators of healthy transition.

The researcher systematically:

1. Examined each of the 40 AAPCGs as an individual case (within-case examination) (Miles & Huberman, 1994; Gerring, 2004).
2. Compared each case with the other 40 cases (across-case comparison) (Miles & Huberman, 1994; Gerring, 2004).
3. Compared each case in the early (0-3 years since the death of CR) phase of post-caregiving group with every other case in that group; compared each case in the middle (4-6 years since the death of the CR) and late (7-10 years since the death of the CR) phase of post-caregiving groups with every other case in its respective group.
4. Compared all cases in the early phase of post-caregiving group with all the cases in each of the other two post-caregiving phases.

### **Other Bases of Analyses**

#### **Socio-Demographic Comparisons**

The researcher compared each case of AAPCGs based on age, gender, socio-economic status to evaluate any notable similarities or differences, if any, based on these

selected criteria. As in the preliminary study, *age* comparison was achieved by grouping participating AAPCGs into four age groups in the following order: 18-29; 30-55; 56-70; and those over 70 years old. As previously asserted from the preliminary study, the majority of the AAPCGs who were interested in this study were in the 30-55 year old range. The age grouping helped to explore the effect of age on adjustment to PCT. Previous research suggested that older age of the PCG seemed to predict better bereavement adjustment for both spousal and adult children PCGs (Bernard, 2003).

#### Gender

Comparisons explore differences in how males and females behave during the PCT. It was also be important to explore potential differences of their gender-based articulation of loss of the caregiving role or loss of the loved one and their subsequent adjustment.

*A socioeconomic* comparison explored the impact of financial well-being on the AAPCGs' adjustment to life after caregiving. It is believed that PCGs who do not have to worry about financial difficulties have more positive adjustment (O'Bryant, 2011).

**Comparisons by associated variables.** Time since the death of the CR was a level of sample stratification, but also served as another point of analytical comparison. Timing subgroups include those whose loved ones died within the last 0-3 years, 4-6 years, and 7-10 years. Time since death of the loved one is important to help evaluate the conclusion that certain emotional and physical impacts of PCT in PCGs improve or dissipate over time. Individuals may report feeling better, improved depression, less anxiety and with reduced physical health challenges (Aneshensel et al., 2004); or may continue and become more detrimental and fatalistic (Schulz & Beach, 1999).

Relationship to the CR also was a basis of sample stratification and presented another important analytical point that was critical to the understanding of PCT. Common relationship groups include spousal PCGs, adult children PCGs, sibling or fictive PCGs. Previous research shows that adult daughters may experience more CG role strain than spousal PCGs, possibly due to combination of other familial and occupational roles that they were engaged in along with caregiving. However, spousal PCGs have a more difficult time adjusting to the loss of the loved one, probably due to the loss of companionship (Bernard & Guarnnacia, 2003).

Comparison was also achieved by grouping those AAPCGs who cared for their CRs at home till the CRs died versus those who cared for the CRs at home before NH placement, or those who transferred care of CR to other relatives. Data collected from PCGs who continued to care for older adults informally in the home was compared with those who were unable to continue caregiving. This helped to further examine the belief that NH placement hastens the death of the older adults, leading to PCGs experiencing increasing guilt as noted in the preliminary study.

The effect of multiplicity of roles was examined by comparing PCGs involved in single (cared for only one CR over 50 years old at home); multiple (cared for more than one CR over 50 years old in their home at the same period); or serial caregiving (cared for one CR over 50 years old after another in their home, one CR at a time). Based on data from the preliminary study, it could be argued that those who are involved in serial or multiple caregiving may experience a more difficult adjustment due to the concurrence of unremitting caregiving.

## **Case- and Variable-Oriented Analytic Strategies**

**Aim 1.** This aim focuses on the types, patterns and properties of PCT in AAPCGS. Analysis emphasized the descriptive phase of inquiry, identifying the full spectrum of transitions, and their influence on PCT in AAPCGs. During interview analysis, when an idea occurred repeatedly in multiple contexts, the researcher identified it as a theme that shaped the post-caregiving experience (Ayres, Kavanaugh & Knafl, 2003). For Aim 1, themes associated with transitions in PCT were explored. The researcher examined each PCG and then compared each PCG with other PCGs, formalizing these comparisons with case summaries. The researcher compared interviews across individuals to develop themes, reflecting variation on a given theme, and discern how themes fit together into case summary profiles. A matrix of theme categories facilitated by Atlas.ti (a computer software used for qualitative analysis; [Zhang & Wildemuth, 2009]) was developed to assist in linking summary profiles (outlines of the characteristics of each case). ATLAS.ti also permitted retrieval of multiple instances of a code or theme within and across cases so that frequencies of those codes and themes could be calculated. In this way, the researcher enhanced credibility/internal validity by looking at multiple PCG cases to find cross-case patterns, then tracked them carefully through all cases to see whether the pattern was repeated (a form of replication). Replication is important in building nursing knowledge because it is considered the bedrock of science (Miles & Huberman, 1994).

The variable-oriented data analysis consisted of both descriptive and inferential methods. Variable-oriented data were double entered, compared, and cleaned using the most current Statistical Package for the Social Sciences (SPSS) procedures. Descriptive

statistics identified distributions for demographic and standardized measures (CES-D, SS and BC). Internal consistency for instruments was assessed using Cronbach's alpha.

Taking advantage of the complementary relationship between case- and variable-oriented approaches (Ragin, 2000), interview data were combined with scores on standardized measures. Case oriented data were converted and quantitized at the analysis level. "Quantitizing" narrative data assisted with data reduction (Borkan, 1991; Elliott, 2005; Miles & Huberman, 1994; Sandelowski, 2000; Sandelowski, 2009). Where appropriate, case-oriented narrative data were converted into items, ranks, scales, or constructs, so that they were represented numerically to facilitate comparison with variable-oriented data. For example, dummy codes (dichotomous variables representing qualitative data, often taking the value of 0 or 1 where one is the presence of that fact and 0 is absence of that fact; Hardy, 1993) were created for categorical variables such as membership or non-membership in a group of PCGs who placed their CR in a NH before the CR died (identified in data from interviews).

Dummy codes for different types of "transitions" were subjected to analysis to study their effects on AAPCGs adjustment to PCT. Dummy codes were created for types of transition, depression, coping, social support and multiplicity of PCG roles (such as single, multiple, or serial caregiving). Simple descriptive statistics such as frequencies provided additional insights, such as the number of times PCGs were involved with caregiving of other loved ones; or how many times a particular "transition" occurred across all PCGs or male PCGs. Such numerical information was then directly compared to data from standardized measures addressing these constructs. Dummy codes of ( $X = 1$ ,  $Y = 0$ ) can be used to represent PCGs who experienced developmental transition were

coded as one, while all others were zero. If PCT was based on health/illness, those who experienced PCT due to health/illness of their CR were coded as one, all others coded as zero (Hardy, 1993).

**Aim 2.** This aim focused on facilitators and inhibitors of PCT in AAPCGs. The researcher used case-oriented data reduction procedures as described above to identify PCG facilitators and inhibitors to achieving progress through PCT. These facilitators and inhibitors were nested within cultural and religious influences on caregiving and post-caregiving experiences of the participants as described in the interviews. Examination of the effects of personal, community, and societal conditions that impacted the AAPCGs' experiences, were completed within and across all cases, separating cases according to early, middle, and late groups of AAPCGs.

One way to link case- and variable-oriented research approaches, is to build knowledge of cross-case patterns from many cases (Ragin, 2000). Thorough, detailed description of personal, community (including culture and religion) and societal influences on AAPCGs including participants' demographic data assisted in creation of a working hypothesis about what might occur in other, similar situations with similar participants (Miles & Huberman, 1994). For Aim 2a, demographic variables such as age, gender, and socioeconomic status were added as covariates to evaluate transition types, depression, coping or social support. Likewise, individual characteristics such as family responsibilities, issues of positive or negative aspects were assessed from interview data to verify if they were facilitators or inhibitors of PCT.

In addition, demographic variables, BC scores, and quantitized case-oriented data were used to identify coping strategies. Correlations were used to examine relationships between personal, community, societal conditions and coping strategies.

**Aim 3.** This aim focuses on process and outcome indicators of PCT in AAPCGs. Examination of the process indicators in interviews for concepts of connectedness, interactions, feeling located or situated, and confidence and/or coping was done using the theoretical framework of Transitions Theory (Meleis et al, 2000). The researcher characterized manifestations of PCT and compared those concepts to the AAPCGs' report of depression, social support and coping.

In Aim 3a, correlations were used to examine relationships between CES-D, SS, and BC scores, and the quantitized concepts of connectedness, interactions, feelings of inclusion, and confidence and/or coping (when observed either together or in parts as process indicators) and depression; relationships between connectedness, interactions, feelings of inclusion, and confidence and/or coping and social support; and relationships between connectedness, interactions, feelings of inclusion, and confidence and/or coping and coping strategies.

Aims 3b and 3c focus on the difference in participating AAPCGs' levels of depression and coping in acquisition of new skills and adjustment to life after caregiving. The level of depression and coping was examined between those who demonstrated acquisition of new skills since PCT and those who did not. New skills were gleaned from interview data and included such things as learning a new hobby, or new job. Presence of data concerning skill acquisition allowed participants to be dichotomized into two groups, those who demonstrated mastery of new skills and those who did not.

Adjustment to life after caregiving is the ultimate goal of PCT and this study sought to explore some of the determinants or outcome indicators of healthy transition. Thus in Aim 3c, the levels of depression and coping in those who demonstrate separation from the caregiving role and healthy transition was compared to those who do not. Healthy adjustment was gleaned from interview data and included activities defined by the participants as indicative of healthy transition including activities such as re-engaging with family, friends and other social network, re-engaging in paid employment, returning to previously enjoyable hobbies or activities or engaging in new interests and activities, etc. Therefore, dichotomous groups of those who demonstrated healthy adjustment to life after PCT and those who did not were identified.

### **Confirmability, Credibility, and Transferability**

Data reduction in mixed methods studies of this type must be carefully and systematically done. Data collection was completed prior to analysis and verification and this proved problematic (Sandelowski et al., 1989). The PI kept detailed audit trails so that reliability and dependability of conclusions could be ensured and other researchers could trace the procedural decisions made during data reduction. The PI also relied on congruency of research design and theory (i.e. Transitions Theory), detailed data collection protocols and check coding (when two researchers code a chunk of data, discuss the definition of the codes, in order to improve the clarity of such codes), adding to the reliability of data conclusions (Miles & Huberman, 1994). Also, the PI enhanced objectivity and confirmability for other researchers by the use of explicit methods and procedures, and linking conclusions with verbatim data throughout the analysis (assisted by use of ATLAS.ti, a computer program useful for tracking verbatim data in this



moderate-sized data set). Throughout this study, the researcher used multiple methods of data collection and analysis, and multiple researchers in order to decrease systematic bias and increase credibility/internal validity of findings.

In the naturalistic paradigm, the investigator cannot specify the degree of transferability (external validity) of findings to another setting but can provide detailed information for other researchers so that they may judge for themselves to what extent conclusions can be extrapolated. In an effort to increase utilization/application of our findings for other researchers, external validity/transferability/fittingness of conclusions were enhanced in several ways. The researcher attended to congruency with Transitions Theory, and considered cultural and linguistic accuracy. For example, although interviews were conducted in English, some AAPCGs utilized intermittent jargon or special linguistic styles commonly used by AA families such as "Ebonics," "Pidgin-English" or "Broken-English," thus, requiring accurate interpretation by the AA researcher to ensure accuracy in capturing intended meanings of statements. Accuracy in interpretation was further facilitated by the researcher's own Nigerian background, common to many participants in this study, which made a unique understanding of cultural nuances possible.

Findings were made intellectually accessible to other researchers by thorough, specific detailed descriptions of data collection and analytic procedures. Such descriptions enable confirmability/objectivity of the research by demonstrating neutrality in interpretations. Given these details (carefully traced through audit trails [raw data, analysis notes, reconstruction and synthesis products such as the matrices, field notes and contact summaries] kept during the study and presentation of verbatim data), other

researchers can estimate the quality of data, the suitability of analytic strategies, and the trustworthiness of conclusions.

In addition, case-oriented research allows the explication of both what is particular to each case and what is general about that case, in relation to other cases (Gerring, 2004). Again, detailed descriptions in this study allow other researchers to judge the relevance of all facts and logical generalizations. There are some opportunities for statistical inferences on depression, coping, and social support in AAPCGs based on the statistical descriptive results of the standardized instruments, during the initial analytic phase before the two data sets are combined. However, the use of the case-oriented approach is, primarily, to make possible logical generalizations, as opposed to statistical generalization (Yin, 2009). Logical generalizations are inferences made from Transitions Theory and the data. Such generalizations can be made from one case or multiple cases in the study (Yin, 2009)

### **Re-Presentation of Data to Add to the Scientific Body of Nursing Knowledge**

Findings were made accessible to other researchers, nurses and members of the interdisciplinary scientific body by creating a thorough report including specific audit trails with detailed descriptions of data collection, analytic procedures, decisions, recommendations and conclusions. Findings will be presented at various national and international nursing and interdisciplinary conferences, and will also be made useful and accessible to the wider health care audience by publishing several articles and papers on the study design, procedures, and findings in diverse professional and refereed journals.

## **Strengths and Limitations of This Study**

**Strengths.** The study added significantly to the science in the area of informal caregiving for older AA adults by identifying PCT experiences of AAPCGs. Understanding of these experiences could lead to interventions by health care providers aimed at ensuring timely and healthy transition outcomes. This study was innovative in its use of mixed methods to compare changes in AAPCGs at different time periods since the death of their CR. This study was also innovative in its examination of the strengths of the AA families to support and ensure healthy transitions; in the comparison of naturally- or socially-occurring (e.g., fictive kin) groups of families who were able to continue serial or multiple community caregiving versus families who admitted their CR to nursing homes; and in its contribution to scientific knowledge about AAPCGs.

This study compared and contrasted family transitions across a variety of dimensions, examining the types, patterns, and properties of transitions (Appendix J) that the AAPCGs experienced, and exploring the factors that could be considered facilitators or inhibitors to transition. The study also evaluated behaviors that constituted progress or outcome indicators for transition (Meleis et al., 2000). Based on these factors, it is hoped that a nursing intervention study will be devised later in this program of research or by other interested nurse researchers, to increase support and prepare caregivers for post-caregiving.

This study focused on an understudied group; limiting the scope to only AAPCGs whose loved ones died is a strength that builds nursing science in this population. The issues and challenges of post-caregiving go beyond the impact on one ethnic population, but this study provides the important foundation work upon which other researchers can

continue to advance end-of-life caregiving and post-caregiving research in both AA and other cultural and ethnic groups.

**Limitations.** The physical setting of the study is limited to two metropolitan geographical Western US locations, Phoenix, Arizona and LA, California. It is suggested that a future, more extensive study that allows participation of individuals from other diverse ethnic backgrounds and from different states and regions of the U.S. be conducted, to allow for comparability amongst various ethnic groups and other diverse populations. Additionally, it is possible that AAPCGs in rural areas or those from lower educational and socioeconomic strata might have different post-caregiving experiences; this merits further investigation.

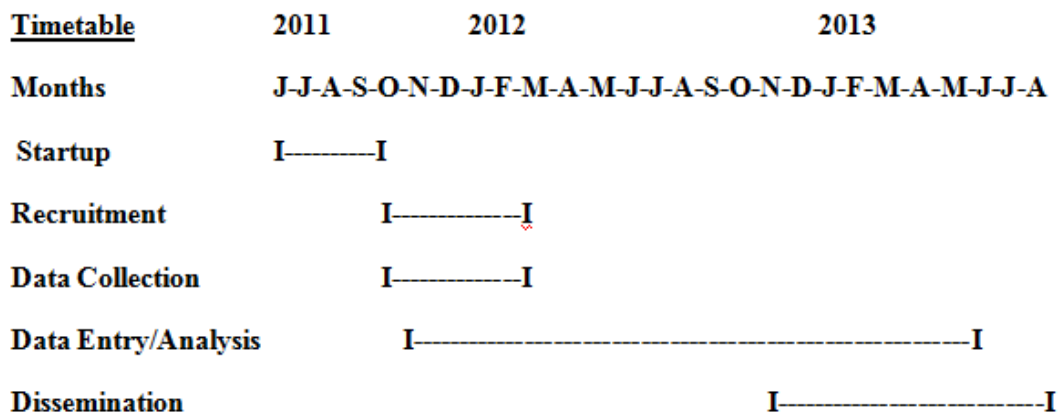
The lack of a standardized measure that directly addressed the post-caregiving experience may have affected the robustness of findings in this study, comparable to results within the other extant sparse literature that considers this phase of caregiving. Both a foundational measure and an instrument designed for and validated in AA populations are needed. It is hoped that this work provides a springboard for those measures.

Finally, the archetypal biases to which qualitative researchers fall prey may be at work in this study. For example, the Nigerian background of the researcher could be conceptualized as both a strength (discussed above) and a hindrance; “making the familiar strange” is a challenge for all qualitative researchers who study in an area which they know well. Her experience as a multiple caregiver could have led to a loss of perspective in analysis related to empathy with the post-caregiving experiences of the participants. In addition, information from articulate, well-educated participants such as

those in this study could have led to elite bias, and interpreting events as more patterned and congruent than they really were could have occurred (the holistic fallacy; Miles & Huberman, 1994).

**The Timetable**

This study commenced in early August, 2011 with recruitment attempts running concurrently with data collection and data analysis. A schematic presentation of the Research Timetable is provided in Figure 2. This study was approved by the Arizona State University (ASU) Institutional Review Board (IRB) under a Socio-Behavioral Exempt status. The IRB approval (Appendix K), number 1106006526, dated June 10, 2011 is attached. The Dissertation Chair approved the application to IRB prior to finalization of the proposal defense, because this research was being considered, and was subsequently approved for a National Institute of Health (NIH) Nursing Research Service Award (NRSA), and IRB approval was required prior to the grant award. A modification of the study design was also approved and included changes in data collection instruments (CES-D, SS, and BC), interview protocol and data collection procedures, and setting to include the use of Skype as described above in this proposal.



*Figure 2. Research Timetable*

**The Feasibility**

This study involved significant cost in time and human effort, and financial costs for transportation, materials, incentives, transcription, and editing. The financial cost was high due to the different metropolitan locations of this study. The study involved several trips to these locations that included airline tickets and hotel accommodations for recruitment and data collection purposes. Other research costs included office materials such as papers, ink, cost of printing, copying and editing; the "thank you gift" of \$20.00 to each of the 40 participants; and transcription of all 40 interviews.

The following funding sources supported this research study in part or fully through academic and research grant funding to this researcher. Support was initially provided for this work through a two-year National Institute of Nursing Research, Research Supplement to Promote Diversity in Health-Related Research from 2009-2012, and a John Hartford Foundation and Evercare pre-doctoral fellowships, 2009-12. Additional awards included grants from the Jonas Center for Nursing Excellence/Hartford Centers of Excellence in Geriatric Nursing a Jonas/Hartford Pre-Doctoral Scholarship, and a John A. Hartford Foundation - Building Academic Geriatric Nursing Capacity (BAGNC) Pre-Doctoral Scholarship. Funds were also provided by a National Institute of Health/National Institute of Nursing Research (NIH/NINR) Pre-Doctoral Nursing Research Service Award (NRSA).

## CHAPTER 4: FINDINGS AND DISCUSSION

This mixed methods study used the Transitions Theory (Meleis et al., 2000), described in chapter two, as a framework to guide analysis and interpretation of semi-structured interviews with 40 AAPCGs. Consonant with the qualitative canon, the findings and discussion are presented in tandem. Demographic data and quantitative results augment and clarify the qualitative findings. I analyzed qualitative data using procedures from Miles and Huberman (1994) while the quantitative data were analyzed using SPSS v.18. Specifically, correlation analysis was done on the study variables at either 0.05 or 0.01 level of significance.

This chapter will present the sample demographics, then consider findings for each aim in relation to the components of the Transition Theory.

### **Demographics**

This study is comprised of 40 AAPCGs who, within the last 10 years, cared for loved ones until the family members died (Appendix L, Table 1). Participants resided in two major United States metropolitan cities, Los Angeles, California ( $n = 31$ ) and Phoenix, Arizona ( $n = 9$ ).

**Gender.** National data show that between 59% and 75% of family caregivers are females; 71% of AA family caregivers are females. Consequently, fewer numbers of male participants were anticipated during the design stage of this study because more females than males tend to be caregivers, especially in African American families (FCA, 2001; NAC, 2009). Women made up an even larger percentage of caregivers in this study, however: 85% females ( $n = 34$ ) and 15% males ( $n = 6$ ; Appendix L, Table 1). These demographics are in close agreement with other qualitative studies using AACGs

such as Bonano, Wortman and Nesse (2004; 87% females and 12.9% males) and Bramble, Moyle and McAllister (2008; 70% females and 30% males).

**Age.** As shown in Appendix L, Table 1, the following age ranges were noted in this study: 30-55 years (45%;  $n = 18$ ); 56-70 years (32.5%;  $n = 13$ ); 70 years and older (12%;  $n = 5$ ) and 18-29 years (2.5%;  $n=1$ ). That youngest participant began caring for her mother at age 12.

A series of Spearman rho correlations were run to evaluate the inter-relationship of lifestyle variables (Appendix M, Table 2). There were significant positive relationships ( $p=.05$ ) between age and hospice utilization ( $r_{s[37]}= 0.334, p = 0.044$ ); age and multiple caregiving ( $r_{s[37]}= 0.343, p = 0.038$ ). These correlations suggest that as AAPCGs age, they may have multiple caregiving roles and thus require additional support; hospice care may be necessary; and that increasing responsibilities of intergenerational or sandwich caregiving (Pierret, 2006) may force AACGs to work outside the home during their active caregiving period.

**Hospice participation.** In this study, only 10 participants (25%) utilized hospice services for their loved ones. There is a strong significant positive relationship ( $p=.05$ ) between those who were uncomfortable with caregiving tasks and hospice utilization (Appendix M, Table 2); ( $r_{s[12]} = 0.674, p = 0.016$ ). Because AAs use hospice infrequently, this finding provides new information on situations in which hospice might be acceptable.

**Worked outside the home during caregiving.** There are strong significant positive relationships ( $p=0.01$ ) between work outside the home during caregiving and return to work after caregiving ends ( $r_{s[39]}= 0.739, p = 0.000$ ), and between working



outside the home during caregiving and income ( $r[38] = 0.541, p = 0.000$ ). Seventy percent of the participants ( $n = 28$ ) worked outside the home at some point during their caregiving period. After caregiving ended, 75% of all the participants ( $n = 30$ ) returned to work (Appendix M, Table 2; Appendix L, Table 1; and Figures 3 and 4).

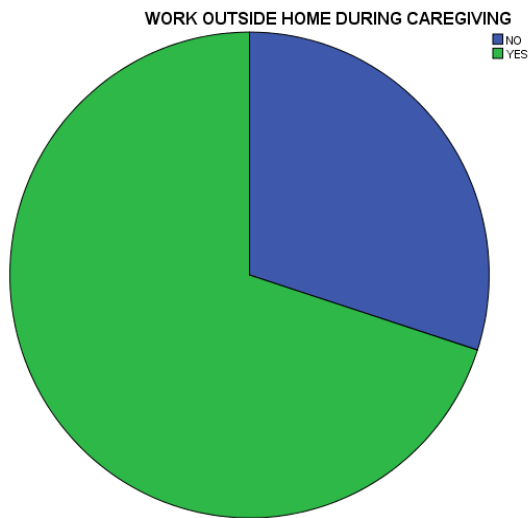


Figure 3. Work outside home during caregiving

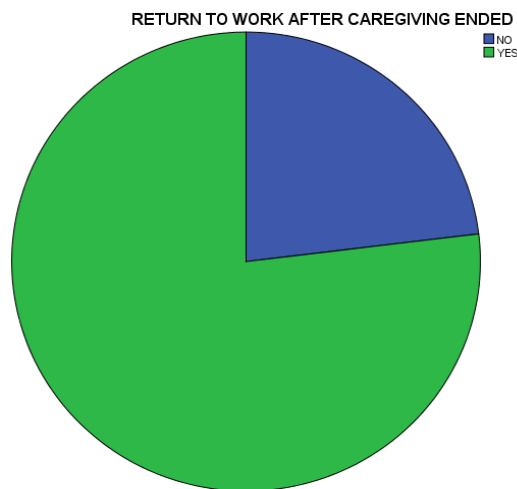


Figure 4. Return to work post-caregiving

**Education.** Although 6 participants did not offer information about their education (Appendix L, Table 1), 27.5% had completed some graduate education ( $n = 11$ )

and another 25% had earned a bachelor's degree ( $n = 10$ ). Still another 17.5% had completed some college courses ( $n = 7$ ) and one had an associate degree. These findings indicate a higher level of education in these AA caregivers than is generally thought to be true (Hart et al., 2007; NAC, AARP, 2009c). For example, the ethnic executive summary of the National Caregiving Alliance Study reported that 41% of AA caregivers possess a bachelor's or graduate degree, whereas this study showed a combined figure of 52.5% ( $n = 21$ ).

**Family income.** As shown in (Appendix L, Table 1), 50% of the AAPCG participants ( $n = 20$ ) had a family income of \$40,000 per year or more, with 22.5% earning more than \$80,000 a year. This was much higher than the income level reported by Dilworth-Anderson, Boswell and Cohen (2007), in which 74% of their 330 African American caregivers had an income of less than \$15,000 per year.

There were significant positive relationships (Appendix M, Table 2;  $p < .01$ ) between income and return to work after caregiving ( $r[38] = 0.518$ ,  $p = 0.001$ ), and between income and caregiver education ( $r[32] = 0.513$ ,  $p = 0.003$ ). Higher income in this study is probably related to the higher educational levels of the majority of the AAPCGs (see discussion on education above; NAC et al., 2009). Many of the participants were professionals such as nurses and school teachers who worked in positions where they had the respect, support and understanding of their colleagues during caregiving and thus were able to continue working. Their return to work may have been an attempt to re-enter their usual lives, and to refill their coffers depleted by caregiving.

**Length of caregiving.** Fifty percent of the participants in this study ( $n = 20$ ) had been caregivers for 4 years or less. More than 12% of the participants ( $n = 5$ ) provided

caregiving for 5-10 years. Another 27% ( $n = 11$ ) provided care for 10-20 years, while 10% ( $n = 4$ ) provided care for more than 20 years. These numbers support previous reports that AA caregivers engage in long-term caregiving of their older family members in their homes (Appendix L, Table 1; NAC et al., 2009).

**Serial caregiving.** Forty-five percent ( $n = 18$ ) provided serial caregiving for their loved ones, caring for one loved one after another. There was a significant positive relationship ( $p = 0.05$ ) between coping and serial caregiving (Appendix L, Table 1; Spearman's  $\rho = 0.356, p = 0.026$ ).

**Relationship of caregiver to care recipient.** A majority of the participants provided care for a parent, with 55% ( $n = 22$ ) assisting their mothers while 15% ( $n = 6$ ) cared for their fathers. Ten percent of caregivers ( $n = 5$ ) were wives who looked after their husbands. Three participants took care of their grandmothers (7.5%), two participants (5%) supported adult children, and two participants (5%) took care of other relatives such as uncles (Appendix L, Table 1).

There was a significant positive relationship ( $p = 0.05$ ) between relationship with CR and age (Appendix L, Table 1; Spearman's  $\rho = 0.329, p = 0.048$ ). This suggests that as AAs become older, they may be more likely to take on caregiving roles for parents, spouses, siblings, grand-parents or even fictive kin.

**Care recipient characteristics.** Care recipients ranged in age from 50-94 years old (Appendix L, Table 1). The majority (56%,  $n = 22$ ) of the CRs had a medical diagnosis of cancer, followed by diabetes (27.5%,  $n = 11$ ), dementia (12.5%,  $n = 5$ ), kidney problems (12.5%,  $n = 5$ ), and stroke (10%,  $n = 4$ ).

**National origin.** The sample in this study was comprised of 47.5% ( $n = 19$ ) Nigerian-born participants and 52.5% ( $n = 21$ ) US-born participants (Appendix L, Table 1). Most of the US-born participants were recruited through organizational type environments such as churches ( $n = 4$ ), the Black Nurses Association ( $n = 4$ ); work/business ( $n = 4$ ); neighborhood organizations ( $n = 5$ ) and personal contacts through referrals from the organizations ( $n = 5$ ). However, all the Nigerian-born participants were recruited through direct, face-to-face efforts.

### **Considerations of Study Aims in Relation to the Transition Theory**

This mixed methods study used the Transitions Theory (Meleis et al., 2000) as a framework to guide the analysis and interpretation. Findings and discussion are presented using concepts from the Transitions Theory, including the nature of transitions faced by AAPCGs, the transition conditions that facilitate or inhibit their PCT, and the patterns of response that the AAPCGs used in dealing with PCT (Appendix A; Figure 1).

This study does not address nursing therapeutics, which is a concept presented in the Transitions Theory, but, instead, focused on the perspectives of the AAPCGs. Transition conditions in this study were discussed only in terms of such transitions because, for AAPCGs, personal transitions were often embedded within community and society so completely that they were inextricable during analysis. To address Aim 1, the discussion will begin with the nature of transitions, including the types, patterns, and properties of transitions experienced by AAPCGs, followed by an exploration of transition conditions that focus on Aim 2. The discussion will conclude with patterns of response as a means of addressing Aim 3.

### **Aim 1. Describe the types, patterns, and properties of the PCT in AAPCGs.**

- a. What are the various types and patterns of PCT responses and how do they differ from one another, as identified by the PCG Interview Protocol?
- b. What are the properties of each type and pattern of PCT response, as identified by the PCG Interview Protocol?

### **Nature of Transitions**

#### **Types of Transitions**

AAPCGs experienced developmental, health and illness, situational, organizational and transnational types of transitions. Although the transnational transition is not identified in the original model depicting the Transitions Theory and created by Meleis et al. (2000, Appendix A, Figure 1), it is discussed within the article which detailed the testing of the theory (Meleis et al., 2000).

**Developmental transitions.** Developmental transitions are life events such as births, entering adolescence, marriage, and death (Meleis et al., 2000). In this study, 35% of the participants (n=14) experienced various developmental transitions during their caregiving and post-caregiving periods. Developmental transitions were often difficult, complicating caregiving and negatively impacting the PCT in several ways. For example, developmental difficulties included loss of freedom to grow and mature like one's peer group; difficulty pursuing one's dreams and aspirations; or creation of long-lasting negative emotions such as anger, anxiety and depression due to the unremitting demands of caregiving. One participant recalled her arduous journey through caregiving that was complicated by becoming an adolescent who yearned for her mother's support.

When I was 12 years old, my mother became diagnosed with multiple sclerosis and she, within a year, she went from being fully functional to being a complete quadriplegic, paralyzed from the neck down... The first thing was I had come upon some anger. She went from being the full-time, active mother to being a cripple and I was upset that I had to learn how to take care of her. I was upset at waking up in the middle of the night to take care of her... Even though she couldn't physically take care of me, it was nice just being close to her. It [after her mother died] was just hard not having her no more, period... I lived. I went to school. I went to work. I kept my rhythm, but I was still very sad and angry at everybody about it.

On the other hand, for some AAPCGs in this study, developmental transitions provided a necessary distraction from the pain and loss that the death of their loved one produced. It motivated individuals to try to move on with their life much quicker, and to brace up with life after caregiving in a logical, progressive manner.

**Health and illness transitions.** This was the most common transition type amongst this group of participants, with 90% ( $n = 36$ ) experiencing such a transition. According to Meleis and Trangenstein (1994), a health and illness transition includes the diagnosis and experience of chronic or acute illness(es), hospitalizations, and recovery process of either the CR and the caregiver (CG). Many of the AAPCGs in this study became caregivers because their loved ones got sick and needed care and assistance. One CG spoke sadly about her cousin's illness:

The hardest thing with him was because he was really depressed over his illness. Then he did not have a strong – he gave up; he did not want to live after that

[diagnosis of Acquired Immunodeficiency Syndrome – AIDS], but he didn't die right away. He died a lot sooner. I mean, he just did not have a strong will to live. That was the hardest part about it, the emotional part, and having to deal with someone who should have fought for his life, but he didn't.

Others experienced their own physical and emotional health concerns during and after caregiving ended which continued to negatively impact their PCT. The caregivers reported such illnesses as hypertension, headaches and pain.

**Situational transitions.** Closely related to health and illness was the situational transition, reported by 45% of the participants in this study ( $n = 18$ ). AAPCGs often deal with issues that produce chaos and uncertainty (Ume & Evans, 2011) in their lives and even impact their health. The situational issues included moving to a new city, state or country, away from family and friends, going through a divorce, losing a job or home, and having all of the children leave for college. One participant described a situation where she and her husband moved from Michigan to Arizona. It contributed to her husband becoming depressed, and it impacted their marriage almost to the point of getting a divorce.

I started noticing that I felt like my husband was getting depressed [be]cause here we had moved, he had never been outta Detroit. We moved here [Arizona], my kids were here and around me. His kids were back in Detroit. I started noticing all these things. I went to counseling with him...At first the Counselor, she didn't think he was depressed. She says she just felt like I was mistaken, but when you know somebody for 40 years, you know...Then at the end of that, that was when the counselor felt like our marriage was gonna really wind up in being divorced.

**Organizational transitions.** These transitions involved issues surrounding organizational structures that affected the caregiver, for example, the CG's job requirements and expectations or nursing home rules when loved ones were placed in long-term care. AAPCGs who continued to work during and after caregiving faced major challenges. Organizational transitions (Meleis et al., 2000) included needing a substitute caregiver for their loved one during the time they were working, financial constraints involved in hiring an alternative caregiver, making a decision to place the loved one in a nursing home which created post-caregiving guilt, and emotional difficulties such as depression and anxiety that continued during PCT. AAPCGs who made frequent changes to their job schedules or called in sick too many times put their job and personal finances in jeopardy when caregiving eventually ended because they dented their reputation so badly. Forty seven percent of the participants ( $n = 19$ ) experienced an organizational transition in this study. One of those participants expressed the effect of organizational transition in her life:

I guess the most challenging thing with her was trying to work. I was still working full-time and I had her at the home, at my home, and just trying to organize meal times and just satisfy her needs as far as the doctors' visits, trying to get time off from work and stuff.

Another exemplar of organizational transition experienced by the AAPCGs in this study was nursing home placement of their older loved ones (27.5%;  $n = 11$ ) during the caregiving period. The rationales for placement included, caregivers' lack of adequate financial standing, working outside the home, structural design of caregiver's home and family conflicts. Such decisions led to caregiver guilt. One female participant expressed



the challenges of caregiving and the result of her family's decision to place their mother in a nursing home,

Trying to meet her needs, trying to feed her, trying to clothe her, and combined with my job, my full-time job. So it was very hard caring for her. Then, when she couldn't walk, it was because of the stairs in the house. It was a very hard thing to help her up and help her down. Sometimes I had to carry her. So, it was a lot...one that I still feel guilty about, is when she had to go to the home... that was the biggest challenge. I tried everything to keep her at home, but it didn't work...I believe if she was here [home], she wouldn't have died.

**Transnational transitions.** The final transition type that played a significant role in this study was the transnational transition. This type of transition deals with the challenges that individuals face due to their immigration to the United States. Although transnational transition was not included by Meleis et al. (2000) in their original depiction of the Transition Theory (Appendix A, Figure 1), it was included in most of the studies described which were used to test the theory (Meleis et al., 2000). In this study, almost half of the participants were Nigerian-born immigrants ( $n = 19$ ). One quarter of the Nigerian-born participants ( $n = 5$ ) mentioned transition challenges that were directly connected to their immigration experience. Such challenges included getting legal documentation for older loved ones who were recent transplants from Africa, who could not access timely or adequate medical care, resulting in a health/illness transition. Another such challenge was the perception by many of the Nigerian-born participants that they would not have suffered some of the caregiving difficulties they experienced if they were in their home country because they would have had other family members or

housemaids to help take care of them. Because they immigrated to the United States and did not have adequate support systems, those difficulties negatively impacted their jobs, and made them feel powerless over their decisions concerning nursing home placement. One Nigerian-born male participant expressed his regret about the ultimate betrayal of placing his mother in a nursing home.

[In Nigeria] Parents stay in our house or they stay in their house. You take care of them in their house. Pretty soon, here [the US], the situation here became such that I became aware that because we had to go to work, because we had to take time off to be at work, there was just no way we could marry the two together [caregiving and working]. Personally, I don't know, of course, the system here. I think the good side of it is that this is something here that gives room to take care of people like that. I think it's good. Back in Nigeria, we would've kept her in our house or somewhere like that. The system somehow would've gotten a relative to do the job... We had to [place her in a nursing home] because, one, I couldn't give her that much attention... There was no way I could take care of her medical needs in the house. She needed time 24 hours. I had to go to work. And the nursing homes were built to take care of such. I mean, down the road, we were just forced to take her there [nursing home]. That was just the way... Even though we didn't like it much, but that was just a way to get us going, because we had to go to work.

Challenges posed by these types of transitions created major difficulties for AAPCGs and the complexity of the PCT grew when various patterns of transition were

added. The next section will present the six patterns of transitions experienced by the participants in this study.

### **Patterns of Transitions**

In this study, several patterns emerged in AAPCG transitions. According to Meleis et al., (2000), transition patterns include single, multiple, sequential, simultaneous, related or unrelated transitions.

**Single transitions.** Single transitions occur in isolation, with only one occurring at any given time. In this study, 25% of the participants ( $n = 10$ ) experienced only one type of caregiving transition during their caregiving and post-caregiving periods. Those participants only reported the health and illness transition that eventually led to the death of their loved one, although this transition may have occurred more than once as they moved through the course of the disease. It is possible that other types of transitions occurred but they were not discussed with the researcher.

**Multiple transitions.** The majority of the AAPCGs in this study experienced multiple transitions (Meleis et al., 2000); 75% of the participants ( $n = 30$ ) experienced two or more types of transition which significantly impacted their caregiving and post caregiving experiences. The majority (40%;  $n = 16$ ) reported three types of transitions, while 27.5% ( $n = 11$ ) experienced only two types of transitions. One participant experienced four different transitions: developmental, situational, health and illness, and organizational; while 5% ( $n = 2$ ) experienced all five types of transitions.

**Sequential transitions.** In the sequential pattern of transition, the individual experiences multiple transitions, occurring one after another. In this study, 40% of the participants ( $n = 16$ ) described sequential types of transition. Sequential transitions

involved issues such as marriage (developmental); beginning to work full time while caregiving (organizational); moving (situational); or multiple losses (health and illness).

One female participant recounted:

And so it was – I worked. I had a full time job, full eight hour job and I was taking care of my dad...I moved out of my apartment, gave away everything I had...I moved here – my husband passed. My dad passed...right after my mom passed 2002, my husband 2003, my dad was 2004 and my sister passed in 2005.

**Simultaneous transitions.** The majority of the participants (60%;  $n = 24$ ) in this study experienced more than one transition, all occurring at the same time. An example of such simultaneous transitions occurred with the experiences of one participant that led to her PCT. This participant was a single parent (developmental). Her parents became sick (health/illness), but they were unable to get timely treatment because they just moved from Nigeria (situational), and did not have documentation to legally stay in the US or to get medical treatment (transnational). That Nigerian-born female participant recalled:

When they [parents] came over here [emigrated from Nigeria to the US], my mom had – she couldn't walk. Her two knees, she had issues with her knees....then my father was asthmatic and some underlying issues that it took several doctors' visits....we had to wait for their medical and all that before they started the full treatment they needed [due to immigration issues]...It was really, really challenging because first of all, I'm a single mother of four. I was working. I was in school. It was, I may say the toughest time of my life, that particular time, because it's like, I would take [the] two of them for their doctors' visits.

This AAPCG poignantly expressed the severity of the health and illness, transnational, developmental, organizational and situational transitions that occurred at the same time. In addition, her father later suddenly died, further exacerbating the chaos of her life (Ume & Evans, 2011).

**Related transitions.** Forty-five percent of the participants ( $n = 18$ ) experienced related transitions, in which one transition affects or impacts another type of transition. In many of the related cases, one transition type - usually health and illness, created the caregiving situation which led to the death of the loved one. That death then created the situational transition of needing to take the body home. This chain of events ultimately could affect the AAPCG's response to PCT. One of the Nigerian-born participants reported,

We had to take the corpse back home to Nigeria. Then we did the burial... We needed to take my father's corpse home was about \$9,000, \$10,000... It's difficult time for the family, for me, for my children and everybody that their grandpa, my father, my mom's husband is gone.

**Unrelated transitions.** This type of transition occurs when the individual experiences multiple transitions that do not connect to one another, but still have significant effect on the PCG's life during and/or after caregiving ends. Thirty-five percent ( $n = 14$ ) experienced unrelated transitions. An example may include many unrelated events in one's life, such as: death of a loved one, marriage, illness, another death, and childbirth. A Nigerian-born female participant recalled that "...my dad passed... Three years after I got married, my husband passed on. He had cancer, which

we didn't find out early. It was only found out two days to his passing on...then I was heavily pregnant.”

The complexity of various types and patterns of each AAPCG's transition experience were compounded by the properties of such transitions. The next section presents the six properties of transitions represented by the participants in this study.

### **Properties of Transition**

According to Meleis et al. (2000; Appendix A, Figure 1), the properties of transition are factors that determine their complexity and structure, and they are interrelated. The following properties of transitions were notable in this study: awareness, engagement, change and difference, transition time span and critical points and events.

**Awareness.** The perception, knowledge and recognition that they are in a transition situation is called an “awareness” of transition (Meleis et al., 2000). In this study, it appears that most of the participants were aware that they were progressing through the PCT. One female participant recalled,

Yeah, so it's not as emotional as it used to be. The first two years, I just cried. I missed my dad very much. You don't get over a person's death, but you deal with it differently as times go on. I deal with my mom's a little different, because it's been so long.

**Engagement.** Engagement addresses the degree to which an individual is actively involved with the PCT process (Meleis et al., 2000). Some caregivers experience PCT without displaying engagement in the process. However, as long as the caregiver appears to understand the extent of his/her hurt, anger, anxiety or other negative dispositions

related to the loss of the loved one, it is a testament to engagement. One of the AAPCGs in this study expressed movement toward engagement:

I didn't [deal with the death of her mother] for a long time until recently. I lived, I went to school, I went to work. I kept my rhythm but I was still very sad and angry at everybody about it. I'm tired of living like that, being upset all the time. Very recently, I started seeing a therapist who's very nice, a little different but nice to talk about things, have an outside perspective and have me understand some things and keep me from getting so sad and depressed.

**Change and difference.** The change and difference property of transition is manifested in a transformation of caregiver identities, roles, or relationships (Meleis et al., 2000). Many AAPCGs in this study experienced transformation of roles - from being an adult child to caregiver; and from caregiver to post-caregiver; or as an alternative parent for other siblings while also maintaining their own identity and role as parents to their own children. The transformation in identity, role and relationship was difficult as a result of the death of one participant's mother. She recalled:

When I was sick, I would go and either lay in her bed or lay on the floor next to her bed just to be close to her. Even though she couldn't physically take care of me, it was nice just being close to her. It was just hard not having her no more, period. When I get sick sometimes or when I'm having a rough day she was always there to talk to, like always. So I think that was one of the hardest things that she wasn't there anymore for the emotional part of me in my life.

**Transition time span.** This pattern of transition relates to the time it took for each transition event to occur, and usually include the caregiver's response during that

event. The participants in this study addressed various transition time spans. Some discussed the time period of their caregiving and the impact on their PCT, while others participant spoke in terms of time since the death of their loved one. Still other participants discussed time span in terms of their recovery or adjustment from the loss of their loved one.

One of the participants reported the time span during which she took care of her husband, elaborating on the challenges during that time, ultimately stating,

I had stayed with him six years, taking care of him six years. Every time he would go in the hospital I would always stay and spend the night. Then by the time it was time for him to go home, I'd be wore out [be]cause I'd done stayed every night, day and night, that by time he come home, I be wore out...My doctor said you have to get rest so when he come home that's when your job begin again.

When he was in the hospital the last time, that's what I did.

**Critical points and events.** According to Meleis et al. (2000), critical points and events bring about new routines and self-care activities, and produce a period of uncertainty. For example, the initiation of the PCT usually produces chaos and uncertainty (Ume & Evans, 2011). Critical points or events in this study were generally expressed in terms of a “reckoning point” when a family member realized that their loved one needed additional support and that they were expected to provide that caregiving (Clark & Huttlinger, 1998) and end points –nursing home placement, transfer of care to other relatives or death of the CR. One participant recounted:



It started, I met my husband...went to a doctor one day and he found out he had diabetes...and he had uncontrollable – his glucose was never in control. His glucose is like 800, 600, never went down below 800 or 600.

Another client reported the critical event that heralded her beginning of her PCT journey – [the] death of her husband.

When I got there [hospital] that Monday morning, soon as I walked in the room he started throwing up and had a heart attack and died just that quick... That just hurt my heart so bad, [be]cause I felt I should have stayed there. I should have stayed there all night and had that time so I could be with him

The critical time and events mark those elements of transition that the individual was unable to quickly forget. The impact and meaning of the PCT events are usually etched in the memory of the AAPCGs for many years. Generally, properties of transition made the transition experience memorable and significant.

In summary, Aim 1 of this study supported the Transition Theory (Meleis et al., 2000) with several exemplars. The nature of transition revealed that these participants experienced all the five types of transitions including developmental, health and illness, organizational and transnational, with health and illness as the most common type of transition leading to caregiving role. This study also revealed that most AAPCGs experienced multiple and simultaneous patterns of transition, thus being highly affected by their PCT because of the depth, severity and complexity of their PCT experiences. Further, this study found that majority of the participants demonstrated the properties of transition by recognizing that they were in transition, actively engaging in the process, and noting a change in the nature of their transition as time elapsed.

**Aim 2.** Explore the facilitators and inhibitors of PCT in AAPCGs.

- a. What are the personal conditions that facilitate or inhibit progress through the PCT, as identified by the PCG Interview Protocol, and measured by the BC, CES-D, and SS?
- b. What are the community and societal conditions that facilitate or inhibit progress through the PCT, as identified by the PCG Interview Protocol, and measured by the BC, CES-D, and SS?

The progress of the AAPCGs through PCT is often characterized by diverse positive and negative transition conditions which act as facilitators or inhibitors of the transition experience.

#### **Transition Facilitators: Personal, Community, and Societal**

In this section, findings based on the following four personal transition conditions noted by Meleis et al. (2000) are presented: meanings; cultural beliefs and attitudes; socioeconomic status (SES); and preparation and knowledge of the transition event. The findings are presented specifically as factors that facilitate PCT. Facilitators are factors such as adaptive strategies that help AAPCGs cope with PCT (Schumacher & Meleis, 1994). Personal, community and societal conditions are inextricable from each other therefore discussion about facilitators will integrate all three.

#### **Meanings**

As individuals navigate the terrain of transitions through loss and grief, they seem to find meaning and comfort in things, behaviors, or activities that validate or reassure them about who they are. They may also find meaning in what they hope they have achieved in life that is worthwhile, valuable, and congruent with previously-held beliefs.

Several participants reflected on accepting the challenge and role of caregiving to their parents, spouse or other loved ones, and how that acceptance promoted inner satisfaction and pride in who they are as human beings. One participant noted,

I'm really happy that I was able to give her [mother] that support at that time and that I was in a position to do it. It would've been very bad if I wasn't able to do it. I was in a position financially and stable to be able to take care of her at that time, so I feel very happy.

AAPCGs also found meaning in acting in culturally acceptable ways or in being applauded by others in their community, social or professional circles. This need for validation was especially important for AAPCGs in relation to care of loved ones and functioned as a facilitator of passage through the PCT. For example, one participant recalled with pride that even her mother's physician acknowledged, approved and validated the quality of care she was providing for her mother. "I remember the doctor told me one day, he says...whatever you're doing for your mother...he says, keep doing it, because what we gave you and told you, your thing is working better than ours".

**Emotional responses.** Another major source of post-caregiving difficulty identified by the participants in this study was the emotional challenges that they experienced after the death of their loved one. Thirty AAPCGs (75%) out of the 40 participants interviewed identified such difficulties. This finding refuted previous literature which reports that African Americans usually do not express emotional difficulties in relation to caregiving (Haley et al., 2004). These emotional experiences will be discussed in terms of their manifestations and management in the post-caregiving period.

**Relief and gratitude.** Several participants ( $n = 22, 55\%$ ) discussed positive emotional responses such as feeling relief or gratitude to God that the care was over and the suffering of their loved one had come to an end. One AAPCG expressed a feeling of relief that the caregiving and the aftermath issues of burial and funeral arrangements and expenditures were complete. She reported,

It [caregiving] was something I wanted to do, that I did, and I didn't care what everybody else thought. It was something that I was gonna do. I felt at that time that that was my purpose, and then after everything was over, the funeral expense, everything, the funeral services, preparing for the funeral services and all that, when it was over, then it was, okay, I'm relieved now, that he's – I did what I was supposed to do.

Some participants also felt relief because the wishes of their loved one had been fulfilled. These wishes may have been expressed before the illness or during the period of severe illness. According to one female participant,

It was a relief when the loved one [mother] passed away because, actually, when she was still alive, she said she didn't want to be bedridden and be punishing any other person [that is, making family members suffer to provide lengthy caregiving to her]. So everybody have their own lives, so I think God granted her wish that she wanted and she didn't stay for too long when she became sick and that was good for her and for everybody.

Also, another PCG reported feeling relief because she finally came to terms with the fact that her father was tired of living and ready to die. She recalled,

He [father] kept saying he was tired. He said it a lot of times that he was tired. He was having so much pain. I knew what he was saying, but the human part of me didn't want to accept it. We kept praying and hoping that he would be miraculously healed, but at the back of my mind, I knew what he was trying to tell us, but we didn't want to accept it. We were in denial. I'm glad he – I'm glad we had no choice in the matter anyway. I'm glad he finally went.

AAPCGs could feel relief because they had the personal satisfaction that the wishes of the loved one had been carried out, such as fulfilling a death-bed promise (Ume & Evans, 2012). One Nigerian-born male participant expressed his relief because he was able to carry out his mother's wishes. He said,

It was very difficult, but thank God everything eventually worked out because she had wanted to be buried next to my father and we were able to do that...just the fact that I was able to accomplish what she wanted, was a big relief. That was the only time that I started having the relief that, thank God, she got what she had said she wanted.

Sometimes caregivers recognized the necessity for the death of their loved one, but still acknowledged the difficulty of dealing with the situation. More than half of the participants who felt relieved by the death of their loved one said the reason for their relief is that their loved ones would no longer be suffering or in pain. For example, one female participant said of her father, "I was glad the day he no longer suffered, but I certainly missed him." One male participant recalled about his grandmother, "She was in so much pain that I didn't want her going through any pain like that. So I was relieved that she had left this world. And she was at peace." However, participants still

acknowledged the difficulty of dealing with the situation and of missing the deceased loved one. A female participant speaking of her mother reiterated, “It was more of not wanting to see her deteriorate. I was totally helpless. I was glad she wasn’t suffering any more, but I was sad she wasn’t around anymore.”

Unfortunately, the burdens and demands of caregiving were sometimes so difficult that it was a relief for some PCGs when the loved one died, and caregiving ended. One female participant expressed her feeling of relief over her mother’s death.

Was a mixture. Half of me was very relieved for selfish reasons and for loving reasons...As for myself, a part of me was selfish to know that I didn’t have to do it anymore and I felt bad about that but that’s just how I felt. I was happy that nobody called me in the middle of the night to come change their diaper.

Sometimes a negative relationship between the care recipient and the caregiver might result in relief when caregiving finally ended. According to a female participant who cared for her husband’s sister,

For me because it was so hard, it was just me. My husband was still working. I didn’t want to tell my husband everything that was going on so that was hard. Yeah, it was a relief. I was taking care of my sister-in-law, my husband’s sister. That was the most stressful. That’s the most stressful. She, oh boy, I can’t even... it was worse than anybody I had ever taken care of [She also took care of her own sister and her father-in-law].

In spite of the difficulties, burdens and stresses of caregiving, PCGs sometimes found relief from several sources. Caregivers in this study identified church, God, and visiting the loved one’s burial place (cemetery) as sources of relief, discussed in more

detail later. According to a female participant who took care of her mother, church and God were her source of relief.

I was able to get relief from the church. It was very hard for me because that was like the second death. Since after I lost my husband. So, this was the second loss for me, somebody very close me...I just went to God. I drew closer to God and the church to find relief.

According to a male participant who took care of his mother-in-law, visiting her burial place was a source of relief. He recalled, "I wanted to see the place and just stand there for a while and then empty my emotions. That's the only way I can feel relieved a bit for me."

Another female participant observed that talking to the researcher provided a source of relief for her. Oftentimes, AAPCGs expressed a therapeutic benefit to the caregiving or end-of-life research process. Other AAPCGs in this study viewed the process of the in-depth personal or focus group interview(s) about their caregiving and post-caregiving experience as supportive intervention(s) that had great benefit for progressing through healthy PCT. This participant admits,

Talking about it. Mostly, I've talked about it. In these ways, it's a big relief talking about it like this. I think this is the first – I talk about it with my sister, with my friends sometimes, but this is kind of therapeutic, you know, seeing it in this light.

**Adjusting to loss.** AAPCGs in this study were satisfied with the care they provided to their deceased loved ones and that helped them deal with loss. Thirty seven participants (92.5%) expressed the common sentiments that one did all one knew to do,

did their part, did the best they could in the circumstances, and were proud and satisfied with the care provided. One participant summarized it thusly:

I didn't experience any guilt, because I think I provided the best of care to the best of my ability, and nothing went wrong because of something that I did.

Everything went right. When my parents passed, I had nothing but peace and calmness, not, 'Oh, my God, I wish I had did this'. I didn't experience that.

Providing care to their loved ones helped these AAPCGs attain adjustment to their losses, thus facilitating their PCT. For some participants, adjustment came in the form of being able to talk about that loved one, remembering the deceased without crying, feeling comforted, or being able to put aside their own personal pain to support other people going through pain. According to one of the participants,

I think I've adjusted very, very well, as much as you can. I think for us, well for me, the adjustment, I think, maybe was a bit easier than for my siblings, because I was with her from the very beginning to the end and watched the process. But for some of my siblings who came at intervals, it was always a shock each time they came. For a while, it was a bit, you know. I think I have adjusted and we all have adjusted. We realize that "oh, she's gone, she's gone." What we have are her memories to go by. So, that is other things we now take pride in and just talk about and laugh.

Another facilitator for AAPCGs was the opportunity to be appreciated by the deceased loved one or other family members for the care they provided. Appreciation provided encouragement to the PCGs and made them feel good about themselves.



My mom's sisters, you know, my aunties were also there and they praised me for all the work I did for him, care I gave to my dad. That I've done what I need to do and I should be happy that I did it, you know, kind of praising me and it kind of gave me that moral support.

Closely related to feeling appreciated was the act of recognition of the caregiver expressed by the care recipient. This recognition also was usually a death-bed act, almost like a final farewell and thank you to the caregiver. This facilitated PCT and provided comfort, peace and joy to that caregiver. One participant proudly reported, "That gave me a joy and a peace, that I'm special. She didn't talk to none of y'all, but me. She wouldn't let nobody take care of her but me."

**Fulfilling death-bed promises.** Another facilitator of PCT for many participants was the ability to carry out the wishes of their deceased loved one. These wishes were often death-bed promises where the older loved one made his/her wishes known to surviving family members, and exacted a promise from them to fulfill those promises (Ume & Evans, 2012). The wishes were varied, numerous, and related to a promise about a specific issue important to the loved one. Some of the wishes were that the loved one would not be placed in a nursing home; that the caregiver would move in to the loved one's home so as to maintain the home for the family; that certain burial arrangements would be ensured, including making sure that the dead body was taken to their home state or country for burial; to ensure that flowers were placed on the grave regularly; that another family member would be cared for; and that the members of the family remain united. When wishes were elicited as death-bed promises (Ume & Evans, 2012), caregivers felt obligated to honor them and felt relieved, blessed and at peace when they

completed the task successfully. One participant expressed his relief after carrying out his mother's wish to be taken home to Nigeria and buried. He said,

She actually asked that if she eventually passed away, she wanted to be buried in Nigeria...She had wanted to be buried next to my father and, you know, we were able to do that...Just the fact that I was able to accomplish what she wanted, you know, was a big relief. That was the only time that I started having the relief that, you know, thank God, you know, she got what she had said she wanted.

**Living out the legacy of the deceased.** Another facilitator expressed by the study participants was the idea of living out their loved ones' legacies. Legacies involved following in that person's footsteps – trying to imitate the good deeds that the person did while they were alive, maintaining the good name and reputation that they had while on earth, or living out the plan and purpose that a parent or grandparent had for their children. One male participant aptly described this legacy:

The advice I would give anybody who lost somebody is to remember the legacy and for you to remember the legacy he left for you and live that legacy – to be able to represent that person very well. Like my mother that died, I tried to represent her anywhere I find myself. People see me and see her in me. If I'm living a bad life, that something, so I want to be able to represent her very well where I find myself. Even though she's gone, she would speak good because what speaks for you when you're gone is who you are, who your children are. They see you through your children. Even though you're dead physically, you're still living in your children. If you remember that legacy for the person then move on.

## **Cultural Beliefs and Attitudes**

**Taking the body home.** One of the major cultural beliefs in this study was the phenomenon of “taking the body home.” There is very little literature available on the phenomenon but the practice entails transporting the body of a deceased loved one back to their native land. This practice can be traced as far back as biblical times. In Genesis 49, verse 29, Jacob commanded his children saying “I am to be gathered unto my people; bury me with my fathers in the cave....” In obedience to that instruction his son, Joseph, got permission from Pharaoh to leave Egypt to take his father’s body home. Joseph and his siblings did as their father commanded them, “They carried him into the land of Canaan, and buried him in the cave...” (Genesis 50:12-13).

Further, the United States Military has always maintained the tradition of bringing the dead bodies of fallen soldiers and dignitaries back home to American soil to provide them a befitting burial amongst their loved ones and to honor them in their communities. Rural Greek Orthodox people also practice this tradition, exhuming their dead and transporting the bones to be re-buried in the village ossuary (Kagawa-Singer, 1994).

This tradition is also practiced amongst the West African countries of Nigeria and Ghana (Smith, 2004; van der Geest, 2006). The concept of taking the body home is discussed poignantly by both the Nigerian-born and US-born participants in this study. For these families, this meant shipping or flying the body to Nigeria or some other city or state of the United States (Smith, 2004).

**Reasons for taking the body home.** Many participants expressed their reasons for taking the body of their loved one to their home city or state, or across international shores to their home country. Many participants felt that by taking the body home they

show their final respect and love. It also gives opportunity to other family members, and the community that loved that person, to come and pay their last respects. One US-born participant spoke about taking her husband's body back to Detroit (their hometown), "He had a huge funeral. Everybody came to show their respect."

This practice is highly valued, especially among the African population. In fact, it is a cultural expectation in the Nigerian community. One participant vehemently explained her family's decision to take her mother's deceased body back to Nigeria, "We can't bury her here. She's not from U.S. We don't bury our loved ones in a foreign land." Several of the participants expressed the notion that one has to send that body home to be buried in order to avoid complaints, abuses and denunciations from other people if family members make the "unwise" decision of burying their loved one in the US. A 75-year old Nigerian widow whose husband died in the US a few weeks after they came here for treatment, recounts that, "We started arranging to take him to Naija (Nigeria) because our people, we feel very....people will laugh at us [if we do not]...everybody will abuse you. They will not talk to you." Therefore, for one's peace of mind, family unity, and cultural acceptance, many AAPCGs adhere to the prescribed societal norms of taking the body home.

Another common reason proffered by many of the AAPCGs was that they were carrying out the wishes, requests and or previous plans of their loved ones (Smith, 2004). Many of the loved ones' instructions appeared to hinge around being buried alongside their previously deceased spouses. According to one Nigerian-born male participant whose mother died in the US, he had to take his mother home because, "She had actually asked that, if she eventually passed away, she wanted to be buried in Nigeria...She had

wanted to be buried next to my father.” Also, a US-born participant reported, “My sister had made arrangements to be buried next to her husband in Chicago...she had already paid for her grave and everything there...She only agreed to come out here (Arizona) to live if her son promised to take her back there to lay beside her husband.”

***Role of social support in taking the body home.*** One of the participants expressed great disappointment over the disheartening behavior of people he encountered professionally and personally when he took his mother’s body home, however, many other participants who took the body of their loved ones home, reported that they got the support of family and friends. A Nigerian-born female participant whose father died here in the US reported:

Nigerian community, we support each other when there’s bereavement...Thank God friends and relatives and people really rallied around, paid for that, donated money to us, and also, even for my mom, to get my ticket was all paid for. I didn’t have to spend a dime of mine to do that. That’s the kind of community we come from, Nigeria. It wasn’t that difficult in terms of raising the money, because people were very supportive.

The support of friends, family and community did not only involve financial assistance. Several Nigerian-born participants reported that people supported them by offering instrumental assistance such as giving material gifts like clothing, bringing food, or helping with burial arrangements. Two US-born participants reported also receiving instrumental support while planning the funeral arrangements in Chicago and Detroit. The participant who buried her husband in Detroit reported that she “got a lot of support

from work and everything” and that her sister also helped her arrange the church service in Detroit.

*Reported effects of taking the body home.* A general consensus amongst the participants who took their loved ones home was that they felt relief. The relief, peace and sense of fulfillment in completing the arduous task of taking the body home was highly desired. Being able to pay respect to the wishes of their deceased loved ones is valued in the African community. Consequently, completion of the task of taking the body home often set the tone for a healthy PCT outcome. As reported by one of the participants discussed above, “Just the fact that I was able to accomplish what she wanted, you know was a big relief...that was the only time that I started having the relief.” Taking his mother home also had a secondary benefit for this participant: it gave him an opportunity to pay respects at his father’s grave.

Death practices such as taking the body home help the family to resume and “re-establish emotional synchrony, sense of equilibrium, group welfare and continuity” (Kagawa-Singer, 1994, p.104). Hertz contends that, “The corpse symbolically represents the values and beliefs of society” (Hertz, 1960; Shroeder, 2001, p.80). Because taking the body home provides powerful symbolic ties for African societies to the place of origin (Smith, 2004), it is very important that loved ones and caregivers carry out the wishes of their deceased loved ones and the community and society at large. The practice also helps to ensure that the deceased loved one eventually finds a restful place at “home” in that final journey to eternity.

### **Nigerian-born versus US-born AAPCGs.**

It appears that the Nigerian-born and US-born AAPCGs who were involved in taking the body home agreed on many things and expressed the same sentiments about the cost of taking the body home and reasons for doing so. However, US-born participants felt that taking the body home is an individual's choice. According to the female US-born participant whose sister made arrangements to be buried in Chicago, it was the sister's choice and preference. This follows then that the individual who prefers to have the body shipped for burial makes sure that they plan and pay for that arrangement ahead of time. In this case, it was, "Not necessarily a cultural thing, it's just something that she [sister] had planned for." However, the Nigerian-born participants felt almost like they had little choice in completing this cultural requirement. It must be done if it is the wish of the deceased loved one. One Nigerian-born participant puts it simply, "She wanted to be buried in Nigeria."

Another major difference noted between Nigerian-born and US-born AAPCGs was the term employed to describe their deceased loved ones. All the Nigerian-born participants who spoke about taking the body of their loved one "home" to Nigeria referred to the dead body as a "corpse." One Nigerian-born female participant said of her mother, "We took her corpse home." On the other hand, the US-born participants generally used the term, "body." A US-born participant noted that her family, "shipped the body there [Chicago]." The meaning of this difference in terminology is unknown.

Taking the body home is a time-honored tradition practiced mostly amongst African and some African American cultures. This tradition supports the wishes of deceased loved ones to bury them in their accepted or designated "home" locations, thus

obeying and carrying out death-bed promises (Ume & Evans, 2012). This obedience helps with coping and dealing with the loss of the loved one and ensures that the family members who are still alive can move on without regrets, but with the joy and peace of knowing that they provided their loved one with a befitting burial. Although this practice is expensive and sometimes fraught with challenges, the benefits claimed by the individuals who engaged in the practice support and produce tangible symbolic meaning for those who remain. The negative aspects of this phenomenon will be discussed later under the inhibitors to PCT.

**Recruitment.** Another difference in cultural beliefs and attitudes surfaced in regard to study recruitment. There appeared to be less trust of strangers in the Nigerian community, such that they would not sign up during attempts made through their churches or local organizations. One person said over the phone, “We don’t talk to strangers about such personal matters.” However, when they actually saw and knew the researcher personally, they were more willing to participate in order to “help” one of their own to succeed. In that spirit of communal support, many of the participants also initially refused the \$20 stipend to show that they were not doing it for the money, but for the altruistic purpose of helping one of their own. They were eventually convinced to accept the money following an explanation that it was being paid through a grant and not from the researcher’s personal funds.

**Community support.** Although social support has been shown to be highly valued amongst African American caregivers (Dilworth-Anderson et al, 1999), in this study, it was observed that the Nigerian-born PCGs often alluded to more than just social support provided by immediate family or friends. There appeared to be a communal



expectation of support, almost a demand, for selfless acts of collective responsibility to share the burdens of others in times of need, especially death and mourning. One Nigerian-born participant described this expectation in detail.

Culture helped because culture makes us mourn the dead. Culture tells you not to keep the pain inside, to cry out...Culture also sees that when someone passes, family members, friends, they all come around... Some of them stayed for a week. That's what our culture [demands]...and during the funeral, the family members from my father's side, from my mother's side, everyone stayed like throughout the mourning period, throughout burial. Everyone comes and that's our culture. You don't feel abandoned. You don't feel left alone. There's always someone with you to console and comfort you.

**“Culture as religion”.** Another notable difference occurred when the Nigerian-born participants were asked how their culture impacted their decision for caregiving. They all immediately talked about their spiritual belief in God or referred to Biblical principles guiding their caregiving decisions. The US-born participants, however, were able to discuss religion separate from culture. Despite the fact that the Nigerian-born participants were highly educated, their inability or unwillingness to separate culture and religion is an interesting phenomenon worthy of further investigation in future studies. It may be that the influence of religion on the Nigerian culture is so profound that it makes the two inextricable from one another. However, a major similarity is that both groups of participants very frequently alluded to their spirituality as a source of strength and comfort in dealing with the loss of their loved ones. Another major similarity between the two groups involves the expression of deep feelings of loss about the death of their loved

ones. Both caregiver groups were deeply saddened, with feelings of loneliness, chaos and uncertainty. The two groups also expressed the joys and rewards of caregiving their loved ones, despite the difficulties and challenges.

### **Socioeconomic Status**

One of the major conditions that affected many AAPCGs in this study was financial difficulties during the caregiving period that continued through the post-caregiving phase. AAPCGs often battled financial challenges that were worsened by demands of caregiving and the subsequent post-caregiving period (see detailed discussion under Family Income in demographics). In the immediate period after the death of a loved one, AAPCGs needed to pay medical bills, mortuary and burial costs, and maintain their homes without the income of the deceased loved one. AAPCGs in this study acknowledged the significance of these financial burdens in their lives. A Nigerian-born male participant prayed with his siblings, “When mom passes away, Lord, let us have money.” However, he recalls that, “God waited until we were broke and then decided to take mom away.”

**Financial conditions.** Caregivers identified specific factors that helped them deal with the financial difficulties they experienced in the post-caregiving phase of caregiving. One such factor was the support of friends and family. Support came in terms of financial contributions and other kinds of instrumental help such as helping to plan wake-keeping or burial events. A male AAPCG who prayed that his mother would not die while he was broke recalled the kindness and support of his friends, “Friends that rallied around us, you know, they rallied around us in such a way that, you know, it didn’t matter if we had a cent or not.”

Another source of help came in the form of deep discounts from the funeral home for mortuary costs. One AAPCG recalled that he and his family were expecting a large mortuary bill due to the extensive time their mother's body was held at the mortuary. He marveled "The bill that they gave to us was totally shocking; [I] expected it to be twice as much...the funeral director went out and in 20 minutes he came back. He said we're taking another \$1,000.00 off of this." This magnanimous support was very encouraging and spiritually uplifting for the family.

Strong spiritual beliefs common amongst African Americans were viable ways of dealing with financial distress. The support from family and friends and the discounts from the mortuary are seen by the religious in spiritual terms, as miracles from an ever faithful and caring God. The AAPCGs believed that God used these people to provide for them. One participant recalled, "We didn't have any money and she - I mean He (God) made himself known to be the giver of, a good provider."

### **Preparation and Knowledge**

It appeared that the participants did not receive much preparation for end of caregiving or the death of their loved one. The few that discussed preparation expressed a lack of knowledge that resulted in a more difficult adjustment after caregiving ended. One participant recalled that her physical and emotional health deteriorated badly in spite of the warnings from her personal physician, but that she did not realize how bad her situation was. Throughout the interviews, there was no data on any preparation for the end of caregiving and what the caregivers should expect or do. This could be partially attributed to the fact that the majority of the caregivers did not participate in hospice. Prior published work on end-of-life and palliative care report only 8% use of hospice and

palliative care services among African American families (Haley et al., 2004; Evans & Ume, 2012). In this study, only 25% ( $n = 10$ ) of the AAPCG participants placed their loved ones in hospice, and 87.5% ( $n = 35$ ) denied attending any support groups.

Although information about preparation and knowledge about post-caregiving was not directly elicited from participants during the interviews, there may have been limited opportunity for preparation for the PCT because the majority did not have formal caregivers to provide them with information. This lack of knowledge may have negatively impacted these AAPCGs physical and emotional conditions during PCT.

### **Transition Inhibitors: Personal, Community, and Societal**

This section discusses the issues and concerns presented by AAPCGs in this study which they believed hindered their progress through PCT. Following the Transitions Theory framework (Appendix A, Figure 1; Meleis et al., 2000), these inhibitors are presented in terms of meanings, cultural beliefs and attitudes, socioeconomic status, and lack of knowledge and preparation. The following inhibitors are discussed within the auspices of the above sub-headings: Negative interactions, beliefs that treatment or nursing home placement led to loved one's death, a part of one's self dying with the loved one, wishing things were different, lack of knowledge and preparation; needing outside validation, family conflicts, disruptions in expectations, avoiding home, and continuing caregiving.

### **Meanings**

Participants in this study relayed their sense of loss and the impact that the loss of their loved ones had on them, and the meaning of that loss to them. Meaning was expressed in terms of the emotional and physical distress which impacted their overall

meaning and understanding of the caregiving and post-caregiving experiences. Emotional distress included experiences of pain, confusion, stress, depression, guilt, and deep sense of loss; whereas physical distress included exhaustion, cognitive challenges, pain, insomnia and related effects on other family members.

**Emotional distress.** Participants in this study expressed deep emotional difficulties with the death of their loved ones and the subsequent termination of their caregiving roles with words such as “devastation,” reporting for example, “When he passed, I was grateful to God. I was devastated and grateful at the same time. I don’t know if that makes any sense.”

**Pain.** Several participants used the words emotional, emotional pain, and sad. One female participant remembered her father, saying, “The day he passed away, I was a basket case, I couldn’t talk; I couldn’t socialize. It was very emotional for me.” Another participant concluded at the death of her mother and the termination of her caregiving role, “Yeah, it was now emotional pain. The physical part ended because you’re not doing, running around as much as you should”. Yet, another related how her memories could conjure up sadness. She says, “I may wake up and feel sad, not to let the sadness take me back and every day is a journey... [be]cause the memories and the sadness can take me back.”

Participants also used words such as “strain”, “stress”, “painful” or “difficult” to express the severity of their loss and the effects that the loss had on them. According to one female participant, “I didn’t realize how tired I was and what a strain this was.” Another female participant stated, “It was really kinda difficult when she died because she died a very slow, very slow drudged-on death.” The slow, painful demise of a loved

one often triggered mental health situations warranting the need for intervention. One female participant recounted, “It’s very difficult mentally, emotionally. I ended up in counseling.”

**Confusion.** Several participants described the post-caregiving period as “stressful,” “traumatized” and “confusion.” Confusion in the post-caregiving period may be severe and may occur with feelings of uncertainty. One participant spoke of her confusion, “After my dad passed, I was so confused, not knowing – confused in the sense that that was the first experience of having somebody very close to you passing on. Confused again that I don’t really know what will be.”

Other participants described how hard the loss was for them, “It hit me hard,” “I really felt bad,” “I took that one pretty hard”. Another participant reported that her mother’s death “hurts. Of course it does, but I think the main thing that hurts me now is mom being gone.”

**Depression.** The post-caregiving period was repeatedly described as mentally and emotionally difficult for these caregivers, although AAPCGs do not usually admit emotional or mental health conditions such as depression and anxiety (Haley et al., 2004). However, as cautioned by Dilworth-Anderson and colleagues (2002), AAPCGs may experience these emotional challenges but may not label them as depression or anxiety.

Depression was measured using a 13-item CES-D scale (Appendix F) that was adapted and used during the REACH II project (Coon et al., 2004). Items 5 and 8 were reverse coded (responses of 0-1-2-3 were reverse-coded as 3-2-1-0). Simple imputations were done to account for missing data in cases 12, 22, 36, and 39. Case 19 was dropped from the analysis because of complete missing data on all items. The imputed data were

used to calculate the total mean (5.49) and standard deviation (5.38). In analyzing specific items like depression, the exact data (what people actually said) were used to report percentages of occurrence and not the reverse-coded data. The Cronbach alpha for this study for the total 12-item CES-D instrument for 40 participants was 0.807.

This instrument utilizes a cut-off point of 15 for demonstrating the presence of depressive symptoms. The total scores on the CES-D for this group of participants had a normal distribution with only 5.2% (n=2) of the participants exceeding the cut-off score of 15 with readings of 19 and 25 respectively (Appendix O, Figure 5, and Appendix N Table 3) for frequency distribution of CES-D scores. Interestingly, those two participants included a male PCG who provided care for his grandmother and who was early-stage (three years) post-bereavement (CES-D score 19). The second participant was a middle-stage female multiple AAPCG who was both a spousal as well as adult child post-caregiver and was more than 6+ years post-caregiving. She scored the highest for depression (CES-D score 25) and presented a passionate account of the loss of her loved ones (husband and father) and the negative impacts their deaths continue to have on her personally. She viewed the loss as the loss of her children, because she took care of them as deeply and unreservedly as if they were her children. Those two participants were involved with multiple and/or serial caregiving situations and, although two participants were not enough to make a statistical inference, their interviews support the notion that multiple caregiving may place caregivers at higher risk for depression.

In this study, only two AAPCGs mentioned depression during their interviews, but only to deny it. One female participant recounted a conversation with her physician, “I said, gee, I am just so tired. The doctor says, ‘Well, are you depressed?’ I said,

‘Depressed? No.’ Another AAPCG also denied experiencing depression although she acknowledged having panic attacks. She said, “Just for my mind to get depressed? No, that didn’t happen because it seemed like that I had too much to think about for him [husband]. Then after he pass[ed], I’ll start having panic attacks.” Although only two participants scored high enough (19 and 25 respectively) on the CES-D scale to be considered to have depressive symptoms, however, the majority of the AAPCGs in this study denied depression. On the specific CES-D question, “I felt depressed”, 69.2% ( $n = 27$ ) of the AAPCGs in this study denied feeling depressed. On the other hand, 23.1% ( $n = 9$ ); 2.6% ( $n = 1$ ); and 5.1% ( $n = 2$ ) of the participants for a cumulative total of 30.8% ( $n = 12$ ), admitted to depression some of the time, occasionally, or most of the time, respectively (Appendix P, Table 4).

Closely aligned to depression was also the CES-D question, “My sleep was restless”. Restless sleep appeared to have a significant positive relationship ( $p < 0.05$ ) with depression amongst these study participants, resulting in Spearman’s Rho = 0.366,  $p = 0.022$  (Appendix M, Table 2). The majority of this study’s respondents (59.0%) answered “rarely” to this question (Appendix P, Table 4).

Emotional lability where AAPCGs experienced mood swings – being happy one moment, then sad and depressed the next moment - was a common finding during the initial period of loss of the loved one. Seven AAPCGs described crying as a very common emotional expression during the initial post-caregiving period. For some PCGs, crying was a daily occurrence and sometimes for many hours at a time. Crying was sometimes interspersed with other joyful or positive emotions or activities. One AAPCG would lock herself in a room, worshipping God, singing praises and crying.



Crying was not limited to females; male PCGs also expressed their emotional experience through crying. One participant noted her lability, saying, “I’m either completely happy or I’m completely not.” These emotional “ups and downs” were sometimes mediated by the timing of the death of the loved one.

Greater emotional difficulty appeared in the immediate post-caregiving period. Although this period was characterized in the study as the first three years after the loved one’s death, some participants report the initial post-caregiving period as the first two years. For example, one participant reported, “The first two years, I just cried. I missed my dad very much.” However, a male PCG whose mother-in-law died almost three years earlier countered that time so far has not yet allowed him to get beyond the loss. He said,

I didn’t adjust [to] nothing. I’m just trying to stay strong. Because I still cry, even this afternoon. When I think of her [mother-in-law], tears come into my eyes again. It doesn’t even wear off at all. Even now as I’m talking to you, I’m already getting off again.

The depth of such emotional difficulties may be unrecognized by the AAPCG or other family members. Several AAPCGs discussed the difficulty that resulted from not having a clear understanding or awareness of one’s emotional path. One participant explained her predicament, “I think I went through two years of major grief and depression, and I didn’t even realize it.”

Various activities, even mundane ones, could bring on memories of the relationship with loved one and elicit emotional responses from the AAPCG. Unfortunately, caregivers were sometimes unprepared for the eruption of emotions that resulted from such memories. One female participant recalled,

The year after he [her father] passed, I remodeled my house, and I was trying to put up a paper towel holder. I could not figure it out, and I just started crying...I was like, this is my daddy's job...He's supposed to do this. I got very frustrated because I could not do something that simple.

Memories were both positive and negative during the post-caregiving period. For some caregivers, memories of their loved ones provided calmness, reassurance and strength. One participant recalled, "I used to remember a lot of things she said, and at that time as soon as she left (died), it hurt me, but as time went on, I realized that that gave me more strength to move on." However, other participants reported that memories of their loved ones brought up feelings of inadequacy, anxiety and stress.

Stress and emotional distress negatively impacted the mental and physical health of some AAPCGs, leading to difficulties in concentration and memory in day-to-day activities. As one participant reported,

I think after my husband died, I just took too many classes at one time, and I just got burned out again [be]cause my mind was still stressing from everything...Now, that's the reason I didn't finish school this time because mentally, just seemed like that since I shut everything down mentally, I really still can't concentrate on everything like I used to... I just can't remember things like I did before.

Feelings of loneliness were difficult for AAPCGs and there was often a need to fill the void left by death of loved ones. AAPCGs used activities such as work to occupy themselves, numb their emotions, and mitigate the loneliness. One participant reported about how the loss of her mother affected her. She described her situation as, "Emptiness.

She wasn't there anymore. That was very, very tough". For similar reasons, another participant recalled, "I think that's probably why I was trying to fill up the void and everything...Like I said, I'm throwing myself back in and I had taken a management position. I'm really putting in hours and everything."

Sometimes, the issue of loneliness involved missing and needing to replace the deceased mate. One participant wondered, "You think about, well, gee are you gonna find another mate or what are you gonna think about doing? How do you learn to live alone?"

**Guilt.** As previously discussed, one major emotional difficulty experienced by PCGs was guilt. Caregiver guilt was sometimes severe and reasons for PCG guilt varied. Some reasons were care-related, such as not being there when the loved one took a turn for the worse or actually died. One participant speaks about the guilt she felt about not sleeping in the hospital the night before her husband died. She experienced long-term guilt despite doing all she could to support her husband throughout his illness.

Another participant also felt very guilty because she was not on hand when her mother died, even though she was there in the morning, provided care, then left to run some errands. She was notified about her mother's death by her nephew.

He said, Grandma's gone...I couldn't believe it. I could not believe it, right, I couldn't believe it...I felt guilty for leaving and going to the Air Force base because I felt if I hadn't of went, this wouldn't have happened.

Guilt was often combined anger; anger against God for taking their loved one, or anger at the deceased loved one for dying and leaving them alone. One participant

mentioned that, “At first I was angry with God. Why you take my family? Why you take my dad and my husband and all, my mom and everybody like this.”

Several participants expressed guilt over the inadequate care they rendered because they did not understand the severity of their loved one’s physical deterioration or extent of illness. A male caregiver regretted not doing more for his mother when she would call for assistance. He thought she was being lazy, without realizing how weak his usually strong mother had become. He reported,

There were times when she needed, you know, little things done and our assumption was that, you know she was not trying hard enough, because when you have known someone who are very strong and then when they cannot put on their shoes and they ask for help to put on their shoes, you know, sometimes you tend to say, “come on now, mom, I mean you can put on your shoes”...I just didn’t know it. I thought that, you know, sometimes she was being, you know, and I hate to use the word, lazy.

A female participant recalled,

With my mother, I remember when she was saying she couldn’t walk up my stairs; initially I didn’t see why she could not do it. I thought she was just pretending. To me, it was very annoying. Then I would say take your time. I can’t see why you can’t do it...Actually, I didn’t put myself in her position to think, you know, that she wasn’t as fit anymore...I’ve lived that guilt though, because I remember I would just be angry. I would say you’re not trying to help yourself at all, but that’s not true.

Other care-related guilt issues included caregivers' remorse for ignoring the loved one's call for help because they could not or would not want to be disturbed at night.

One female participant admitted,

I'm ashamed. There were times she might have called for me in the middle of the night and I pretended to be asleep just so I didn't have to get up. I know I heard her. I hear her calling for me for whatever reason and I just didn't want to get up and I just ignored her. Now I feel so ashamed. I'm so mad. There are times I just break down and cry. I get so upset because I feel like I was just awful.

Other care-related guilt occurred because the AAPCG failed to do what he or she should have done or acted in accordance with their training and experience. One female participant, who was a nurse, cared for her husband until he died and also cared for her mother with Alzheimer's disease. She, said, "When he [husband] arrested. The day that he passed, I was wondering, 'What could I have done?' I panicked. I didn't do CPR."

Even PCGs who took care of their loved one well enough according to public opinion felt guilty when they thought back to their caregiving experience. Some felt guilty because they believed they were undeserving of praise in the face of hidden resentment about the caregiving. One female participant aptly expressed this reason for guilt over her care of her late sister, saying,

I feel kinda guilty because I got tired sometimes of her being here [home], but I did what I had to do. I didn't mistreat her or nothing like that. It was just that I was kinda tired of the responsibility. Sometimes I feel – because people praise me for it and then I feel guilty because it wasn't all what they're saying to me.

Sometimes, PCGs did not feel guilty about the actual care they provided, but still felt regret or guilt over other non-care related issues or decisions concerning the diagnosis or death. According to one female participant,

My feeling guilty wasn't so much about the caregiving. It's the fact that maybe we could have caught it earlier [her mother's breast cancer]... I think that's what keeps going through my head that, maybe if we were home, that something else could have happened. Then it wouldn't have been so late in the day. She would have been able to have more years, [be]cause this [mother's death] was like in less than four months. She was gone after the diagnosis. That is where I feel guilty. With regards to her care, I don't.

PCGs sometimes felt guilty about decisions they made on behalf of the loved one which they believed contributed to their demise. According to a male PCG consented to a surgical procedure on his mother-in-law's behalf.

The only thing I feel bad about was the decision when they did the surgery...after surgery, she went down the drain. That is the only thing that I regret about. Every other thing, we did right. I think we took care of her, so I don't have any regrets.

As previously discussed under financial conditions, PCG guilt also was related to the inability to financially provide adequate care. One female participant wondered, "That maybe if I had enough money, you know, bought all of the things for her, maybe she wouldn't have passed. You know that's just my little way of thinking about it, though."

The challenge of affording necessities of life such as medications and equipment for the care of the loved one at home sometimes led caregivers to work outside the home,

while still providing active caregiving. Outside employment usually took the caregiver away from home, thus creating a foundation for PCG guilt. A female participant reported,

I think I did the best I could. I just felt that I – I did feel guilty that I could not, that I had to work and I couldn't spend more time with her [mother]. I guess that's the only thing that I really felt sad about, the fact that I had to work during the time when I was trying to take care of her at the same time.

The regret and guilt over not spending enough time with the loved one was a concern for many AAPCGs in this study. When the loved died, this perceived inadequacy of quality time created or intensified PCG guilt, thus negatively impacting the PCT journey. According to one female participant,

In that caring for my mom during that time, I can't say I have any regret; regrets I can say I have is some time before she got diagnosed spending time with her; that I had regret about, some of the things I could have did you know, with her before she got diagnosed with the cancer, before she got terminally ill.

Sometimes the challenges of finances, outside employment, or other care-related issues forced caregivers to place their loved ones in nursing homes, the most common reason expressed by participants for PCG guilt. For example, one male participant said, "If I'd been more affluent, I would've made sure she stayed in my house so that is a little bit of regret to me." His sister, who was their mother's primary caregiver, also admitted

One that I still feel guilty about is, when she had to go to the home. Because my house has stairs, it became impossible for her to climb the stairs...I thought about different things I could do to help, but it didn't work...So, that was the biggest challenge. I tried everything to keep her at home, but it didn't work.

Sometimes, guilt was so severe because the caregiver believed that his or her decision to place the loved one in a nursing home led to the loved one's death.

According to the above female participant, "That was the biggest regret, [be]cause I believe if she was here [at home], she wouldn't have died...It's like, I let her down."

Unfulfilled promises to the loved one were also a reason for PCG guilt. Some of the participants discussed their inability to fulfill promises they made, such as purchasing a special bed, taking their loved one to the US for treatment, taking a special trip with him or her, or bringing their new spouse or new baby to visit. The inability to fulfill those promises was related to lack of funding, inability to obtain the necessary visas, or just being too busy with other aspects of their lives to fulfill those promises. Whatever the reason for having unfulfilled promises, the AAPCG who made the promises lived with the guilt long after the loved one died. According to a Nigerian-born female participant,

The only regret I had was leaving them [parents] in Nigeria to come to the US.

Then my dad wanted us to take him to the U.S. for treatment and we couldn't get his papers...so he had that hope and expectation that he was coming to the U.S. and get treatment and he was sure once he gets here, he'll be okay. It never happened, so I feel so bad about that.

Another female caregiver reported feeling guilty that she did not insist that her grandmother's wishes concerning resuscitation be honored by her mother, who had the power of attorney. She said, "I really feel guilty because I think I should have fought harder to have my mother's medical power of attorney challenged. You know that it was really her wishes. I really feel like I should have spoke[n] up."



Survival guilt was another reason for emotional distress. Sometimes, caregivers were so engrossed and vested in their caregiving role, that when those loved ones died, the caregivers felt like they personally failed their loved ones. One female participant expressed survival guilt in this manner:

Sometimes, now, it's hard to be happy. Sometimes now it's hard to express a deep happiness because I figure though I have that guilt for how am I so happy and my family's not here or how am I so happy and I miss my husband and I miss my dad.

One inhibitor of PCT that was described by five participants was their belief and ensuing guilt that different treatment-related issues contributed to the deaths of their loved ones. Such treatment decisions included allowing surgery and having the elder's condition worsen rapidly after that, and allowing nursing home staff to resuscitate a husband, who "was never the same when they brought him back." Another participant felt bad that she did not perform CPR and that is why her husband died. Finally, one nurse participant felt that giving her mother potassium in a pill form versus liquid may have led her to choke.

One of the treatment decisions seen as leading to the elder's death was nursing home placement. African Americans have a disdain for institutionalization (Sudha & Mutran, 1999), thus when they are forced by circumstances to place older loved ones in nursing homes, and those loved ones die, they may blame themselves for their loved ones' death. One participant said,

So, that was the biggest challenge. I tried everything to keep her at home, but it didn't work. That was the biggest regret. [Be]cause I believe if she was here

[home], she wouldn't have died. That's my own feeling. It's like I let her down but I sat there and I thought I said, well I did the best I could. I didn't have a choice. I don't have another house...I think it's bitterness, just bitterness and just anger towards the nursing homes. That's what has really been my real problem. That's what has really hindered me from moving on. [Be]cause I believe she still had years. They [NH] cut it short...

Sometimes PCGs experienced guilt that was unrelated to their direct caregiving situation, such as guilt from speaking negatively about one's deceased parent or loved one. Especially in the African tradition, a child dare not speak negatively about a living parent. Even more importantly, it is almost considered an abomination that any child would speak negatively about a deceased parent. Dead parents or ancestors are held in such high regard that such apparent disrespect and expression of bitterness, anger or ill-thought towards a deceased elderly parent, may be perceived to be disastrous to the former caregiver's life. Family members and the community at large would publicly denounce that individual and may go as far as placing a curse on that person for ill-treatment of their dead. This is an important difference for AAPCGs, as opposed to Anglos. The communal denouncement can create a feeling of guilt, remorse, regret and increased stress for that AAPCG.

This negative speaking may be rooted in the foundation of a poor relationship that existed between the caregiver and care recipient. According to one Nigerian-born female participant who admitted to having a rocky relationship with her mother,

Sometimes with my friends, I say something, oh my mom was like that; my mom did this; my mom did that. Then when I go home, I said that's your mom; you

shouldn't say things like that about your mom and that guilt comes again... With my mom, I felt – I think family members made me feel guilty. I know I gave her the best I could give, but they made me feel like I didn't give enough... During the funeral, they gave us so much stress. They made me feel like, you know, you did not take care [of your mom].

In Nigeria, providing caregiving for one's parents is not a choice, it is an expectation. Therefore, if there is a perception from the community that an adult child especially a daughter, did not provide the level of care expected of that daughter, then there is collective denunciation of the individual. This participant admitted that she was angry at her mother and blamed her for the stroke the mother suffered, and for being careless about her health and not taking care of herself:

When she [mother] had the stroke, I was angry.... When I went to the other city [where her mother lived] to stay with her, I was too angry because I felt she caused it on herself... It was so stressful, but I had to leave. Then when I left, I went back home, I had cousins that were calling me and like "Oh, why? You're not with your mom?" ... She [cousin] felt embarrassed that my mom didn't have food.

The extent and length of guilt varied. Although many of the participants that spoke about their caregiver guilt did not address how long it lasted, one participant reported, "I have let it go, but boy it lasted so long, that guilt."

***Deep sense of loss.*** To circumvent these feelings of guilt, caregivers sometimes wished that their loved ones remained alive despite the severity of the caregiving situation and the poor quality of life. This finding supported previous published reports

that African Americans are family-centered, prefer to keep loved ones at home and seek aggressive treatments for their loved ones (Evans & Ume, 2012; Hines Smith, 2002).

According to one Nigerian-born female participant, “I would say we didn’t want to lose her (mom). I personally didn’t want to lose her. I don’t care if she only sits down somewhere and doesn’t do anything, but let her stay alive for us, you know?”

Unfortunately, when that loved one did not stay alive, AAPCGs found themselves battling the loss. Some participants in this study believed that their loss was deeper and of greater magnitude than normal loss. According to one female participant who identified the death of her father and husband as the loss of her children, this loss suggested a deeper pain and hurt of a greater degree than is ordinarily attached to the death of a husband or father. She states, “Not like I felt I lost a husband and I lost a dad, but they had, we had grown and was closer than a husband or a dad. I had lost my children.”

This deeper, more painful loss was expressed by crying or by being stoic and shutting down emotionally from others. Tears were seen by several AAPCGs as a balm to sooth their aching souls. These AAPCGs found it useless to cry, at least publicly, because they believed that crying is benign, and an inadequate expression for the magnitude of their loss. One participant said, “There was no tears that could replace him, so there’s none – and people wonder sometimes why I get so melancholy or whatever, because it’s something that you can’t cry for.” Sometimes, AAPCGs avoided crying in order to avoid losing complete control of their emotions. They may try to “keep it together,” always: “I tell somebody, why you never cry? I said, because I’ll lose control if I cry, so you don’t cry.” Crying may represent a deep sadness in AAPCGs, but so may lack of tears.

Memories of the deceased loved one may conjure up sadness for the PCG which may reverse the progress made in the journey towards healthy PCT. AAPCGs who dwell on the memory of the deceased loved ones may not be able to progress through PCT. A female participant speaks of her daily internal struggles to keep her memories in check, “I could let my memories take me back and I make an effort everyday not to let the memories take me back ...I may wake up and feel sad...and every day, it’s a journey”.

The journey of bereavement and response to loss of a loved one may be different for each family member. Some divergence of emotional experiences in these AAPCGs could be attributed to the type or quality of relationship that existed between a particular caregiver and the deceased loved one. One participant, whose family first took care of their father, then their mother, explained the differences in how she and her sister reacted to each loss.

Like my sister tends to get emotional sometimes behind it [their mother’s death] because there may be some things this round that she’s enduring and going through like I did with dad...She didn’t go through what I went through with dad...Not to say she didn’t love him, or never the less, but sometimes different family members take things differently.

The divergence of emotional experiences amongst family members may also affect how they mourn the loss of their loved ones and how they support each other during the immediate post-caregiving grieving period. According to a participant who cared for her mother, “Everybody else seems to have let go and gone on, but I’m still stuck in still one place, so to speak...I’m still a prisoner.”

**Physical distress.** AAPCGs in this study reported various physical difficulties which served as inhibitors to their PCT. These physical difficulties seem to align with PCGs' concerns in other research studies and publications (Li, 2005; Stajduhar et al., 2010; Ume & Evans, 2011). For example, 22.5% of the participants in this study ( $n = 9$ ) reported concerns about the physical difficulties they experienced post caregiving, including fatigue and exhaustion, breathing problems, dizziness, fainting, cognitive difficulty, pain, headaches, hypertension and insomnia.

***Fatigue and exhaustion.*** This was the major inhibitory concern for most of the participants who spoke of physical difficulties in the PCT period. Six out of the nine (66.6%) participants who talked about physical challenges reiterated in different ways how physically drained, exhausted, fatigued, tired and strained they were when caregiving ended. AAPCGs reported feeling too drained even to open sympathy cards, being more physically challenged than emotionally drained, and unaware at the time of how fatigued and strained they were.

The physical exhaustion of the post-caregiving period was often exacerbated by the necessity to continue activities related to caregiving after the loved one died. One female participant's situation was compounded because she had to continue the second stage of post-caregiving – the closing down stage (Larkin, 2009) by making long distance final arrangements for her husband's burial out of state (Glendale, Arizona to Detroit, Michigan). Alternatively, some caregivers also found themselves aggravating their physical difficulties by continuing previous caregiving tasks even after their loved ones died, such as preparing their meals; maintaining the deceased person's room as if he or she was still alive; and maintaining previous caregiving routines like waking up very

early to get things ready for caregiving, but then realizing that the loved one is dead.

According to a female participant who took care of her mother until she died about one year before this interview,

It [caregiving] was hard and stressful...It wasn't over because I'm still going through the motions that I went through when she was here. I still get up at 5.00 and 6:00 to make coffee for my mother and give her her continental breakfast, but guess what? The coffee's still there. She's not here...I get up sometimes and I walk through the house...I just make a run around the house like that's all I could do. Still some of the same things I do. I hadn't even gotten rid of her clothing or anything. Sometimes, I just go back and fold them and refold them.

Sometimes AAPCGs kept themselves so busy that they neglected their own health, leading to deterioration. One female spousal PCG reported:

I didn't even know how bad I had got, [be]cause I wasn't on my stuff and I didn't realize how bad my condition had got physically until after he died and then after they start doin' all the tests and everything and this here, I found out this and this and this [several health conditions] was going on.

Some of the health concerns included seemed serious. For example, that participant reported,

I didn't even know what was going on. I'd be out on the patio trying to read my Bible and stuff, and I would just, couldn't breathe, and I couldn't – everything would start going around...My son found me passed out in the hallway one day when he came home...I couldn't even make it through the house. That's how bad it had got. I never would go to the doctor.

**Cognitive difficulties.** PCGs also experienced cognitive difficulties, perhaps due to increased stress. Forgetfulness was reportedly a serious and common condition that tended to last a long time after the termination of the caregiving role. According to one participant, “Now mentally, I’m not – I just can’t remember things like I did before...I really wasn’t grasping everything like I should.”

**Pain.** Certain physical difficulties from caregiving may continue or become exacerbated during the post caregiving phase. Conditions such as back problems, osteoarthritic pain, or incessant headaches, continued to affect some PCGs for a long time after caregiving ended. According to a female participant who cared for her husband,

I think [be]cause of all the heavy work I used to do, and all the liftin’ him, now I got bad disks and bad spine myself. I got fibromayalgia and osteoarthritis, so in pain everyday...I kept getting this headache. I’m already hypertensive...I kept getting this headache and it would not go away...then, so that’s when the doctor just think he’d put me on two different blood pressure medications, but I could not get rid of the headache. Even though my blood pressure came down, I still, it was just like this headache.

**Insomnia.** Occasionally, insomnia was a major concern for AAPCGs. In this study, insomnia sometimes started during caregiving and persisted through the post-caregiving period (Carter, Mikan, & Simpson, 2009). According to one participant,

At first, it was kinda hard because I found myself waking up anywhere from two to four times a night...I would be like, what woke me up? I couldn’t figure out what it was. Then it started decreasing to three, two, and then, but here, I notice



that it's starting back again where I'm kinda waking up at two and three in the morning or whatever.

Although physical difficulties affected the caregiver directly, sometimes such difficulties also affected other family members. An older spousal PCG reported that her physical condition, coupled with that of her husband's, was taking a toll on her adult daughter.

It was very difficult. It is very, very, because it's not long we came [from Nigeria to the US], after three weeks, my husband dies. And I have my own problems [knee problems that also required immediate surgery]. My daughter was up and down. Take me to the hospital, take my husband. It's too much, too much.

Sometimes AAPCGs recognized that going to their doctor helped and sometimes they found that the expectations of others who believed that they were doing well helped to energize them. One participant quipped, "I'm just borrowing from people who already think I have it together. I'm just like, okay, well, I've got them fooled, so let me just suck it up and deal with it and just roll with it."

### **Cultural Beliefs and Attitudes**

**Taking the body home.** Although family members had good intentions of fulfilling their loved one's wishes to take the body home, the process was often fraught with issues and challenges that made the situation difficult for the surviving loved ones. Many AAPCGs had to make funeral arrangements while working at their paid employment without taking time off. In order to take their loved one's body home, they needed to save up their vacation, bereavement, and sick time for travel outside the country and the funeral ceremonies. This pressing need drastically impinged on the

ability of the AAPCGs to effectively grieve the loss of their loved one, or to fully articulate the meaning and impact of the death and the termination of their caregiving role. This ineffective grieving may have negatively impacted their PCT journey.

Taking the body home was often an expensive and elaborate venture (Smith, 2004; van der Geest, 2006). According to one Nigerian-born participant, family members expected that the people bringing the body of their loved one from the US were coming with lots of money to spend; to have huge burial celebrations “for a life well-lived.” Associated with the act of taking the body home was the exorbitant cost of shipping the dead body to Nigeria. According to one Nigerian-born participant, the amount “we needed to take my father’s corpse home was about \$9,000.00 to \$10,000.00.” This amount was merely the cost of the flight for the corpse, but did not include associated costs such as the mortuary fees including cold storage of the body for long periods of time (in some cases two months or more) while the arrangements for the international burial were underway (Smith, 2004). Other costs included plane tickets for the AAPCG and other family and friends to travel home for the burial; the cost of feeding and elaborate entertainment for the entire community that lasts many days or weeks, and the burial ceremony, depending on the particular Nigerian tribe or community involved.

Another related challenge with taking the body home to a foreign country like Nigeria involved getting clearance from that country’s US-based embassy or consular office to fly a dead body into that country. Additionally, once the body actually got to Nigeria, there were challenges associated with clearing the body through customs and dealing with (sometimes) corrupt airport officials.

I paid for the flight and everything. I was gonna take the body to Nigeria. I had to make sure that I was there to receive the body...It was like clearing the cargo...People at the clearing part of the airport back over there, you know, had dollar signs written all over their faces, so it took some money also.

One of the major challenges reported by the AAPCGs was the difficulty of trying to coordinate the planning and execution of cross-country or international funeral arrangements and the cultural expectations associated with a funeral. For example, a male participant who took his mother's body back to Nigeria, recalled several frustrating experiences:

Having to coordinate with those back in Nigeria for their own side of the arrangements... it's different from the way we look at it. For them it's like, hey, it's party time...and for them it's like, you're bringing money ...those were very, very difficult.

Relatedly, participants felt that locals tried to take advantage of the situation, especially when the body was shipped to Nigeria from the United States, because of the perception that people who live in the United States are wealthy. The participants spoke of community members and in one case, church leaders, attempting to extort money from them.

On the other hand, they were looking to cash in on the situation...to capitalize on the situation...the church she used to go to, decided that she lived here [US] for five and a half years, so they were expecting ...10 percent tithe for all that time.

**Family conflicts.** A major inhibitor was the issue of family conflicts experienced by AAPCGs. In this study, participants noted conflicts and disagreement between

siblings that sometimes began during caregiving and extended into the PCT period. The following types of problems posed or exacerbated conflict amongst AAPCGs and their siblings: finances, living in the family house, participation in or sharing caregiving tasks, disapproval over care or treatment decisions made by the primary caregiver, and support of the primary caregiver at the end of caregiving. One Nigerian-born female participant explained the culturally-specific conflict in her family

It's like my dad died; his brothers were there. Everybody was grieving the same way, you know. Then the burial, of course, everybody wanted to be part of the financial contribution. As a matter of fact, my dad's brothers, it's like a practice in the family but this is just exclusive to our family that when somebody dies, all the grown-up adults, adult men contribute 10,000 Naira to bury the person, right?

They did that, but I asked them to take it back, to take their money because I felt I needed to give my father the best I can ever do. I wouldn't give him anything that does not cost me something, you know... The [uncles] felt disrespected that age-old tradition that I should come up and just decide to break it but I wanted to bear the financial burden of burying my father.

The different ways family members and AAPCGs grieved seemed to create or exacerbate family conflicts. Some family members expected or demanded that other family members provide a level of emotional support to them. Others, however were dealing with the loss in a different way, and were unable or unwilling to provide the expected caring or emotional support, thus potentiating family conflicts. One US-born female participant reported that her sister, who was their mother's primary caregiver,

demanded her siblings' support throughout caregiving and especially after their mother's death. This female participant recalled her sister saying,

I need you. I need you here. You should be here, but it wasn't saying, I need you here. She was saying the family, the family...I know that she was crying out for me...But here's where the conflict comes in. What my sister failed to realize is that I was in mourning exactly like her...And I couldn't comfort her because I needed someone to comfort me... Except, I wasn't looking for her to comfort me. I had a man at that time. And he comforted me...And he was the one I wanted to do that.

The manner in which the request for support or response to the request was verbalized appeared to further intensify conflicts, sometimes even leading to volatile outbursts. Sometimes family conflicts were exacerbated because individuals were at different places in the grieving process. Family members were sometimes unable to be honest about their needs or extend themselves personally:

I may have said a lot of things that she [my sister] really didn't need to hear at that time...I would have told her, I'm so sorry, but I can't. I'm not strong. I can't be here with you because I need somebody...And that is what hurts me the most because my siblings just simply will not leave me alone.

Participants believed that the negative attitudes of their siblings were destructive, especially to AAPCGs who had given up their own home, job or who made other sacrifices to move in, or to accept and take care of the loved one. They suggested that AAPCGs who shared a common residence with their loved one experienced a higher degree of distress than non-resident caregivers. One female participant reported that her

siblings believed that she would, “probably be hurt the most, because mom stayed with me.” This expectation was challenging for these AAPCGs, who found it difficult to pick up the vestiges of his or her life after being a direct, hands-on caregiver, sharing residence with that loved one.

**Negative social support.** African American communities in general believe social support is the bedrock of recovery from the death of a loved one. Although literature showed that social support is very good for caregivers and bereaving families, sometimes caregivers reported negative social support (Kaufman, Kosberg, Leeper, & Tang, 2010; Rolf et al, 2004). In this study, we considered AAPCG-reported negative social support situations as inhibitors to PCT. Negative social support could mean too much support, which the AAPCG then perceives as intrusive. It could also include the lack of support or social support persons acting in ways that the AAPCG finds disrespectful, insensitive or offensive (Wilsey & Shear, 2007; Burke, Neimeyer, & McDevitt-Murphy, 2010).

The last domain of the Social Support Instrument was negative interactions. In this study, negative interaction showed ( $M=3.13$ ;  $SD=2.30$ ) with a maximum score of 8 compared to satisfaction with support ( $M=9.90$ ;  $SD 2.48$ ) with a maximum score of 12 (Appendix Q, Table 5), revealing that although AAPCGs appreciated and were satisfied with the social support they received from family, friends, and co-workers, they occasionally felt that some of that support may be inconveniencing and intrusive.

It is almost a culturally-required activity that when a member of the AA community loses a loved one, family, friends and relatives all show up and linger or

“smother” the bereaving family with support and attention. Taking the body home to Nigeria exacerbates this situation. According to one Nigerian-born female participant,

The thing with our culture is that you have lots of people around you. People bring you food... We always have lots of people around. So, I think at some point it helps. Even though at some time you just want to be on your own... It's just that some people come with advice that you don't need at that time. All that culture or they bring up all sorts of things. You're trying to deal with the loss of your mom, [and] somebody's telling you, 'When you get here, don't eat from that particular plate. Or, don't go to the other side when you get to the funeral'. I mean at that point, that's not what we wanted to hear.

The above advice, “don't eat from that particular plate,” refers to concerned Nigerian family members advising the immediate bereaved family not to accept gifts or money, to avoid eating or drinking from certain people in the village. This is for fear that some evil people may attempt to poison the bereaved family members who brought their loved one home for burial. Furthermore, negative social support may be a lack of social support altogether. These AAPCGs reported large throngs of social support immediately after the death of their loved ones but that huge amount of support gradually dissipated over time, leaving the AAPCG in a lonely and uncertain situation. One female participant mourned the absence of companionship, created by the deaths of her husband, father and mother [all her care recipients]. These deaths left a vacuum in terms of who to go out with to the movies, restaurants or vacations. She said:

Then you think about gee, how do you learn to live alone?... I had not developed friendships and things outside of work... That part was kinda difficult... Just even

think about going on vacation. Who do you go on vacation with? [be]cause, I, in all these years never went to the show but once in my lifetime by myself. It was always someone. Then you think about well you can go out and eat by yourself, but it's not as much fun as it is with someone.

Another aspect of negative social support was when family members or friends demonstrated behaviors that the AAPCG found disturbing. The female participant above spoke of her children's well-meaning but hovering and overly protective behavior, which she perceived as a negative support situation. She reported, "Then, I didn't want my kids to feel as if they had to be worried about me [be]cause, like, my God! They started actin' like my mother."

Another aspect of negative social support was reported in regard to co-workers who ignored the AAPCGs after the loss of their loved ones or who made insensitive comments that the AAPCG perceived as offensive. One Nigerian-born male participant recalled,

The least support came from my workforce. Nobody even sent me a card. Nobody cared. Nobody cared about me. I was really disappointed in them...I didn't get any support from them which made me think as if, maybe I wasn't socially acceptable within them or what?...Why did that happen to me at work? I didn't get any support from them at work.

Another male participant also concurred regarding the apparent lack of support and insensitivity at the workplace and lamented.

I'm sorry to say the Americans are the co-workers...after the first few days, they say it's finished, so they don't treat me specially anymore. Yeah, it's finished.



They move on. Let's face the present thing. Let us forget about what happened to you. Come on, work. My friend, face your work and do your job. They don't really care about you, but your friends keep calling you.

Despite the above negative interactions reported by some of the AAPCGS in this study, it is interesting to note that many African Americans pride themselves on having support for one another. They may not often perceive negative support interactions. A majority (66.7%) of the people who answered the CES-D question (n=26), "People were unfriendly" and 84.6% of the participants who answered the question (n=33), "I felt that people disliked me," all denied the possibility of unfriendliness or dislike by others (Appendix P, Table 4). It may be that social support was so engrained within the AA society that they may find it difficult to perceive others as unfriendly or that they may not be liked.

### **Socioeconomic Status**

**Financial conditions.** AAPCGs reported financial difficulties that began during caregiving, continued even after caregiving ended, and led to other challenging, stressful and burdensome situations. A major pervading concern was the enduring guilt and regret they felt over their perceived inability to financially provide for their loved ones. They expressed regret that they could not take the time off from work to care for their loved one, purchase all the medication or other recommended items such as a Tempurpedic mattress, or to take the loved one on a vacation. For those caregivers, this guilt over the decisions made during caregiving continued through to the post-caregiving period.

Sometimes, caregivers vacillated between regret and guilt for things they believed they could have done, or could have done better. One PCG who cared for her mother

said, “There was a lot of things I wanted to do, you know, the funds that might not have been there. There was always something that I thought the outcome could probably be different if I had done that...There is a guilt within me.”

Financial difficulties sometimes led AAPCGs to second guess the quality of care they provided to their loved one, and to wonder if the outcome of their caregiving could have been different, if more resources were available. According to a female participant who thought her lack of resources led to her mother’s death:

The hardest thing for me then was that I blamed myself so much in the sense that maybe I didn’t do the things I was supposed to do for her...taking care of her in the sense that maybe if I had enough money, because at that time, I wasn’t working. I didn’t have a good job... maybe if I had enough money, you know, bought all the things for her, maybe she wouldn’t have passed.

This line of thinking, fueled by guilt and regret, often created constant worry in AAPCGs. Some participants denied such worries, but admitted that they had financial concerns. According to one participant, “I don’t think too much of anything. Financially, that’s the only thing I can think of...trying to make ends meet.” These worries and concerns could be traced to a number of causes identified by these caregivers.

***Causes of financial difficulties.*** One cause of AAPCG financial difficulties was the loss of income from the loved one for routine expenses such as making mortgage payments. Sometimes the AAPCG needed to take on additional employment to meet the shortfall. According to one older female participant, “Now I don’t have my sister. I was getting a little check for her. I don’t get anything anymore, so I have to work more.”

Another major cause was the mortuary and burial costs associated with the care recipient's death, especially for international or out of state burial circumstances. A Nigerian-born participant, who had to return his mother's body to Nigeria for burial, recalls, "Mom was in the mortuary for almost two months because we were making preparations back in Nigeria." As previously described, the cost of shipping the body to Nigeria and dealing with family members who solicited gifts of money from bereaved family members posed additional burdens to the family in the aftermath of caregiving and led to larger financial problems for the PCG.

Sometimes, AAPCGs lost everything (assets and properties) due to financial difficulties experienced during the active caregiving period, thus throwing them into further financial crisis in the post-caregiving phase. The pain of financial crisis was pervasive. One participant reported,

And it was painful. It's just like, I tell people all the time, I say you don't know where I've been. I've been some place where you lose everything and then you feel like that's not enough and somebody just cut you open. It's just painful.

Occasionally, the post-caregiving financial difficulties are caused by the continuing management of the loved ones' responsibilities after their death. For example, one PCG took over the care of her mentally ill cousin in obedience to a death-bed promise made to her aunt (Ume & Evans, 2012). "[I'm] trying to take care of my cousin because my cousin has mental problems and keep[ing] up the house now that I'm retired and not working, I don't have any extra money to put in [to maintaining the cousin's house]." She went further to explain some of the issues she is dealing with and her proposed solution to sell her aunt's home. She stated,

My cousin cannot, with the money that she gets from social security, take care of herself and the house. I've had windows replaced. I had steps repaired... I have a \$3,000.00 water bill because one of her phobias is bathing. She will strip the water faucet and they'll run for a month. More than once, we've had water bills over \$1,000.00.

The challenges posed by such situations were major stressors for AAPCGs. Additionally, financial difficulty was often exacerbated by other inhibitory factors such as job or home loss.

**Job loss.** Threat to one's job, actual job loss, or inability to get a job was cited by the AAPCGs as a major inhibitor contributing to their progress through the PCT.

Caregivers often had to give up their jobs and change or reduce their hours at work to accommodate rising caregiving demands. These changes usually reduced income which perpetuated financial difficulties. Oftentimes, the incessant need to call in sick or late led to threats of job loss or to actual job loss, further complicating the already difficult financial plane. One male participant (a secondary AAPCG) explained that, "The only drawback [to caregiving], was the fact that there was a lot of stress... eventually going to lose one's job...I was constantly late. My sister [the primary caregiver] was constantly calling in sick." The severe time constraints and incessant, unremitting caregiving demands made it difficult for some caregivers to accept certain jobs, either due to the required schedules or the locations of the job. The inability to find suitable employment contributed significantly to the persistent and pervading financial difficulties experienced by caregivers during and after the end of caregiving. One AAPCG recalled:

It took me a minute to really try to get back focused. I mean, [be]cause, I mean everything was constantly built up around him. And like now as far as like this job thing, you know this recession type stuff was going on, and you know to where I couldn't really do a lot of stuff because of him...I couldn't take out of town work a lot. And you know, I guess turning down a few of them jobs kinda [is] affecting me right now. So I'm trying to bounce back from that.

**Home loss.** The incessant caregiving demands sometimes meant that caregivers gave up their homes to move in with their loved one, leading to the loss of their own home, another inhibitory factor. Sometimes, caregivers moved in with their elders to facilitate caregiving or because the demands of caregiving made it difficult for them to keep their jobs, during active caregiving. At the end of caregiving, this move, whether it was made sacrificially, voluntarily or forced by dire financial circumstances, sometimes created its own challenges. One AAPCG who gave up her own apartment at her mother's request before she died lamented,

The hardest thing for me was to let the apartment go...and mom asked me to....The only thing I'm really trying to, the hardest thing is being in this house. Because this house holds a lot, a lot, a lot, a lot, a lot, a lot of memories.

#### **Lack of Knowledge and Preparation.**

**Inadequate information.** Several participants discussed the inhibitory effect of not having adequate information about end-of-life or caregiving to be able to make an informed decision (Evans & Ume 2012; Herbert, Schulz, Copeland, & Arnold, 2009). One Nigerian-born participant who had to transfer care of her father to other family

members while she transplanted her immediate family to the US, also expressed a deep regret,

It kind of took me unawares when he died – passed, a year after I left...I mean I cried. I wept like a baby. I refused to be comforted...I still feel sad that he passed because if I knew, I wouldn't meet him, I probably would've left him in a totally different mindset...but I didn't expect anything to happen.

Sometimes the lack of knowledge and preparation was expressed as having problems in getting all necessary legal documents, such as wills and powers of attorney paperwork, ready. Another participant also spoke about lack of knowledge in terms of available community resources to support caregivers during and after caregiving. She said,

You know there's resource out there but you usually don't find out about them until after the person's not here. A lot of different programs, well I don't know about a lot but there are some programs and different things that can help with - but it's not like – I don't know, like, not widely known or common knowledge. But just like everything else you've got to look for them but under type of trauma and distress the family's going through I don't think anybody's thinking of that kind of stuff, so maybe if that information was distributed. I'm not saying it isn't but I didn't get any times, I was there. At any of the doctor's offices or hospitals or different things about different programs [are] out there.

**Disruptions in expectation(s).** Some participants pointed out that they had hopes and dreams to do important things with and for their elderly parents before they died, such as taking them to exotic vacations or buying them a luxury car, but these dreams

were denied them due to the death. A 50+ year old female participant deeply expressed her disillusionment, visibly upset and crying because of her mother's death, because she did not expect her terminally-ill elderly mother to ever die. This deep emotional discordance negatively impacts the PCG's journey through PCT.

I don't know. I don't know if I actually coped very well. I was very, very emotional about her death and I kept on like blaming her that she didn't tell us she was gonna die. Yes, which is true. She didn't tell us she was gonna die. I saw her like a super mother. A hero mother that she won't die, you know? So I didn't know one day she would really go because I mean even though I knew she was sick and the doctor said she was gonna die, but she didn't prepare us that she was gonna die one day. You know we all thought she was gonna live forever.

### **Summary of Inhibitors**

AAPCGs battled many challenges due to their caregiving roles which continued long past the termination of caregiving. Those challenges inhibited their progress to healthy PCT and they included emotional and physical distress issues that influenced the overall meaning ascribed to their caregiving experiences specifically and their lives in general. Other inhibitory conditions that strongly affected the AAPCGS included cultural beliefs such as taking the body of a deceased loved one to their native country or state, family conflicts or negative social support. Progress through the PCT was directly affected by lingering financial issues and lack of adequate information about resources, or disruptions in caregiver expectations. Overall, these inhibitors continued to affect AAPCGs however, they were sometimes mitigated by facilitators of the PCT journey that also influenced individuals' patterns of response.

**Aim 3. Describe the process and outcome indicators of the PCT in AAPCGs.**

- a. How do the process indicators of connectedness, interaction, feelings of inclusion, and confidence/coping manifest themselves in the PCT, as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?
- b. Is there a difference in levels of depression, coping and social support between AAPCGs who demonstrate mastery of new skills in the PCT and those who do not as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?
- c. Is there a difference in levels of depression, coping and social support between AAPCGs who demonstrate separation from the caregiving role and adjustment to life without the CR in the PCT and those who do not, as identified by the PCG Interview Protocol, and as measured by the BC, CES-D, and SS?

**Patterns of Response**

Although an AAPCG may experience diverse transition conditions that may facilitate or inhibit their PCT journey, the manner in which that individual responds to the PCT constitutes a unique pattern. According to Meleis et al. (2000), patterns of response can be evaluated through process and outcome indicators.

**Process Indicators**

According to Meleis et al. (2000), process indicators demonstrate progression through the PCT. They include connectedness, interactions, locating or being situated, and confidence or coping (Appendix A, Figure 1). In this study, case-oriented data



provided various exemplars of these indicators; all exemplars were organized into a checklist which set forth exemplars with their corresponding indicators (Appendix R, Table 6). Each case was then examined for presence or absence of the exemplars. Because each participant discussed only some of the exemplars in their interviews (for example, one participant might have discussed making connections with old friends but not with new ones), frequencies could not be calculated. Within the current limits of the list, however, the most frequently expressed exemplars could be determined. Participants provided exemplars for connectedness, interaction, locating and being situated, and confidence or coping.

**Connectedness.** The first process indicator of movement towards healthy transition is the ability to connect or reconnect to family, friends and other well-wishers. Returning to work or school also provides opportunities for connectedness.

***Reconnecting to friends and family.*** Participants reported that reconnecting with family and old friends or making new friends helped them progress through PCT. Some had friends who came to support them in the immediate period of loss, while others found outside activities that provided avenues to meet new friends or reconnect to old friends. One female participant reported,

I have been looking for something good. I found the pool. I found a different set of people, friends, to be around. I ran into a lady that I hadn't seen since I was like 10 years old, so her and I reconnected and she knows my mom and my family and everything and it was a good reconnection with her.

***Returning to work.*** Another exemplar participants provided was the return to work. Many female participants described their workplace as a place to reconnect with

people who supported them with their adjustment during PCT. A female participant who complained that loneliness was difficult for her after her mother died, reported that she always tried to surround herself with people, and that “going to work, meeting people, talking to people” was helpful for her.

Returning to work appeared to be a major milestone for many AAPCGs in this study who were adjusting to the death of the loved one and termination of caregiving. Although, in some cases, they returned to work due to organizational mandates or because they needed their income, many of the participants noted that returning to work was a sign of adjustment. For example, one male participant explained...

What helped me is that life has to continue. We have to take care of the children. We cannot all come and fold our hands because we lost somebody and then the house crumbles, so we have to work to eat and to live. Those of us on earth and the children we have to take care – we have to take care of them, so we need to do something to take care of them. We can't just fold our hands because she's dead and then stay in the house and live in – stay in the house and then stay mourning forever. No. Even though we feel it in our hearts, but she's gone. It's the Lord. Moving onto work is the first step to do. It's kind of a distraction from what happened, to help you to really not focus so much on it, yeah.

Managing the emotional difficulties of the post-caregiving period required several strategies by the AAPCGs. Caregivers sought out emotional support from both formal and informal quarters in order to cope. Family, friends, or co-workers were a great source of emotional support to the AAPCGs. According to one female participant, “I guess

having a family and children and a husband to take care of, it's a positive thing because then you don't have to dwell on your wounds or your loss."

However, formal care such as working with a counselor or therapist was also considered by some of these AAPCGs to be very important. Although generally AA caregivers do not utilize the services of counselors and therapists as part of bereavement, some AAPCGs in this study found positive value (Evans & Ume, 2012; Haley et al., 2004; Barrett & Heller, 2002). One female participant insisted,

I just can't harp on how much I think it's important to get some kind of – I mean, I don't know if it's therapy, some kind of extensive emotional support. It's one thing to have people that love you and want to be there for you, it's another to really be able to sit down and talk about how you're feeling, because to keep it inside, it's going to explode one day...because more than people know, so many of us who are caregivers who probably deal with a lot of anger and sadness and regret and just a whole emotions in general.

It was important for PCGs to recognize the difficulties associated with caregiving early enough to seek the necessary help to promote personal well-being and optimal progression through the PCT. According to one female participant,

When someone's gone like that, who was such an important part of your life, the good and bad, you need to make sure you focus on both, your emotional side and your physical, you know. I think I did one side, but I didn't do the other.

Emotional support for caregivers needed to begin during the active caregiving period. One female participant passionately suggested, "I think therapy is so important

you know, from the beginning, you know even while you're caregiving, even while the person – even before the person passes away.”

The ultimate goal of the PCT is a healthy adjustment to the loss of the loved one and end of caregiving. Besides getting formal and informal emotional support from healthcare professionals and family members, it is important that the PCGs begin to institute self-focused activities that would help propel them towards that healthy goal. Such self-focused activities might include returning to previous, familiar routines like school, work or social activities. One female participant suggested what she thinks adjustment after caregiving should look like: “After the fact, you see the person going back to their normal lives, being whatever they...maybe the person has come to terms with it or has adjusted back to what their life used to be before the caregiving.”

The idea of coming to terms with the loss involves being “mentally ready” to let go. For these AAPCGs, being ready to let go might come soon after the burial is completed, after one and half years have passed, or to up to 10 years. Letting go is a psychological state that releases the dead loved one and allows or permits oneself to “move on” more effectively with one's own life (Bowlby, 1973). Letting go may start small, but should increase progressively to encourage recovering AAPCGs to gently accept the situation of their loss and termination of their caregiving role. It is important for PCGs to understand their individual strengths and limitations as they journey through PCT. One female participant reported that after her father died, it took her sometime to be able to unpack his work lunch bag. She reported, “Just last year, a year and a half later, I unpacked his lunch bag...I do things as I'm mentally ready to do it.”

For the AAPCGs in this study, the PCT began with the death of the loved one, which Bridges and Bridges (2009) identifies as the ending that precedes the transition. For some PCGs, that death entailed planning for the burial, which may provide a coping mechanism; caregivers immersed themselves in the burial arrangements as a way of taking their minds off their loss. According to one female participant,

When it was done [mother died], I tried to like hold myself together and you know, face the next things. In Nigeria, usually you start thinking about burial...At that time, is not the time you start crying. We cry, but I just faced it that it was, you know, it's over and you know, I have to move on.

Another aspect of connectedness reported by these participants is the spiritual visitation from the deceased which is perceived as comforting. Several participants relayed different stories about their spiritual encounters) with their deceased loved one. For some, their loved one appeared to them in a dream and comforted them. Another saw a dove walk into their home soon after her mother was buried and the graceful way the dove was gliding through the house convinced the participant and her siblings that it was their mother that came to supervise the renovations they made. When satisfied that all was well, the dove quietly walked out and flew away. This incident was comforting and empowering to the participant and encouraged her that her mother was happy. In another case, the PCG was visited and thanked by her cousin for whom she cared; that visit that helped her to move on. Although some of these stories may represent intense longing for the departed, they have the important value of providing comfort, encouragement and peace to the grieving AAPCG and other family members. According to one female participant talking about her mother,

I always feel her. I always remember her. I always think about her...But one day I saw her in my dream and she started patting on my shoulder and when I looked up I saw her....She now said that she wanted me to stop crying. That it was okay. That I should stop crying, stop thinking about her, remembering all this stuff, it's okay. She was talking to me.

***Experiencing a relationship with God facilitates spiritual coping.*** A majority of the AAPCGs in this study passionately declared that their personal relationship with God was one of the most important facilitators of their PCT. A relationship with God provided core teachings and beliefs that laid the foundation for family caregiving. Such foundational core beliefs included honoring one's parents and bearing one another's burdens. Other spiritually-based beliefs also assured comfort and hope in mourning such as knowing that one will see their loved one again in heaven and that one should not mourn without hope in Christ Jesus, because there is a reason for everything. Additionally, despite the deep sadness and loss that one feels because of the death of their loved one, biblical teaching prescribes that one ought to be thankful to God, no matter what the situation. Therefore, to get through all the difficulties and challenges of post caregiving, one will activate the power of prayers, bible reading, listening to gospel music, and engaging in active forgiveness, thus ensuring peace and comfort in the bereavement and beyond.

The foundational spiritual belief of honoring one's parents was the most popular reason given by these study participants about the importance of caring for their older loved ones. They claimed that their beliefs were helpful as they went through the myriad challenges besetting the PCT. Thirty percent (n=12) of the participants expressed this

core belief by citing the bible verse in Exodus 20:12 (nd) that instructs Christians to “Honor thy father and thy mother that thy days may be long upon the earth.” For example, one female participant summarized it saying, “Yes, the foundation for it [caregiving]. In honoring my father and my mother, I have to care for them. I have to love them. I have to be with them no matter the circumstances. I cannot abandon them.”

Another biblical foundational belief found in Galatians 6:2 which instructs believers to “bear one another’s burdens” was also cited by many AAPCGs in this study as being instrumental to caregivers agreeing to, and maintaining, the caregiving role until the end. This belief continues to underlie these AAPCGs’ continued engagement in serial and multiple caregiving roles even as one caregiving situation ends. One female caregiver explains,

I try to be a more compassionate and giving person. If someone needs something, I try my best to help them and then by praying to God to make me a better person...because if you believe in God you do try to help. You do try to do and you know what he asks of you and what he wants of you and you try to do that.

Despite family caregivers’ best efforts, deaths of their loved ones still occurred and they had to dig deep into those same biblical beliefs to select a greater arsenal to help comfort them and give them hope and peace in the crises. Such beliefs acknowledged that there is a reason for everything, and a time and season to die, as found in Ecclesiastes 3: 1-2; which enjoins loved ones not to mourn as those without hope, but assures them of the promise of resurrection, that they will see their loved ones again in heaven (1Thessalonians 4:12-18). These beliefs assured hope, comfort and peace to the bereaved

AAPCGs, and a strong connection to the higher power which facilitated their journey through PCT. One participant recalls,

I just have to kind of get myself stronger. Of course, people support families and friends and talk to you and all that. My religion of course is the main thing because I know that my father has gone – he’s gone to heaven to be with the Lord. We all will get there one day. Those are the consolation[s]. I say, “Oh, no, I have to. I can’t cry forever for this. I have to just be strong. It helped. It worked.”

The relationship with God provided comfort to these AAPCGs; provided help in dealing with the loss and grief; furnished the only help in the difficult situation; offered reassurance that God had not given up on them; gave strength to carry on; helped them to see caregiving as an opportunity to give back and help out; and finally, afforded an avenue of spiritual coping with the deep loss and grief. One participant reported,

I was able to just release the pain. The healing process also was something I did just praising and worshipping God. The moment I continued to worship him – like I said before, people didn’t understand how I was able to cope and what they didn’t know was, I would lock up myself in the room. It was painful. It was a painful experience but I would lock up myself in the room and I’ll just begin to worship God, just to begin to sing praises, just out crying. Myself and my sister would cry for hours. We wish he could stay to enjoy more of his hard work, but we’re able to cope just by knowing that God is an awesome God and He loves us. In his time, He does what he has to do.

To achieve or improve this personal relationship with God, each AAPCG utilized a variety of religious practices and beliefs. Prayer and bible reading were the two most



cited religious practices. Quantized qualitative interview data revealed significant use of prayers for coping by 72.5% of the 40 participants ( $n = 29$ ). The Bible was described as a “footstool” by one participant – a foundation or core for dealing with PCT. Reading the Bible was done by 55% of the participants ( $n = 22$ ). Fifteen percent of participants ( $n = 6$ ) listened to gospel music for coping while only three people discussed forgiveness as helping them to cope during PCT. One female participant wrote,

Oh praying a lot. We did pray a lot. We prayed a lot. We spoke the word about it to my mom and even to ourselves. It was the Bible - scriptures from the Bible encouraged us through the whole thing. Then we had hope so we were not like people who didn't have hope. The hope kept us alive and kept us going.

The use of prayers to deal with the situation and getting close to God was very important to AAPCGs, and helped them with the arduous PCT journey. According to one of the participants, “We chose to stay close to God. I've always known him [God].” Another participant agreed that “definitely praying more” helped. She explained, “There were times I was in the car driving to work or from anywhere when I just had to start praying for strength to keep me from crying and being depressed.”

Sometimes it was not just the AAPCG's spirituality that was important and comforting. It was also important for the family to believe that the deceased loved one knew God on a personal level. Another female participant reported being comforted spiritually, knowing that her father died as a Christian. “It would have been very difficult to cope because for a day or two, I was in a daze...the realization that he [father] died as a Christian, also helped me move on.”

**Interactions.** Closely related to reconnecting with friends, family and colleagues was the process indicator of interaction with others. Interaction was defined as the caregivers' ability to safely relate with other people who can help support and guide them towards healthy transition. One female participant who took care of her father expressed how the constant interactions with her husband helped her achieve healthy transition.

I couldn't come up with any strategy except that my husband talked to me. He talked to me, and he counseled me and made me understand that it was meant to happen like that. Left alone, I mean I didn't have any strategies. I couldn't come up with any.

Another process indicator in the area of interactions involved the AAPCG's ability to identify, separate and classify types of social support that were most essential and effective for him or her as an individual. Although many AAPCGs relied on family and friends for support, family members were also grieving and could not always provide positive encouragement. They sometimes, in fact, provided toxic support that inhibited the individual's healthy progression through PCT. Thus, the ability to recognize that they needed other types of support was an indication of progress in PCT. One female participant responded,

What I did was, I called everybody I knew, just for conversation, any words of wisdom. If someone says, "if you need to talk, need somebody to listen, call me", I took them up on it. I called my... basically my family and friends. It might not have been my immediate family because they were hurting in more than one way. I would have to reach out to the second family – my cousins, not my immediate siblings, yeah, my cousins.

**Locating and being situated.** In this study, the process indicator of locating and being situated is defined as the individual's need to feel a sense of belonging and stability. An exemplar expressed by study participants in this regard was feeling the need to give back to society through such activities as volunteering to help other older people. This altruistic exemplar supported the notion that one's previous caregiving role prepared that person for a future life of caregiving. One participant responding to a question of what helped her with PCT, said:

If I'm able to go to a good nursing home maybe, and I see the way people are cared for. Because nowadays I feel the urge to do something for somebody old, so I think that would help me too. Maybe If I'm able to volunteer and make a difference in a nursing home. Maybe eventually, one day I will have my own nursing home...And do what I'm supposed to do, you know. Make sure everybody gets the care. That's something that may help. I mean go volunteer to help an aged person. Give her my best.

### **Social Support**

Given that the above three process indicators of connectedness, interactions and feeling situated are interwoven, a discussion of the impact of social support in the lives of these AAPCGs seems appropriate. Social support provides the foundation for these three process indicators and is an intricate precursor to the last process indicator of confidence and coping discussed in the next section.

Social support has been found in several studies to be a strong and valuable support for African American caregiving and bereaved families (Dilworth-Anderson, Williams, & Gibson, 2002). This discussion of social support is organized based on

social networks (family, friends, confidants), received support (emotional, tangible, informational), and satisfaction with support (Clay, Roth, Wadley & Haley, 2008). Negative interactions in social support will be discussed under the inhibitor section (Clay, et al., 2008).

Social support was measured using a social support instrument (Appendix H) adapted for the REACH and REACH II projects (Roff et al., 2004). The highest possible total score was 55, however the highest total score for this group of participants was 52. Simple imputations with only the positive items were done for missing data on cases 12, 13, 29, 31, 33, and 36. The Cronbach's alpha with 40 participants for the Social Support Instrument used for this project was a 0.683 for the total 15 item instrument. The Cronbach's alpha for the 11 positive items was 0.802 and 0.469 for the four negative items.

**Social networks.** Social networks refer to the total number of social support people that each AAPCG had to provide them with effective, adequate and meaningful support during their PCT journey. Question from the instrument (Appendix H) include, "How many relatives, friends, and neighbors do you see or hear from at least once a month?" A cumulative calculation of 95% ( $n = 38$ ) see more than 3-4 people once a month. This validates have adequate social support in this group of AAPCGs, which is helpful during PCT. Another question was, "How many relatives, friends, and neighbors do you feel close to? That is, how many people do you feel at ease with, can talk about private matters, or can call on for help?" More than 80% ( $n = 35$ ) had a very close knit relationship with their social support network. The social support network has ( $M=10.88$ ;  $SD=2.94$ ) and a maximum score of 15 (Appendix Q, Table 5), thus showing

that this cohort of AAPCGs had a strong social support network, as noted in a prior study with African American caregivers (Williams & Dilworth-Anderson, 2002). Participants in this study frequently mentioned the supportive care that their family, friends, church members, co-workers and others provided. Almost all the participants verified that they received the most support from their family. One male Nigerian-born participant acknowledged,

I would say there was a lot of social support because, one, my brothers and sisters are around and we had to share it [the loss of their mother] equally. The burden was just not mine. I was looking at them and saying, oh, yeah, they lost their mother too.

Social support networks were particularly visible to the AAPCG during the immediate PCT period. Family and friends were visibly supportive and helpful in providing diversions and distractions for the bereaved individual(s):

Social support plays an important role, too, especially at the initial stage; you need people that are close to you to stand by you, to encourage you, and to support you because that time you don't think straight as to know what to do...The first week, people are around you, will try to distract you as much as possible...Friends and well-wishers play a very important part at that initial time particularly.

Other individuals that formed the social support network for these participants included social connections such as fraternity brothers of the deceased, students of the deceased, and other people who had also gone through loss after caregiving. People who had previously experienced a similar loss were particularly useful because they

understood what the individual was going through and could directly speak to those experiences and emotions that the AAPCG was attempting to articulate. One female spousal AAPCG reported her encounter with another woman:

There were so many people that touched my life going through what I was going through. There was this one lady I was sitting in there in the hospital one day and she tells me, she says, “Honey, I lived with my husband for 50 years and he died and I didn’t think I could make it.” She said, “I’m here with you right now talking.” She said, “I’m not here with you for no reason.” She said, “God put me here.”

**Received support.** The participants described the types of social support that AAPCGs received from family, friends and well-wishers after the death of their loved ones. The score on received support was ( $M=8.78$ ;  $SD=3.06$ ) with a maximum score of 14 (Appendix Q, Table 5), which measured the individuals’ perceptions of how much support they received from their families, friends, and co-workers who provided assistance with planning the burial, bought plane tickets to bury the deceased and brought foods and drinks for the family and the steady stream of visitors supporting the bereaved.

Participants described such received support as emotional, tangible and informational support. Emotional support was a major type of social support during PCT. Halbesleben (2006) defines emotional support as being sympathetic to the affective demands of the loss. It involves caring for the person who is exhibiting symptoms such as sadness, sense of loss, and hopelessness. In this study, AAPCGs battled significant emotional difficulties (see detailed discussion under Transition conditions - Inhibitors), which tended to negatively impact their efficient progress through PCT. One mitigating

factor in dealing with the tremendous emotional difficulties was the presence and support of family, friends and others. One female participant re-affirmed:

Yeah, definitely social support is what helps most people. Because if you're mourning in isolation; depression sets in faster; and it can lead to a very destructive path way. When people call, for the fact that people can call and talk to you, encourage you, support you and just let me know whatever you want me to do. People will come to your door, bring food. People will just come and visit without telling you they are coming. It's something that is good. It's something that you cherish so much. It's only when you lose a loved one that you appreciate those things you take for granted like a simple phone call from somebody to say, 'Oh, how are you? I hope you're doing fine'. It encourages you and you know that people can always – people are there supporting you and thinking about you and praying for you. Of course prayers from friends and relations is [are] a very powerful support thing to – it's incredible.

Tangible or instrumental support, occurred when individuals provided actual items, financial resources, or other specific kinds of support for the bereaved AAPCG or their family members (Halbesleben, 2006). For example, a support person took on the role of making the arrangement with the church and priest for the funeral and arranging for the flowers and the food. One Nigerian-born male participant aptly described the role that tangible social support played in his life during his PCT.

Well, being it did help because people rally around you. Being an African...this translates to, when you have people around you - it's like being clothed as opposed to if you don't have anyone around you - that you're kind of like naked.

Even while I was going through what I was going through here with my mom [after her death], a lot of my friends stood by me, not just physically, but financially...They asked, what needed to be done...Without them, the final wish of having to take her to Nigeria would not have been accomplished because like I said, I was very broke. So it was out of these, that I was able to have money for plane ticket, some money to spend even for the funeral back in Nigeria. So, friends were – they were God-sent.

Informational support was another important aspect that participants reported. During the acute phase of the loss, the individual may lack knowledge of resources to assist in the most basic things such as making burial arrangements, hence may require informational support (Halbesleben, 2006). Participants discussed getting information about planning the funeral or wake-keeping or where to get counseling support. Spiritually, they also sought information about comforting biblical words. According to one female participant:

I met a friend...He was there doing a seminar and he started talking to me and about God and Yahweh and I never knew the depths that he went into talk about Yahweh and with him going into and he knew the Bible front and back, every upside down... And he started talking to me about the Bible and talking to me how God works in your life and how you should forgive and you're not to give up and God do everything in your life for a reason...So, he would talk to me morning, noon and night.



This quote is representative of the spiritual teaching prevalent in AA churches that there is a reason for every situation in one's life. This belief is meant to empower the believers, giving them hope that their suffering or loss has some divine purpose.

**Satisfaction with support.** Received support deals with the types of support the participants received during PCT, whereas, satisfaction with support describes how content the AAPCGs were with the support they received. In analyzing specific questions to gain more clarity, one question on the social support instrument was, "Overall, how satisfied have you been with the help you have received from family members, friends, or neighbors?" and 77.5% ( $n = 31$ ) of the participants reported that they were "very" satisfied. The score for satisfaction with support was ( $M=9.90$ ;  $SD=2.48$ ) with a maximum score of 12 (Appendix Q, Table 5). The majority of the AAPCGs expressed their appreciation and satisfaction with the support they received from family members and friends. These participants felt that their social support networks were physically present with them, which helped to relieve a lot of their initial anxiety, and were supportive for a long period of time after the death of their loved one and during their PCT. This depth of social support helped to improve their confidence and boost their coping with the loss of their loved ones. One Nigerian-born participant expressed his satisfaction saying:

Well, you know what? One of the things for me is the appreciation of those around you. The appreciation of your wife, the appreciation of your kids, the appreciation of my sister who helped me, because without her, each moment would have been very difficult...Thank God, she was here and she took care of

that aspect of it, sometimes dressing up and the bathing...so I don't take them for granted.

**CES-D and social support domains.** Spearman rho correlations were run to evaluate the relationships between age, time since bereavement, CES-D total, and the social support domains of satisfaction, received support, support network, and negative interactions. These correlations were run for the entire sample, as well as the Nigerian-born participants, and US-born participants separately in order to examine similarities and differences between the two groups. Means and standard deviations appear in (Appendix Q, Table 5). A statistically significant inverse relationship was found between CES-D and social support satisfaction for the Nigerian-born group ( $r_{s[19]} = -.581, p < .05$ ); the US-born were ( $r_{s[20]} = -.500, p < .05$ ); and the entire sample ( $r_{s[39]} = -.496, p = .001$ ). The pattern suggests there is a similarity across the groups in that, as social support satisfaction increases, depressive symptoms decrease for these former caregivers.

A statistically significant inverse relationship was also found between CES-D and social support network for the entire sample ( $r_{s[39]} = -.330, p < .05$ ) suggesting that as the social support network increases for the participants, fewer depressive symptoms were reported. This relationship was significant only in the entire sample, even though similar correlations were found within the Nigerian born ( $r_{s[19]} = -.334, p > .10$ ) and U.S. born ( $r_{s[20]} = -.373, p > .10$ ). The lack of statistical significance may have been due to the sample size. Still, within the Nigerian-born group, social support network also appeared to be an important domain that had a strong positive relationship with their satisfaction with social support ( $r_{s[19]} = .654, p < .005$ ). This supports the qualitative findings that the Nigerian-born group valued their communal connectedness more than just individual

social support and it is demonstrated in the collective way they come together to support one another during a bereavement in their community. However, there was also a relationship with received support and social support satisfaction amongst the US born ( $r_{s[21]}=.604$ ,  $p<.01$ ) and the entire sample ( $r_{s[40]}=.587$ ,  $p<.001$ ), suggesting that they may place more value in the type of support received rather than the number of people providing the support. This may be due to a more individualistic nature of the American culture (Becker et al., 2012).

On the other hand, there was a statistically significant relationship between received support and social support network amongst the Nigerian-born participants ( $r_{s[19]}=.654$ ,  $p<.01$ ) and the entire sample ( $r_{s[40]}=.437$ ,  $p<.005$ ). A positive relationship also emerged between received support and social support satisfaction ( $r_{s[40]}=.587$ ,  $p<.001$ ). These findings are important because it emphasizes that the type and nature of the social support is important and relates to one's social support network and how satisfied they are with the support they received. This has implications for nurses to carefully craft a detailed assessment of the AAPCGs social support system. This will help in planning and individualizing the care the AAPCGs.

Another source of difference noted between the groups is that there is a statistically significant positive relationship between CES-D and negative interaction amongst the entire sample ( $r_{s[38]}=.520$ ,  $p=.001$ ) and the US-born group ( $r_{s[20]}=.710$ ,  $p<.001$ ). This relationship with negative interaction was not noted amongst the Nigerian-born group. This could be explained possible by the strong cultural bond among the Nigerian-born group as drawn from the qualitative interviews.

An independent-samples t-test was conducted to compare age in Nigerian-born and US-born participants. There was a significant difference in the ages of the Nigerian-born ( $M=46.39$ ;  $SD=10.08$ ) and US-born ( $M=58.55$ ;  $SD=13.63$ ) participants; ( $t [36]= -3.10$ ,  $p = 0.004$ ). The significant age difference between the Nigerian-born versus the US-born participants may have an effect on an array of factors in this study including depressive symptoms, social support, and the coping responses of the different groups as they undergo PCT. On average, there was a 12 year difference in age between the two groups with the US-born being older - almost a different generation, with differing beliefs and attitudes about life, death and family. This supports the finding within the entire sample of this study that age had an inverse significant relationship with CES-D scores ( $rs[37]= -.372, p<.05$ ) and with negative interactions specifically among the US-born group ( $rs[20]= -.510$ ,  $p<.05$ ). These findings suggest that younger US-born AAPCGs might be more susceptible to depressive symptoms, especially if they report more negative interactions. This has significant practice implications for nurses in terms of early and on-going assessments for depression and other negative emotional behaviors in younger AAPCGs even during active caregiving as well as the need to plan interventions that will support them to cope with the loss of their loved ones.

**Confidence and coping.** Developing confidence in one's ability to cope is an important time-linked indicator that signifies positive progress during PCT. For example, some AAPCGs revealed that it was difficult to talk about or to view pictures of their deceased loved one, especially early in their PCT journey. It took time for them to get to a point where they could talk about that loved one. Other AAPCGs had difficulty getting themselves to a point where they could attend to the closing down activities of post-

caregiving (Larkin, 2009), such as making funeral arrangements, attending to legal matters, and packing and discarding the loved one's clothing and personal items. One female participant whose mother died almost ten years earlier expressed difficulty looking at her mother's pictures or talking about her for many years after termination of the caregiving role, but validated the process indicator of developing confidence and coping as part of her journey through transition. By the time of the study, she was able to view her mother's pictures and talk about her mother with her siblings.

I have really adjusted well because if not, maybe before I don't like looking at her pictures. I don't like talking about her you know. Not that I don't want to – if I talk about her I will be crying you know, so I don't like...but this is what I tell my brothers, get me her pictures. I want to put [them] in my house. But before I didn't think it was something I could do. I never saw her, you know, the burial pictures and video tapes. I never wanted to watch it. I never wanted, you know, but now I think I'm very strong now, you know.

AAPCGs recognized that recovery takes time, but the willingness to keep talking or remembering the memory of that loved one was a part of the process of adjustment. Participants felt that even the act of agreeing to this research interview showed their progress in transition. One female participant whose mother died more than five years prior to this interview, known personally by the researcher, said, with tears rolling down her cheeks;

I've moved on somehow, but I'm still – well, I don't like talking about it. It's just because it's you [researcher]. If it's somebody else, I see them, it make my memory, you know, everything will come back again, especially that I was the

last person that seen her [mother] when she gave her last breath. So I always feel somehow. I always feel it when you ask about her, the things start coming back in my head, you know. So, that is it. I'm just trying to – I'm trying to – I've adjusted but I'm just trying to see if it can clear my mind more.

In some cases this avoidance of talking about the loved one or being able to view pictures of the loved one lasted up to five years. A female participant whose mother died almost ten years ago, reported:

It took me a long time. It took me like four years or five to start feeling like I can look at her pictures now. I can look at magazines, wherever she is and look at it and you know get pictures of where my son was baptized, she was there. Before, I wasn't doing all of that. I couldn't do that.

Some AAPCGs recognized the value of self-motivation and positive self-talk as critical elements for coping with emotional difficulties. Having a positive outlook of life might help to mitigate some of the negatives of the post caregiving period. One female participant pointed out, "You still have moments and then you say, 'Oh gee, I'm gonna pick myself up or whatever'. Then it'll last for a short time and then you kinda fall back into those moments again." Another participant reported, "Right now, I'm just trying to get myself together and my body together so I can have a bright future. My future, I'm looking forward for my future to be better than my past." Another sign of confidence and positive coping, as well as connectedness, was the ability of AAPCGs to return to school after their loved ones died. When the caregiver was able to productively engage in school, they could channel their energy and interest into a more productive venture that took their minds off loss and grief. According to a female participant in this study,

I had to start – I had to do like from the bottom up at school...Going back to school was one. Well, right after he passed away, like I said, I ran a lot to keep from being home because I couldn't face the idea that he's not there anymore...then I end up going back to school. That helped keep my mind off of things and put it on something more positive.

**Coping domains.** The version of the Brief Cope (Carver, 1997) used in this study was the 22-item instrument with 11 of the 14 original domains (Appendix G). These domains included: self-distraction, active coping, denial, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, acceptance, and self-blame, but did not address the domains of humor, religion and substance use. Religious coping was elicited as part of both the demographic questionnaire and the interview. Humor and substance abuse were elicited from the interview where applicable when participants answered questions about coping strategies used during PCT.

The total score was not calculated for the Brief Cope items per the recommendation of the author (Carver, 1997). However, descriptive statistics were run for each item (Appendix S, Table 7), and a sum of each of the 11 domains was calculated. Since there are two items in each of the 11 domains, the participants' responses ranged from 0-6 except in the domains of acceptance and self-blame which ranged from 0-3 (Appendix T, Table 8). To ensure clarity and ease of presenting the results, total scores for scores other than the 0 score were summed for each domain. The Cronbach's alpha for the Brief Cope instrument used for this project was a 0.845 for the total 22-item

instrument with 39 participants. The alpha for the 12 positive items was 0.834; the alpha for the 10 negative items, it was 0.763.

This section presented the findings of the 11 domains/domains (Appendix T, Table 8) of coping according to the Brief Coping (Appendix G). Simple imputations were done for missing items in cases 13. Imputation was done with only the positive domain items. Cases with more than 20% (4.4 missing items) were discarded. For the Brief Coping, case 18 was discarded because it had six missing items.

The domain of “active coping” showed that 17.9% ( $n = 7$ ) were not actively coping, and 82.0% ( $n = 32$ ) admitted to having at least some active coping. This supported the qualitative findings of this study which suggested that the participants utilized various coping strategies as facilitators of their PCT (Meleis et al., 2000), such as religious coping like praying, reading the bible, singing Christian songs; engaging in productive ventures such as writing for publication, traveling, visiting or avoiding the cemetery, reminiscing about the deceased loved ones, viewing family mementoes etc.

The domain of “planning” showed that 74.4% ( $n = 29$ ) of the participants put plans in motion to deal with the situation they were in. For the next domain of “positive reframing”, 94.9% ( $n = 37$ ) of the participants admitted to trying to see the situation in a better light, which helped with their coping. Another domain was “acceptance” and it explored the participant’s intent or experience with accepting their situation. An overwhelming majority of the participants (97.5%,  $n = 39$ ) admitted to accepting their PCT situation at some level. Although, this might appear to conflict with the qualitative findings that AAPCGs continue to experience deep sense of loss that continues even up to 10 years after their loved one dies and caregiving ends; however, an individual might



accept the existence of a negative situation, but still continue to feel sad about the totality of that loss.

Other domains include: emotional support, instrumental support, self-distraction, denial, venting, behavioral disengagement and self-blame (Appendix T, Table 8). Over 90% ( $n = 37$ ) of the participants admitted to using or receiving emotional support from others concerning emotional conditions. This was supported by the qualitative findings (see detailed discussion under emotional conditions [facilitators]) such as having extended family visits during the immediate bereavement period, family and friends bringing food and contributing money to enable them take the body of the deceased loved one home. Also, 72.5% ( $n = 29$ ) admitted to using instrumental support; 80% ( $n = 32$ ) used self-distractions as a coping strategy, while only (42.5%,  $n = 17$ ) reported using denial. The majority of participants ( $n = 23$ ) reported not using denial at all. This might be because AAs believe in and pride themselves in their ability to face reality with strength and faith, so denying the loss might seem almost disloyal to the spirit and legacy of the deceased loved one.

Another domain that showed significant results was behavioral disengagement. An overwhelming majority (90%,  $n=30$ ) denying any form of behavioral disengagement in coping with the PCT. Most AAPCGs demonstrated resilience even in the face of adversity and continued to try to cope with whatever situation they confronted. In fact, a few of the participants reacted strongly to those questions, almost as if they were being insulted by the suggestion that they may be giving up or failing to cope.

The last domain dealt with self-blame. Almost half of the sample (45%,  $n = 18$ ) admitted to varying degrees of self-blame. The tendency to self-blame supports the

qualitative findings of PCG guilt such as the guilt a daughter felt about placing her mother in a nursing home prior to her death. This is a frequent theme in the interviews (For more detailed discussion of PCG guilt, please see the section on Inhibitors - Emotional conditions).

**CES-D and Brief Cope domains.** A series of Spearman rho correlations (Appendix U, Table 9) were run to evaluate the relationship between age, time since bereavement, CES-D total and the 11 Brief Cope domains of active coping, planning, acceptance, positive reframing, emotional support, instrumental support, behavioral disengagement, self-distraction, denial, venting, and self-blame. These correlations were run for the entire sample, as well as the Nigerian-born participants, and US-born participants separately in order to examine similarities and differences between the two groups. The means and standard deviation table for the entire sample and the two groups is noted (Appendix V, Table10).

The similarities noted with the entire sample and the two groups include relationships between CES-D and acceptance, denial and self-blame. Statistically significant inverse relationships emerged between CES-D and acceptance for the entire sample ( $r_{s[39]} = -.511, p = .001$ ), the Nigerian-born group ( $r_{s[19]} = -.630, p < .005$ ), and the US-born ( $r_{s[20]} = -.497, p < .05$ ). The similar relationship found across groups, suggest that as acceptance of the loss increases, depressive symptoms decrease for participants. Conversely, two positive relationships emerged suggesting that an increase in depressive symptoms was associated with two other coping styles in all three groups. These include a positive relationship between CES-D scores and denial with the entire sample ( $r_{s[39]} = .502, p = .001$ ); Nigerian-born participants ( $r_{s[19]} = .560, p < .05$ ); and US-born

participants ( $r[20]=.517, p<.05$ ). Likewise, significant positive relationships were found between CES-D and self-blame for the entire sample ( $r[39]=.603, p<.001$ ); the Nigerian-born ( $r[19]=.552, p<.05$ ); and the US-born ( $r[20]=.656, p<.05$ ). These findings are important for practice because they provide evidence for the need for assessment of AAPCGs and the importance of early recognition of signs of denial or self-blame which may be precursors to depression in the AAPCGs. These may in fact serve as signals for the often unreported depressive symptoms in AACGs and PCGs (Haley et al., 2004).

Differences were also noted between the groups. There were positive significant relationships between CES-D and active coping in the entire sample ( $r[38]=.387, p<.05$ ) and the Nigerian-born participants ( $r[18]=.538, p<.05$ ); and, the CES-D and venting in the entire sample ( $r[39]=.506, p=.001$ ) and the Nigerian-born participants ( $r[19]=.669, p<.01$ ). These relationships were not noted amongst the US-born participants, although the correlations for these former caregivers were both positive in nature. A review of the coping items for each scale suggests that the wordings of the items may allow for possibility of the seemingly conflicting perspectives. For example, a person may “concentrate his/her efforts in doing something” (active coping); or may “express negative feelings” (venting) about the situation he/she is in, but still feel sad, depressed and emotional about that situation. Another difference was that the Nigerian-born participants showed an inverse relationship between age and self-distraction ( $r[18]= -.524, p<.05$ ) in contrast to the US born. As the Nigerian immigrants got older, they were more likely to report using self-distraction as a way of coping than their younger immigrant counterparts.

Differences also emerged that were only related to either the entire sample or the US-born participants. These include a statistically inverse relationship between CES-D and emotional support amongst the entire sample ( $r[39] = -.407, p < .05$ ) and the US-born participants ( $r[20] = -.510, p < .05$ ). As the use of emotional support increases, depressive symptoms decrease. An independent-samples t-test was conducted to compare the use of emotional support as a coping strategy by the Nigerian-born and US-born participants. There was a significant difference in the use of emotional support by the Nigerian-born ( $M=4.95, SD=1.43$ ) and US-born ( $M=3.48, SD=2.27$ ) participants; ( $t[38]=2.42, p = 0.020$ ), with the Nigerian-born participants reported more frequent use of emotional support as a coping strategy than their US-born counterparts. Also, there was a positive relationship between length of time since bereavement and positive reframing for the entire sample ( $r[38] = .336, p < .05$ ) and the US-born participants ( $r[20] = .549, p < .05$ ), suggesting that participants tend to be able to reframe the loss in a more positive light with time. This was not evident among the Nigerian-born participants.

Finally, several statistically significant inverse relationships were noted with the entire sample, which were not notable with the two groups. Still, these are important to consider given the overall small sample size. These significant negative correlations include: age and depressive symptoms ( $r[37] = -.372, p < .05$ ) and age and instrumental support ( $r[38] = -.321, p = .05$ ); as well as age and three coping styles, venting ( $r[38] = -.335, p < .05$ ), behavioral disengagement ( $r[38] = -.370, p < .05$ ), and self-blame ( $r[38] = -.371, p < .05$ ). Thus, age appears to be an important factor related to AAPCGs' choice of coping strategies. These findings imply that younger, inexperienced AAPCGs may need

more hands-on assistance, to direct them toward and provide access to formal resources that will help alleviate their depressive symptoms.

**Coping strategies.** Many of the AAPCGs expressed diverse coping strategies which helped them to cope with the PCT and facilitated their grieving during the bereavement period. These facilitators included engaging in productive ventures as outlets for coping; doing what needs to be done; recognizing that time heals; enjoying family mementoes; reminiscing about the loved one; welcoming a new baby to the family; experiencing relationship with God; realizing that loved one is in a better place; and realizing that others have gone through similar situations and social support.

*Engaging in productive ventures as outlets for coping.* Some of the participants engaged themselves in various ventures as a means of coping with active caregiving, and they found those ventures also helped them with PCT. Several of the participants wrote just for their own private edification and release, whereas others started writing their caregiving experiences as a relief measure, and then decided to take it a step further into publications and public presentations to supplement their income. This writing continued to help them through the PCT period. One participant reported,

I had a doctor that had taken care of my dad, my husband and myself, and he saw me one day, he said, 'I'm not gonna let you go like this. I'm not gonna let you go out like that because I know what's happened. I know what's going through'. He told me to write. He said, 'Start writing'. He said, 'I don't care what time you write or what you write [be]cause nobody not gonna read it but you. You can tear it up, burn it up or anything you want to do, but write'. I had written I'm sure by now about three books...The writing releases. The writing is better than tears.

Participants reported other facilitators, including: returning to school, traveling, and changing the layout of the room that they shared with the deceased. These activities helped to take their minds off their losses and encouraged positive PCT. One participant recalls:

Going back to school was one. Well, right after he passed away, like I said, I ran a lot to keep from being home because I couldn't face the idea that he's not there anymore. I did a lotta running. Anytime friends said let's go, I was gone. I was in town somewhere, but then like I said, after I couldn't keep running the roads, then I end up going back to school. That helped keep my mind off of things and put it on something more positive.

***Recognizing that time heals.*** Many participants determined that time provided the necessary healing during the PCT. They expressed the belief that the loss was greater initially, but got significantly easier as time progressed. One female participant suggested, "You would think it would be a smooth transition, but sometimes it's hard. I feel that it really takes a lot of time to adjust, and you should give yourself time with the support of your family members."

***Enjoying family mementoes.*** Participants suggested that sharing family mementoes such as pictures, videos, music, and other artifacts helped the PCGs deal with the loss of their loved ones and to start the journey towards healthy transition. According to one male participant,

They [family members] all showed up and so it was a joyous, ceremony. Yeah, it was a reunion actually. We had a good time. So from time to time, I will bring out, you know, the photo album. I look at all these different people and show to

my kids...so, you know, you just shared a lot of old stories. Yeah so that was one of the things, you know, that helped, you know, after caregiving to be able to get back to sanity.

***Reminiscing about the loved one.*** Closely related to sharing mementoes was the facilitating activity of reminiscing about the deceased loved one. The participants reported that talking about their loved ones, remembering things they used to say or do, the wisdom they used to pass on, or their kind and caring gestures was helpful for the caregivers and other family members as a means of coping during PCT. One female participant stated, “I think talking about it helps, or talking about her helps. Every one of us, we still remember it was some things she used to say. We repeat it to ourselves. We laugh about it.”

***Welcoming a new baby to the family.*** A new baby in the family usually brings hope and joy to the family, but culturally, a new birth represents a new beginning. In Nigeria, there is also the belief that the newborn might be a reincarnation of the deceased loved one, returning to bless the family that he or she left behind. This belief was more prevalent among the Nigerian-born participants in our study, as expected. In post-caregiving, a new baby acts as a facilitator because he/she helps the AAPCG to re-focus attention on another individual. A Nigerian-born male participant reported,

My grandchild just came, that’s my mother [deceased loved one] right there...That’s a form of rejuvenation for me. I call her my mom. You have been seeing that I’ve been playing around. Once I think about my mom, I just call them. That’s part of what is keeping me happy now with the baby that’s coming in the last one month...Traditionally in my family, once somebody dies, like my

mother died, and a baby girl is born, that means the mother has come back, so she's my mother come back.

***Realizing that loved one is in a better place.*** Another common sentiment closely related to spiritual coping amongst the participants of this study was the comforting belief that their loved one had gone on to a better place, a place where there was no pain, sickness, disease, or suffering. Some believed that the death of the loved one provided an opportunity for that individual to spend eternity with previously deceased loved ones such as spouses or parents. One male participant reported,

The good thing was, I was looking at it to see that she was going to be with my dad, because my dad was a believer. I was also seeing it that she was going to be with my grandmum because my grandmum and grandparents were believers and a host of my other uncles and aunties who had gone before her. The joy was in me that they would be together and someday that I will join them.

The foundation for this belief in a "better place" was rooted in religious terms. The majority of the participants who alluded to this sentiment believed that their loved ones were in heaven. It comforted them to know that heaven was a safe place for their loved ones and they no longer had to worry about them. According to a female participant, "So, that's what got me over it. That's why I don't really have any regrets, and I don't have any regrets for his life. I don't feel sad for him, because I know that he's in Heaven."

The foundation of this belief of a better place is rooted in the biblical promise in John 14: 1-4 (Bible, n.d) which alluded to Jesus Christ going to prepare a place for the



believers. Thus, many AAPCGs stood on this promise and were comforted that truly their loved one is in a better place. This facilitates their PCT journey.

Although the majority of AAPCGs in this particular study may have believed in the promise of their loved ones going to a better place and were comforted by it, one participant questioned the validity of this belief. Nearly ten years after her mother died, she recalled a conversation with her mother's friend who tried to comfort her with those words but the AAPCG wondered, "We should be coping, that she's in a better place and I'm like, what other better place can anybody be than to be with your children? I don't understand that, you know." It is rare amongst AAs to question the validity of a biblical promise, but questioning helped this particular AAPCG to put her mother's death in perspective and facilitated her PCT.

***Realizing that others have gone through similar situations.*** Another facilitator for healthy transition in AAPCGs is the realization that other people have gone through the same thing, and that they were not alone in their feelings, emotions or thoughts regarding the loss of their loved ones or the termination of their caregiving role. One female participant reports,

Seeing that you're not the only one, other people feel the same way you do or have gone through some of the things that you've gone through. They tell you how they handled it and sometimes it may be for you and sometimes it may not be.

On the other hand, sometimes it is the AAPCG who values the opportunity to use his or her own experience to counsel or support other caregivers going through similar

situations. They reported that giving back helped in their own healing and coping. One male caregiver related his own experience with providing support for others,

The same thing happened to them. They lost their mom. And so I was able to leave my pain alone, and kinda help them with theirs. And give them encouragement, and this and that. And, you know I had somebody to relate to, and it helped me. I helped. Well, I got my mind off of my stresses and pains a lot by helping them out with theirs.

*Visiting the cemetery.* Both the act of visiting and the act of avoiding the cemetery where the deceased loved one was buried were discussed by the AAPCGS as facilitators. In some cases, they felt that visiting that loved one's burial site provided them comfort and peace, brought the loved one closer and even provided clarity when they felt overwhelmed or in doubt. One male participant who cared for his mother-in-law expressed how these visits facilitated his PCT.

I made a constant visit to her burial place. Whenever I feel, sometime I come back from work, I feel it. I just drive down there and then pour my emotions again and over and over again. I didn't even tell my wife about that. Whenever I feel that I miss her [deceased mother-in-law] so much, I just go to the grave there, drive, stand there for a while till I pour my emotions again and over and over. The first time I went, I found it difficult to find the place, because there was no stone there, so I was really devastated that day. I finally got to find the place. That was really difficult. I wanted to see the place and just stand there for a while and then empty my emotions. That's the only way I can feel relieved a bit for me.

Others avoided going to the cemetery, especially in the early PCT period. They could not bear to view the grave of their loved one or be in the place of separation, leaving that loved one there after each visit. According to one female participant,

No, I haven't been able to go [cemetery]. I haven't been able to do that. I don't know why, but I don't have the urge to go. Cause, I don't just know. Is it that I'm not accepting? ... I haven't been able to make myself to go there. I think I just want to have that – even to look at her body was hard. So I just want to have that memory of how she was before she died. I don't think I wanna see.

Often times, the visits to the cemeteries entailed performing some ritualistic activities such as beautifying the burial place or having family gatherings there for the holidays or during anniversaries of the death of that loved one. These activities helped the family to deal with the loss in a more constructive manner. One participant reported,

The hardest thing after caregiving ended, which means after my mom died, the hardest thing for me was actually going to see my mother's name on the stone...After taking care of her, was taking care of her, the second part. What I mean by that is that on every holiday... I decorated her and my father's gravesites. I go to the gravesite and I take all the grass from around and I brush it off. I wipe it off. I decorate with the things that I know she liked and my father like...Once again, nothing has changed, but it's easy for me now. It's easy for me to take care of both of them together by myself. That's the easy part now that was hard at first.

## **Outcome Indicators**

Outcome indicators were those behaviors and actions by AAPCGs that demonstrated positive adjustment to their PCTs. Similar to process indicators, outcome indicators were arrayed on the checklist. Exemplars of each indicator were sought within the interview data from each case and organized under the categories of outcome indicators: mastery and fluid integrative identities (Meleis et al., 2000).

**Mastery.** Mastery refers to evidence that the individual is making a positive adjustment to the PCT. Participants described mastery of the PCT in a variety of ways that appeared to involve an active re-entry into life: managing a new environment, making decisions, taking action, preparing for one's own life and death, retirement investments, planning death, writing a will or purchasing insurance, and caring for self, including the ability to recognize stress and burden of the loss, recognize one's own limitations, maintain balance and do things that made one happy, and move on with life.

***Managing a new environment.*** The ability for a PCG to move into a different environment was a landmark move towards adjustment in PCT. Thus, stepping out of familiar environments to live alone, or change the layout of their current homes to make it more comfortable for them was indicative of progressive healthy outcome of PCT.

One female participant reported,

I used to feel lonely and I got over the lonely feeling because of knowing that it was a choice I made to live by myself and to live alone [be]cause I didn't have to move here and be by myself. That got me over [be]cause I could have stayed with my son and daughter-in-law...I moved because I needed my – I need to be

independent. I need to grow. So I got over being lonely because of that reason [be]cause I made a choice to live by myself.

***Making decisions.*** Oftentimes in the throes of immediate loss of a loved one and the chaos and uncertainty (Ume & Evans, 2011), caregivers experienced so much disorganization that they were not able to make decisions about their own lives or the future. In this study, AAPCGs reported the ability to make decisions as a measure of progression through the PCT. One participant admitted,

I'm at an adjustment now where I feel I can make decisions in my life now.

First, I was – I couldn't even make a decision. Okay, what bill do I pay? What do I do? What do I do next? I wasn't used to paying any bills. I wasn't used to doing anything like that.

***Taking action.*** Many of the participants noted that the death of their loved one produced in them a resolve to improve their lives. One male participant reported that his sister who was the primary caregiver for their mother was not able to change anything from the mother's room for up to six months after the death of their mother, but eventually she began the packing up and taking down process (Larkin, 2009). After the death of her father, another participant emerged stronger and more focused in what she needed to do to progress in her life, so she returned to school. She reported,

I'm more inspired. I'm more focused. I will say after my father died, I kind of reevaluated myself and say, okay. It helped me to kind of focus on things I needed to do and know that I have to do them.

***Readying oneself for another caregiving role.*** Another sign of progression was the readiness and ability of the PCG to begin or continue other caregiving roles. One

female participant reported, “Yeah, back to work. Well, I guess I am taking care of my mom now... Yeah, so I’m taking care of my mom and a couple of other people from the church.” So in certain situations, serial caregiving might be a measure of adjustment in PCT.

***Preparing for one’s own life and death.*** Another demonstration of progression was the ability to better plan one’s life and future death based on the experience of caring for their loved one and lessons learned from it. One lesson was about the importance of eating well, exercising, and planning one’s death so as not to burden other family members. This advance planning was done by purchasing adequate life and health insurance, investing for retirement, selecting burial plots, and setting things in order ahead of time. One participant stated,

I hopefully planned for myself to make that a little easier for her (daughter) because I don’t want her to go through it by herself...I decided from the experience with my mom, when I get old and I can’t take care of myself, I planned out a particular retirement home to go to...I’m gonna make sure that all the arrangements are made beforehand, the way I want them to be, so she (daughter) doesn’t have to worry about them. That includes me having my burial plot picked out and planned and all ready, the headstone...

***Caring for self.*** Another sign of PCT adjustment was the evidence of self-care by the individual. It was important for AAPCGs to recognize the stress and burden that the loss of loved ones and the change in caregiving roles placed on them. They recognized their limitations and did not overstretch themselves by accepting every request or demand for their time and attention. It was crucial that they maintained balance, took time to do

things that made them happy, and pampered themselves by engaging in exercise, adequate nutrition, rest and sleep. One participant said,

It should be balanced to where you're not always giving, giving, giving and saying yes, when you really feel like saying no. It should be a life of doing for yourself and knowing how to be happy, independent, you know.

A marker of the AAPCGs' re-entry into life was their self-perception of adjustment to the PCT. This marker was the participants' own assessment of their progress through PCT, including their coping abilities and general sense of well-being. Interestingly, a majority ( $n = 10$ , 58.8%) of the early PCT group (0-3 years) felt that they were positively adjusting to PCT, while the rest ( $n=7$ , 41.2%) admitted that they were not adjusting well to PCT. Within the middle PCT group (4-6 years), also a majority ( $n=6$ , 66.7%) reported positive adjustment, whereas ( $n=3$ , 33.3%) admitted to not adjusting well to PCT. Although not surprising, almost all the participants ( $n=12$ , 92%) from the 7-10 year group felt they were adjusting well to PCT (Appendix W, Table 11). This finding suggests that the AAPCGs appeared to adjust better over time with PCT.

**Fluid integrative identities.** Although this concept is not clearly delineated in the Transitions Theory, for the purpose of this study, fluid integrative identities referred to subjective emotional experiences or behaviors identified by the AAPCGs which provide evidence of a stable, adjusted life. Exemplars of achieving fluid integrative identities included a focus on a sense of balance; peacefulness and joy; fulfillment, and compassion; remembering without pain; and establishing a new identity.

**Sense of balance.** Learning to maintain a sense of balance in one's life was expressed by the AAPCGs as evidence of a fluid integrative identity. Sometimes life

balance required that activities still provided necessary rest and rejuvenation. One participant stated, “It’s to keep me healthy and it keeps something to do since I retired from work, just keep me balanced so I won’t sit up in the house and stare at TV and not have anything to do.”

***Peacefulness and joy.*** Participants expressed that they had peace in their lives because they did all they could for their deceased loved ones. They felt at peace because of the quality of care they provided and insisted that their evidence for appropriate or healthy adjustment in the PCT was that they had a peaceful life and not confusion or chaos (Ume & Evans, 2011). One female participant stated,

I’m in a really good place in my life where I have a lot of peace in my life now...And I keep peace around my life. I don’t try to put myself in a lot of confusion. I keep myself in a really peaceful place because I know where he [God] could take me.

Joy was defined as the emotion of experiencing happiness once again in one’s life after loss of a loved one and the caregiving role. Oftentimes, the AAPCGs who described joy as a sign of healthy transition also discussed it in terms of achieving peace in their lives. One female caregiver reports,

Like I said I have inner peace because I did the best I could. That gave me the joy that, oh you were there for her when she needed you. You gave her all the support. Even though it was like I had no life. I couldn’t do any other thing but to just be there for her.

***Fulfillment.*** Another demonstration of a fluid integrative identity recognized in this study was that AAPCGs felt enriched and fulfilled by their past role as caregivers



and in their current role as PCGs who were able to move on with their normal life and continue to give back to society. One participant stated,

The life a person should have after caregiving, you know, it should be more enriched and they should feel more fulfilled and still be able to go about their daily routines and just find other ways to give back.

**Compassion.** Many AAPCGs developed increased compassion as a result of their caregiving role. They defined compassion as providing support for other caregiving families by visiting and talking to caregivers to provide encouragement; placing more value in life, not on material things; enhancing spiritual support in caregiving; being more sensitive to the needs of others; and knowing when and how to care for other caregivers. Furthermore, compassion ignited volunteerism and encouraged AAPCGs to give back by volunteering in a hospice or children's hospital. Compassion was also expressed in terms of not taking older adults for granted, but recognizing their presence and contribution to society.

**Remembering without pain.** Many of the participants recalled that one measure for them of healthy transition was that they were able to talk about their loved one without the sad emotions that often accompanied such discussions in the early periods of PCT. According to one participant,

I think I've fully achieved, you know, what I needed to achieve getting back because, you know, I don't feel anything. I don't feel any sorrow. You know every time I recall, you know, the times that we had together, a smile comes on my face.

*Establishing new identity.* Another sign of achievement of a fluid integrative identity was the establishment of a new self after the termination of the caregiving. The participants spoke of the need to find out who they were and to create a new life for themselves in light of the death of the loved one. One Nigerian-born participant reported,

Yeah, I think when my father died...I came to terms with it eventually...I just kind of looked at myself, okay, my father is gone. I just have to be who I am. It's like a new part of me. A new life or a stronger me is coming up. I know, yes, I don't have a father anymore. Yeah, thank God my mom is still around, but a mother can never replace a father...My father just passed, but it's like a new me came out. Maybe from the experience, going for the burial, because that's the first time that sorta thing happened to me, the burial and all that, and that made me stronger, and made me look at things that maybe I would say, no...Things like going back to school, went back to school and all that. I think it really helped me to be more focused than otherwise, yeah.

In Nigerian society, a father is very much respected and valued but when a father is no longer there, the obvious protection and respect accorded to the family is often threatened. Thus, the children from that home may need to grow up quickly to be able to meet the onslaught of family and community issues. Thus, this participant's statement was not a negative reflection against the mother, but an affirmation that society respects masculinity so much. Thus, the children of that home had to immediately develop an inner strength that manifested power and external strength which was necessary to withstand the guiles of the extended family.

An allied concept that was strongly tied to the idea of establishing a new self was “growing up”. Two Nigerian-born participants directly used the term “growing up too fast” to discuss that once their parent died, they felt the need to immediately grow up and become more responsible for themselves, as well as for their siblings. Although all the participants in this study were adults, they were referring to the emotional development and maturity that occurs when, one must take charge of one’s own life, without the luxury of parental wisdom to guide them or their siblings through life. One female participant recalls,

I guess we grew up too. That’s the thing that came out of it. We all had to grow up fast and look out for each other. But I think talking about it helps, or talking about her helps. Every one of us [siblings], we still remember things that she used to say.

### **Summary**

The patterns of response experienced by AAPCGs in this study served as the foundation for understanding PCT in this population. These participants identified various process and outcome indicators which indicated their healthy progression through PCT. They gave exemplars of such process indicators as connectedness by reconnecting with friends and family, returning to work or school and other forms of connectedness. They also demonstrated interactions through social support from family and friends; while manifesting locating and being situated through their willingness to volunteer, especially amongst the AAPCGs in the 0-3 year time frame. Finally, they expressed their confidence and coping through the use of several coping strategies.

AAPCGs reported a variety of exemplars that indicated mastery and fluid integrative identities. To demonstrate mastery, they identified activities such as managing new environments, making decisions, taking action, readying oneself for another caregiving role, preparing for one's own life and death, and caring for self. AAPCGs also identified the following attributes as evidence for achieving fluid integrative identities: maintaining a sense of balance, peacefulness and joy, fulfillment, compassion, remembering without pain and establishing a new identity. The checklist (Appendix R, Table 6) developed for this study, on which these exemplars are set forth, provides a basis for instrument development of standardized measurement of PCT. This is a much needed instrument since there is currently no standardized tool to measure transition and particularly PCT.

## CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

The major purpose of this mixed methods study was to explore the PCT in AAPCGs using the research question, "How does the PCT evolve for AAPCGs?" The Transitions Theory (Meleis et al., 2000) provided a theoretical framework to guide every aspect of the study, including the design, data collection, data analysis and presentation of findings.

In the previous chapter, findings and discussion were presented together, using the Transitions Theory as a framework (Appendix A, Figure 1). This chapter uses the specific aims of the study as scaffolding for presentation of conclusions. In this way, it can be determined if the aims of the study were met, and if so, to what extent.

This chapter summarizes major findings of this study; explores limitations; and presents the implications and contributions to science and the nursing body of knowledge. Finally, this chapter offers recommendations for practice and future research.

### **Summary of Transitions Domains and Specific Aims**

Each specific aim is presented in turn to guide the conclusions of the study.

#### **Aim 1. "Describe the types, patterns, and properties of the PCT in AAPCGs."**

This study used The Transitions Theory (Appendix A, Figure 1, Meleis et al., 2000) to determine the various types, patterns and properties of transitions experienced by AAPCGs. The five types of transitions that Meleis et al. (2000) articulated were all identified in this study, including developmental, health and illness, situational, organizational and transnational. The most common type of transition experienced by this cohort of AAPCGs was, as expected, health and illness. This type of transition was most

relevant to AAPCGs because many of the participants began caregiving because their elderly loved ones became ill and could no longer care for themselves. Those loved ones needed the assistance of family members to help with either their activities of daily living such as bathing, dressing, feeding; or with instrumental activities of daily living such as medication management, completion of household chores or shopping, going to physician's appointments, or managing finances. On occasion, the participants were also involved with health issues of their own that further complicated their PCT.

Some participants suffered from emotional challenges such as depression, worry, anxiety, stress or guilt during caregiving which continued during the post-caregiving phase. Only two participants scored high enough on the CES-D scale to be considered depressed. These two participants did not admit during their interviews that they were depressed; two other participants referred to depression during their interview, but then only to deny it. Although these AAPCGs did not articulate their feelings as depression, they experienced closely related emotional states. Many participants spoke about their intense sadness, sense of loss, worry, anxiety and sustained guilt, supporting previous studies which suggested African American caregivers usually do not report depression (Dilworth-Anderson, Williams, & Gibson, 2002; Haley et al., 2004). These post-caregivers also worried about reclaiming their lives and achieving PCT adjustment. For example, spousal post-caregivers worried about re-entering the dating scene or establishing new relationships. These worries appeared to produce additional stress.

One in four AAPCGs in this study expressed challenges such as healthcare access and health disparity issues during caregiving and post-caregiving for their newly emigrated loved ones. However, it must be noted that almost half of the participants

were Nigerian-born immigrants, who were potentially affected by many challenges related to transnational transitions.

The most prevalent pattern amongst this group of AAPCGs was that of multiple, simultaneous transitions. This was an important finding because it demonstrated the myriad, complex, competing and sometimes conflicting situations that might negatively impact AAPCGs. These challenging situations include home and job losses, disturbing family conflicts, isolation, and emotional and physical problems. These already difficult situations may be impacted by additional concerns such as poor access to health care and health disparities that may overwhelm the AAPCGs' limited financial, emotional or physical resources. The resultant complexity may further be worsened by visa, embassy or global health concerns affecting the PCT, such as, taking the bodies of their loved ones home or returning to work.

The properties of transitions, including awareness, engagement, change and difference, time span, and critical points and events appear to contribute significantly to an individual's progress and eventual achievement of healthy PCT. The most frequent property noted in this study involved the individual's awareness of their PCT and what that meant to them, suggesting that this may be an important component of healthy adjustment and recovery from the loss of loved ones. Further, the changing roles from caregiver to post-caregiver often created chaos and uncertainty in AAPCGs which sometimes lingered and negatively impacted healthy progression through PCT (Ume & Evans, 2011). This lingering uncertainty bred deeper, sustained grieving that marked significant time spans, critical events and life points such as marriages, childbirths and

retirements that all contributed, positively or negatively to the achievement of healthy PCT.

**Aim 2. “Explore the facilitators and inhibitors of progress through the PCT in AAPCGs.”**

As noted in chapter 4, the AAPCGs’ personal transition conditions were so completely embedded within community and society conditions that they were inextricable. None of the participants discussed any aspect of societal transitions but many reflected on the effect of community conditions such as their African American heritage, religious affiliations, and family and social support experiences that facilitated or inhibited their PCT.

**Facilitators.** AAPCGs often succeeded in moving on with their lives despite their continued grief by utilizing core attributes prevalent in AA communities. The most common facilitators of achieving healthy PCT included strong and supportive social networks of family, friends and church; strong faith and spirituality emphasis (Evans & Ume, 2012), which supported religious coping and the belief in the supremacy of God as the healer, provider and the comforter. This strong belief in God helped them deal with the financial, physical and emotional challenges they experienced.

Other important facilitators included feeling relief that the caregiving demands and burdens were finally over and that the loved one was no longer suffering. AAPCGs acknowledged that they wanted their loved ones to remain alive, even in the face of a long-term end-of-life caregiving commitment. However, they recognized that unnecessary suffering and prolongation of a miserable and painful life was of no benefit to their loved ones. Therefore, when death mercifully ended that pain and burden, most of



the surviving AAPCGs expressed relief and acknowledged their gratefulness that their loved one was finally at peace.

One poignant facilitator described by participants in this study was the visitation by the spirit of their loved ones that came in various forms such as a dove, a voice, or a dream. These forms of visitation allowed for comfort and closure and helped the AAPCGs “move on” and progress more easily through the PCT.

These AAPCGs believed in and committed to end-of-life caregiving for their loved ones, no matter the length and depth of the endeavor. Thus, when such intense caregiving ended, virtually all of the participants were proud that they did the best they could, under the circumstances. They were pleased when they carried out the wishes of their loved ones in such situations as taking the body home. As presented in chapter four, the AAPCGs believed that providing care for their elderly loved ones gave them a sense of fulfillment and made their PCT adjustment easier. Recognition and appreciation of that caregiving by the deceased and other family and friends was a major source of encouragement for the AAPCGs and facilitated the progression through PCT.

**Inhibitors.** In this study, the major inhibitors identified included financial and emotional difficulties. The financial difficulties began during caregiving and worsened during the post-caregiving period. These continuing financial challenges included medical bills, burial costs, household mortgages, and other obligations which could not be met without the deceased loved one’s income (sometimes these challenges led to home loss). Lingering financial difficulties were exacerbated by job loss or inability to immediately return to work after caregiving ended. Poor economic status demanded that

individuals continued working most of their caregiving period and returned to work soon after caregiving ended.

Oftentimes, emotional difficulties during the post-caregiving period resulted from economic challenges that forced the participants to work outside the home, in addition to maintaining their caregiving responsibilities. These caregivers suffered feelings of self-doubt, guilt and regret about the quality of care they provided. In some cases, they experienced tormenting, accusatory thoughts that blamed their inability to financially provide for their loved one as a possible cause of death. These tormenting thoughts made AAPCGs second-guess their caregiving actions and decisions, thus making it difficult to move past their grief to attain healthy PCT.

The majority of these AAPCGs felt proud and blessed by the opportunity to care for their loved ones at home. However, many also expressed guilt and regret about the nature of their caregiving, despite the fact that they provided lengthy, unremitting caregiving to highly-debilitated loved ones. Such recriminations impacted their personal, family and professional lives, sometimes to the detriment of their physical and emotional health.

The emotional cost of caregiving can be profound, and AAPCGs may experience prolonged, unremitting grief (Goldsmith, Morrison, Vanderwerker, & Prigerson, 2008). In this study, AAPCGs expressed grief, characterized by emotional lability, sadness and loneliness, even up to 10 years after their loved ones died. Although they attempted to move on with their lives despite their unremitting, often untreated, grief, some AAPCGs who lost a loved one 10 or more years prior to the study expressed deep loss, just as if the person recently died. This continued grief was different from complicated grief in that

these AAPCGs were able to continue to function in their roles. They recognized that, in order for their immediate families to survive, they must deal with the loss in a private, isolated manner while carrying out their expected roles and responsibilities within their families, jobs, or church, doing so without complaints. This study demonstrated that AAPCGs continue to work, return to work, continue other caregiving or take on new caregiving roles, and serve in church roles soon after the death of their loved ones. They attempted to “move on” without disruption, suggesting that they may not take the personal time necessary to completely deal with loss. Therefore, a continuous, low-key, prolonged grief situation festers for many years.

**Aim 3. “Describe the process and outcome indicators of the PCT in AAPCGs.”**

**Process indicators.** This section responds to Specific Aim 3A (manifestations of connectedness, interactions, feeling of inclusion, confidence and coping). This study evaluated the presence of connectedness, interaction, feelings of inclusion, and confidence/coping in AAPCGs that appeared to be very important to their progression through PCT.

Reconnecting with friends and family, as described in this study, was important for the majority of the AAPCGs who were coping with the death of their loved one and the end of caregiving. Reconnecting through return to work was shown to be a major milestone for many AAPCGs in this study. The decision to return to work was usually not a voluntary one, but a decision born out of financial necessity, a major concern amongst these AAPCGs.

Interaction with family, friends and co-workers also emerged as a process indicator. An important indication of interaction was that AAPCGs were able to identify

and separate levels of social support. These AAPCGs were able to identify individuals in their social network with whom they could share deep concerns, those who could assist them with personal or instrumental support, and those who might negatively influence them through a toxic relationship. It appeared that time since bereavement had an influence on interactions, in that a majority of those in early PCT (0-3 years), gave fewer exemplars for interactions than those in middle or advanced PCT, despite the fact that those in the early PCT provided more exemplars of connectedness than the other two groups. This may suggest that in early PCT, there may be more social support but the caregiver may not access it.

Many AAPCGs reported altruistic behaviors as a result of their caregiving experience, especially in the early PCT period. This altruism demonstrates the transition concept of locating and being situated. These post-caregivers showed interest in helping others who need help or who may be going through similar caregiving situations. The belief and commitment to support of others in need is speculated to be the basis of serial caregiving amongst this cohort of AAPCGs who continue to care or pick up new and varied caregiving situations.

**Outcome indicators.** This section responds to Specific Aim 3B (differences in levels of depression, coping and social support in those who demonstrate mastery and those who do not). The indicators of mastery and fluid integrative identity in Meleis' theoretical model evaluate progression toward healthy PCT. In this study, returning to school; managing a new environment; decision making; taking action; readiness for another caregiving role; and preparation for one's life and caring for self, provided objective evidence of mastery. Almost three-quarters of the AAPCGs in this study

believed that they were adjusting positively to life after caregiving and only two met criteria for clinical depression, based on the CES-D. Many of the participants, however, reported prolonged, sustained grief, characterized by a deep sense of loss, continuing up to 10 years after the death of their loved ones. This deep grief may continue even longer but this cohort reported only up to 10 years. This finding indicates that, although AAPCGs may think they are adjusting well to the loss of their loved one, they may still require nursing support.

On the other hand, fluid integrative identities which usually refer to subjective emotional experiences or behaviors such as experiencing peace or joy, seemed to provide evidence of a stable, adjusted life after caregiving. AAPCGs identified behaviors that promoted a sense of balance, which involved making time for adequate and necessary rest and rejuvenation. This supported the need for future nursing interventions to foster and promote self-care in AAPCGs, so that they have the strength to carry on for the long haul, the necessary continuation of familial responsibilities. Promotion of self-care also promotes a sense of peace, joy, fulfillment and compassion, attributes that provide supportive demonstration of positive and healthy PCT.

**Separation in PCT.** In response to Specific Aim 3C (differences in levels of depression, coping and social support between those who demonstrate separation from the caregiving role and those who do not), it was noted that early PCT participants demonstrated higher scores on CES-D, were satisfied with their social support, and appeared to be coping well, even though they reported more negative self-perception of adjustment than those in the middle and advanced PCT groups. The middle PCT group appeared to be progressing through PCT relatively well with very low scores on CES-D,

except for one person with an extremely high score and another with a borderline significant score. However, their coping and self-perception of adjustment were mostly positive, demonstrating a positive journey through PCT. All of the participants who were at the 10 year mark of their PCT journey had low CES-D scores for depression, showed more satisfaction with their social support, were coping well, and perceived that they were adjusting well to their loss. However, many of them also reported during their interviews that they still occasionally experienced a profound sense of loss, loneliness and sadness about their deceased loved ones, and that those feelings were just as devastating as when they first entered their PCT journey. Thus, this study suggests that although, there are apparent improvements in depression, coping and social support based on time since bereavement, individuals still float in and out of deep grief for many years after bereavement of the loved one. Then one might argue that they have not completed the PCT.

### **Limitations of this Study**

Although this study made a stringent effort to tease out the cultural differences among participants' responses, West African customs, including those from Nigeria, have become a part of the U.S. AA landscape (Mann, 2001). Consequently, although responses from Nigerian immigrants were carefully examined for culturally-based differences from U.S-born respondents, customs already integrated into our society could not be differentiated.

The findings of this study, however, may not be transferable to the entire U.S. AA population, since almost half of the participants were Nigerian-born post-caregivers.

Some findings may not be representative of the many Black Americans who do not share these cultural or religious viewpoints.

This study participants were all Christians whose views and opinions may not be representative of AAPCGs of other religious backgrounds such as Muslim. Therefore the findings may not be generalizable to non-Christians in such specific situations as taking the body home. This practice, described by many participants in this study, may not be possible in Islamic religious burial practices which prescribe that a deceased individual must be buried as soon as possible after the death. Consonant to the theoretical framework which describes personal meaning and cultural beliefs, the recruitment of an all-Christian sample for this study was unavoidable because recruitment was done at traditional recruitment settings where African Americans are largely congregated like churches, hair shops, community events (Carter-Edwards, Fisher, Vaughn, & Svetkey, 2002; Derose, et al., 2000; Dilworth-Anderson, 2011; Fouad, 2000; Markens, Fox, Taub & Gilbert, 2002; Moreno-John et al., 2004; Yancey, Ortega, & Kumanyika, 2005). However, there is need to explore PCT in other African American groups with different ethnic backgrounds such as Congolese, Ugandians, Kenyans, Belizians, Panamanians, or Ethiopians..

The checklist for healthy PCT (Appendix R, Table 6) provides only a preliminary basis for instrument development in an area lacking a valid and reliable tool. The plan is to continue to refine and redesign this checklist with the goal of developing it as the first standardized instrument for measuring PCT.

## **Implications of the Study**

### **Implications for Practice and Policy**

The average age of the AAPCGs in this study was 52.7 years; age is related to multiple caregiving. As AAPCGs age, it may be anticipated that they will enter into multiple caregiving roles and thus require long-term or more intensive support than those who care for only one family member. This knowledge suggests the need for future health care planning and policy making that will recognize the demands on this aging caregiving workforce and provide the necessary support to ensure their safety and well-being as they embark on these multiple caregiving roles.

The relationships between age, multiple caregiving, and hospice utilization in this study are complex and important ones. Although the AAPCGs used hospice infrequently as most AAs do (Colón & Lyke, 2003; Taxis, 2006), this study showed that when they were faced with multiple caregiving roles, they were more likely to engage hospice services to help alleviate the stress and burdens of caregiving.

This has valuable implications for policy and health care planning to ensure that AA caregivers, particularly older, multiple, or serial ones, are given adequate information about hospice and that access to hospice care is available for all AA patients and their families. Nursing can take the lead in provision of information and early identification of caregivers who are good candidates for hospice support during end-of-life caregiving. This critical assessment could be helpful in planning and delivery of effective, supportive and timely nursing care to help improve access to and utilization of hospice services (Evans & Ume, 2012).



AAPCGs coped more effectively in PCT if they had time to plan and prepare for their loved ones' peaceful deaths. There is need for AA caregivers to be educated about expected end-of-life situations and to be encouraged to proactively plan for the "good death" experience of their loved ones (Ruland & Moore, 1998) before they actually confront those situations. This finding is important and contributes to the understanding that African American caregivers who may not have the time or knowledge to plan for the death of their loved ones because of intense caregiving, multiple or serial caregiving situations may have a more difficult time with adjustment to PCT (Herbert et al., 2006). It may be speculated that this may be one of the reasons for their long-term intense grief experienced by AAPCGs, and thus, may contribute negatively to their PCT.

Distractions such as physical activity and social interactions with friends or family may have been impossible to combine with the demand of active caregiving, but mitigated the sense of loss and sadness of the PCT. Nurses could help AACGs recognize the worth of, and plan diversionary activities that encourage relaxation and rejuvenation, both during active caregiving and post-caregiving.

Discomfort with caregiving tasks in these AAPCGs was not unusual for minority caregivers who keenly feel the need for health information (Evans et al., 2007). In addition to hospice information, AACGs need education about provision of hands-on daily care that takes culture, socioeconomic status, and spirituality into account. Caregivers who had difficulty performing the tasks of caregiving clearly needed timely nursing assessment and intervention.

In this study, caregivers with more education tended to return to work after caregiving; they may have had better access to jobs or may have managed to maintain

their jobs throughout caregiving. This cohort of caregivers returned to work after caregiving because of financial constraints, not just because they wanted to. This has major implications for policy makers who should consider the economic survivability of family caregivers when making health care, social service, and budgetary decisions.

The suggested budgetary or financial support for family caregivers and post-caregivers could be funded from the already ear-marked \$10 billion allocation for the period 2011-2019 through the Affordable Care Act (Naylor, et al., 2011). Another source of funding could be the \$500 million allocation for community-based care transitions programs for 2011 -2015 to health care and community organizations that provide care interventions to high-risk Medicare recipients (Naylor, et al., 2011).

AAPCGs, especially those involved in multiple or serial caregiving, may need more time to effectively work through their grief, and find effective coping strategies that would help them move through the PCT before returning to work.

Understanding of the gender differences in caregiving were important in this study because the female caregivers were mostly the primary caregivers, and had full responsibility for the care of the loved one until death, whereas almost all the male caregivers in this study were secondary caregivers who filled in when the female primary caregivers were unavailable or played supportive roles with shopping or doing laundry or providing other supportive care. This is important because it may also pose physical and emotional health risks for the female caregivers (Yee & Schulz, 2000). It may have implications for the type and quality of relationships between caregivers and their care recipients, especially when they are of different genders. For example, Mexican-American sons called upon to provide personal care for their mothers break cultural

taboos and struggle to meet the challenge (Evans, Belyea, & Ume, 2011). Male caregivers require more support or a different type of caregiving support than females. This may also be a consideration in the relationship between level of discomfort and multiple caregiving. This might suggest that nurses pay particular attention to male caregivers and assess the need for support to ensure effective caregiving and post-caregiving experiences.

Older AAPCGs might require more resources and tangible hands-on assistance during and after caregiving. In addition to resources, this study shows that older AAPCGs may not vent their distress and burden in relation to caregiving as easily as younger AAPCGs. They may need careful monitoring to ensure that they are able to verbalize their concerns and access mental health care for stress and grief management.

There was an important relationship between positive reframing and coping in this study which has important implications for nursing practice, education and research. State and federal governments, private organizations or healthcare providers who support or interface with caregivers and post-caregivers should design programs that promote stress-relieving activities to help AAPCGs to achieve better, active coping strategies that would serve them well throughout their PCT. Caregivers should be encouraged to look on life in a positive way and to reframe every situation to be able to see the brighter side of life, so that they could better cope with both active and post-caregiving situations in which they find themselves.

Planning of PCT may increase the use of instrumental support, because it prepares the AAPCGs to have clearer expectations about the PCT journey, thus they know what their needs would be and how to get the help they need. This knowledge has important

practice implications for nurses and other health care workers, especially those who work in hospice, palliative care, home health or long-term care facilities. Nurses in these settings should help families plan every step of end-of-life caregiving, along with ways to support all family members throughout that process.

While it is recognized that denial may be either a protective coping mechanism or a maladaptive one, in this study, there was less use of denial by AAPCGs when emotional support was high. This may be related to the family and friends who support the caregivers and “tell it like it is;” people who would not allow them to pretend to be doing well emotionally if they were not, or vice versa. In addition, the study found that AAPCGs who relied on denial as a coping mechanism often failed to vent their troubles to others. This provides evidence of the need for strong social support networks that holds people accountable, even for healthy behaviors, and indicates a role for nursing in teaching AAPCGs to seek and rely on positive social support.

Acceptance was an important aspect of coping and evidence of adjustment to PCT for these AAPCGs. It appeared that the younger the caregiver, the more difficult it was to accept their loss, and healthy PCT adjustment might be delayed. This finding supports the need for effective early intervention systems for caregivers, with the goal of helping family caregivers identify and navigate through various phases of caregiving. Nurses and health care providers should recognize that acceptance might be more difficult for younger AAPCGs than for older ones, thus, more support might be necessary to facilitate the individual’s healthy progress through PCT.

This study found that as individuals begin to accept the loss of their loved ones, they may slowly let go and distance themselves from their identities and roles as

caregivers. This distancing may position them to rebuild, restructure, restore and reorganize their lives in order to achieve healthy PCT (Shaw et al., 1997). Thus it is important for nurses to do thorough assessments in service of support in these activities.

Self-blame also was very important for these AAPCGs because it may be considered a precursor to, or a part of, caregiver guilt which had multiple health consequences for AAPCGs. Therefore, it is important for nurses and healthcare workers who care for AA family caregivers to support them in preplanning their caregiving roles; fostering positive relationships with care recipients; and developing clear expectations about a peaceful death, so AAPCGs do not resort to self-blame when loved ones finally dies.

The low rate of depression in this group of AAPCGs could be related to the presence of several coping mechanisms (facilitators) with which they managed the often difficult and challenging period of post-caregiving. Those caregivers who perceived themselves as adjusting to the PCT appeared also to be less depressed. This has implications for nursing practice, to ensure that nurses follow family caregivers closely and evaluate their self-perceptions about adjustment in order to assess their risk for depression or other emotional challenges. It is also possible that teaching AAPCGs about the PCT might allow them to gauge their own progress through the transition and provide an incentive for forward movement.

The higher incidence of connectedness in the early PCT group and a drop and leveling off of connectedness in the middle and advanced PCT periods may be related to a finding in this study that AAPCGs experienced more social support in the immediate

period of bereavement, but that, slowly, those people begin to reduce their visits and availability for routine and instrumental support for the caregivers.

A majority of the early PCT participants expressed some interest in volunteering to support other people going through similar situations or other older adults. This may have been because their loss was still fresh, and they were seeking ways to make sense of and gain meaning for their loss. Only one person in the middle PCT group reported willingness to participate in volunteerism. At this stage, individuals may just be becoming involved with personal activities, rather than volunteering. Many participants in the advanced group, however, were taking the time to volunteer, perhaps because they had worked through their caregiving issues and had the time to provide support to others.

There was evidence that time helped with PCT adjustment. The longer the progression through the PCT, the more confidence and ability to cope that the caregivers exhibited. Nurses can encourage caregivers to “hang on”. They could teach them to remain active in health and wellness promoting activities, and reassure them that, eventually, they will develop better ways to cope with their loss and will achieve overall confidence in managing their life after caregiving.

### **Implications for Education**

The findings in relation to lengthy PCT adjustment and recovery time for AAPCGs have implications for education of all health care professionals. Current knowledge appears to lean towards support for patient and family at the end-of-caregiving, but a gap remains in providing EOL education for health care professionals about the post-caregiving phase for surviving family members.

This study strongly suggests the need for a curricular adjustment in all geriatrics-related EOL or caregiving courses to ensure that the period of post-caregiving is established as a very important phase that may continue to negatively affect AAPCGs long after the family members' deaths. It is important that health care providers recognize that the secondary patients (family caregivers) would continue to need formal care and support for many years.

### **Implications for Research**

The positive relationship of serial caregiving and coping may be an indication that the care-giving "learning-curve" decreases with each caregiving episode, thus caregivers may cope better with subsequent caregiving roles because of their previous experience dealing with diverse caregiving situations. This may have implications for exploring some type of mentoring relationship, where people with more caregiving experience may mentor those with less experience. Such mentorships could provide a foundation for a pilot project where mentor-caregivers (serial caregivers) are provided a stipend and mentorship training in order to mentor less experienced caregivers. The hope will be that this partnership would be mutually beneficial through provision of another layer of social support for both caregivers.

The use of the CES-D, although well validated in other studies, may deserve further evaluation with its use in AAPCGs. This question "I felt more depressed" appeared to be more sensitive to identifying depressive symptoms than the total CES-D score which only isolated two individuals versus twelve that admitted feeling depressed sometimes. This is an important contribution that alerts other scientists and practitioners that this instrument may not always be sensitive and effective for use with AAPCGs.

There were also discrepancies noted between the AAPCGs reported self-perceived adjustment to PCT and the scores on active coping as measured by the Brief Cope. The discrepancy is significant in that it validates that although majority of AAPCGs may perceive that they are adjusting to PCT, this is not validated by objective evidence. Given this discrepancy, it is vital that researchers carefully evaluate their measurement tools to ensure that they are culturally responsive to the needs of AAPCGs.

### **Contributions to Science**

A major contribution of this study to the scientific body of knowledge is the foundation for development of a checklist to assess progression through the PCT. To the best of my knowledge, there is no standardized instrument available for measuring transition, and none particularly to measure PCT. In the past, researchers interested in transition work, utilized or recommended co-variables such as depression, coping, anxiety or grief to ascertain the well-being of caregivers and post-caregivers in various transition situations (Personal communication, Afaf Meleis, 2009). Although the goal for this study is an empirical and rigorous description of healthy PCT for AAPCGs, I believe that the subjective and candid self-evaluation of the participants provides a valuable piece of comparative data that can stand alone or support other findings. Therefore, as part of the checklist, I included an exemplar that addressed participants' self-perception of adjustment.

Another major contribution of this study is its primary focus on AAPCGs, and it provides in-depth understanding about the PCT phenomenon among African American caregivers. This is critical because very few previous caregiving research studies focus on



the post-caregiving phase of caregiving and, even fewer, focus on the African American post-caregiving experience.

This study also presents important findings that are relevant and applicable to other ethnic groups. These findings extend, support and validate the EOL caregiving research findings by Phillips and Reed (2009) that described EOL caregiving as unpredictable, intense, complex, frightening, profoundly moving and affirming. However, the Phillips and Reed's study used only Anglo participants. Other attributes which were reported in previous studies that were also validated in this study include the reliance of AAPCGs on social support and spirituality. This reliance was noted in previous reports to be prevalent amongst African Americans, but also demonstrated in other cultures such as the Hispanics (Evans & Ume, 2012).

This study provides knowledge regarding special vulnerability of AAPCGs who may continue to experience long-term grief patterns. Nursing and other health professionals who care for African American caregivers need to be aware of this unique, prolonged and deeper sense of loss and grief that AAPCGs experience at the death of their older loved ones, even many years after caregiving ends. Thus, this study sets the stage for improved care for AAPCGs to support these vulnerable caregivers for longer periods after the termination of their caregiving, and indeed other post-caregivers of other cultures, who are also going through PCT experiences.

### **Future Research**

The financial challenges of caregiving which continue through post-caregiving constitute major concerns for AAPCGs. It is important that future research include financial consideration in planning intervention studies that would support AAPCGs. A

study that supports them and protects their work schedule will be more easily adhered to than one that does not respect each individual's need to work.

The concept of taking the body home constitutes only a small part of the PCT cultural expectations experienced by the AAPCGs in this study. It is a custom shared by both the US-born and Nigerian-born participants. In spite of its wide practice, the phenomenon of taking the body home has garnered little interest in literature. Physical, emotional and financial difficulties relating to this phenomenon may create chaos and uncertainty in the lives of surviving family members, and may complicate PCT. Future researchers may consider the experience of taking the body home and how the physical, emotional and financial difficulties may impact the long-term PCT experience of AAPCGs who ascribe to it.

Another key difference between the Nigerian-born versus the US-born which may be critical is the age of caregivers and its relationship to their coping with PCT. In this study, the mean age of the Nigerian-born group was 12 years younger than the mean age of the US-born group. Also, the Nigerian-born group ( $M=4.79$ ) had an overall lower CES-D total score than the US-born ( $M=6.15$ ) and a wider social network (US-born  $M=10.38$ ; Nigerian-born  $M=11.42$ ). These findings were also congruent with the Nigerian-born participants' perceptions of received support and satisfaction with the support, creating an imperative for future researchers to examine carefully the impact of social support and CES-D amongst different AAPCG groups. These key differences may be helpful for researchers to note in designing appropriate, culturally congruent intervention studies.

Nursing therapeutics is one arm of the Transitions Theory (Appendix A, Figure 1; Meleis et al., 2000). However, the dearth of knowledge about PCT in AAPCGs, called for a descriptive study which focused particularly on the AAPCGs' perspectives. Although a few participants referred to the support they received from formal care providers such as their home health nurse, therapist or psychologist, most focused on the support from family, friends, and church. The descriptive nature of this study lays the foundation for future investigation of nursing interventions supporting AAPCGs in their journey through the PCT. Therefore, I recommend that future researchers should extend the scope of this work by looking at the role of nurses and other healthcare providers in caring for AAPCGs and supporting their PCT. This recommendation is supported by published work from the REACH project which showed that inclusion of cognitive behavioral therapy was helpful in decreasing complicated grief amongst Alzheimer's caregivers (Holland, Currier & Gallagher-Thompson, 2009). A previous study by Schulz et al. (2006) suggested a psychosocial caregiver intervention that was introduced during active caregiving but showed important results of preventing complicated grief, reducing depressive symptoms and burden in those caregivers, which helped them even in the post-caregiving phase.

Future instrumentation research is necessary to convert the newly begun checklist for healthy PCT (Appendix R, Table 6) into a standardized instrument. Future research should design and test the reliability and validity of the instrument in both AAPCGs and other population samples. This will contribute significantly to the science in the areas of end-of-life caregiving and post-caregiving. Through the generous funding of the John Hartford Pre-Doctoral Scholarship award, this researcher plans to attend a course on

Instrumentation: Development, testing and revision this summer to gain the technical knowledge necessary to carry this PCT instrument development work forward.

### **Recommendations**

This study recommends timely identification and assessment of all AACGs whose loved ones are nearing the end of life, planning seamless transition protocols of support which commence prior to bereavement. A higher intensity of support is recommended during the initial period of loss, but strength-based, intermittent support of AAPCGs should continue for many years during the post caregiving phase. This recommended protocol could contribute strongly to the health of AAPCGs.

There is a vital need to design and provide long-term, on-going interventions to support AAPCGs at various stages of caregiving and post-caregiving. Ideally, the recommended support must begin before the death of the loved ones and routinely provide systematic psychoeducational interventions that continue support to AAPCGs for many years after the death of their loved ones and the termination of their caregiving role. The efficacy of psychoeducational Cognitive Behavioral Therapy has been shown in previous studies to be very effective in reducing caregiver distress and to improve well-being overall for the caregivers who participated (Coon, & Evans, 2009; Coon, Thompson, Steffen, Sorocco & Gallaher-Thompson, 2003; Gallagher-Thompson & Coon, 2007; Wisniewski et al., 2003;).

This need for continued support is especially important because a majority of the AAPCGs will engage in additional caregiving, involving multiple or serial caregiving of their elderly family members or fictive kin. It is important for nursing practice to

recognize that even experienced post-caregivers may still have issues coping or managing their PCT.

It is important that policy makers and health care providers consider the important aspects of transnational transition when crafting healthcare-related caregiving policies and interventions. These policies and interventions will help to alleviate the difficulties of caregiving and provide the necessary support which immigrant caregivers and their older adult loved ones need, such as improved access to health care that removes unnecessary delays which could lead to fatalistic outcomes.

In conclusion, the continued lack of care for this population of AAPCGs will expand the health care disparity gap in the US and have global implications (Evans & Ume, 2012). A huge overall negative human capital impact will occur for AAPCGs here in the US and globally if adequate attention and care is not provided to this group of caregivers. Caregivers saved the US health care system about 450 billion dollars in 2009 in services they provided to their loved ones (Feinberg et al., 2011) and African American caregivers represent 29% of that volunteer workforce (NAC, 2009). Therefore, a continued lack of support for a significant part of our workforce, albeit volunteer, will have a profound impact on our nation's overall health and economy. It is important to continue the necessary research, education and policy work that are necessary to extend understanding of this phenomenon, to ensure that family caregivers receive the support that they deserve and desire.

## REFERENCES

- AARP (2008). Chronic care: A call to action for health reform. *AARP Public Policy Institute, Beyond 50.09*, 1-116.
- Aborampa, O. (1999). Women's roles in the mourning rituals of the Akan of Ghana. *Ethnology*, 38(3), 257-271.
- Almberg, B., Grafstrom, M., & Winblad, B. (2000). Caregivers of relatives with dementia: experiences encompassing social support and bereavement. *Aging & Mental Health*, 4(1), 82-89.
- Anderson, J. R., & Turner, W. L. (2010). When caregivers are in need of care: African-American caregivers' preferences for their own later life care. *Journal of Aging Studies*, 24(1), 65-73.
- Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior*, 45(4), 422.
- Aneshensel, C. S., Pearlin, L. I., Levy-Storms, L., & Schuler, R. H. (2000). The transition from home to nursing home mortality among people with dementia. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 55(3), S152.
- Aranda, M. P., & Knight, B. G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37(3), 342.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13(6), 375-384.
- Ayres, L. (2000). Narratives of family caregiving: Four story types. *Research in Nursing and Health*, 23, 359-371.
- Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871.
- Barrera, M., Sandler, I. N., & Ramsay, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology*, 9(4), 435-447.
- Barrett, R. K., & Heller, K. S. (2002). Death and dying in the Black experience. *Journal of Palliative Medicine*, 5(5), 793-799. doi:10.1089/109662102320880714
- Basmajian, C. & Coutts, C. (2010). Planning for the disposal of the dead. *Journal of the American Planning Association*, 76(3), 305-317.

- Becker, M., Vignoles, V. L., Owe, E., Brown, R., Smith, P. B., Easterbrook, M., ... & Yamakoğlu, N. (2012). Culture and the distinctiveness motive: Constructing identity in individualistic and collectivistic contexts. *Journal of personality and social psychology, 102*(4), 833.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., . . . Lee, C. C. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine, 145*(10), 727.
- Bentelspacher, C. E., Duncan, E., Collins, B., Scandell, D. J., & Regulus, T. (2006). African American informal support networks. *Social Work in Mental Health, 4*(3), 23-43.
- Bernard, L. L., & Guarnaccia, C. A. (2003). Two models of caregiver strain and bereavement adjustment: A comparison of husband and daughter caregivers of breast cancer hospice patients. *The Gerontologist, 43*(6), 808.
- Bern-Klug (2008). The emotional context facing nursing home residents' families: A call for role reinforcement strategies from nursing homes and the community. *Journal of the American Medical Directors Association, 9*(1), 36.
- Bible (n.d.). John 14: 1-4 (King James Version).
- Bonanno, G. A., Wortman, C. B., & Nesse, R. M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging, 19*(2), 260.
- Bond, M. J., Clark, M. S., & Davies, S. (2003). The quality of life of spouse dementia caregivers: changes associated with yielding to formal care and widowhood. *Social Science & Medicine, 57*(12), 2385-2395.
- Borkan, J. M., Quirk, M., & Sullivan, M. (1991). Finding meaning after the fall: injury narratives from elderly hip fracture patients. *Social Science & Medicine, 33*(8), 947-957.
- Bowlby, J. (1973). Attachment and loss: Separation (Vol.2). New York: Basic Books.
- Bramble, M., Moyle, W., & McAllister, M. (2009). Seeking connection: Family care experiences following long-term dementia care placement. *Journal of Clinical Nursing, 18*(22), 3118-3125.
- Brammer, L. M., & Abrego, P. J. (1981). Intervention strategies for coping with transitions. *The Counseling Psychologist, 9*(2), 19-36. doi: [10.1177/001100008100900203](https://doi.org/10.1177/001100008100900203)
- Bridges, W., & Bridges, S. (2009). It isn't the changes that do you in. In W. Bridges (Ed.), *Managing transitions: Making the most of change* (3rd ed., pp. 5). Philadelphia, PA: Da Capo Lifelong Books.

- Brown, M. A., & Powell-Cope, G. M. (1991). AIDS family caregiving: Transitions through uncertainty. *Nursing Research*, 40.
- Bullock, K., Crawford, S. L., & Tennstedt, S. L. (2003). Employment and caregiving: Exploration of African American caregivers. *Social Work*, 48(2), 150-162.
- Burke, L. A., Neimeyer, R. A., & McDevitt-Murphy, M. E. (2010). African American homicide bereavement: Aspects of social support that predict complicated grief, PTSD, and Depression. *Omega: Journal Of Death & Dying*, 61(1), 1-24. doi:10.2190/OM.61.1.a
- Burton, A., Haley, W., & Small, B. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Ageing & Mental Health*, 10(3), 319-326.
- Cadell, S. & Marshall, S. (2007). The (re)construction of self after the death of a partner to HIV/AIDS. *Death Studies*, 31, 537-548.
- Carter, P. A., Mikan, S. Q., & Simpson, C. (2009). A feasibility study of a two-session home-based cognitive behavioral therapy–insomnia intervention for bereaved family caregivers. *Palliative and Supportive Care*, 7(02), 197-206.
- Carter-Edwards, L., Fisher, J. T., Vaughn, B. J., & Svetkey, L. P. (2002). Church rosters: Is this a viable mechanism for effectively recruiting African Americans for a community-based survey? *Ethnicity and Health*, 7, 41–55.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92-100.
- Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science & Medicine*, 30(11), 1161-1172.
- Chick, N., & Meleis, A. I. (1986). Transitions: A nursing concern. *School of Nursing Departmental Papers*, , 9.
- Chow, T. W., Ross, L., Fox, P., Cummings, J. L., & Lin, K. M. (2000). Utilization of Alzheimer's disease community resources by Asian-Americans in California. *International Journal of Geriatric Psychiatry*, 15(9), 838-847.
- Clark, M., & Huttlinger, K. (1998). Elder care among Mexican American families. *Clinical Nursing Research*, 7(1), 64-81.
- Clay, Roth, Wadley & Haley (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry*, 23: 857–862.



- Colón, M., & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice and Palliative Medicine*, 20(3), 182-190.
- Conerly, R. C., Baker, F., Dye, J., Douglas, C. Y., & Zabora, J. (2002). Measuring depression in African American cancer survivors: The reliability and validity of the Center for Epidemiologic Study-Depression (CES-D) scale. *Journal of Health Psychology*, 7(1), 107.
- Coon, D. W. & Evans, B. C. (2009). Empirically Based Treatments for Family Caregiver Distress: What Works and Where Do We Go from Here? *Geriatric Nursing*, 30(6), 426–436.  
<http://dx.doi.org/10.1016/j.gerinurse.2009.09.010>
- Coon, D., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., & Arguelles, T. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: findings from the REACH study. *Aging & Mental Health*, 8(4), 330-345.
- Coon, D. W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and Depression Management: Psychoeducational Skill Training Interventions for Women Caregivers of a Relative With Dementia, *The Gerontologist*, 43 (5), 678–689.
- Cooper, C., Katona, C., & Livingston, G. (2008). Validity and reliability of the brief COPE in carers of people with dementia: The LASER-AD Study. *The Journal of Nervous and Mental Disease*, 196(11), 838.
- Cox, C., & Monk, A. (1990). Minority caregivers of dementia victims: A comparison of Black and Hispanic families. *Journal of Applied Gerontology*, 9(3), 340.
- Cox, C., & Monk, A. (1996). Strain among caregivers: Comparing the experiences of African American and Hispanic caregivers of Alzheimer's relatives. *The International Journal of Aging and Human Development*, 43(2), 93-105.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* Sage Publications, Inc.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130.
- Creswell, J. W., & Plano-Clark, V. L. (2007). *Designing and conducting mixed methods research* Sage Publications, Inc.
- Davies, S., & Nolan, M. (2003). 'Making the best of things': relatives' experiences of decisions about care-home entry. *Ageing & Society*, 23(04), 429-450.

- Davies, S., & Nolan, M. (2006). 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies*, 43(3), 281-291.
- Dellasega, C., Mastrian, K., & Weinert, C. (1995). The process and consequences of institutionalizing an elder. *Western Journal of Nursing Research*, 17(2), 123.
- Derose, K. P., Hawes-Dawson, J., Fox, S. A., Maldonado, N., Tatum, A., Kington, R. (2000). Dealing with diversity: Recruiting churches and women for a randomized trial of mammography promotion. *Health Education and Behavior*, 27, 632-648.
- Dilworth-Anderson, P. (2011). Introduction to the science of recruitment and retention among ethnically diverse populations. *The Gerontologist*, 51(suppl 1), S1.
- Dilworth-Anderson, P., Boswell, G., & Cohen, M. D. (2007). Spiritual and religious coping values and beliefs among African American caregivers: A qualitative study. *Journal of Applied Gerontology*, 26(4), 355.
- Dilworth-Anderson, P., Thaker, S., & Burke, J. M. D. (2005). Recruitment strategies for studying dementia in later life among diverse cultural groups. *Alzheimer Disease & Associated Disorders*, 19(4), 256.
- Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research. *The Gerontologist*, 42(2), 237.
- Dilworth-Anderson, P., Williams, S. W., & Cooper, T. (1999). The contexts of experiencing emotional distress among family caregivers to elderly African Americans. *Family Relations*, 48(4), 391-396.
- Ejiogu, N., Norbeck, J. H., Mason, M. A., Cromwell, B. C., Zonderman, A. B., & Evans, M. K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. *The Gerontologist*, 51(suppl 1), S33.
- Ellifritt, J., Nelson, K. A., & Walsh, D. (2003). Complicated bereavement: A national survey of potential risk factors. *American Journal of Hospice and Palliative Medicine*, 20(2), 114.
- Elliott, B. J. (2005). *Using narrative in social research: Qualitative and quantitative approaches*. Sage Publications Ltd.
- Evans, B. C., Belyea, M. J., & Ume, E. (2011). Mexican American males providing personal care for their mothers. *Hispanic Journal of Behavioral Sciences*, 33(2), 234-260. doi:10.1177/0739986311398615

- Evans, B. C., Coon, D. W., & Crogan, N. L. (2007). Personalismo and breaking barriers: Accessing Hispanic populations for clinical services and research. *Geriatric Nursing, 28*(5), 289-296.
- Evans, B. C., Coon, D. W., & Ume, E. (2011). Use of theoretical frameworks as a pragmatic guide for mixed methods studies: A methodological necessity? *Journal of Mixed Methods Research, 5*(4), 276-292.
- Evans, B. C., Crogan, N., Belyea, M., & Coon, D. (2009). Utility of the life course perspective in research with Mexican American caregivers of older adults. *Journal of Transcultural Nursing, 20*(1), 5-14.
- Evans, B. C. & Ume, E. (2012). Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where we are and where we need to go. *Nursing Outlook, 60*, 370-375.
- Fahy, P. J. (2003). Indicators of support in online interaction. *The International Review of Research in Open and Distance Learning, 4*(1), Article 4.1. 6.
- Family Caregiver Alliance (2001). Selected caregiver statistics (Fact Sheet). San Francisco, CA.
- Family Caregiver Alliance. (2010). *Health care reform and family caregivers*. 1-4. Retrieved on March 28, 2013 from website:  
<http://caregiver.org/caregiver/jsp/content/pdfs/HCR%20provisions%20for%20caregivers-2010.pdf>
- Feinberg, L., Reinhard, S. C., Houser, A. & Choula, R. (2011). Valuing the invaluable: 2011 Update. The growing contributions and costs of family caregiving. *AARP Public Policy Institute: Insights on the Issues*.  
<http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>
- Fontana, A., & Frey, J.H.(2008). The interview: From neutral stance to political involvement. *Collecting and Interpreting Qualitative Materials, , 115-160*.
- Fontana, A., & Frey, J. (1998). Interviewing: The art of science. In N. Denzin, & Y. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp. 47-78). Thousand Oaks, CA: Sage.
- Fouad, M. N., Partridge, E., Green, B. L., Kohler, C., Wynn, T., et al. (2000). Minority recruitment in clinical trials: a conference at Tuskegee, researchers and the community. *Annals of Epidemiology, 10*, S35–40.
- Fowler, F. J., Coppola, K. M., & Teno, J. M. (1999). Methodological challenges for measuring quality of care at the end of life. *Journal of Pain and Symptom Management, 17*(2), 114-119.

- Fox, K., Levkoff, S., & Hinton, W. L. (1999). Take up the caregiver's burden: stories of care for urban African American elders with dementia. *Culture, Medicine and Psychiatry*, 23(4), 501-529.
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging*, 22(1), 37-51. doi:http://dx.doi.org/10.1037/0882-7974.22.1.37
- Gary, L. E., & Berry, G. L. (1985). Depressive symptomatology among Black men. *Journal of Multicultural Counseling and Development*, 13(3), 121-129.
- Gaugler, J. E., Pearlin, L. I., Leitsch, S. A. & Davey, A. (2001). Relinquishing in-home dementia care: Difficulties and perceived helpfulness during the nursing home transition. *American Journal of Alzheimers Disease and Other Dementias*, 16(1), 32-42. Doi: 10.1177/153331750101600102
- George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26(3), 253.
- Gerdner, L. A., Tripp-Reimer, T., & Simpson, H. C. (2007). Hard lives, God's help, and struggling through: Caregiving in Arkansas Delta. *Journal of Cross-Cultural Gerontology*, 22(4), 355-374.
- Gerring, J. (2004). What is a case study and what is it good for? *American Political Science Review*, 98(2), 341-354.
- Godden, S., Ambler, G., & Pollock, A. M. (2010). Recruitment of minority ethnic groups into clinical cancer research trials to assess adherence to the principles of the Department of Health Research Governance Framework: National sources of data and general issues arising from a study in one hospital trust in England. *Journal of Medical Ethics*, 36(6), 358.
- Goldsmith, B., Morrison, R., Vanderwerker, L., & Prigerson, H. (2008). Elevated rates of prolonged grief disorder in African Americans. *Death Studies*, 32(4), 352-365.
- Gonyea, J. G., Paris, R., & de Saxe Zerden, L. (2008). Adult daughters and aging mothers: The role of guilt in the experience of caregiver burden. *Aging & Mental Health*, 12(5), 559-567.
- Grant, I., Adler, K. A., Patterson, T. L., Dimsdale, J. E., Ziegler, M. G., & Irwin, M. R. (2002). Health consequences of Alzheimer's caregiving transitions: Effects of placement and bereavement. *Psychosomatic Medicine*, 64(3), 477.
- Guberman, N & Maheu, P. (1999). Combining employment and caregiving: An intricate juggling act. *Canadian Journal on Aging / La Revue Canadienne du vieillissement*, 18, 84-106. Doi:10.1017/S0714980800009648.

- Halbesleben, J. R. B. (2006). Sources of social support and burnout: A meta-analytic test of the conservation of resources model. *Journal of Applied Psychology, 91*(5), 1134-1145. doi:10.1037/0021-9010.91.5.1134
- Haley, W., Gitlin, L., Wisniewski, S., Mahoney, D., Coon, D., & Winter, L., et al. (2004). Well-being, appraisal, and coping in African American and White dementia caregivers: Findings from the REACH study. *Aging & Mental Health, 8*, 316–329.
- Hardy, M. A. (1993). *Regression with dummy variables*. Sage Publications, Inc.
- Hassan, E. (2006). Recall bias can be a threat to retrospective and prospective research designs. *The Internet Journal of Epidemiology, 3*(2), 339–412.
- Hebert, R. S., Copeland, V. C., Schulz, R., Amato, C. A., & Arnold, R. M. (2008). Preparing family caregivers for the death of a loved one: Implications for hospital social workers. *Journal of Social Work in End-Of-Life and Palliative Care, 4*(4), 269-285. doi:10.1080/15524250903081533
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine, 9*(3), 683-693.
- Hebert, R. S., Prigerson, H. G., Schulz, R., & Arnold, R. M. (2006). Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *Journal of Palliative Medicine, 9*(5), 1164-1171. doi:10.1089/jpm.2006.9.1164
- Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management, 37*(1), 3-12.
- Hesse-Biber, S. (1997). *Am I thin enough yet? The cult of thinness and the commercialization of identity*. Oxford University Press, USA.
- Hines-Smith, S. (2002). "Fret no more my child... for I'm all over heaven all day": Religious beliefs in the bereavement of African American, middle-aged daughters coping with the death of an elderly mother. *Death Studies, 26*(4), 309-323.
- Holtzlander, L. F., & Duggleby, W. D. (2009). The hope experience of older bereaved women who cared for a spouse with terminal cancer. *Qualitative Health Research, 19*(3), 388-400.
- Holland, J. M., Currier, J. M. & Gallagher-Thomson, D. (2009). Outcomes from the Resources for Enhancing Alzheimer's Caregiver Health(REACH) program for bereaved caregivers. *Psychology and Aging, 24*(1), 190-202.

- Horowitz, M. J., Siegel, B., Holen, A., Bonanno, G. A., Milbrath, C., & Stinson, C. H. (2003). Diagnostic criteria for complicated grief disorder. *Focus, 1*(3), 290.
- James, W. (1907). *Pragmatism, a new name for some old ways of thinking: Popular lectures on philosophy* Longmans, Green.
- James, W. (1975). *Pragmatism* Harvard University Press.
- James, W. (1981). *Pragmatism and the Meaning of Truth* Harvard University Press.
- Janevic, M. R. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience. *The Gerontologist, 41*(3), 334.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112.
- Kagawa-Singer, M. (1994). Diverse cultural beliefs and practices about death and dying in the elderly. *Cultural Diversity and Geriatric Care: Challenges to the Health Professions*. In D. Wieland, et al. The Haworth Press Inc, 101-116.
- Kaufman, A. V., Kosberg, J. I., Leeper, J. D., & Tang, M. (2010). Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. *Journal of Gerontological Social Work, 53*(3), 251-269.
- Knobf, M. T., Juarez, G., Lee, S. Y. K., Sun, V., Sun, Y., & Haozous, E. (2007). Challenges and strategies in recruitment of ethnically diverse populations for cancer nursing research. *Oncology Nursing Forum, 34*(6) 1187-1194.
- Koop, P. M., & Strang, V. R. (2003). The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research, 12*(2), 127.
- Krause, N. (1995). Negative interaction and satisfaction with social support among older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 50*(2), P59.
- Krause, N., & Markides, K. (1990). Measuring social support among older adults. *The International Journal of Aging and Human Development, 30*(1), 37-53.
- Larkin, M. (2009). Life after caring: The post-caring experiences of former carers. *British Journal of Social Work, 39*(6), 1026.

- Leech, N. L., & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. *School Psychology Quarterly*, 22(4), 557.
- Li, L. W. (2005). From caregiving to bereavement: Trajectories of depressive symptoms among wife and daughter caregivers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 60(4), P190.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications, Inc.
- Lowey, S. E. (2008). Communication between the nurse and family caregiver in end-of-life care: A review of the literature. *Journal of Hospice and Palliative Nursing*, 10(1), 35-45.
- Lubben, J. E. (1988). Assessing social networks among elderly populations. *Family & Community Health: The Journal of Health Promotion & Maintenance*, 11(3), 42-52.
- Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing and Society*, 23(4), 487-506.
- Mann, K. (2001). Shifting paradigms in the study of the African diaspora and of Atlantic history and culture. *Slavery and Abolition*, 22(1), 1-2.
- Markens, S., Fox, S. A., Taub, B., Gilbert, M. L. (2002). Role of Black churches in health promotion programs: lessons from the Los Angeles mammography promotion in churches program. *American Journal of Public Health*, 92, 805-10.
- Martyn, K. K., & Belli, R. F. (2002). Retrospective data collection using event history calendars. *Nursing Research*, 51(4), 270.
- McCallum, T., Longmire, C. F., & Knight, B. G. (2007). African American and White female caregivers and the sociocultural stress and coping model. *Clinical Gerontologist*, 30(4), 25-37.
- Meleis, A. I., Sawyer, L. M., Im, E. O., Hilfinger Messias, D. A. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12-28.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Moreno-John, G., Gachie, A., Fleming, C. M., Nápoles-Springer, A., Mutran, E., Manson, S. M., & Perez-Stable, E. J. (2004). Ethnic minority older adults participating in clinical research. *Journal of Aging and Health*, 16(5 suppl), 93S.
- Morgan, D. L. (1997). *Focus Groups as Qualitative Research*. Sage Publications, Inc.

- Morse, C. A., & Messimeri-Kianidis, V. (2002). Keeping it in the family: Caregiving in Australian-Greek families. *Social Work in Health Care, 34*(3-4), 299-314.
- National Alliance for Caregiving, & AARP. (2009, November 2009). *Caregiving in the U.S.: A focused look at the ethnicity of those caring for someone age 50 or older.*
- National Alliance for Caregiving, & AARP. (2009). *Caregiving in the U.S.: A focused look at those caring for someone age 50 or older.* The MetLife Foundation; AARP. Retrieved October 22, 2011, from [http://www.caregiving.org/data/Caregiving\\_in\\_the\\_US\\_2009\\_full\\_report.pdf](http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf)
- National Alliance for Caregiving & Evercare (2006). Evercare study of *caregivers in decline*. A close-up look at the health risks of caring for a loved one, 1-48. Retrieved April 2, 2013, from [www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf](http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf).
- National Institute of Health. (2001). Decision tree for inclusion of minorities in clinical research (not an NIH-Defined Phase III Clinical Trial) *NIH/OER*. Retrieved from [http://grants.nih.gov/grants/peer/tree\\_minorities\\_clinical\\_research.pdf](http://grants.nih.gov/grants/peer/tree_minorities_clinical_research.pdf)
- Naylor, M. D., Aiken, L. H., Kurtzman, E. T., Olds, D. M. & Hirschman, K.B. (2011). The importance of transitional care in achieving health reform. *Health Affairs, 30*(4), 746-754. doi: 10.1377/hlthaff.2011.0041
- Ntiri, D., & Stewart, M. (2010). Recruitment challenges: lessons from senior centers and older African-American participants in a literacy study. *Educational Gerontology, 36*(2), 148-154.
- Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory*. McGraw, New York.
- Orzeck, P., & Silverman, M. (2008). Recognizing post-caregiving as a part of the caregiving career: Implications for practice. *Journal of Social Work Practice, 22*(2), 211-220.
- Owen, J. E., Goode, K. T., & Haley, W. E. (2001). End of life care and reactions to death in African-American and White family caregivers of relatives with Alzheimer's disease. *Omega, 43*(4), 349-361.
- Pang, F., Chow, T., Cummings, J., Leung, V., Chiu, H., Lam, L., . . . Wang, S. (2002). Effect of neuropsychiatric symptoms of Alzheimer's disease on Chinese and American caregivers. *International Journal of Geriatric Psychiatry, 17*(1), 29-34.
- Pargament, K. I., Ensing, D. S., Falgout, K., Olsen, H., Reilly, B., Haitsma, K., & Warren, R. (1990). God help me: Religious coping efforts as predictors of the



outcomes to significant negative life events. *American Journal of Community Psychology*, 18(6), 793-824.

- Paskett, E. D., Reeves, K. W., McLaughlin, J. M., Katz, M. L., McAlearney, A. S., Ruffin, M. T., . . . Gehlert, S. (2008). Recruitment of minority and underserved populations in the United States: The centers for population health and health disparities experience. *Contemporary Clinical Trials*, 29(6), 847-861.
- Patterson, T. L., Semple, S., Shaw, W., Yu, E., He, Y., Zhang, M., . . . Grant, I. (1998). The cultural context of caregiving: a comparison of Alzheimer's caregivers in Shanghai, China and San Diego, California. *Psychological Medicine*, 28(05), 1071-1084.
- Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods* (3rd ed.). London: Sage Publications.
- Pearlin, L. I., & Zarit, S. H. (1993). Caregiving systems: Informal and formal helpers. In S. H. Zarit, L. I. Pearlin & K. W. Schaie (Eds.), *Research into Informal Caregiving: Current Perspectives and Future Directions* (pp. 155-168) Lawrence Erlbaum Associates, Inc.
- Phillips, L. R. & Reed, P. G. (2009). Into the abyss of someone else's dying: The voice of the end-of-life caregiver. *Clinical Nursing Research*, 18(1), 80-97. Doi: 10.1177/1054773808330538
- Pierret, C. R. (2006). The 'Sandwich Generation': Women caring for parents and children. *Monthly Labor Review*, 129, 3-9.
- Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45(1), 90.
- Poindexter, C. C., Linsk, N. L., & Warner, R. S. (1999). "He listens... and never gossips:" Spiritual coping without church support among older, predominantly African-American caregivers of persons with HIV. *Review of Religious Research*, 40(3), 230-243.
- Popay J., Rogers A. & Williams G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research*, 8(3), 341-351.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1(3), 385-401.
- Ragin, C. (2000). *Fuzzy-Set Social Science*. Chicago: The University of Chicago Press.

- Richardson, V. E. (2010). Length of caregiving and well-being among older widowers: Implications for the dual process model of bereavement. *OMEGA--Journal of Death and Dying*, 61(4), 333-356.
- Roberts, R. E. (1980). Reliability of the CES-D scale in different ethnic contexts. *Psychiatry Research*, 2(2), 125-134. doi:10.1016/0165-1781(80)90069-4
- Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(4), P185.
- Rubio, D. M. G., Berg-Weger, M., Tebb, S. S., & Parnell, L. A. (2001). Comparing the well-being of post-caregivers and noncaregivers. *American Journal of Alzheimer's Disease and other Dementias*, 16(2), 97.
- Ruland, C. M. & Moore, S. M. (1998). Theory construction based on standards of care: A proposed theory of the Peaceful End-of-Life. *Nursing Outlook*, 46, 169-175.
- Ryan, A., & Scullion, H. (2000). Nursing home placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing*, 32(5), 1187-1195. Doi:10.1046/j.1365-2648.2000.01589.x
- Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in Nursing and Health*, 16(3), 213-218.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*,
- Sandelowski, M. (1995). Triangles and crystals: On the geometry of qualitative research. *Research in Nursing & Health*, 18(6), 569-574.
- Sandelowski, M. (2000). Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Research in Nursing and Health*, 23(3), 246-255.
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33(1), 77-84.
- Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative studies. *Qualitative Health Research*, 13(7), 905.
- Sandelowski, M., Davis, D. H., & Harris, B. G. (1989). Artful design: Writing the proposal for research in the naturalist paradigm. *Research in Nursing and Health*, 12(2), 77-84.
- Sandelowski, M., Voils, C. I., & Knafl, G. (2009). On quantitizing. *Journal of Mixed Methods Research*, 3(3), 208.

- Sanders, S., Ott, C., Kelber, S., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*(6), 495-523.
- Sarason, I. G., Levine, H. M., Basham, R. B., & Sarason, B. R. (1983). Assessing social support: The social support questionnaire. *Journal of Personality and Social Psychology, 44*(1), 127.
- Sarason, I. G., Sarason, B. R., Shearin, E. N., & Pierce, G. R. (1987). A brief measure of social support: Practical and theoretical implications. *Journal of Social and Personal Relationships, 4*(4), 497.
- Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use. *Journal of Gerontological Social Work, 47*(1), 133-156.
- Shaw, W. S., Patterson, T. L., Semple, S. J., Grant, I., YU, E. S. H., Zhang, M. Y. He, Y., & Wu, W. Y. (1997). A cross-cultural validation of coping strategies and their associations with caregiving distress. *The Gerontologist, 37*(4): 490-504  
doi:10.1093/geront/37.4.490
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality. *JAMA: The Journal of the American Medical Association, 282*(23), 2215.
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., . . . Burton, L. (2001). Involvement in caregiving and adjustment to death of a spouse. *JAMA: The Journal of the American Medical Association, 285*(24), 3123.
- Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *JAMA: The Journal of the American Medical Association, 292*(8), 961.
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *American Journal of Geriatric Psych, 14*(8), 650.
- Schulz, R., Hebert, R., & Boerner, K. (2008). Bereavement after caregiving. *Geriatrics, 63*(1), 20.
- Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., . . . Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*(20), 1936-1942.
- Schumacher, K. L., & Meleis, A. I. (1994). Transitions: A central concept in nursing. *Image Journal of Nursing Scholarship, 26*(2), 119-127.

- Schon, D. (1983). *The Reflective Practitioner*. New York, NY: Basic Books.
- Scientific Software. (2008). *ATLAS.ti 5-Revised*. Cologne, Germany:
- Selye, H. (1976). Forty years of stress research: Principal remaining problems and misconceptions. *Canadian Medical Association Journal*, *115*(1), 53.
- Sharma, M., & Romas, J. A. (2008). *Theoretical foundations of health education and health promotion* (pp. 49-50). Sudbury, Massachusetts: Jones and Bartlett Publishers.
- Sheikh, A., Halani, L., Bhopal, R., Netuveli, G., Partridge, M. R., Car, J., . . . Levy, M. (2009). Facilitating the recruitment of minority ethnic people into research: Qualitative case study of South Asians and asthma. *PLoS Medicine*, *6*(10), e1000148.
- Smith, D. J. (2004). Burials and belonging in Nigeria: Rural-urban relations and social inequality in a contemporary African ritual. *American Anthropologist*, *106*(3), 569-579.
- Spradley, J. P. & Baker, K. (1980). *Participant observation* Holt, Rinehart and Winston New York.
- Stahl, S. M., & Vasquez, L. (2004). Approaches to improving recruitment and retention of minority elders participating in research. *Journal of Aging and Health*, *16*(5 suppl), 9S.
- Stajduhar, K. I., Martin, W., & Cairns, M. (2010). What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative and Supportive Care*, *8*(03), 277-289.
- Sudha, S., & Mutran, E. J. (1999). Ethnicity and eldercare comparison of attitudes toward adult care homes and care by families. *Research on Aging*, *21*(4), 570-594.
- Tashakkori, A., & Teddlie, C. (2010). *Sage Handbook of Mixed Methods in Social and Behavioral Research*. Sage Publications, Inc.
- Taxis, J. C. (2006). Attitudes, values, and questions of African Americans regarding participation in hospice programs. *Journal of Hospice and Palliative Nursing*, *8*(2), 77-85.
- Taylor, D., Kuchibhatla, M., Østbye, T., Plassman, B., & Clipp, E. (2008). The effect of spousal caregiving and bereavement on depressive symptoms. *Aging and Mental Health*, *12*(1), 100-107.

- Turner, W. L., Wallace, B. R., Anderson, J. R., & Bird, C. (2004). The last mile of the way: Understanding caregiving in African American families at the end-of-life. *Journal of Marital and Family Therapy*, 30(4), 427-438.
- U.S. Census Bureau. (2011). State and County Quickfacts. Retrieved June 14, 2011, from <http://quickfacts.census.gov/qfd/states/00000.html>
- U.S. Department of Health and Human Services, & U.S. Department of Labor. (2003). *The future supply of long-term care workers in relation to the aging baby boom generation*. Report to Congress. (Washington: DHSS).
- Uhlenberg, P. (1996). Mutual attraction: Demography and life-course analysis. *The Gerontologist*, 36(2), 226.
- Ume, E., & Evans, B. C. (2012). Death bed promise: Burden or blessing? *Issues in Mental Health Nursing*, 33(6), 400-402. doi: 10.3109/01612840.2011.639483
- Ume, E. P., & Evans, B. C. (2011). Chaos and Uncertainty: The Post-Caregiving Transition. *Geriatric Nursing*, 32(4), 288-293.
- Van der Geest, S. (2006). Between death and funeral mortuaries and the exploitation of liminality in Kwahu Ghana. *Africa*, 76(4) 485-501.
- Wallace Williams, S., Dilworth-Anderson, P., & Goodwin, P. Y. (2003). Caregiver role strain: The contribution of multiple roles and available resources in African-American women. *Aging and Mental Health*, 7(2), 103-112. DOI:10.1080/1360786031000072312
- Walsh, S. M., Estrada, G. B., & Hogan, N. (2004). Individual telephone support for family caregivers of seriously ill cancer patients. *Medsurg Nursing : Official Journal of the Academy of Medical-Surgical Nurses*, 13(3), 181-189.
- Williams, I. C., & Corbie-Smith, G. (2006). Investigator beliefs and reported success in recruiting minority participants. *Contemporary Clinical Trials*, 27(6), 580-586.
- Williams, S. W., & Dilworth-Anderson, P. (2002). Systems of social support in families who care for dependent African American elders. *The Gerontologist*, 42(2), 224.
- Williams, S. W., Dilworth-Anderson, P., & Goodwin, P. (2003). Caregiver role strain: The contribution of multiple roles and available resources in African-American women. *Aging and Mental Health*, 7(2), 103-112.
- Wilsey, S. & Shear, K (2007). Description of social support in treatment narratives of complicated grievers. *Death Studies*, 31, 801-819.

- Wisniewski, S. R., Belle, S. H., Coon, D. W., Marcus, S. M., Ory, M. G., Burgio, L. D., . . . Schulz, R. (2003). The resources for enhancing Alzheimer's caregiver health (REACH): Project design and baseline characteristics. *Psychology and Aging, 18*(3), 375.
- Yancey, A. K., Ortega, A. N. & Kumanyika, S. K. (2005). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1- 28. DOI: 10.1146/annurev.publhealth.27.021405.102113.
- Yee, J. L., & Schulz, R. (2000). Genders differences in psychiatric morbidity among family caregivers: A review and analysis. *Gerontologist , 40*, 147–164.
- Yin, R. K. (2009). *Case Study Research: Design and Methods* Sage Publications, Inc.
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20*(6), 649.
- Zhang, B., Mitchell, S. L., Bambauer, K. Z., Jones, R., & Prigerson, H. G. (2008). Depressive symptom trajectories and associated risks among bereaved Alzheimer disease caregivers. *American Journal of Geriatric Psychiatry, 16*(2), 145.
- Zhang, Y., & Wildemuth, B. M. (2009). Qualitative analysis of content. *Applications of social research methods to questions in information and library science*, 308-319.

APPENDIX A  
TRANSITIONS THEORY

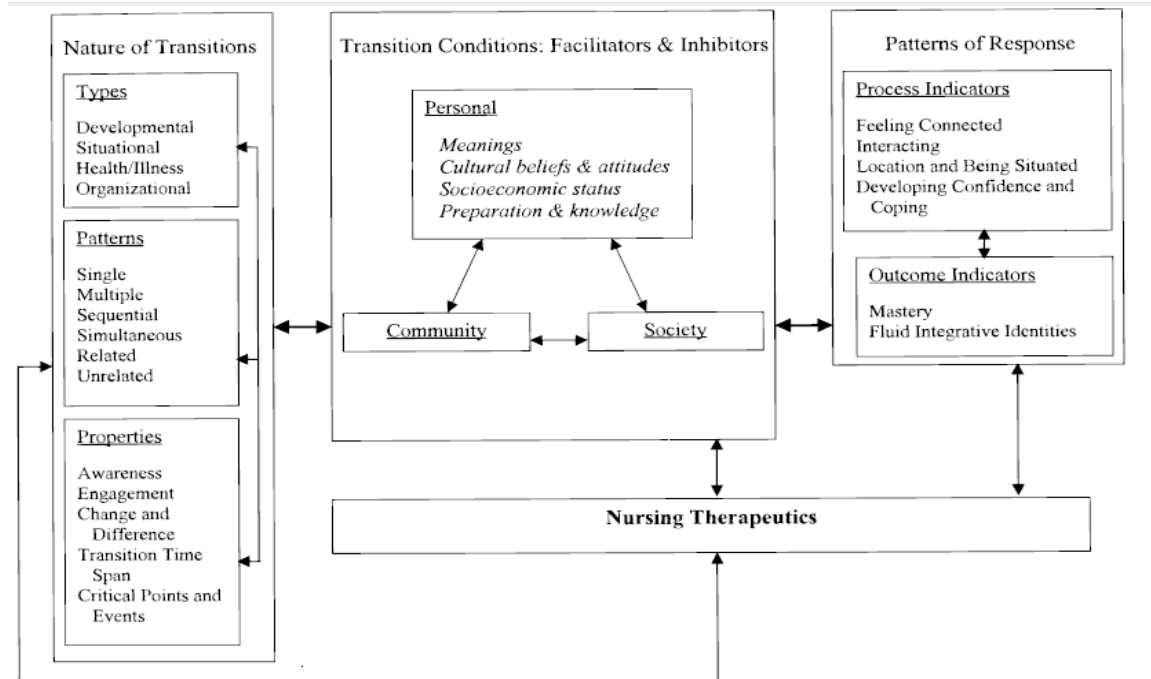


Fig 1. Transitions: a middle-range theory.

Figure 1. Transitions: A middle range theory (Meleis et al., 2000).

*“Reprinted by permission: Afaf. I. Meleis”*



APPENDIX B

SAMPLE OF STRATIFIED SAMPLING PLAN: PCT IN AAPCGS

EARLY POST-CAREGIVING 0-3 years since death of CR				MIDDLE POST-CAREGIVING 4-6 years since death of CR				LATE POST-CAREGIVING 7-10 years since death of CR			
Spouse		Other		Spouse		Other		Spouse		Other	
Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female

ROW 1. Select the box that represents the length of time since death of CR

ROW 2. Working down in that column, select the box that represents the relationship of the PCG to the deceased CR (spouse or other)

ROW 3. Working down in that column, select the box that represents the gender of the PCG (male or female)

The selected cell in the last row represents this case (Each case is an AAPCG)

Stratified Sampling Plan

**Legend:**

S= Post-Caregiver is “spouse”

O= Post-Caregiver is “other” (sibling, daughter/son, niece/nephew, neighbor, friend, etc.)

M=Post-Caregiver is “male”

F= Post-Caregiver is “female”

APPENDIX C  
DATA COLLECTION PLAN

Aim/ Research Question	Data Collection Device	Concept/Variable
Screening 1.a. and 1.b.  2.a. and 2.b.	Screening/Demographic forms PCG Interview Protocol	Screening Caregiving experience, transitions, coping/ adaptive strategies, religious/spiritual coping, social support, cultural and religious influences.
2.a. and 2.b. 3.a. and 3.b.	Brief Cope PCG Interview Protocol	Coping strategies Caregiving experience, transitions, coping/ adaptive strategies, religious/spiritual coping, social support, cultural and religious influences.
3.a. and 3.b. 3.a. and 3.b. 3.a. and 3.b.	Brief Cope CES-D Social Support	Coping strategies Depression Social support

APPENDIX D

TELEPHONE SCREENING FORM/DEMOGRAPHIC QUESTIONNAIRE

**Telephone Screening Form/Demographic Questionnaire**

I would ask you some questions to see if you qualify to participate in our study. This will only take about 15 minutes.

Is this ok with you? **(Received verbal or telephone consent: \_\_\_\_\_)**

1. Gender: \_\_\_\_\_ 2. Age: \_\_\_\_\_ 3. Age at the time care was provided: \_\_\_\_\_

20. Caregiver Education: None \_\_\_ K-12 \_\_\_ HS \_\_\_ Some College \_\_\_ AA/AS \_\_\_ BA/BS \_\_\_ Grad \_\_\_

Code	0.	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	
A	None	Wife	Husband	Mother	Father	Grand-mother	Grand-father	Daughter	Son	Aunt	Uncle	Niece	Nephew	Friend	Sister	Brother	Other		
4.	<b>Primary Care: Who did you provide care to? (Check all that apply based on Code A)</b>																		
5.	How old was the above Care Recipient? _____																		
6.	How long did you provide care? _____ Years _____ Months																		
7.	How long ago did your caregiving stop? _____ Years _____ Months																		
8.	What was the medical diagnosis for the Care Recipient?																		
	0.	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.

9.	B	What kind of Assistance did your loved one that died need?	None	Bathing	Dressing	Grooming	Oral Care	Toileting	Transferring	Walking	Climbing Stairs	Eating	Shopping	Cooking	Managing Meds	Using the Phone	House work	Doing Laundry	Driving	Managing Finances	Decision making
B0	CR independent																				
B1	CG, sole helper																				
B2	CG + Other FCGs helped																				
B3	Paid CG helped																				
B4	Don't know																				
10.	<b>Multiple Caregiving:</b> If you cared for more than one person (age 50+) in your home during the same period of time, who else did you provide care to? <b>(Check all that apply based on Code A)</b>																				
11.	<b>Serial Caregiving:</b> If you cared for one person (age 50+) after another in your home, who else did you provide care to? <b>(Check all that apply based on Code A)</b>																				
12.	Additional CGs- <b>(Use B)</b>																				
13a	Male CG: Y_N_	0.	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.			
13b.	Relationship to CR <b>(Check using Code A)</b>																				
13c.	Uncomfortable with care Y_N_																				

13c.	<p>If yes, what was your reason for being uncomfortable?</p> <ul style="list-style-type: none"> <li>• Cultural: Y_ N_</li> <li>• Religious: Y_ N_</li> <li>• Personal: Y_ N_</li> <li>• Medical: Y_ N_</li> <li>• Other: Y_ N_</li> </ul>
14a.	Did you work outside your home during the time you provided caregiving? Y_ N_
14b.	Did you return to work after caregiving ended? Y_ N_
14c.	How long after caregiving ended before you returned to work? _____ Years _____ Months
15a.	How long after caregiving ended did you feel confident in your ability to cope and manage challenges? Years _____ Months
15b.	<p>On a scale of 1-5 (1- being not confident, 5 being very confident), how confident do you feel about coping/managing challenges at this time?</p> <ul style="list-style-type: none"> <li>• 1 – Not Confident</li> <li>• 2 – A Little Confident</li> <li>• 3 – Somewhat Confident</li> <li>• 4 – Confident</li> <li>• 5 – Very Confident</li> </ul>
16	<p>What is the range of your family income?</p> <ol style="list-style-type: none"> <li>0. No Income</li> <li>1. Less than \$19,000</li> <li>2. \$20,000-\$39,000</li> <li>3. \$40,000-\$59,000</li> <li>4. \$60,000-\$79,000</li> <li>5. More than 80,000</li> </ol>



17.	Was your loved one in hospice? Y_ N_
18.	Did you attend support group? Y_ N_
19.	<ul style="list-style-type: none"> <li>a. How important is religion or spirituality to you?</li> <li>b. Do you have a religious affiliation?</li> <li>c. How often do you engage in religious practices?</li> <li>d. Which religious practices do you participate in?</li> </ul>

**Thank you for your willingness to participate in our study. Please kindly provide your contact information so that we may arrange a specific time to talk to you in more detail.**

APPENDIX E  
INTERVIEW PROTOCOL

- **Remind participant that you will be taping this Interview Session.**
- **Encourage participant to participate only in English.**
- **“I have some questions that will help us understand your views on the caregiving experience. Remember, there are no “right” or “wrong” answers to these questions.”**
- **You are free to refuse to answer any questions.**
- **Everything you say here will be confidential.**
- **Thank you.**

1. Tell me a little bit about your experience of caregiving, for example,
  - a. How did it happen that you started caregiving?
  - b. What difficulties, challenges or burden did you experience? (Gonyea et al, 2008)
  - c. Some people say that caregiving is so difficult and emotionally draining that they feel relieved when caregiving ends. Others say that it was very difficult watching their loved one suffer and that it was a relief when the loved one passed away. What was the experience like for you?
2. What was the hardest thing for you after caregiving ended?
3. Tell me about the strategies you used as you were trying to adjust to life after caregiving, both those that worked and those that did not.
4. What influence did being African American or the influence of culture, have on...
  - a. Your decision to become a caregiver?
  - b. How you dealt with the loss of your loved one?
  - c. How do you think that religion/spirituality influenced your decision to become a caregiver?
5. How did spirituality help you as you worked to adapt to life after caregiving?
6. People say that social support is what gets them through the loss of a loved one.
 

What kind of support (from your family, friends or others) was most meaningful to you after caregiving ended and your loved one died?

  - a. From where did you get most of your social support?
  - b. From whom did you get the least social support?

7. Some people say they feel guilty about some things they did, or did not do, in regards to the care they provided to their loved one, despite doing the best they could at the time (for, example, leaving that loved one alone sometimes). (Spillers, Wellisch, Kim, & Mathews, 2008): What was your experience in regard to your loved one?
8. Although caregiving can be challenging, some people say that it made them feel useful, or gave them an opportunity to pay back their loved one for previous care. They may also notice negative aspects of caregiving such as it was exhausting and sad. What were the positive or negative aspects of your caregiving experience?
9. Finally, please tell me what you believe adjustment to life after caregiving or life after the loss of your loved one should look like.
10. To what extent do you believe that you have achieved that adjustment?
  - a. What helped (or what could help) you achieve adjustment?
  - b. What has hindered you from achieving adjustment?
11. Is there anything that I have not asked you that you will like to tell me?

**Thank you so much for participating in our project. We appreciate your time and opinions.**

**KEEP THE TAPE RUNNING FOR AFEW MINUTES  
AFTER YOU ARE FINISHED**

APPENDIX F  
SAMPLE CES-D

*This section deals with statements people might make about how they feel. For each of the statements, please indicate how often you felt that way during the past month.*

	<i>Rarely or none of the time</i>	<i>Some or a little of the time</i>	<i>Occasionally or a moderate amount of time</i>	<i>Most or almost all of the time</i>	<i>Unknown</i>	<i>Refused</i>
	( <1 day)	(1-2 days)	(3-4 days)	(5-7 days)		
1. <i>I was bothered by things that don't usually bother me.</i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
2. <i>I had trouble keeping my mind on what I was doing.</i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
3. <i>I felt depressed.</i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
4. <i>I felt that everything I did was an effort</i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )
5. <i>I felt hopeful about the future.</i>	0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

6. *I felt fearful.*      0 ( )    1 ( )    2 ( )    3 ( )    4 ( )

7. *My sleep was restless.*    0 ( )    1 ( )    2 ( )    3 ( )    4 ( )

APPENDIX G  
SAMPLE BRIEF COPE



We are interested in how people respond when they confront difficult or stressful situations in their lives, like providing caregiving, and dealing with the death of your loved one. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you did when you experienced stress related to the end of caregiving and the death of your loved one. Obviously, difficult situations bring out somewhat different responses, but think about what you do when you are under a lot of stress associated with the loss of your loved one. {RC 73}

1. *I've been concentrating (I concentrated) my efforts on doing something about the situation I'm in.*

<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this a medium amount</i>	<i>I've been doing this a lot</i>	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

2. *I've been taking (I took) action to try to make the situation better.*

<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this a medium amount</i>	<i>I've been doing this a lot</i>	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

3. *I've been trying (I tried) to come up with a strategy about what to do.*

<i>I haven't been doing this at all</i>	<i>I've been doing this a little bit</i>	<i>I've been doing this a medium amount</i>	<i>I've been doing this a lot</i>	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

4. *I've been thinking (I thought) hard about what steps to take.*
- |   |  |   |                                   |         |         |
|---|--|---|-----------------------------------|---------|---------|
| <i>I haven't been doing this at all</i> | <i>I've been doing this a little bit</i> | <i>I've been doing this a medium amount</i> | <i>I've been doing this a lot</i> | Unknown | Refused |
| 0 ( )                                   | 1 ( )                                    | 2 ( )                                       | 3 ( )                             | -3 ( )  | -4 ( )  |
5. *I've been trying (I tried) to see it in a different light, to make it seem more positive.*
- |   |  |   |                                   |         |         |
|---|--|---|-----------------------------------|---------|---------|
| <i>I haven't been doing this at all</i> | <i>I've been doing this a little bit</i> | <i>I've been doing this a medium amount</i> | <i>I've been doing this a lot</i> | Unknown | Refused |
| 0 ( )                                   | 1 ( )                                    | 2 ( )                                       | 3 ( )                             | -3 ( )  | -4 ( )  |
6. *I've been looking (I looked) for something good in what is (was) happening.*
- |   |  |   |                                   |         |         |
|---|--|---|-----------------------------------|---------|---------|
| <i>I haven't been doing this at all</i> | <i>I've been doing this a little bit</i> | <i>I've been doing this a medium amount</i> | <i>I've been doing this a lot</i> | Unknown | Refused |
| 0 ( )                                   | 1 ( )                                    | 2 ( )                                       | 3 ( )                             | -3 ( )  | -4 ( )  |
7. *I've been accepting (accepted) the reality of the fact that it has happened.*
- |   |  |   |                                   |         |         |
|---|--|---|-----------------------------------|---------|---------|
| <i>I haven't been doing this at all</i> | <i>I've been doing this a little bit</i> | <i>I've been doing this a medium amount</i> | <i>I've been doing this a lot</i> | Unknown | Refused |
| 0 ( )                                   | 1 ( )                                    | 2 ( )                                       | 3 ( )                             | -3 ( )  | -4 ( )  |

APPENDIX H  
SAMPLE SOCIAL SUPPORT INSTRUMENT

*Now I would like to ask you some questions about your friends and family, and the support you receive in the last one month.*

1. Overall, how satisfied have you been with the help you have received from family members, friends, or neighbors?

<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

2. How many relatives, friends, and neighbors do you see or hear from at least once a month?

<i>None</i>	<i>One</i>	<i>Two</i>	<i>Three or Four</i>	<i>Five to eight</i>	<i>Nine or more</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )

3. How many relatives, friends, and neighbors do you feel close to? That is, how many do you feel at ease with, can talk to about private matters, or can call on for help?

<i>None</i>	<i>One</i>	<i>Two</i>	<i>Three or Four</i>	<i>Five to eight</i>	<i>Nine or more</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )

4. How many relatives, friends, neighbors do you feel you can call on for help with chores, transportation, etc.?

<i>None</i>	<i>One</i>	<i>Two</i>	<i>Three or Four</i>	<i>Five to eight</i>	<i>Nine or more</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )

5. *When other people you know have an important decision to make, do they talk to you about it?*

Never	Seldom	Sometimes	Often	Very Often	Always	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	4 ( )	5 ( )	-3 ( )	-4 ( )

6. *In the last one month, how often has someone, such as a family member, friend or provided transportation, pitched in to help you do something that needed to get done, like household chores or yard work, helped you with shopping and /or burial arrangements, packing up your loved one's belongings?*

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

7. *Overall, how satisfied have you been in the last one month, with the help you have received with transportation, housework and yard work, and shopping?*

Not at all	A little	Moderately	Very	N/A	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-2 ( )	-3 ( )	-4 ( )

8. *In the last one month, how often has someone been there with you (physically) in a stressful situation, provided comfort to you, or expressed concern about your well-being?*

Never	Once in a while	Fairly often	Very often	Unknown	Refused
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

9. *In the last one month, how satisfied have you been with the support, comfort, interest and*

*concern you have received from others?*

<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>Very</i>	<i>N/A</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	-2 ( )	-3 ( )	-4 ( )

*10. In the last one month, how often has someone given you information and guidance on some action? For example, they made a difficult situation clearer and easier to understand or told you what they did in a similar situation?*

<i>Never</i>	<i>Once in a while</i>	<i>Fairly often</i>	<i>Very often</i>	<i>Unknown</i>	<i>Refused</i>
0 ( )	1 ( )	2 ( )	3 ( )	-3 ( )	-4 ( )

APPENDIX I  
INFORMATION LETTER

## POST-CAREGIVING TRANSITIONS IN AFRICAN AMERICAN CAREGIVERS

Date: \_\_\_\_\_

Dear \_\_\_\_\_

I am Ebere Ume, RN, MSN, a graduate student under the direction of Professor Bronwynne Evans, PhD, RN, FAAN in the College of Nursing and Healthcare Innovation at Arizona State University. I am doing a research study about the experience of African American family caregivers who cared for an older adult at home, and what happens after that loved one dies. We want to talk about your caregiving experience and what happened when it ended.

I invite you to join our study. To join, you must have provided care to an adult 50 years of age or older for at least three months within the last ten years. Home caregiving must have stopped because the loved one that you cared for died. You must be of African American or African descent, 18 years of age or older, speak and read English, and be willing to participate.

If you want to be in the study, we will interview you privately in person or via skype or video conferencing. We will also ask you to answer some written demographic questions about your home caregiving experience such as the age of the person you cared for, when you cared for them, and whether you cared for more than one person. We will then talk together about your caregiving experience. After the interview, if you prefer, we can continue the written questions on the same day or I can call you by phone and we can complete those questions by phone. You will also be asked to answer some written questions about your social support, how happy or sad you were, or coping strategies that you use during the caregiving experience and since caregiving ended. The total participation time including both the interview and written questionnaire is about two hours.

This interview will be audio-recorded. If we are talking via skype or video conferencing, we will be able to see each other but only the audio will be recorded. The recorded interview files will be saved in a locked cabinet in Dr Evans' office. The recordings will be kept for seven years or until the future intervention grant application based on these data is funded, at that point, all data-related documents including interview files will be destroyed by: Shredding, destroying of interview files and deletion of computer files.

Joining this study is completely voluntary. It is OK for you to say "no." Even if you say "yes" now, you are free to say "no" later, refuse to answer any question, or withdraw from the study at any time. If you withdraw, we will not ask you for any more information but we will use the information you already gave us. The confidentiality of your information will continue to be protected just as if you had continued with the study.



Although there may be no direct benefit to you, you may enjoy telling us your story about caregiving. Your story may be helpful to other African-American caregivers across the country, and to nurses who help other caregivers. The only foreseeable risk or discomfort to you is that the discussions may bring up some emotions about your caregiving experience. If you have trouble dealing with these emotions, we will talk with you about them and give you a list of healthcare providers who could help you.

We want your decision about joining the study to be absolutely voluntary. However, as a “thank-you” for participating, you will receive \$20.

All information you give us is strictly confidential. We will not identify you by name but by a pseudonym and unique study I.D. number. The results of this study may be used in reports, presentations, and publications, but the researchers will not identify you or your family members.

If you prefer a Skype or video conferencing interview, we will read this letter to you and audio-record your verbal consent in order to continue talking with you. Your continued participation in the interview will also serve as your implied consent to participate in this study.

If you have any questions concerning the research study, please contact the research team: Co-Investigator, Ebere Ume at 602-496-0728 or 602-628-1499 and Principal Investigator, Dr. Bronwynne Evans at 602-496-0766. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

We also would like the opportunity to be able to contact you for further studies relating to your caregiving and life after caregiving. If you are willing to be contacted again at a later date for another study:

Please check: Yes  NO

Your name \_\_\_\_\_ Phone Number \_\_\_\_\_

Email \_\_\_\_\_ Signature \_\_\_\_\_

Thank you very much for joining our Study.

## APPENDIX J

### TYPES AND PATTERNS OF TRANSITIONS

Case	Types of Transitions					Patterns of Transitions							
ID	Developmental	Situational	Organizational	Health/illness	Transnational	Total	Single	Multiple	Sequential	Simultaneous	Related	Unrelated	Total
1.													
2.													
3.													
4.													
5.													
6.													
7.													
8.													
9.													
10.													
11.													
12.													
13.													
14.													
15.													
16.													
17.													
18.													
19.													
20.													
21.													
22.													
23.													
24.													
25.													
26.													
27.													
28.													
29.													
30.													
31.													
32.													
33.													
34.													
35.													
36.													
37.													
38.													
39.													
40.													
Totals													

**Analytical decision rules:**

One strike represents any qualifying events within a transition type.

- Developmental (D) = marriages, childbirth, etc.
- Situational (S) = Loss of home, moving, or moving parent to nursing home.
- Health and Illness (HI) = Illness of care recipient, caregiver or family member.
- Organizational (O) = Work or job demands.
- Transnational (T) = Emigration issues

APPENDIX K  
IRB APPROVAL LETTER

**To:** Bronwynne Evans  
NHI

**From:** Mark Roosa, Chair *MR*  
Soc Beh IRB

**Date:** 06/10/2011

**Committee Action:** Exemption Granted

**IRB Action Date:** 06/10/2011

**IRB Protocol #:** 1106006526

**Study Title:** Post-Caregiving Transition in African American Caregivers

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2).

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.

APPENDIX L: TABLE 1

DEMOGRAPHIC DESCRIPTION OF AAPCGS AND CARE RECIPIENTS (CR)

Post-caregivers (n = 40)		Length of caregiving	
Age ranges		0 – 4 years	20(50%)
Caregivers	25-78 years	5-10 years	5(12.5%)
Care Recipients	50-94 years	10-19 years	11(27.5%)
CG gender		>20 years	4(10%)
Male	6	Time since CR's death	
Female	34	0-3 years	17 (43.5%)
Relationship to CR		4-6 years	9 (23%)
Spouses	5 (12.5%)	7-10 Years	13 (33.5%)
Adult Children	35 (87.5%)		
CGs' Years of Education		CR's medical diagnoses	
K-12	4 (10.0%)	Kidney Disease	5 (12.5%)
High School	1 (2.5%)	Stroke	4 (10%)
Some College	7 (17.5%)	Heart disease	4(10%)
AA/AS	1 (2.5%)	Cancer	14(35%)
BA/BS	10 (25.0%)	Dementia/Alzheimer's Dx	5 (12.5%)
Graduate degree	11 (27.5%)	Diabetes	11(27.5%)
Missing	6 (15.0%)	Hypertension	2(5%)
CG's Range of Family Income			
No income	1 (2.5%)		
Less than \$19,000	2 (5.0%)		
\$20,000-\$39,000	15 (37.5%)		
\$40,000-\$59,000	5 (12.5%)		
\$60,000-\$79,000	6 (15.0%)		
More than \$80,000	9 (22.5%)		
CR utilized hospice services			
No Hospice	29 (72.5%)		
Hospice	10 (25.0%)		
CG Attended Support Group			
No Support group	35 (87.5%)		
Support Group	2 (5.0%)		
Multiple/Serial Caregiving			
Multiple caregiving	11 (27.5%)		
Serial Caregiving	18 (45.0%)		
CG worked outside the home during caregiving			
Worked outside	28(70%)		
Did not work outside	12(30%)		



CG returned to work after caregiving ended  
Returned to Work 30 (75.0%)  
Did not return to work 9(22.5)

National Origin of participants  
US-Born 21 (52.5%)  
Nigerian-born 19 (47.5%)

Location of Participants  
Los Angeles, California 31(77.5%)  
Phoenix, Arizona 9(22.5%)

---

APPENDIX M: TABLE 2

INTER-RELATIONSHIP OF LIFESTYLE VARIABLES

Relationships	Spearman Rho	<i>p</i> value
Age and hospice (n=37)	0.334	0.044
Age and multiple-CG (n=37)	0.343	0.038
Age and positive mastery (n=37)	0.384	0.019
Serial caregiving and Coping (n=38)	0.356	0.026
Serial caregiving and my sleep was restless (n=39)	0.459	0.003
Multiple caregiving and hospice (n=38)	0.365	0.024
Relationship to caregiver and CG education (n=8)	0.710	0.048
Income and caregiver education (n=32)	0.513	0.003
Income and work outside the home (n=38)	0.541	0.000
Restless sleep and feeling depressed (n=38)	0.366	0.022
Income and return to work after caregiving (n=38)	0.518	0.001
Self-perception of adjustment and feeling depressed (n=38)	-0.334	0.037
Uncomfortable & hospice (n=13)	0.674	0.016
Uncomfortable and multiple caregiving (n=13)	0.674	0.016
Work outside the home and return to work post caregiving (n=39)	0.739	0.000

APPENDIX N: TABLE 3

TOTAL CES-D SCORES FREQUENCY DISTRIBUTION

---

Mean: 5.95

Standard Deviation: 5.74

---

Total CESD Scores	Frequency (n)	Percent (%)
0.0	7.0	17.5
1.0	3.0	7.5
2.0	6.0	15.0
3.0	3.0	7.5
5.0	2.0	5.0
6.0	2.0	5.0
7.0	3.0	7.5
8.0	3.0	7.5
10.0	4.0	10.0
11.0	1.0	2.5
12.0	1.0	2.5
13.0	2.0	5.0
14.0	1.0	2.5
19.0	1.0	2.5
25.0	1.0	2.5
TOTAL	40.0	100.0

---

APPENDIX O  
CES-D HISTOGRAM

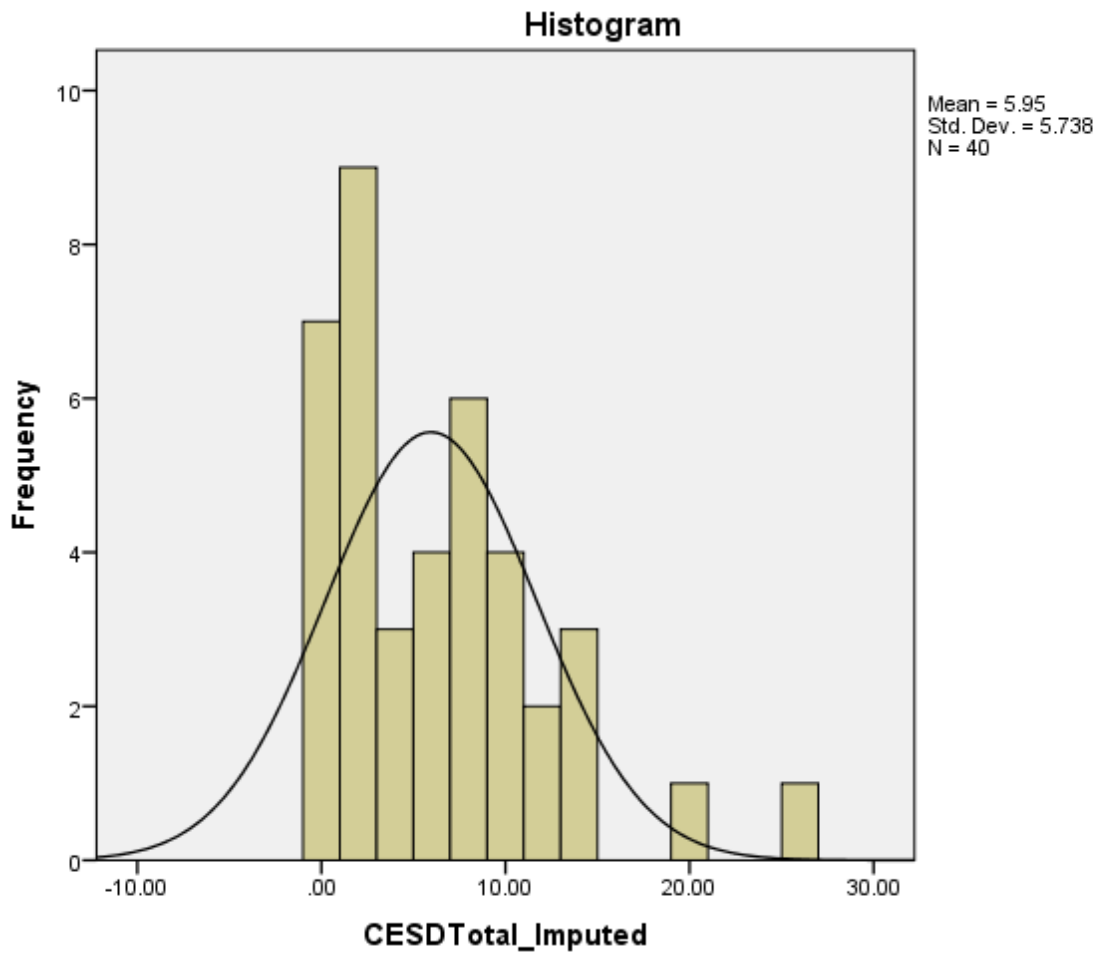


Figure 5. Total CES-D scores

APPENDIX P: TABLE 4

MEASURES OF WELL-BEING ACCORDING TO CES-D ITEMS



Mean CESD Score (n=40)	5.95				
Standard Deviation	5.74				
Maximum CESD Score	25				
Minimum CESD Score	0				
CESD Questions	Rarely	some of the time	Occasionally	Most of the time	Total % of pop. Responding
I was bothered by things that don't usually bother me ( <i>n</i> = 38)	53.8	20.5	23.1	2.6	100
I had trouble keeping my mind on what I was doing ( <i>n</i> = 38)	51.3	33.3	7.7	7.7	100
I felt depressed ( <i>n</i> = 39)	69.2	23.1	2.6	5.1	100
I felt that everything I did was an effort ( <i>n</i> = 39)	56.4	23.1	2.6	17.9	100
I felt hopeful about the future ( <i>n</i> = 38)	5.1	7.7	5.1	79.5	100
I felt fearful ( <i>n</i> = 39)	76.9	12.8	10.3	0.0	100
My sleep was restless ( <i>n</i> = 39)	59.0	28.2	2.6	10.3	100
I was happy ( <i>n</i> = 38)	5.1	10.3	17.9	64.1	100
I felt lonely ( <i>n</i> = 39)	66.7	25.6	0.0	7.7	100
I could not get "going" ( <i>n</i> = 39)	74.4	12.8	10.3	2.6	100
People were unfriendly ( <i>n</i> = 38)	66.7	25.6	2.6	5.1	100
I felt that people disliked me ( <i>n</i> = 39)	84.6	15.4	0.0	0.0	100
	YES		NO		
Mood or emotional well-being improved in past 6 mo. ( <i>n</i> = 35)	71.4		28.6		100

APPENDIX Q: TABLE 5

MEANS TABLE FOR RELATIONSHIP WITH SOCIAL SUPPORT DOMAINS

	<b>US-Born</b>			<b>Nigerian-Born</b>			<b>Entire Sample</b>		
	Mean	SD	n	Mean	SD	n	Mean	SD	n
Age of CR	72.85	12.28	20	75.79	10.49	19	74.28	11.39	39
Length of PCT	4.55	3.15	20	4.97	2.81	19	4.75	2.96	39
CES-D Total	6.15	6.52	20	4.79	3.88	19	5.49	5.37	39
Received Support	8.91	2.90	21	8.63	3.30	19	8.78	3.06	40
Satisfaction with Support	9.38	2.89	21	10.47	1.84	19	9.9	2.48	40
Social Support Network	10.38	3.23	21	11.42	2.55	19	10.88	2.94	40
Negative Interaction	3.76	2.43	21	2.42	1.98	19	3.13	2.30	40

APPENDIX R: TABLE 6

SAMPLE OF CHECKLIST TO MEASURE HEALTHY POST-CAREGIVING  
TRANSITION

Case Numbers		1	2	3	4	5	6	7	8	8	10	11	12	13	14	15	16	17	18	19	20 et c.	
Length of PCT: Early, Middle or Late PCT (E/M/L)																						
Spousal Vs. Adult Child/Other PCG (S/AC/O)																						
<b>Process Indicators</b> Behaviors and actions that demonstrate progression through the PCT																						
Meleis' Domains	Process Indicators																					
Connecte dness	Connected to new friends																					
	Connected to old friends																					
	Connected to family																					
	Returning to work																					
	Connection to God																					
Interactio ns	Interactions with family																					
	Interactions with friends																					
	Identify, separate and classify levels of social support																					
	Toxic relationships (contentious and conflicting)																					
	Non-Toxic relationships																					
Locating/ Being situated	Volunteerism																					
	Being at the right place																					
Confiden ce/ Coping	Able to talk about the deceased without crying or getting upset																					
	Able to see pictures/videos/mementoes of the deceased without crying or getting upset																					
	Able to touch or pack up items																					

	belonging to the deceased																						
	Returning to school																						
<b>Outcome Indicators</b>																							
Behaviors and actions that demonstrate positive adjustment to PCT																							
<b>Case Numbers</b>		1	2	3	4	5	6	7	8	8	10	11	12	13	14	15	16	17	18	19	20 et c.		
<b>Mastery</b>	Managing new environment <ul style="list-style-type: none"> <li>Living alone</li> <li>Changing layout of home</li> </ul>																						
	Ability to make decisions about their lives or future																						
	Ability to take action to improve their lives																						
	Readiness for another caregiving role																						
	Preparing for one's own life and death																						
	<ul style="list-style-type: none"> <li>Planning life – making healthy choices</li> </ul>																						
	<ul style="list-style-type: none"> <li>Retirement investments</li> </ul>																						
	Planning death – Burial plan and plot																						
	Writing a will																						
	Purchasing insurance																						
	Caring for self																						
	1. Ability to recognize stress and burden of the loss																						

	2. Ability to recognize one's limitation																		
	3. No accepting every request and demand																		
	4. Maintaining balance																		
	5. Taking time to do things that make one happy and pampering self																		
	6. Moving on																		
<b>Fluid Integrative Identities</b>	Sense of balance – rest and rejuvenate																		
	Being at peace																		
	Feeling joy																		
	Feeling fulfilled and enriched																		
	Remembering loved one without pain																		
	Establishing new Identity																		
	Growing up too fast																		
Being compassionate <ul style="list-style-type: none"> <li>• Proving support and empathy for other caregiving families by visiting or talking</li> <li>• Place more value in life not material things</li> <li>• Enhance</li> </ul>																			

	spiritual support <ul style="list-style-type: none"> <li>• Be more sensitive to the needs of others</li> <li>• Know when and how to care for other</li> </ul>																		
	Self-perception of adjustment to PCT																		
	Nursing home placement																		
	Support Group																		



APPENDIX S: TABLE 7

MEASURES OF COPING ACCORDING TO THE BRIEF COPE ITEMS

Brief Cope Items	Total <i>n</i>	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I concentrated my efforts on doing something about the situation I'm in	39	10(25.6%)	5(12.8%)	9(23.1%)	15(38.5%)
I took action to try to make the situation better	39	7(17.9%)	5(12.8%)	7(17.9%)	20(51.3%)
I tried to come up with a strategy about what to do.	39	10(25.6%)	7(17.9%)	8(20.5%)	14(35.9%)
I thought hard about what steps to take	39	13(33.3%)	6(15.4%)	4(10.3%)	16(41%)
I tried to see it in a different light, to make it seem more positive	39	6(15.4%)	6(15.4%)	9(23.1%)	18(46.2%)
I looked for something good in what was happening	39	5(12.8%)	5(12.8%)	8(20.5%)	21(53.8%)
I accepted the reality of the fact that it has happened	40	2(5%)	4(10%)	9(22.5%)	25(62.5%)
I learnt to live with it	40	1(2.5%)	5(12.5%)	8(20%)	26(65%)
I got emotional support from others	40	6(15%)	6(15%)	8(20%)	20(50%)
I got comfort and understanding from someone	40	6(15%)	5(12.5%)	7(17.5%)	22(55%)
I tried to get advice or help from other people about what to do	40	17(42.5%)	9(22.5%)	3(7.5%)	11(27.5%)
I got help and advice from other people	40	12(30%)	14(35%)	5(12.5%)	9(22.5%)
I turned to work or other activities to take my mind off things	40	13(32.5%)	5(12.5%)	4(10%)	18(45%)
I did something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping	40	10(25%)	4(10%)	5(12.5%)	21(52.5%)
I said to myself, "This isn't real"	40	25(62.5%)	8(20%)	3(7.5%)	4(10%)

I refused to believe that it has happened	40	29(72.5%)	4(10%)	5(12.5%)	2(5%)
I said things to let my unpleasant feelings escape	40	27(67.5%)	9(22%)	2(5%)	2(5%)
I expressed my negative feelings	40	22(55%)	10(25%)	6(15%)	2(5%)
I gave up trying to deal with it	40	37(92.5%)	2(5%)	1(2.5%)	0.0%
I gave up the attempt to cope	40	36(90%)	2(5%)	1(2.5%)	1(2.5%)
I criticized myself	40	25(62.5%)	10(25%)	3(7.5%)	2(5%)
I blamed myself for things that happened	40	25(62.5%)	11(27.5%)	4(10%)	0.0%

APPENDIX T: TABLE 8

MEASURES OF COPING ACCORDING TO BRIEF COPE DOMAINS

Brief Cope Domains	Total <i>n</i>	0	1	2	3	4	5	6
Self-distraction	40	8(20.0%)	2(5.0%)	3(7.5%)	5(12.5%)	4(10.0%)	3(7.5%)	15(37.5%)
Active coping	39	7(17.9%)	0(0.0%)	2(5.1%)	4(10.3%)	10(25.6%)	5 (12.8%)	11(28.2%)
Denial	40	23(57.5%)	8(20.0%)	2(5.0%)	0(0.0%)	3(7.5%)	2(5.0%)	2(5.0%)
Emotional support	40	3(7.5%)	1(2.5%)	7(17.5%)	4(10.0%)	2(5.0%)	6(15.0%)	17(42.5%)
Instrumental support	40	11(27.5%)	3(7.5%)	11(27.5%)	2(5.0%)	4(10.0%)	2(5.0%)	7(17.5%)
Behavior disengagement	40	36(90.0%)	1(2.5%)	1(2.5%)	0(0.0%)	2(5.0%)	0(0.0%)	0(0.0%)
Venting	40	20(50.0%)	6(15.0%)	7(17.5%)	3(7.5%)	2(5.0%)	2(5.0%)	0(0.0%)
Positive reframing	39	2(5.1%)	2(5.1%)	5(12.8%)	4(10.3%)	6(15.4%)	6(15.4%)	14(35.9%)
Planning	39	10(25.6%)	1(2.6%)	4(10.3%)	4(10.3%)	5(12.8%)	4(10.3%)	11(28.2%)
Acceptance	40	1(2.5%)	0(0.0%)	4(10.0%)	3(7.5%)	3(7.5%)	8(20.0%)	21(52.5%)
Self-blame	40	22(55.0%)	5(12.5%)	8(20%)	1(2.5%)	3(7.5%)	1(2.5%)	0(0.0%)

APPENDIX U: TABLE 9

SIGNIFICANT INTER-RELATIONSHIPS OF COPING PER THE BRIEF COPE

Significant Inter-relationships of coping variables	<i>n</i>	Spearman's Rho	<i>p</i> Value	<i>p</i> Value
			Sig: 0.01	Sig: 0.05
Age and instrumental support	38	-0.321		0.050
Age and behavior disengagement	38	-0.370		0.022
Age and venting	38	-0.335		0.040
Age and self-blame	38	-0.371		0.022
Active coping and self-distraction	39	0.428	0.007	
Active coping and instrumental support	39	0.369		0.021
Active coping and venting	39	0.384		0.016
Active coping and positive reframing	39	0.497	0.001	
Active coping and planning	39	0.647	0.000	
Active coping and self-blame	39	0.414	0.009	
Self-distraction and instrumental support	40	0.528	0.000	
Self-distraction and positive reframing	39	0.387		0.015
Self-distraction and planning	39	0.540	0.000	
Denial and emotional support	40	-0.367		0.020
Denial and behavior disengagement	40	0.362		0.022
Denial and venting	40	0.703	0.000	
Emotional support and instrumental support	40	0.319		0.045
Emotional support and venting	40	-0.369		0.019
Instrumental support and Planning	39	0.474	0.002	
Behavior disengagement and venting	40	0.319		0.045
Positive reframing and acceptance	39	0.350		0.029
Positive reframing and planning	39	0.401		0.011
Acceptance and age	38	-0.374		0.021
Acceptance and denial	40	0.357		0.024
Acceptance and behavior disengagement	40	1.000	0.000	
Acceptance and venting	40	-0.349		0.027
Acceptance and emotional support	40	0.588	0.000	
Self-blame and self-distraction	40	0.912	0.000	
Self-blame and instrumental support	40	0.520	0.001	
Self-blame and positive reframing	39	0.358		0.025
Self-blame and planning	39	0.373		0.019

APPENDIX V, TABLE 10

MEANS TABLE FOR RELATIONSHIP OF CES-D AND BRIEF COPE DOMAINS



	Entire Sample			Nigerian-Born			US-Born		
	Mean	SD	N	Mean	SD	N	Mean	SD	N
<b>I</b> When Did Caregiving End	4.76	2.9600	39	4.97	2.81	19	4.55	3.15	20
Participant's Age	52.8	13.42	38	46.39	10.08	18	58.55	13.63	20
CES-D Total	5.49	5.38	39	4.79	3.88	19	6.15	6.52	20
Active Coping	3.77	2.12	39	4.33	1.88	18	3.29	2.24	21
Planning	3.26	2.38	39	3.39	2.17	18	3.14	2.59	21
Positive Reframing	4.15	1.89	39	4.44	1.72	18	3.91	2.02	21
Acceptance	4.88	1.57	40	5.00	1.53	19	4.76	1.64	21
Emotional Support	4.18	2.04	40	4.95	1.43	19	3.48	2.27	21
Instrumental Support	2.48	2.18	40	2.79	1.93	19	2.19	2.40	21
Self-Distraction	3.60	2.37	40	3.37	2.22	19	3.81	2.54	21
Denial	1.15	1.85	40	1.47	2.07	19	.86	1.62	21
Venting	1.18	1.50	40	1.32	1.46	19	1.05	1.56	21
Behavior Disengagement	0.28	0.93	40	0.53	1.31	19	0.05	0.22	21
Self-Blame	1.03	1.41	40	1.00	1.10	19	1.05	1.66	21

APPENDIX W: TABLE 11

SELF -PERCEPTION OF ADJUSTMENT TO PCT

<b>Years PCT</b>	<b>Yes (Adjusting to PCT)</b>	<b>No (Not adjusting to PCT)</b>	<b>Total n=39</b>
0-3 Years	n=7 (41%)	n=10 (58.8%)	n=17 (100%)
4-6 Years	n=3 (33.3%)	n=6 (66.7%)	n=9 (100%)
7-10 Years	n=1 (0.77%) n=11	n=12 (92.2%) n=28	n=13 (100%) n=39

APPENDIX X:  
BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME	POSITION TITLE
Ume, Ebere	Instructor
eRA COMMONS USER NAME (credential, e.g., agency login): EBEREUME EBEREUME	

**EDUCATION/TRAINING** *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable.)*

INSTITUTION AND LOCATION	DEGREE <i>(if applicable)</i>	MM/YY	FIELD OF STUDY
California State University, Dominguez Hills, CA	BSN	1999	Nursing
California State University, Dominguez Hills, CA	MSN	2001	Nursing (Educator Option)
California State University, Northridge, CA	Health Serv. Cert.	2003	School Nursing Credential
Arizona State University, Phoenix, AZ	PhD Candidate	In progress	Nursing, Gerontology and Education

## PERSONAL STATEMENT

This proposal seeks funding to complete my dissertation study for my PHD program. The study is to explore the post-caregiving transition in African Americans who cared for older family members at home for at least three months before their deaths. The study will utilize the theoretical framework of Transition Theory to examine the types, patterns, and properties of transitions experienced by caregivers due to bereavement; the transitional conditions that facilitate or inhibit caregiver ability to achieve healthy transition; and progress and outcome indicators. Although we know little about this crucial transition in African American post-caregivers, they may need supportive interventions to achieve the goal of healthy transition. This foundational study is proposed to develop the necessary science upon which intervention studies can be based.

I am particularly well-suited for this fellowship because, prior to PhD program entry, I identified my area of research interest and selected a mentor whose work ran parallel to my own desired outcomes. Upon entry to the program, I quickly established a close working relationship with my mentor/Sponsor (Dr. Bronwynne Evans) in August 2009 as her Research Assistant, funded by NINR through a Research Supplement to Promote Diversity in Health-Related Research, under her current R01 – *Momento Crucial*. My Co-Sponsor (Dr. David Coon) is a Co-Investigator on Dr. Evans' R01 study and PI of 5 other funded grants. They both provide me with intense, active mentorship in the areas of caregiving; qualitative and mixed methods research; various aspects of grant management; and gerontological care. Dr. Evans furnishes supportive and empowering guidance to help me develop skills and leadership in nursing research and education and, as a result, I have made rapid progress in the PhD program. I completed one core qualitative design class with her and by spring semester, I would complete 15 additional credits of independent study on qualitative research inquiry and design. I worked very closely with her in designing my own preliminary study with a focus group of 12 African American post-caregivers that supports a foundational inquiry into the phenomenon of post-caregiving transition in African American caregivers. I have collaborated closely with Dr. Evans and Dr. Coon to co-author four articles (one accepted (Appendix G), two are in revision, and one is under review), in refereed journals, and one presentation. Both Dr. Evans and Dr. Coon are Co-Chairs of my dissertation committee and are well placed to sponsor me for this grant funding.

### B. Positions and Honors

#### Positions and Employment partial list

1995-1998	Home Health Nurse, NurseFinders
1998-2000	Home Health Nurse, Kaiser Permanente
1998-1999	Psychiatric Nurse, Washington Medical Center
1999-	Rancho Los Amigos National Medical Center
1999-2005	School Nurse, Compton Unified School District
2000-2001	Nursing Faculty, Compton Community College
2003-2005	Nursing Faculty, Compton Adult School
2005-2006	Psychiatric Nurse, Maricopa Integrated Health Services

- 2005-2006 Nursing Faculty, Southwest Skills Center (Estrella Mountain Community College)
- 2005-2009 Assistant Professor, Grand Canyon University
- 2006-2010 Director of Nursing Education, Grace Institute Inc.
- 2009-2012 Graduate Research Assistant, ASU College of Nursing and Health Innovations
- 2012-Present Nursing Instructor, Mervyn M. Dymally School of Nursing, Charles R. Drew University

**Academic and Professional Honors**

- 2011-2013: National Institute of Nursing Research (NINR) F31 National Research Service Award (NRSA)
- 2011-2013: Building Academic Geriatric Nursing Capacity (BAGNC) Pre-Doctoral Scholarship
- 2010-2012: Jonas-Hartford Pre-Doctoral Scholarship, ASU
- 2009-2011: National Institute of Nursing Research (NINR) RO1 Research Supplement to Promote Diversity in Health-Related Research, CONHI, ASU
- 2009-2010: Hartford-Evercare Pre-Doctoral Fellowship, ASU

**Current Memberships in Professional Organizations**

- 2007-2011 Arizona Psychiatric Nurses Association
- 2007-present National Alliance for the Mentally Ill (NAMI)
- 2005-2011 Arizona Nurses Association
- 2004-present Sigma Theta Tau International Honor Society of Nursing
- 2011-present International Society of Psychiatric Nurses

**Licenses, Certifications:**

Registered Nurse, State of California	1995
Public Health Nurse, State of California	1995
Registered Nurse, State of Arizona	2005
School Nurse Certificate, State of Arizona	2005

**A. Selected Peer-Reviewed Publications**

Evans, B. C., & Ume, E. (2012). Psychosocial, cultural, and spiritual health disparities in end-of-life and palliative care: Where we are and where we need to go. *Nursing Outlook*, 60(6), 370-375. <http://dx.doi.org/10.1016/j.outlook.2012.08.008>. NIHMSID#403155.

Evans, B. C., Coon, D. W., Belyea, M. J. & Ume, E. (Under revision). Collective

care: Multiple caregivers and multiple care recipients in Mexican American families. Manuscript submitted for publication. *Journal of Health Care for the Poor and Underserved*.

Evans, B.C., Coon, D.W., Belyea, M. & Ume, E. (2012). Activities of daily living in Mexican American caregivers: The key to continuing informal care. OnLine First *Journal of Family Nursing*, June 26, 2012. DOI:10.1177/1074840712450210.

Ume, E. & Evans, B.C. (2012). Death-Bed Promise: Burden or blessing? *Issues in Mental Health Nursing*, 33:400–402. DOI: 10.3109/01612840.2011.639483

Ume, E. & Evans, B.C. (2011). Chaos and uncertainty: The post-caregiving transition. *Geriatric Nursing*, 32(4), 288-293.

Evans, B. C., Belyea, M., & Ume, E. P (2011). Mexican American males providing personal care for their mothers. *Hispanic Journal of Behavioral Health*, 33(2), 234-260. DOI 10.1177//0739986311398615. NIHMSID#294216.

Evans, B. C., Coon, D. W., & Ume, E. (2011). Use of theoretical frameworks as a pragmatic guide for mixed methods studies: A methodological necessity? *Journal of Mixed Methods Research*, 5(4), 276-292. DOI: 10.1177/1558689811412972

#### **B. Podium/Poster Presentations:**

Ume, E. (2012). Recognizing Generational Caregiving Expectations in African American Caregivers. Podium presentation presented at the Gerontological Society of America (GSA) 65th Annual Scientific Meeting: Charting New Frontiers in Aging Conference. November 14-18, 2012, San Diego, CA.

Ume, E. & Evans, B. (2012). Post-caregiving Transitions in African American Caregivers. Poster presented at the 2012 National Hartford Centers of Gerontological Nursing Excellence Leadership Conference. November 12-14, 2012, San Diego, CA.

Ume, E. & Evans, B. (2012). Recruiting African American Caregivers of Older Adults for Research Studies. Poster presented at the 44th Annual Western Institute of Nursing Research Conference, April 18-21, 2012, Portland, OR.

Ume, E. & Evans, B. (2012). Post-Caregiving Transitions: Emotional Burden, Chaos And Uncertainty in African American Caregivers. Poster presented at the International Society of Psychiatric Nurses (ISPN) Conference, March 27-31, 2012, Atlanta, GA .



- Ume, E. & Evans, B. (2012).** Caregiver Guilt. Poster presented at the International Society of Psychiatric Nurses (ISPN) Conference, March 27-31, 2012, Atlanta, GA.
- Ume, E. & Evans, B. (2011).** Post-caregiving transitions in African-American Caregivers. Poster presented at the National Institute of Nursing Research-National Institute of Health, End-of-Life and Palliative Care Conference, August 8-10, 2011, Bethesda, MD.
- Ume, E. (2011).** Post-caregiving transitions in African-American caregivers. Poster presented at the 43<sup>rd</sup> Annual Western Institute of Nursing Research Conference, Las Vegas, NV
- Evans, B., Belyea, M., Coon, D., Castro, F. & **Ume, E. (2011).** The utility of theoretical frameworks in guiding mixed methods studies: *Momento Crucial*. Symposium presented at the 43<sup>rd</sup> Annual Western Institute of Nursing Research Conference, Las Vegas, NV
- Ume, E., Evans, B. C., Coon, D.W., Belyea, M., Castro, F. G. (2011).** "Get out of my House": Senate Bill 1070 and transitions in research recruitment. *Momento Crucial*. Symposium presented at the 43<sup>rd</sup> Annual Western Institute of Nursing Research Conference, Las Vegas, NV

### C. Research Support

#### **Ongoing Research Support**

National Institute of Nursing Research (NINR) F31 National Research Service Award (NRSA). 2011-2013

Ume (PI): The Post-caregiving Transitions in African American Caregivers

Building Academic Geriatric Nursing Capacity (BAGNC) Pre-Doctoral Scholarship, 2011-2013

Ume (PI): The Post-caregiving Transitions in African American Caregivers

#### **Completed Research Support**

National Institute of Nursing Research, RO1 Research Supplements to Promote Diversity in Health-Related Research, 3R01NR010541-02S1 2009-2011

Evans (PI): The Caregiving Trajectory for Community-Dwelling Mexican American Elders: A longitudinal mixed methods descriptive study designed to intensively explore the natural course of caregiving, caregiving burden and strain, caregiver gain, and admission to nursing homes among Mexican-American families.  
Implementation

Jonas-Hartford Pre-Doctoral Scholarship, ASU, 2010-2012:  
Ume (Pre-Doctoral Education Scholarship): The Post-caregiving Transitions in African  
American Caregivers

2009-2010: Hartford-Evercare Pre-Doctoral Fellowship, ASU  
Ume (Pre-Doctoral Education Scholarship): The Post-caregiving Transitions in African  
American Caregivers