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Resilience in African-American and Caucasian Caregivers of Family Members With  
Alzheimer's Disease or Related Dementia (ADRD)

A DISSERTATION

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By

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# Resilience in African-American and Caucasian Caregivers of Family Members with Alzheimer's Disease or Related Dementia (ADRD)

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The objectives of this study were to compare resilience in African-American and Caucasian caregivers of family members with ADRD; examine resilience when caregiver strain, and memory and functional status of the family member was statistically controlled; compare differences in selected sociodemographic variables and caregiver strain; and to describe study variables predictive of resilience. The Family Resiliency Model of Stress, Adjustment, and Adaptation was the theoretical framework for this investigation. The sample included 52 African-American and 30 Caucasian caregivers of family members with ADRD from a large metropolitan area. The majority of the participants completed the study via telephone. Data analysis of scores from the Resilience Scale [RS], the Caregiver Strain Index [CSI], and the Blessed Dementia Scale [C2A] as well as items from the researcher developed Family Member Caregiver Form were analyzed via descriptive statistics, *t*-test, analysis of variance and covariance as well as regression analysis. African-American caregivers had higher resilience scores than Caucasians. Resilience scores were not influenced by caregiver strain or functional status of the family member with ADRD. African-American female caregivers scored much higher than Caucasian male caregivers. Gender was a significant sociodemographic variable in examining caregiver strain. Age, ethnicity, and gender were predictors of resilience in caregivers of family members with ADRD. Resilience in African-American caregivers of family members with ADRD may be attributed to cultural values and

gender role theory. Information from this study supports further investigation of perceptions of resilience in caregivers of ADRD family members.

This dissertation by Kimberly Denise Battle fulfills the dissertation requirement for the doctoral degree in Nursing approved by Sr. Mary Elizabeth O'Brien, PhD, as Director, and by Janice B. Griffin Agazio, PhD, and Sharon Dudley-Brown, PhD, as Readers.

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## Dedication

On March 9, 2008, my brother, Phillip Patrick Battle, received his wings entering Heaven. He was the consummate caregiver, friend, and sibling. I dedicate this dissertation to him. *You will always be remembered....*

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Because of my relationship with my family, I could easily relate to the 82 caregivers who participated in this study as they shared the significance of their family members. I am forever in awe of the strength and wisdom demonstrated by my parents, Phillip E. and Myrtle T. Battle. Thank you so much for your continuous prayers, support, guidance, love and encouragement!

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## Chapter I

### THE PROBLEM

#### Introduction

The estimated number of individuals diagnosed with Alzheimer's Disease and Related Dementia (ADRD) worldwide is 24.3 million with a projected increase to 81.1 million by the year 2040 (Brangman, 2006). In the United States alone, 5.1 million people age 65 and older will be diagnosed with ADRD (Alzheimer's Disease Association, 2009). In the Southern region where Washington, DC is located, the Alzheimer's Disease Association predicts a 30 to 50 percent increase in the number of individuals diagnosed with ADRD (2009).

As the age 65 and older population increases in the United States, the prevalence and incidence of Alzheimer's Disease and Related Dementia (ADRD) is expected to increase exponentially over the next 25 years with a corresponding increase among minority populations (Prigerson, 2003). According to the 2000 United States Census, African-Americans represent 13% of the population with 2.7 million of the population 65 and over being African-American. By 2050, this figure is estimated to increase to 8.6 million (US Census, 2000). The incidence of ADRD is specifically higher among African-Americans in comparison to other minorities and Caucasian Americans (Dilworth-Anderson & Gibson, 1999).

The process of caring for a family member with ADRD is associated with increased financial burden, psychological stress, and symptoms of anxiety and depression. Race and ethnicity as well as urban living have been shown to compound

these stressors and burdens (Andrulis, 2003). Wagnild (2003) defines resilience as "...a personality characteristic that moderates the negative effects of stress and promotes adaptation" (p.42). The aim of this study was to examine resilience in Caucasian and African-American urban dwelling caregivers of family members with Alzheimer's Disease and Related Dementia (ADRD). This chapter provides an overview of the epidemiology of ADRD followed by presentations on family caregivers and African-American family caregivers of family members with ADRD. The theoretical framework is presented. The statement of the purpose, research questions, hypotheses, definition of terms, assumptions, significance of this study to nursing, and chapter summary also are included in this chapter.

### Caregivers of ADRD Family Members

The impact of caring for a relative with ADRD on the family and society is phenomenal. Clinically characterized by the gradual loss of intellectual abilities affecting cognition, function, and behavior, individuals diagnosed with ADRD become dependent, ultimately requiring constant supportive care (Teel & Carson, 2003). The duration of caring for someone with ADRD is extensive, with recent figures reporting from 8 years after the initial ADRD diagnosis extending to 20 years after the onset of symptoms (Prigerson, 2003). The long duration of caring for a relative with ADRD predisposes families to a tremendous amount of stress contributing to higher physiological stress symptoms and greater use of psychotropic medications by family caregivers (Prigerson, 2003; Parks & Novelli, 2003). The associated level of depression is higher in ADRD family caregivers in comparison to those providing care for individuals with other

chronic illnesses (Parks & Novelli, 2003; Prigerson, 2003). Depression, burden and care recipient problematic behaviors attribute to poor indicators of quality of life in caregivers of family members with ADRD (Belle, Burgio, Burns, Coon, Czaja, & et. al., 2006).

According to recent statistics from the Alzheimer's disease Association (2009), the percentage of Americans receiving hospice services with a primary diagnosis of ADRD increased from a reported 6.8 percent in 2001 to a reported 10.1 percent in 2007. Although ADRD patients are increasingly more likely to receive palliative care services, there is no direct association with a decrease in the burden of caring for patients in the community or home setting by family caregivers. Compounding this problem is the estimated economic impact of families caring for relatives with ADRD. The extensive period of caring for a family member with ADRD as well as their deteriorating mental and physiological condition may lead to an increased incidence of caregiver burden (Prigerson, 2003). African-American caregivers may have different reactions to providing care to family members with ADRD.

#### African-American Family Caregivers of ADRD Relatives

The past 15 years have seen an increase in the number of research studies investigating the characteristics of African-American caregivers of family members with ADRD. These studies have primarily been in response to previous investigations initially published describing ADRD family caregiving (Segall & Wykle, 1989; Kuhlman, Wilson, Wood & Parham, 1990; Hutchinson, & Wallhagen, 1991; & Stanford & Torres-Gil, 1992). In a study exclusively comprised of African-American family caregivers of

family members with ADRD, Lawton, Rajagopa, Brody, and Kleban (1992) discovered that women provided most care, which is consistent with other ethnic caregiver populations. However, in comparison to Caucasians, fewer spouses and more non-spouse and non-child caregivers rendered care. African-American caregivers of ADRD family members indicated greater experiences of caregiver satisfaction with fewer perceptions of caregiving as being intrusive in their own lives in comparison to their Caucasian counterparts (Hargrave, 2006).

### Urban Dwelling

Approximately 80 percent of adults with ADRD are cared for in the community by family caregivers (Brangman, 2006). The importance of completing this study in an urban environment such as the Washington, DC metropolitan area is supported by the fact that minorities living in urban communities traditionally utilize fewer community health services, which may lead to increased caregiver stress (Andrulis, 2003). The urban community of interest in this study was Washington, DC, our nation's capital. According to the District of Columbia Office on Aging (DCOA), one out of every seven residents is age 60 or older with ADRD being the 8<sup>th</sup> leading cause of death (DCOA, 2005). Moreover, 28% of all households in the city are composed of an elderly person age 60 years or older with the majority of seniors living with spouses or other relatives (DCOA, 2005). The DC Office on Aging reports that 16% of the elderly population age 65 and older lives below the poverty level, and 68% of the elderly age 60 years and older

identify themselves as Black or African-American and 28% identify themselves as White or Caucasian (DCOA, 2005).

### Statement of the Problem Questions

The problem questions addressed were as follows:

1. Is there a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members?
2. Is there a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD are controlled?
3. What are the differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD?
4. Are selected study variables predictive of resilience in urban dwelling caregivers of family members with ADRD?

### Theoretical Framework

The theoretical framework that guided this study was The Family Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1991). The literature supports that The Resiliency Model may be utilized as a framework for managing family stress associated with clinical problems in psychiatric, pediatric, and community health settings across the lifespan with chronic illnesses (Chen & Rankin,

2002; & Svavarsdottir, McCubbin, & Kane, 2000). The model is congruent with the origins of family stress theory because it is a systems model that is composed of interacting components. Consequently, the model's classification as an interaction model is necessary for the clinical management of a complex problem such as caring for a family member with ADRD in an urban environment.

In applying the theory to nursing, the nurse is the facilitator in assisting the family to accomplish the primary goal of extending beyond adjustment to adaptation. This may be accomplished by focusing the family on identifying their strengths and aptitude for responding to stressors (Bomar, 2000). Thus, the perceived stressor that may become a family stressor is a challenge that the family adapts to utilizing their strengths (Freidman, Bowden, & Jones, 2003). Assumptions of the Family Resiliency Model of Family Stress, Adjustment, and Adaptation are as follows:

1. Family caregivers face hardships and changes as a natural and predictable aspect of family life over the life cycle
2. Family caregivers develop basic strengths and capabilities designed to foster the growth and development of family members and the family unit and to protect the family from major disruptions in the face of family transitions and changes
3. Family caregivers develop basic and unique strengths and capabilities designed to protect the family from unexpected or normative stressors and strains and to foster the family's adaptation following a family crisis or major transition and change

4. Family caregivers benefit from and contribute to the network of relationships and resources in the community, particularly during periods of family stress and crisis (McCubbin & McCubbin, 1991, p. 3)

The family caregiver's response to stress is the adaptation process described as either Bon-Adaptation or Maladaptation. Bon-Adaptation is the goal of the family caregiver's response to the stress or the synonymous term strain (Kasywy, Polare-Bailey, & Takeuchi, 2000). This response symbolizes stability, cohesiveness, and congruency. Maladaptation is defined as the undesirable outcome whereby the growth and developmental goals of the family caregiver are unmet creating chaos and the equivalent of a secondary crisis (Robinson, 1999). Resilience may be instrumental in facilitating Bon-Adaptation.

For the purpose of this investigation, resilience is viewed as a modifiable characteristic that moderates the negative effects of stress and caregiving promoting adaptation in urban dwelling caregivers of family members with ADRD. Determining if there was a difference in resilience of Caucasian and African-American urban dwelling caregivers of family members with ADRD added scientific evidence detailing characteristics of these populations. Information derived from this investigation may be incorporated into designing programs that enhance positive outcomes in urban dwelling caregivers of family members with ADRD.

### Statement of the Purpose

The purpose of this study was to: (a) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD; (b) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD when care giver strain, and memory and functional status of the family member are controlled; (c) compare differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD; (d) describe study variables predictive of resilience in urban dwelling caregivers of family members with ADRD.

### Hypotheses

The hypotheses tested included the following:

H<sub>1</sub> There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members.

H<sub>2</sub> There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD are controlled.

H<sub>3</sub> There will be a difference in the selected sociodemographic variables of age and gender and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD.



H<sub>4</sub> Selected study variables of age, gender, and ethnicity will be predictive of resilience in urban dwelling caregivers of family members with ADRD.

### Definition of Terms

Relevant definitions for understanding this study are presented as follows:

#### *Caucasian*

- a. Theoretical definition: White American of European descent (Hill, 1998).
- b. Operational definition: anyone who identifies himself or herself as Caucasian American or White of non-Hispanic descent.

#### *African-American*

- a. Theoretical definition: Black American of African ancestry (Hill, 1998).
- b. Operational definition: anyone who identifies himself or herself as African-American or Black American of non-Hispanic descent.

#### *Resilience*

- a. Theoretical definition: a modifiable personality characteristic that moderates the negative effects of stress and promotes adaptation (Wagnild, 2003).
- b. Operational definition: resilience is defined by the scores on the Resilience Scale [RS].

#### *Caregiver*

- a. Theoretical definition: a fundamental social unit [individual] typically including spouses, adult children, siblings, and distant relatives who provide care for a disabled or ill member (Pallett, 1990).

- b. Operational definition: a self-identified person who provides care at least 10 hours a week for a person they identify as a family member with ADRD.

*Family Members with Alzheimer's Disease or Related Dementia (ADRD)*

- a. Theoretical definition: a person experiencing "...a chronic neurodegenerative disorder involving the loss of memory and other cognitive functions, a decline in ability to perform activities of daily living (ADL), changes in personality and behavior, increases in resource utilization, and eventual death" (Desai & Grossberg, 2005, p.S34).
- b. Operational definition: a person identified by a care giver as a family member with ADRD

*Urban Dwelling*

- a. Theoretical definition: of or located in a city (Hardy, Concato, & Gill, 2004).
- b. Operational definition: person who resides in the Washington, DC metropolitan area.

*Caregiver Strain*

- a. Theoretical Definition: "... enduring problems that have the potential for arousing threat, a meaning that establishes *strain* and *stressors* as interchangeable concepts." (Robinson, 1983, p. 344).
- b. Operational Definition: caregiver strain is defined by the scores on the Caregiver Strain Index [CSI].

*Memory and Functional Status of the Family Member with ADRD*

- a. Theoretical Definition: intellectual and personality deterioration in conjunction with the activities of daily living experienced by individuals with presumed ADRD.

b. Operational Definition: memory and functional status of the family member with ADRD is defined by the scores on the C2A Blessed Dementia Scale [C2A].

### Assumptions

The following were assumptions of this study: (a) resilience can be measured in urban dwelling Caucasian and African-American caregivers of family members with ADRD; (b) illness of one individual family member places a strain on the family; and (c) families can adjust and adapt to the crisis caused by stress of an illness.

### Significance of the Study

Due to the increased aging population with a corresponding increase in the prevalence of ADRD, the provision of care for caregivers and family members with ADRD is a health care priority. The associated psychological, physical, and financial ramifications of caring for ADRD patients have previously been documented (Brangmon, 2006; Parks & Novelli, 2003; Prigerson, 2003; & Teel & Carson, 2003). Information obtained in this study will add to the nursing knowledge pertaining to resilience in both Caucasian and African-American urban dwelling caregivers of family members with ADRD. Results from this investigation may assist in designing interventions to augment resilience and may be useful in developing an intervention for caregivers of family members with ADRD designed that will promote positive health outcomes. Findings may have an impact on policy development and implementation related to caregiving in an urban environment such as the Washington, DC metropolitan area.

### Summary

This chapter presented information delineating the increasing prevalence and incidence of ADRD in the United States with corresponding increases in minority populations, specifically African-American. The socioeconomic impact incurred by family caregivers as they provide care for their relative throughout the extensive disease trajectory is discussed. Psychological characteristics descriptive of urban dwelling caregivers of family members with ADRD are described. Mitigating factors associated with caring for urban dwelling family members with ADRD were presented. The theoretical framework used to guide this study was discussed. The statement of purpose, research hypotheses and questions, definition of terms, and study assumptions were also presented. Finally, the significance of this research study to nursing concludes this chapter.

## Chapter II

### REVIEW OF THE LITERATURE

Resilience is “a [modifiable] personality characteristic that moderates the negative effects of stress and promotes adaptation” (Wagnild, 2003). Urban dwelling caregivers of family members with ADRD may exhibit resilience through the process of adapting and adjusting to various stressors encountered in providing and coordinating care for their relatives. The intent of this review of the literature is to provide a synopsis of research in the following areas: (a) overview of ADRD, (b) the process of caring for family members with ADRD, (c) caregiver strain, (d) comparison and contrast of family caregiving in different neurological disease processes, (e) perspectives of resilience in nursing and other disciplines, and (f) resilience in African-American family caregivers.

#### Overview of Alzheimer’s Disease and Related Dementia

Alzheimer’s disease and related dementia (ADRD) is a chronic neurodegenerative disease that is the sixth leading cause of death among people age 65 and older in the United States (ADA, 2009). By the year 2010, Medicare projected spending for ADRD is anticipated to increase by fifty-four percent to \$49.3 billion dollars annually with Medicaid spending rising by eighty percent to \$33 billion dollars over the same period (Prigerson, 2003). Clinically characterized by a gradual cognitive and functional decline as well as declines in daily function, people diagnosed with ADRD experience personality and behavioral changes making caring for them by relatives in a community

setting extremely difficult (Desai & Grossberg, 2005; Maslow, Selstad & Denman, 2002).

The physiological symptoms explicitly associated with neuropathophysiological changes indicative of ADRD include the development of amyloid-rich senile plaques, neurofibrillary tangles, neuron degeneration, and synaptic loss as well as a decrease in the quantity of cholinergic neurons (Desai & Grossberg, 2005). Definitive diagnosis of ADRD remains by histopathologic autopsy of brain tissue. The literature (Maslow, Selstad, & Denman, 2002; Prigerson, 2003) indicates that anywhere between fifty and sixty percent of people greater than age 75 meet the classification criteria for dementia disorders. Currently, there are no specific neuroimaging or diagnostic tests available to substantiate a diagnosis of ADRD. Clinical diagnosis of ADRD is associated with criteria of inclusion as opposed to exclusion. Thus, collateral information sources, such as family, friends, and neighbors provide insightful details regarding the cognitive baseline function of the person with ADRD and are essential in formulating a formal diagnosis (Maslow, Selstad, & Denman, 2002).

A formal diagnosis of ADRD usually occurs after a crisis, such as a fall, financial disaster, hospitalization, or becoming lost (Desai & Grossberg, 2005). ADRD is classified according to disease severity as mild (Mini-Mental State Examination scores between 21 to 26), moderate, (MMSE scores between 10-20), or severe, (MMSE scores less than 10) (Brangman, 2006). Unfortunately, for those diagnosed with ADRD, there is no cure. Treatment centers upon establishing an early, accurate diagnosis; early pharmacological intercession to increase the neurotransmitter acetylcholine and reduce

stimulation of glutamate receptors; treating any co-existing diseases; providing referrals for appropriate services, treatment of behavioral and psychiatric symptoms with nonpharmacologic and pharmacological interventions; and outlining caregiver needs (Desai & Grossberg, 2005).

The median survival from initial diagnosis of ADRD was estimated to be 4.2 years for males and 5.7 years for females (Larson, et al., 2004). Associated comorbidities such as diabetes mellitus, congestive heart failure, gait disturbance, and poor cognition are all critical indicators of poor prognosis with ADRD (Larson, et al., 2004). Current disease management programs strongly emphasize medication management with cholinesterase inhibitors such as galantamine (Razadyne) and rivastigmine (Exelon) for mild to moderate ADRD; Donepezil (Aricept) for all three stages with Memantine (Namenda) an N-methyl-D-aspartate antagonist approved for treatment of patients with moderate to severe ADRD (Brangmon, 2006). Demonstrated benefits of early initiation of treatment with cholinesterase inhibitors reveal a postponement in the onset of behavioral and psychiatric symptoms associated with ADRD by as much as one year with preliminary results indicating positive benefits in moderate to severe patients living with ADRD as well as patients in long-term care settings (Desai & Grossberg, 2005). The goal of pharmacological treatment is not curative but curative, but instead it is viewed as method of delaying the progression of the disease versus non-treatment. Of note, everyone who receives treatment will not necessarily improve (Brangmon, 2006). Because of the unclear diagnosis period and lengthy duration of illness, the process of caring for a family member with ADRD presents a multitude of issues.

### Process of Caring for a Family Member with ADRD

The term “caregiving” describes the process of caring for family members. Since 1975, there has been an exponential increase in the literature discussing caregiving and the incidence of family members taking care of an elderly or chronically ill person at home (Pepin, 1992). Research originally focused on the roles, tasks, and consequences of caregiving. The majority of the early research performed outside the discipline of nursing by gerontologists, psychologists, and social workers, centered on defining the duties and responsibilities of caregiving and led to the development of what is widely known as the Activities of Daily Living Scale (ADL) and the Instrumental Assistance of Daily Living Scale (IADL) (Pepin, 1992). These scales are utilized today to assess function.

Throughout the 1980s, research progressed to include the advancement of measurement concepts such as burden, caregiver function, and caregiver strain (Pepin, 1992). During this period, nurse researchers contributed significantly to expanding the concept of family caring to include “...the provision of needed services to functionally impaired elderly parents” (Pepin, 1992). Archibold (1981 & 1982) supported organizing the categories in the following manner: (a) care provision, (b) care management, and (c) care transfer. Utilizing an exploratory descriptive method, Archibold (1981 & 1982) uncovered that family care providers focused on time and energy versus duties and responsibilities. Bowers (1987) expanded the focus on the affective aspects of caregiving. Through the process of grounded theory, she proposed organizing family caring into the following



five categories: anticipatory, preventive, supervisory, instrumental (identified as caregiving), and protective.

Through a critical review of the literature, Pallet presented the details of a conceptual framework for assisting caregivers to cope with the burden of caring for a loved one with Alzheimer's-type dementia. According to Pallet (1990) who applied the new definition of caregiving developed by Bowers (1987) in constructing a conceptual framework for studying caregiver burden, the four domains that affect caregiver stress and well-being are (1) characteristics of the impaired relative, (2) characteristics of the primary caregiver, (3) characteristics of the relationship between the caregiver and recipient of care, and (4) the caregiver's social support resources. Pallet's intention was to have this conceptual framework serve as a guide for investigating caregiving burden within the context of family management of an elderly relative with Alzheimer's-type dementia.

Although this article is almost 20 years old, it is valuable because it delineates a conceptual framework specifically for Alzheimer's dementia nursing research. More importantly, it organizes the characteristics of ADRD caregiver stress. Additionally, the emergence of social support mechanisms such as informal and formal support groups and respite programs, serve to provide reassurance and strengthen the morale of family caregivers by encouraging a forum for discussion of like issues among people experiencing similar situations. A criticism of this conceptual framework is that it lacks discussion of adaptation and adjustment to the stress of caregiving.

### Caregiver Strain

Behavioral symptoms by the family member with ADRD usually occurring during the Activities of Daily Living (ADLs) become stressful secondary to the reported increase in aggressive behaviors of the relative. This is due to the impaired family member's inability to participate in the ADL activity, desire not to have physical contact, or inability to recognize the need to participate (Farran, Loukissa, Lindman, McCann, & Bienias, 2004). The behavioral symptoms associated with increased caregiver stress usually occur in moderate to advanced ADRD and are associated with sleep disturbance, agitation, aggression, and psychosis leading to the caregiver's inability to maintain their relative at home safely (Farran, Loukissa, Perraud, & Paunn, 2004).

Caregiver burden is a multidimensional term encompassing (Fitzgerald, 2000) and synonymous with caregiver stress and caregiver strain (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Caregiver burden may be defined as "...the physical, psychological or emotional, social and financial problems experienced by family caregivers indicative of both subjective and objective aspects of the impact of care..." (Acton & Kang, 2001, p.350). Another definition of caregiver burden is "...strain or load borne by a person who cares for an elderly, chronically ill or disabled family member." (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

An outcome of the inequity between the demands and resources available to family caregivers in the community results in caregiver burden that is characteristically separated into two classifications: objective and subjective. Objective caregiver burden refers to the interruption of the family developmental life cycle and the interpersonal and

financial impact upon caregivers. Subjective caregiver burden refers to the caregiver's emotional response to the process and cycle of caring. Subjective and objective burden may have an incongruous relationship (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

In developing the Caregiver Strain Index (CSI), Robinson (1983) defined caregiver strain as "...enduring problems that have the potential for arousing threat, a meaning that establishes *strain* and *stressors* as interchangeable concepts." (p.344). The instrument was designed and tested to measure the following stressors in family caregivers: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, parent seeming to be a different person, work adjustments, feelings of being completely overwhelmed, sleep is disturbed, physical strain, and financial strain (Robinson, 1983). Robinson (1983) called for additional research utilizing the instrument to predict specific caregivers that may be at risk.

Caregiver strain is a multidimensional response to caregiver burden reflective of the reality of caregiving (Hoskins, Coleman, & McNeely, 2005). Significant to this study is that caregiver stress, burden, and strain have been associated with an increase in the prevalence of depression, chronic fatigue, and anger in family caregivers of ADRD relatives (Dibartolo, 2002). The caregiver stress-burden-strain phenomenon is best viewed comprehensively as opposed to positively or negatively. The CSI is a frequently cited and recommended instrument to measure caregiver strain in caregivers of disabled family members (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

### Comparison and Contrast of Family Caregivers in Other Diseases and ADRD

In examining how family caregivers of ADRD patients compare and differ with family caregivers of relatives with other diseases, the literature offers descriptions or comparisons with two other neurological diseases, Cerebral Vascular Accident (CVA) and Amyotrophic Lateral Sclerosis (ALS). All three diseases leave the victims physically, cognitively, and psychosocially impaired. As with ADRD, family caregivers of CVA patients assist the patient in remaining in a home setting. Although the caregiver responsibilities are similar, the ADRD and CVA disease trajectories differ. ADRD is a progressively slow, mental decline that affects the physical functioning of the individual. CVA is abrupt with physical and psychological changes associated with increased function followed by a plateau.

In a study reported by Clark and King (2003) comparing family caregivers who had similar levels of responsibility caring for CVA and ADRD relatives, results demonstrated no difference in fatigue and family hardiness. Scores on the instrument utilized to measure family hardiness demonstrated similar scores in family caregivers of family members with cancer and receiving radiation, and two studies of children with developmental delays. This poorly designed study did not validate that the instruments measured fatigue and family hardiness. The study utilized a very small sample size that did not have any diversity. In addition, the sample group was very well educated with most indicating that they had completed some college.

In evaluating family caregivers of relatives with another neurodegenerative disease, Amyotrophic Lateral Sclerosis (ALS), Rabkin, Wagner, and Del Bene (2000)

found that family caregivers spend an average of eleven hours per day providing care for their relative. Additionally, they found that the financial costs associated with providing home care create financial distress in this population because often the family caregiver had to leave their job and health insurance rarely covered all of the patient's expenses. This study revealed that the quality of life of caregivers defined as mental health and well-being, declined as the ALS patient's health declined. Caregivers were also as likely as patients to be depressed. Findings revealed that subjective caregiver burden was positively associated with finding positive meaning in caregiving in this study sample.

#### Perspectives of Resilience in Nursing and Other Disciplines

The concept of resilience is familiar to the discipline of social work. Much discussion has occurred pertaining to resilience within the mental health populations and crisis intervention. These studies have transitioned from viewing intrinsic to extrinsic perspective on resilience (NASW, 2004); meaning, the first generation of research and inquiry centered on examining the concept of resilience exclusively as an individual personality characteristic referred to as *ego-resiliency* (Earvolino-Ramirez, 2007).

Wagnild & Young (1990) reported resilient characteristics of elderly women identified as successfully adjusted to a major life loss. Twenty-four (24) participants interviewed primarily in their homes, answered six open-ended questions designed to elicit information regarding individual characteristics unique to their experience of successfully adjusting to a major loss. Areas addressed were limited to the following:

(1) identification and description of the event, (2) response to the event, (3) management of the event, (4) management of difficult times in general, and (5) perception of life now.

Five themes that emerged from the data were equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness. The authors relate their themes to various philosophical writings reflective of the ability to survive adversity, ultimately arriving at a core concept equivalent to resilience. Using the constant comparative method associated with grounded-theory, the authors identify five themes reflecting the ability to survive adversity, ultimately arriving at core concepts indicative of resilience. The themes are equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness. Equanimity is defined as "... [the] ability to consider a broader range of experience, thus modulating extreme responses to adversity" (p.253). Perseverance connotes "... a willingness to continue the struggle to reconstruct one's life and to remain involved" (p. 253). Self-reliance is "...a belief in oneself and capabilities" (p.254). Meaningfulness is "...the realization that life has a purpose and the valuation of one's contributions" (p. 254). Existential aloneness is "...the realization that each person's life path is unique; while some experiences are shared, there remain others that must be faced alone" (p. 254). These findings from Wagnild & Young (1990) served as the foundation for the 1993 development of the first and most tested scale for measuring resilience in nursing.

Earvolino-Ramirez (2007) reports that over the past 10 to 20 years, the paradigm has shifted in resilience research from ego-resiliency to examining the concept as a dynamic modifiable process. An important factor distinguishing resilience from ego-

resiliency is exposure to adversity. With this evolution, a second generation of research focusing on evaluating resilience based interventions and prevention programs have emerged. Attributes of resilience include rebounding and reintegration, high expectancy/self-determination, social support for adults, meaningful relationships with peers and or family, adaptability, sense of humor and self-esteem/self-efficacy. Some of the consequences or outcomes of resilience include effective coping, mastery, and positive adaptation. Current research reflective of this second generation of resilience research examines resilience as dynamic modifiable process with the aim of identifying and developing resilience-based interventions and prevention programs. Moreover, Earvolino-Ramirez (2007) states that examining protective processes is essential in identifying methods that enhance resilience and prevent negative outcomes is crucial for future inquiry. The need for empirical inquiry quantifying resilience in diverse populations and evaluating outcomes of resilience interventions has been identified as the focus of future research.

Wagnild (2003) investigated resilience and successful aging among low and high-income older adults. The study participants who were identified as low income (annual income less than \$15,000.00) averaged scores that indicated less resilience in comparison to their higher income peers. However, the scores were still in the moderate range of the scale leading to inconclusive interpretation of resilience in lower income older adults. Thus, resilience may facilitate indicators of successful aging (life satisfaction, morale, and stress management, decrease levels of depression, better health, and health promoting

behaviors) regardless of income. This study reiterated the need for additional research to examine ethnic, cultural, and geographic factors in relation to resilience.

Although the behavior and personality changes associated with ADRD are troublesome to most caregivers, there are quantitative studies supporting differences in the level of caregiver stress and caregiver burden among racial and ethnic groups in the United States citing that African-Americans view caregiving of a family member with ADRD positively for a multitude of reasons (Toth-Cohen, 2004; Lawton, Rajagopal, Brody, & Kleban, 1992). Sterritt and Pokorny (1998) discovered that African American family caregivers associated caring for relatives with ADRD as being an act of love rooted in the tradition of family. Four major themes emerged from Sterritt and Pokorny's (1998) study: (1) caregiving as a traditional family value, (2) caregiving as an act of love, (3) social support as a mediator of caregiver burden, and (4) caregiving as a female role. The results of this study further expanded on the findings of researchers studying African-American caregivers of ADRD relatives in rural communities. Contrary to these findings, recent qualitative research has provided information indicative of caregiver strain such as burnout, grief, and isolation previously undiscovered in survey instruments utilized by social scientists (Hargrove, 2006) and previous qualitative studies. More research designed to explore variables, which may contribute, to adjusting and adapting to the process of caregiving in African-Americans and other minority populations is encouraged.

Dilworth-Anderson's (2005) predictions of African-Americans scoring higher than Caucasians on the Cultural Justifications Caregiving Scale (CJCS) (Cronbach alpha



of .86) suggested the difference is in the reasons associated for providing care to older relatives. She found that the impact of enculturation and increased education were inversely associated with decreased altruistic motives of caregiving for elders.

Additionally, she found that Caucasian males provide care by default and that, African-American families may be described traditionally as more egalitarian and flexible in comparison to Caucasian families. The author called for examination of the processes whereby caregivers are socialized to provide care for elders.

Caregiver satisfaction, caregiver gain, and caregiving rewards are collectively called positive aspects of caregiving (PAC). It is believed that PAC leads to reduction in the stressors associated with caregiving as well as improving caregiver outcomes (Hill, 1998). Resilience may also be a factor that decreases caregiver stress and is worthy of further exploration. Rewards of caregiving in African-Americans usually are associated with religiosity with older caregivers reporting more rewards than younger caregivers (Hill, 1998). Additionally, there are reportedly more benefits or gains associated with PAC in African-Americans in comparison to their Caucasian counterparts. African-American females reported more perceived rewards than did their Caucasian counterparts. African-Americans identified less distress by their ADRD relatives' disruptive behaviors than Caucasian (Roff, Burzio, Gitlin, Nichols, et al., 2004). Roff et al., (2004) identified a relationship between race and PAC explaining this finding by the lower social economic status (SES), lower behavioral bother, lower anxiety, and higher religiosity of African-Americans in comparison with their Caucasian counterparts.

According to the authors', justification for this positive perception of caregiving may be attributed to the historical, cultural, and familial experiences of African-Americans in the United States. The lack of data in the literature that examines resilience in both urban dwelling Caucasian and African-American caregivers of ADRD family members supports the need to investigate this problem.

In a study by Scharlach, Kellam, Ong, Baskin, Goldstein, et al., (2006), the research team identified that minorities utilized formal support services substantially less than their non-Hispanic Caucasian peers. This decreased usage is associated with unmet needs leading to greater need for formal support services, increased levels of unmet social needs and mental health needs than non-Hispanic White peers. This qualitative study explored reasons for restricted service usage among caregivers from eight racial and ethnic minority groups giving particular attention to commonalities of experiences from diverse groups. A sample of 76 research participants was recruited from throughout the state of California and from the following ethnic/racial groups: African-Americans, Chinese, Filipino, Korean, Native American, Hispanic, Russian, and Vietnamese. Three constructs were identified familiasm, group identity, and service barriers. In the focus discussion groups, African-Americans reported the prevalent reason for negatively influencing the decision and desire to access services as being historical as well as current experiences of discrimination, prejudice, dislocation and other hardships. Additionally, they reported a self-perception that their own cultural group differed from Caucasian and other minority groups because of the uniqueness of their experiences as well as the manner in which they culturally view care and treatment of the elderly. Authors called

for further research to understand the ways in which cultural norms, race, and ethnicity may mediate care experiences (Scharlach, Kellam, Ong, Baskin, Goldstein, et al., 2006).

The cultural and ethnic considerations identified by Scharlach, Kellam, Ong, Baskin, Goldstein, et al., (2006); Roff, Burgio, Gitlin, Nichols, et al, (2004); and Sterritt and Pokorny (1998) in conjunction with the historical context of family caregiving, which Pallet (1990) attributed to past examples of caring and love, rooted in the past relationship between the caregiver and the care recipient necessitate the need for this proposed study. Because the behavioral and personality changes associated with the disease process of ADRD, the relationship between caregiver and family member is altered, decreasing affection and increasing stress.

### Resilience in African-American Family Caregivers

The significance of resilience to caregivers is rooted in the past relationships between the caregiver and the relative prior to onset of the disease that serve as a foundation and model for the family caregivers to provide care for their relatives. Often the caregivers are viewed as the second victim of ADRD (Prigerson, 2003) or the hidden patient (Parks & Novelli, 2003). With statistics demonstrating that one-fourth of all households in the United States are involved in caregiving, researchers must explore intrinsic factors that enable family caregivers to provide care for their relatives with ADRD in the home setting (Parks & Novelli, 2003). Research has identified the negative outcomes of caregiving such as caregiver burden, stress, strain, and the increased

incidence of anxiety, depression, and mortality (Parks & Novelli, 2003; Prigerson, 2003; & Acton & Kang, 2001).

Positive values of resilient individuals in African-American families include a high regard for the elderly and their wisdom in African-American families and the provision of social and economic support to African-Americans (Hill, 1998). Characteristically, African-American family values include a high respect for parents, high status of the elderly, strong emphasis on mutual support or reciprocity, i.e., the obligation to assist one another. Hill (1998) cited a major source of resilience in African-American families as being rooted in cultural characteristics.

There appears to be a lack of research in the nursing literature regarding resilience and urban dwelling Caucasian and African-American caregivers of family members with ADRD. In all of the previously discussed articles with the exception of the Toth-Cohen (2004) study, diverse populations are underrepresented. The RS [Resilience Scale] is useful in identifying resilient individuals or those possessing the capacity for resilience in vulnerable populations (Wagnild & Young, 1993). Therefore, there is a demonstrated need for empirical evidence examining resilience in caregivers of family members with ADRD, which may yield insight into the process of psychosocial adaptation to caregiving in an urban environment within a diverse population. Due to the current state of the science regarding resilience and caregivers, more research is needed to examine resilience in Caucasian and African-American caregivers of family members with ADRD.

## Conclusion

The need identified for a more globalized, culturally inclusive view of family health in the community necessitates examining factors that may influence positive outcomes among urban dwelling caregivers of family members with ADRD (Kulig, 2000). Due to the multitude of demands associated with caregiving, family caregivers experience stress. Individual perceptions of strain as stress or burden may be positive or negative. Results from previous research indicated that African-Americans exhibit positive attitudes and affirmations in caring for relatives with ADRD in the community. Although research comparing caregiving characteristics of Caucasian and African-American caregivers of ADRD family members exists (Dilworth-Anderson, 2005; Farran, Loukissa, Perraud, & Paunn, 2004; Farran, Miller, Kaugman, & Davis, 1997; Haley, Gitlin, Wisniewski, Mahoney, Coon et al., 2004; Hardy, Concato, & Gill, 2004; & Lawton, Rajagopa, Brody, and Kleban, 1992), none compared resilience or caregiver strain in these groups. Because of the many stressors and challenges associated with providing extended care for their family member as well as the corresponding increased aging population and associated increase in the prevalence of ADRD, an understanding of the second generation of the concept of resilience in both urban dwelling Caucasian and African-American caregivers of family members with ADRD is imperative. Overwhelming predominant racial with Resilience Scale scores reported has been Caucasians with small numbers from African-American, Hispanic, Native Americans, and Asian with Wagnild (2009) identifying that the future of resilience research needs to

quantify resilience in diverse populations. The intention of this study was to add to the body of nursing knowledge the following:

1. Documentation of resilience in urban dwelling caregivers of ADRD family members.
2. Documentation of a description of the differences in the selected sociodemographic variables of age and gender and caregiver strain in urban dwelling caregivers of family members with ADRD
3. Documentation of study variables (age, gender, and race) that best predict resilience in urban dwelling caregivers of family members with ADRD.

### Summary

This chapter has reviewed the literature on related variables essential to the proposed research questions: R1: Is there a difference in resilience of urban dwelling African-American and Caucasian caregivers of family members ADRD? R2: What are the differences in selected sociodemographic variables of age and gender and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD? R3: What study variables (age, gender, and race) best predict resilience in urban dwelling caregivers of family members with ADRD? Literature related to the pathophysiology of ADRD; the process of caring for family members with ADRD; specific characteristics of African-American family caregivers of ADRD patients; perspectives of resilience both within and outside the discipline of nursing; and caregiver strain were presented.

## Chapter III

### Methodology

The purpose of this study was to: (a) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD; (b) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD when caregiver strain, and memory and functional status of the family member are controlled; (c) compare differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD; (d) describe study variables predictive of resilience in urban dwelling caregivers of family members with ADRD. This chapter delineates the detailed steps utilized to conduct the study. It addresses research design, the sample selection, survey instruments, setting, research participants, and setting as well as data analysis. The chapter concludes with a brief summary.

### Problem Questions

The problem questions addressed were as follows: (a): Is there a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members? (b) Is there a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD are controlled? (c) What are the differences in selected sociodemographic variables and caregiver strain in

urban dwelling African-American and Caucasian caregivers of family members with ADRD? (d) Are selected study variables predictive of resilience in urban dwelling caregivers of family members with ADRD?

### Hypotheses

The hypotheses to be tested included the following: H<sub>1</sub> There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members; H<sub>2</sub> There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD are controlled; H<sub>3</sub> There will be differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD; H<sub>4</sub> Selected study variables will be predictive of resilience in urban dwelling caregivers of family members with ADRD.

### Setting

Subjects were recruited from the community encompassing the Washington, DC metropolitan area in the southern region of the United States. This geographical area is very diverse and populated with generational Caucasian and African-American that were accessed via churches, synagogues, and neighborhood communities. The researcher collected data from each participant in a comfortable setting, such as the research participant's home or via telephone, at a mutually agreeable date and time. This



approach was demonstrated to be useful in conducting research with minorities in the community to illicit trust as well as establish a relationship of reciprocity (Paatsdaughter et al, 2001 & Earl & Penny, 2001).

### Subjects

The researcher recruited a purposive sample of Caucasian and African-American family caregivers who were eligible to participate if they met the following inclusion criteria: (1) caring for their self-identified family member with ADRD (2) consent to participate in the study (3) age 18 or older (4) primary caregiver for at least 10 hours per week of an Caucasian or African-American family member with ADRD (5) able to participate and engage in data collection lasting approximately 45 to 60 minutes in length (6) self-identified as Caucasian or African-American and (7) are English speaking.

Because the literature demonstrates that family caregivers experience strain continuously throughout the process of caring for their family member with ADRD (Parks & Novelli, 2003), the researcher did not impose length of time for caring for an ADRD family member as being an inclusion criteria. Network sampling has proven to be beneficial and useful in reaching hard to discover populations, thus, subjects were purposefully recruited utilizing this methodology (Burns & Grove, 2001).

### Protection of Human Subjects

No potent psychological or physical risks to participants were inherent in this study. Because the RS and demographic data may elicit psychological risks from reminiscing about the challenge of caring for their ADRD, the researcher was prepared to

refer subjects to support groups. One subject was referred to a support group because of their response to certain questions on the Caregiver Strain Index. No subject felt uncomfortable, thus, the researcher did not have to stop any encounters. The researcher was prepared to assess the participant and offer reassurance or referral to a counselor and/or arrange to contact family or friends to assist if necessary. Of particular note, several subjects noted how participating in the research study provided them encouragement that someone cared about them and what they were experiencing as caregivers of a family member with ADRD. Every subject received an oral and written explanation of the study, with verbal discussion prior to signing the consent form (Appendix D), and received a mailed copy of the signed consent form. Benefits of participation in the study included contributing information to the body of nursing knowledge as well as the community. Paatsdaughter et. al., (2001), found that potential study participants are more likely to participate in research studies they identify as beneficial to the community. The researcher verbally provided an explanation of the benefits of the study to potential subjects to encourage their participation as well as to recruit other subjects. Efforts to maintain confidentiality consisted of assigning identification numbers to each subject and keeping identification information separate from data as well as securing and storing data in a locked file cabinet to which only the investigator had access.

### Instrumentation

Four instruments used for this study are as follows: (a) Family Caregiver's Profile Form (b) The Resilience Scale (RS); (c) Caregiver Strain Index (CSI); and (d) The C2A Blessed Dementia Scale (ADL).

#### *Family Caregiver's Profile Form*

The Family Caregiver's Profile Form, created by the researcher, included the caregiver's address, age, caregiver/family member relationship, socioeconomic status, and caregiver/family member health status. Extrinsic factors such as provision of care, relationship and number of other people residing in the home of the family member with ADRD, compensated or uncompensated people who assist in the caregiving process as well as utilization of respite services were collected. All of the above information was obtained by the researcher in collaboration with the caregiver of the family member with ADRD for descriptive purposes only. Research has demonstrated that these factors may influence attitudes and perceptions regarding caring for urban dwelling family members with ADRD making it necessary to catalogue this information in this study.

#### *The Resilience Scale (RS)*

The RS is a 26-item questionnaire designed to identify resilient individuals or those possessing the capacity for resilience. The reported reliability coefficient is 0.91 (Wagnild & Young, 1990). Data exists that documents a range from 0.73 to 0.91 in reported studies in the literature (Wagnild, 2009). Content validity has been determined for the five dimensions of resilience: equanimity, perseverance, self-reliance,

meaningfulness, and existential aloneness, as operationally defining resilience (Wagnild & Young, 1990). The instrument may be self-administered by having research participant's evaluate their feelings to 26 individual statements designed to evaluate individual resilience on a 7-point Likert scale from 1, Strongly Disagree to 7, Strongly Agree. Possible scores range from 26 to 182. Scores of 120 or less are classified as low resilience, 125 to 145 low to moderate resilience and scores greater than 145 indicative of moderately high to high resilience (Wagnild, 2009). The overall score for each participant was computed by summing the 26 individual scores provided by each participant arriving at one score per participant. No subscales were utilized for this study. The computed Cronbach's  $\alpha$  was equivalent to 0.85 for this study.

#### *The Caregiver Strain Index (CSI)*

The Caregiver Strain Index (CSI), an interviewer-administered 13-item dichotomous instrument designed to measure objective strain, has a reported reliability coefficient of 0.86. The instrument has been determined to have construct validity by associating the measures with physical and emotional health of caregivers (Robinson, 1983). The computed reliability was  $\alpha = 0.81$  for this study. For each participant who responded Yes to items read, their responses were scored as 1 and 0 for all No responses. A summation of all Yes responses for each participant yielded an overall score for that participant. A score of at least 7 yes responses indicates a positive screen for caregiver strain.

*The C2A Blessed Dementia Scale (ADL)*

The C2A is an 11-item Likert-type modified version of the Blessed Dementia Scale that was originally designed to objectively measure the degree of intellectual and personality deterioration in conjunction with the activities of daily living experienced by individuals with presumed ADRD as reported by an informant (Blessed, Tomlinson, & Roth, 1968). Utilized in the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) study to measure memory and functional performance in dementia patients as reported by the caregiver, this instrument was utilized in this study to control for function and memory loss of the family member with ADRD. Responses are reflective of the family members' with ADRD loss of ability in performing tasks during the preceding six months. The informant is asked to indicate if the loss is physical, mental, or both. Items are scored from 1, total incompetence, 0.5, partial, variable, or intermittent incapacity, and 0, fully preserved. The C2A version includes an additional rating of 9 indicating "unable to ascertain", or "information unavailable" (Morris, Mohs, Rogers, Fillenbaum, and Heyman, 1988). The caregiver rates the subject with dementia ability to eat, toilet and dress without assistance =0; with minor assistance = 1; with much assistance = 2 or unable to complete as 3. Scores range from 0 to 17 with higher scores indicating poorer function with activities of daily living (ADLs) and more memory loss in the family member with ADRD. In an international study that utilized this instrument, the reliability coefficient was determined to be 0.925 (Pena-Casanova, Monllau, Bohm, Aguilar, Sol & et. al., 2005). The reliability coefficient for this study was 0.81. Each individual's score

to each item were tabulated and an overall score of all items was derived for this instrument. No subscale scores were computed.

Table1

*Study Instrument Reliability Summary*

Scale	# of items	Range	Reliability
Resilience [RS]	26	119-182	0.85 (0.91)
Caregiver Strain Index [CSI]	13	0-13	0.81 (0.86)
Blessed Dementia Scale [C2A]	11	1-17	0.81 (0.925)

*#s in parentheses reported in the literature*

### Study Design

This study was a comparative, descriptive design. The ADRD Family Caregiver Form was analyzed to develop a description of the study sample. In examining the first research question of this study, if a difference in resilience of urban dwelling African-Americans and Caucasian caregivers of family members with ADRD exists in this sample, statistical analysis of the results from the RS were analyzed using SPSS 17.5 for two tailed, independent non-directional t-test to compare resilience in the two groups. Selected study sociodemographic variable of gender and caregiver strain were then analyzed using descriptive statistics and correlation via SPSS 17.5 to identify covariances between the selected study sociodemographic variables (gender and race) and resilience. Multiple regression was utilized to predict which selected sociodemographic variables (age, race, gender) may account for resilience. To determine reliability of the RS,

Caregiver Strain Index, and C2A in this study, Cronbach's coefficient alpha was calculated for the RS, CSI and C2A instruments in this study.

## Validity

### *Internal Validity*

Factors jeopardizing internal validity were controlled due to previous reliability testing in this study. See Table 1. Subjects completed all questionnaires once during data collection interacting with only one data collector, the researcher. Therefore, there was no threat to history, maturation instrumentation or attrition. Reliability for the RS, CSI, and the C2A in this study were calculated at the conclusion of data collection and compared to published data utilizing these scales (Campbell & Stanley, 1963).

### *External Validity*

The study findings may only be generalized to the study subjects and to other caregivers of family members of ADRD with similar sociocultural backgrounds. Analysis of the Caregiver Strain Index (CSI) and the Blessed Dementia Scale (C2A) were completed to control for caregiver strain and family member with ADRD function.

## Pilot Study

The researcher conducted a pilot study with approximately ten subjects for the purpose of evaluating logistics, comfort, and ease with study enrollment and the data collection process. Additionally, feasibility and ease of use of the research design and procedures were also evaluated during this pilot study. All participants completed an

informed consent prior to participating in the pilot study. Results from this pilot study were included with the data for subsequent analysis as no major changes were identified.

### Procedure

Official permission to conduct the study was obtained from The Catholic University and the District of Columbia Baptist Convention (DCBC). Utilizing network sampling, an “Invitation to Participate” flyer (Appendix C) and recruitment letter was distributed via the DCBC to its 150 members throughout the metropolitan Washington, DC area. From a monthly distribution, the researcher was contacted by an Adult Day Center Program Registered Nurse in the District of Columbia who invited the researcher to attend a caregiver support group to recruit subjects. From this meeting, several opportunities to recruit via the National Capital Area Alzheimer’s Association support groups emerged as well as individual referrals to people in the community who were not connected with support groups. In an effort to balance the sample of African-American and Caucasian caregivers, the researcher recruited extensively throughout the entire metropolitan Washington area for the full 12 month enrollment period allocated by the IRB of the university.

The Invitation to Participate flyer contained information about the purpose of the proposed study as well as the researcher’s contact information and a sentence encouraging people who might be interested or who knew someone caring for a family member with ADRD to contact the researcher directly. Once the researcher was contacted, an explanation and discussion of the study purpose and details for participation



proceeded. The researcher determined if the caregiver met the criteria for inclusion in this study. After ascertaining if the study criteria was met, a mutually agreeable setting, date, and time for data collection was established. Because the literature stated that data collection sites should be convenient and familiar to subjects to promote their trust, data collection in this study occurred either via telephone or at a mutually established place such as in the subjects' home (Paatsdaughter et. al., 2001). The estimated length of time for data collection was between 25 to 90 minutes. All instruments were read to the subjects by the researcher to avoid literacy issues.

The researcher offered contacted potential study subjects a copy of a pamphlet detailing community resources for caregivers. Research subjects completing the data collection process received a gift certificate valued at \$10.00 to a local grocery store. This was not an inducement or payment for participation, but rather as a token of appreciation of their time. Documented suggestions for minority research participation included maintaining contact through personal meetings, telephone calls, and letters as well as demonstrating appreciation via thank you notes or gifts (NCI, 2005; Paatsdaughter et. al., 2001). During the proposal development phase of this study, meetings with community leaders from preliminary sites yielded feedback on anticipated recruitment barriers as well as general information regarding strategies for accessing this population.

### Data Analysis

Appropriate analytical procedures were employed to describe the sample and test the hypotheses. SPSS version 17.5 was used for all data analysis. Descriptive statistics such as mean and standard deviation were computed to obtain univariate statistics on the Family Member Caregiver Profile Form. The hypotheses tested as follows H<sub>1</sub>, independent non-directional t-test; H<sub>2</sub>, ANCOVA; H<sub>3</sub> Chi Sq for nominal level data and t test for interval level data; H<sub>4</sub> multiple regression analysis. Alpha was originally set at 0.5.

### Summary

In summary, this chapter delineated the design and method utilized to compare resilience in urban dwelling Caucasian and African-American family caregivers of ADRD family members. The setting, subjects, research procedure, protection of human subjects, and instruments are discussed. Data collection, management, and analysis procedures are outlined.

## CHAPTER IV

### Presentation and Analysis of the Data

The purpose of this study was to: (a) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD; (b) compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD when caregiver strain, and memory and functional status of the family member are controlled; (c) compare differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD; and (d) describe study variables predictive of resilience in urban dwelling caregivers of family members with ADRD.

The findings of this study are presented in four sections: description of study subjects; instrument information, hypotheses testing using independent t-test, ANOVA, Pearson product-moment correlation, ANCOVA, and hierarchical regression, and summary of the chapter.

### Description of the Study Subjects

There were 82 subjects who volunteered to participate in the study, one declined to provide their income for the Caregiver Profile Questionnaire. A purposeful sample of 82 participants who completed all sections of the questionnaires was used for statistical analysis with the exception of income. Data were collected over a 12 month period.

Power analysis was set at 0.80 for a minimum of 90 with a medium effect size of .30 for multiple regression analysis (Cohen & Cohen, 1983). The collected sample size was sufficient meeting the requirements of the following formula ( $N \geq 50 + 8m$ , where

m=number of factors) (Abu-Bader, 2006).

**Table 2**

*Summary of Family Caregivers Personal Data Information*

Personal Data Information	Frequency	Percentage(%)
<b>Age</b>	<b>82</b>	<b>100.00</b>
28-45	11	13
46-62	36	44
63-80	26	32
≥ 81	9	11
<b>Gender</b>	<b>82</b>	<b>100</b>
Male	14	17
Female	68	83
<b>Income</b>	<b>81</b>	<b>100.00</b>
0-15,000.00	18	22
15,001 -30,000	11	14
30,001 -45,000	6	7
> 45,000	46	57
<b>Education</b>	<b>82</b>	<b>100</b>
Grade/HS	16	19
Trade School	4	5
College	32	39
Graduate/Professional	30	37

Since the collected sample exceeds 74, the result of this equation, the sample is sufficient for multiple regression analysis.

Seventy-four percent (n=61) of the subjects elected to complete the questionnaires via telephone in comparison with 26% (n=21) electing to have home visits to complete the questionnaires in person. Of the 82 participants, 63% (n=52) self-identified as African-American (Black) and 37% self-identified as Caucasian (White).

The age of the participants ranged from 28 to 88 with a mean age of 61.77 (SD = 13.80). Seventy-six percent (n=62) of the participants' age ranged between 46 and 80. There were three times as many females (n=68) as males (n=14) who participated in this study. Over 56% (n=46) of the participants reported an income greater than \$45,000.00. Twenty-nine percent of the 81 participants, who disclosed their income, reported an income less than \$30,000.00.

Seventy-five percent (n= 62) of caregivers in this study had attended college. Thirty-seven percent (n=30) of participants reported having a graduate or professional degree. For the purpose of this study, graduate or professional degree included masters, doctorate, law or medical degree.

### Instruments

#### *Family Caregiver Profile Form*

Twenty-six participants (32%) classified their relationship to their family member with

ADRD as daughters, followed by 20% (n=20) classifying themselves as wives. Less than fifty percent (n=37) of the participants in this study were retired with 26% (n=21) of the participants working full-time. Ten percent of the participants identified themselves as being retired and working with the same percentage identifying themselves as being unemployed. An overwhelming majority (77%) of the participants answered positively to receiving respite services. Respite for their family member with ADRD was equally provided by Home Health Aides [HHA] (30%) and Adult Day Care Services (30%).

The majority (44%) of the participants denied being treated for any health problems. There were only 18% (n=15) of the study subjects who identified themselves as being diagnosed with multiple health problems. Hypertension was the primary health problem cited with 13% of caregivers taking medication.

#### *The Resilience Scale (RS)*

Participant scores ranged from 119 to 182. The mean score was 160.72 (SD=13.105) with a median score of 164. One study participant scored in the low resilience range (less than or equal to 125) with 11% (n=9) of study participants scoring in the moderate low to moderate range (scores ranging from 125 to 145). Most of the participants (88%) scored in the moderate high to high resilience range (greater than 145).

#### *The Caregiver Strain Index (CSI)*

Scores ranged from 0 to 13 with only one participant recording a score of 0 (1%) and four recording a score of 13 (5%). Eighteen percent (n=15) of the participants responded with a score of 9. Eleven percent (n=9) responded equally with scores of 10

and 12. Ten percent (n=8) recorded scores of 6, right on the border of having a positive strain score. Seventy-one percent (n= 58) of the participants responded with positive screens for caregiver strain with scores equal to or greater than 7. The mean score for participants was 8.23 (SD=3.267) with a median score of 9 indicating feelings of caregiver strain.

*The C2A Blessed Dementia Scale (ADL)*

The mean score was 9.287 (SD=4.05). The median score was 9.25 with scores ranging from 1.0 to 17.0. One participant recorded a score of 1 (1%) with six participants recording scores of 17 (7%) and 10 (7%). Six percent (n=5) of participants responded with a score of 12.5. Table 2 summarizes descriptive statistics of study instruments utilized in this research study.

**Table 3**

*Descriptive Statistics of Study Instruments*

Variable	Median	Mean	SD	Range
Resilience Scale (RS)	164.00	160.72	13.105	119-182
Caregiver Strain Index (CSI)	9.00	8.23	3.267	0-13
C2A Blessed Dementia Scale (C2A)	9.250	9.287	4.0499	1-17

## Hypothesis Testing

In performing the statistical analysis necessary for hypotheses testing in this study, two (2) independent two-tailed *t*-test were computed followed by analysis of variance and Pearson's product coefficient culminating with hierarchical regression analysis.

### *Statistical Hypothesis 1*

Statistical Hypothesis #1 ( $H_{O1}$ ): There is no significant difference between resilience in urban dwelling African-American and Caucasian caregivers of ADRD family members.

To examine the difference between resilience collectively in urban dwelling African-American and Caucasian caregivers of ADRD family members, an independent two-tailed *t*-test analysis was computed. The results demonstrated a significant difference between the two groups ( $t_{df=80} = 2.081$ ;  $p < 0.05$ ). The null hypothesis was rejected; thus, the research hypothesis was supported. These results are reported in Table 4.

In this study, African-American caregivers of family members with ADRD have significantly higher levels of resilience (Mean = 162.96) than Caucasian caregivers of family members with ADRD (Mean = 156.83). The mean difference is 6.13. Additionally, female caregivers of family members with ADRD have significantly higher levels of resilience (Mean = 162.13) than their male counterparts (Mean = 153.86) in this study. These results are supported by further comparisons that revealed African-American female caregivers had the highest level of resilience (Mean = 163.434) with white males having reported the lowest level of resilience (Mean = 142.480) in this study.

The one-way ANOVA was utilized to further distinguish significant differences among male and female African-American and Caucasian caregivers of family members



with ADRD. The results show an overall significant difference in mean scores of at least two family caregiver groups ( $F_{df\ 3,78}=3.978; p<.05$ ).

The Bonferroni post hoc test was run to determine which family caregiver groups were significantly different. The results of the Bonferroni test revealed that African-American female caregivers of family members with ADRD reported significantly higher

**Table 4**

**Descriptive Statistics of the Dependent Variable Resilience Scores by Gender and Race**

Race x Gender		N	Mean	SD
Black	Male	9	159.33	8.930
	Female	43	163.72	11.671
	Total	52	162.96	11.291
White	Male	5	144.00	18.138
	Female	25	159.40	13.525
	Total	30	156.83	15.193
Total	Male	14	153.86	14.437
	Female	68	162.13	12.462
	Total	82	160.72	13.105

**Table 5**

*Independent t-test for Resilience by Ethnicity*

Variable	N	Mean	SD	<i>t</i>	<i>p</i>
African-Americans	52	162.96	11.29	2.081	.041
Caucasians	30	156.83	15.193		

[*t* (*df*=80), *p*<.05, 2-tailed *p*]

**Table 6***Results of One-Way ANOVA Resilience*

	Sum of Squares	df	Mean Square	F	Sig
Between groups	1845.89	3	615.30	3.978	.011
Within groups	12064.65	78	154.68		
Total	13910.55				

levels of resilience than Caucasian male caregivers of family members with ADRD (mean difference = 19.721). No significant difference was determined between African-American female caregivers and African-American males (mean difference = 4.388) or Caucasian female caregivers (4.321). See Tables 4 through 6.

*Statistical Hypothesis 2*

Statistical Hypothesis #2 (HO<sub>2</sub>): There will be no significant difference in resilience between urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain [CSI], and memory and functional status [C2A] of the family member with ADRD are controlled.

The second hypothesis was tested by conducting a two-way analysis of variance to examine the effects of race on resilience. Results of the two-way ANOVA show an overall significant difference in resilience between African-American and Caucasian caregivers in this study ( $F_{(1, 82)} = 7.238, p < .001$ ). Moreover, caregiver strain ( $F_{1, 82} = .468, p > .05$ ) nor memory or functional status ( $F_{1, 82} = 2.916, p > .05$ ) of the ADRD family member demonstrated any significant impact on resilience in this study. The null hypothesis was not rejected. The research hypothesis was not supported.

African-American caregivers had a mean score of 162.96 (SD=11.291) compared to Caucasian caregivers mean score of 156.83 (SD=15.193). Additionally, the results of the two-way ANOVA show a difference in resilience between male and female caregivers of family members with ADRD ( $F_{1,80} = 7.320, p < .001$ ). Caucasian male caregivers had the lowest mean scores of all four groups (Mean=144, SD = 18.138) with African-American female caregivers having the highest scores (Mean=163.72, SD=11.671). The results of the two-way ANOVA did not demonstrate significance in race by gender interaction effect on resilience ( $F_{1,82} = 3.164, p > .05$ ) in this study.

**Table 7**

Tests of Between-Subjects Effects Resilience

Source of Variance	SS	df	MS	<i>F</i>	<i>p</i>
CSI	71.214	1	71.214	.468	.496
C2A	443.505	1	443.505	2.916	.092
Main Effect 1 (Race)	1100.744	1	1100.744	7.238	.009*
Main Effect 2 (Gender)	1113.166	1	1113.166	7.320	.008*
Interaction Effect (Race x Gender)	481.088	1	480.088	3.164	.079
Error	11557.351	76	152.070		

*Statistical Hypothesis 3*

Statistical Hypothesis #3 (HO3): There will be no significant differences in selected sociodemographic variables (age and gender) and caregiver strain [CSI] in urban dwelling African-American and Caucasian caregivers of family members with ADRD. An independent two tailed *t*-test as well as Pearson product-moment correlation were conducted to test the third hypothesis. There was a significant difference in the dependent variable, caregiver strain and gender ( $t_{df=80} = 1.90; p < .01$ ). To examine the significance between age and caregiver strain, the Pearson product-moment correlation

coefficient was utilized. The results did not show a significant relationship ( $r = -.137$ ,  $p > .05$ ), indicating that age did not have a significant correlation with caregiver strain in this study. The null hypothesis was not rejected. Therefore, the research hypothesis was not supported.

**Table 8: Independent *t*-test for CSI by Gender**

Variable	N	Mean	SD	<i>t</i>	<i>p</i>
Males	14	6.21	3.87	.010	.01
Females	68	8.65	2.996		

$t_{(df=80)}$ ,  $p < .01$ , 2-tailed

#### *Statistical Hypothesis 4*

Statistical Hypothesis #4 (HO4): Selected study variables (age, gender, and ethnicity) will not be predictive of resilience in urban dwelling caregivers of family members with ADRD.

In examining the selected study variables of caregiver age, ethnicity, and gender that would be predictive of resilience in urban dwelling caregivers of family members with ADRD, stepwise multiple regression was conducted to estimate a model that best predicts resilience in urban dwelling caregivers of family members with ADRD. Both gender and ethnicity were recoded as dummy variables (0 and 1) to satisfy the assumption of multiple regression. The results of the analysis revealed that all three variables emerged as significant predictors of resilience ( $F_{3, 81} = 7.919$ ;  $p < 0.001$ ). With a beta of .36 ( $p < .010$ ), caregiver age emerged as the strongest predictor of resilience, accounting for 9.8% of the variance in resilience. The second strongest factor was

caregiver ethnicity ( $\beta = -.28$ ;  $p < .010$ ) accounting for an additional 7.5% of the variance in resilience scores. The third strongest factor was gender ( $\beta = .25$ ;  $p < .05$ ), accounting for 6% of the variance in resilience scale scores. In this study, older caregivers who are African-American and female, experience greater levels of resilience. The null hypothesis was rejected; and the research hypothesis was accepted. Overall, the model explains almost 23% of the variance in resilience scores ( $R = .48$ ). Almost 78% of the variance in resilience is unaccounted for by this model.

**Table 9**

*Results of Multiple Regression Analysis: Predictors of Resilience*

Factor	<i>R</i>	<i>R</i> <sup>2</sup>	$\beta$	<i>t</i>	<i>p</i>	<i>F</i>	<i>p</i>
1. C Age	.313	.098	.356	3.553	.001*	8.665	.004*
2. Ethnic	.416	.173	-.280	-2.794	.007*	8.268	.001*
3. C Gender	.483	.233	.246	2.479	.015*	7.919	.000*

*p* < .05

### Summary

There was a difference in resilience between African-American and Caucasian caregivers of family members with ADRD in this study. However, there was no difference in resilience between urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain [CSI], and memory and functional status [C2A] of the family member with ADRD was controlled in this study. Additionally, there was no difference in the selected sociodemographic variable of age and caregiver strain [CSI] in urban dwelling African-American and Caucasian caregivers of family members with ADRD. However, there was a difference in the selected sociodemographic variable of gender and caregiver strain [CSI]. Age, ethnicity, and gender all emerged as predictors of resilience in caregivers of family members with ADRD in this study.

## CHAPTER V

### FINDINGS, DISCUSSION, CONCLUSIONS, RECOMMENDATIONS

#### Problem

As the age 65 and over population increases in the United States, Alzheimer's Disease and Related Dementia (ADRD) will remain a major concern to health professionals, particularly nurses. The duration of caring for a family member with ADRD may be extensive, confining, and demanding on family caregivers. It is estimated that approximately 80% of people diagnosed with ADRD in the United States are cared for in the community by a family member (Brangman, 2006). In a survey of 1700 caregivers over a 6 month period, approximately 5 days of work was missed with an average of 85 hours per week of providing care to their family member with ADRD (Brangman, 2006).

The morbidity and mortality associated with Alzheimer's Disease and Related Dementia (ADRD) has increased in the United States such that every 70 seconds a person dies from ADRD (ADA, 2009). Treatment of this chronic neurodegenerative disorder primarily is limited to pharmacological agents that increase the neurotransmitter acetylcholine and decrease production of glutamate receptors as well as treating coexisting diseases (Desai & Grosberg, 2005). People diagnosed with ADRD may suffer for 8 to 20 years leading to a prolonged duration of caregiving characterized by increased memory loss and decreased functional status of the family member with ADRD (Covinsky & Jaffe, 2004). The long duration of caring for an ADRD family member may lead to increased levels of mental stress in comparison to other caregivers of chronic

illnesses (Parks & Novelli, 2003; Prigerson, 2003). Recent statistics place the costs of provision of services for people with ADRD between 51 to 88 million dollars a year (ADA, 2009).

Caring for a family member with ADRD is associated with increased financial burden and psychological stress leading to increased caregiver strain, which is synonymous with stress and burden (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Over the past 30 years, there has been an increase in research studies delineating the ADRD caregiving process as being burdensome and stressful in comparison to other caregivers of family members with debilitating illnesses such as Cerebrovascular (CVA) and Amyotrophic Lateral Sclerosis (ALS) (Clark & King, 2003; Rabkin, Wagner, & Delbene, 2000). Stressors associated with caring for a family member with ADRD may be divided into subjective and objective stressors (Kasuya, Polgar-Bailey & Takeuchi, 2000). Tasks specifically affiliated with caring for family members with ADRD include assisting the relative with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) as well as managing disturbing behaviors (Farran, Loukissa, Lindman, McCann, & Biennas, 2004).

Ethnic identity and urban living may compound these stressors and burdens (Andrulis, 2003). Despite the increased caregiver strain experienced by family caregivers, African-American family caregivers have previously demonstrated more positive characteristics and attributes of caring for their family members with ADRD (Hill, 1998). As a result of the process of caring for a relative with ADRD, family



members may develop resilience by adapting to the many subjective and objective stressors.

The past 15 years have seen the emergence of more research studies investigating characteristics of African-American family caregivers of family members with ADRD. Information from these studies has led to the development of a description of the African-American caregiver as being a female who may not be a biological relative of the person with ADRD. The African-American caregiver may also indicate more positive experiences of caregiver satisfaction with fewer perceptions of caregiving being intrusive or time consuming in comparison to their Caucasian counterparts (Hargrove, 2006).

Resilience is “a personality characteristic that moderates the negative effects of stress and promotes adaptation” (Wagnild, 2003). Reflective in this definition of resilience is the change in the paradigm of resilience research from ego-resiliency to investigating this concept as a dynamic process precipitated by adversity, the second generation in resilience research. Because the stressors experienced by family members caring for family members with ADRD may be viewed as an adversity, investigating resilience in caregivers of family members with ADRD is indicative of the second generation of resilience research. Investigators move to extend this second generation to include the development and testing of interventions, which may lead to the augmentation of resilience in populations. Moreover, the need for empirical inquiry quantifying resilience in diverse populations and evaluating outcomes of resilience interventions has been identified as the focus of future research (Earvolino-Ramirez , 2007).

The variables of resilience, ethnicity, age, and caregiver strain may influence the extensive caregiving process of urban dwelling caregivers of family members with ADRD. The research gap this study addressed was to explore resilience in urban dwelling family caregivers of ADRD family members to determine if differences existed. Additionally, the influence of socioeconomic variables (age, gender, and ethnicity), caregiver strain, as well as memory and functional status of the family member with ADRD on resilience was also examined.

### Purpose

This study identified whether a difference existed in resilience between African-American and Caucasian caregivers of family members with ADRD and if caregiver strain as well as memory and functional status of the family member with ADRD impacted resilience. The influence of age and gender on caregiver strain was examined in this population. Finally, sociodemographic variables of age, gender, and ethnicity were analyzed to determine which variables would be predictors of resilience in urban-dwelling caregivers of family members with ADRD.

### Discussion of Findings

#### *Research Design*

Utilizing a non-experimental descriptive comparative design, the researcher determined differences in resilience between the African-American and Caucasian caregivers of family members with ADRD as well as if resilience was influenced by caregiver strain and memory and functional status of the family member with ADRD. Statistical analysis conducted to test the hypotheses included regression analysis, one way

analysis of variance and analysis of covariance, independent two tailed t-test, and chi-square. Descriptive statistics provided analysis of demographic data and univariate relationships.

### *Research Hypotheses and Findings*

The research hypotheses investigated in this study and related findings are discussed.

#### *Research hypotheses:*

**H<sub>1</sub>:** There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members.

**H<sub>2</sub>:** There will be a difference in resilience of urban dwelling African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD are controlled.

**H<sub>3</sub>:** There will be differences in selected sociodemographic variables and caregiver strain in urban dwelling African-American and Caucasian caregivers of family members with ADRD.

**H<sub>4</sub>:** Selected study variables will be predictive of resilience in urban dwelling caregivers of family members with ADRD.

*Findings:* There was a difference in resilience between urban-dwelling African-American and Caucasian caregivers of family members with ADRD. The independent variables of caregiver age, ethnicity, and gender accounted for almost 23% of the variance in the resilience scores in this study. There was a difference in resilience between African-American female and Caucasian male caregivers who participated in

this study. Caregiver strain and memory and functional status of the family member with ADRD did not influence resilience in the caregivers who participated in this study.

Gender was significant when examining caregiver strain; however, age was not significant when examining caregiver strain in this study.

[H1] The results demonstrated a significant difference in resilience between African-American and Caucasian family caregivers of ADRD family members. Further analysis of resilience scores by gender and race revealed a significant difference between African-American female caregivers and Caucasian male caregivers in this study.

Descriptive analysis revealed that all groups possessed high resilience scores.

The implications of finding that African-Americans scored significantly higher on the RS as compared to Caucasians, suggest they differ from Caucasians in how they view the caregiving process. Sterritt and Pokorny (1998) identified that African Americans family caregivers associated caring for relatives with ADRD as being an act of love rooted in the tradition of family. Research by Lawton, Rajagopal, Brody, and Kleban (1992) reported that African-American caregivers in comparison to White caregivers identify with traditional values, which encourage providing care for older dependent family members in the community. Positive aspects of caregiving (PAC) [caregiver satisfaction, caregiver gain, and caregiving rewards] are believed to reduce the stressors associated with caregiving as well as improving caregiver perceptions. There are more benefits or gains associated with PAC in African-Americans in comparison to their Caucasian counterparts (Roff, et al., 2004).

The statistical significance in resilience that existed between African-American female and Caucasian male caregivers in this study may be attributed to a few reasons. First, findings may be attributed to gender role perceptions of the caregiving process. African-American females have an altruistic perception of caring for loved one with ADRD, assuming ownership of this role (Sterritt and Pokorny). Caucasian males are viewed to provide care by default as opposed to African-American males being more exposed to a more egalitarian familial structure (Dilworth-Anderson, 2005). Furthermore, African-American females reported more perceived rewards from caring for a chronically ill relative than Caucasians (Roff et al., 2004).

Since the Resilience Scale was constructed from a sample consisting exclusively of all females, bias may exist towards one gender (Wagnild, 1990) as well as the disproportion of female to male participants in this study. In this study, 83% of the participants were females with over half of the females identifying themselves as being African-American females (52%). Several studies report more females as being caregivers of family members with ADRD than males; however, this study had less than the average percentage (28%) of estimated male caregivers providing care for ADRD family members in the United States (Houde, 2002).

Although all assumptions for the T-test were met (including Levine's test of homogeneity), these findings may have been influenced by unequal sample sizes as well as this not being a random sample. The percentage of female caregivers in this study (83%) was significantly higher than two state reports of 57% (Washington State) and 58% (California) by the Alzheimer's Disease Association (2009), but congruent with

demographics from the geographical area where research participants were recruited (DCOA, 2005). Moreover, Brodaty & Green (2002) reported national figures noting that 77% of caregivers for family members with ADRD are female.

[H2] Results of the two-way ANOVA revealed no difference in resilience between African-American and Caucasian caregivers of ADRD family members when caregiver strain, and memory and functional status of the family member with ADRD were controlled in this study.

The significance in this study's findings that there was no difference in resilience between the two ethnic groups of caregivers when caregiver strain and memory and functional status was considered may be attributed to the high educational level and socioeconomic status of the research participants. An item on the CSI directly asks if it is a financial strain to care for their loved one. Seventy-four percent of the study's population responded "no".

Prior investigations report a difference between African-American and Caucasian caregivers with Caucasian caregivers experiencing increased strain with decreased levels of function of the care recipient (Williams, Dilworth-Anderson, & Goodwin, 2003). African-American family caregivers are frequently described in the literature as having more positive attributes and views of caregiving (Hill, 1998; Lawton, Rajagopal, Brody, & Kleban, 1992; Sterrit & Pokorny, 1998; Toth-Cohen, 2004) as well as being strong and adaptable in the caregiving culture (Williams, Dilworth-Anderson, & Goodwin, 2003). Despite the socioeconomic variables or level of function of the caregiver or care recipient, the literature reaffirms the positive caregiving perspective of African-American

caregivers. Cultural views and perspectives may prevent African-Americans from responding negatively to questions that describe their caregiving experience.

The Blessed Dementia Scale (ADL) [C2A], used to measure memory and functional status of the family member with ADRD is a common measurement instrument of functional abilities in individuals diagnosed with dementia (Blessed, Tomlinson, & Roth, 1968). Memory and functional status of the family member with ADRD in this study was self-reported by the caregiver utilizing the C2A. A disadvantage of self-report is that family members may underrate the functional status of the family member leading to a biased evaluation of the individual's abilities (Zanetti, et. al.,1998). Although caregiver appraisal is a reliable resource utilized by health professionals in the diagnosis and management of ADRD, disagreements may exist between assessments of health professionals and family members (Zanetti, Frisoni, Rozzini, Bianchetti & Trabucchi, 1998). No professional appraisal of the memory and functional status the family member with ADRD was completed.

[H3] There was a significant difference in the dependent variable, caregiver strain and the socioeconomic variable of caregiver gender; however, age was not a significant demographic variable when examining caregiver strain in this study.

The literature has mixed findings regarding gender differences in stress among caregivers. Researchers have found minimal to no significant differences in the gender of caregivers of family members with ADRD (Ford, Goode, Barrett, Harrell, & Haley, 1997; Miller, 1987; Pruchno & Resch, 1989). Gender differences in this study may be attributed to gender role socialization theory. Gender role socialization theory essentially

attributes individual's perspectives about caregiving to intrinsic cultural gender roles where women assume more traditional duties of caregiving, such as personal care and men will gravitate towards instrumental activities, such as financial management (Miller & Cafasso, 1992). Thus, when either gender has to assume the opposite functions of their gender, this may lead to increased stress producing negative perceptions of the caregiver role.

Robinson (1983) did not find significant differences in caregiver strain scores in examining gender when developing the Caregiver Strain Index. However, younger participants in the report of the CSI psychometrics recorded increased strain scores.

An international study comparing caregivers of family members with dementia to caregivers of family members without dementia as well as family members possessing no caregiving responsibilities generally found that females experienced more strain than males, specifically female caregivers of dementia individuals (Almberg, Jansson, Grafstrom, & Winblad, 1998). Moreover, the investigators identified that male caregivers experience limited social support and lack a positive outlook leading the investigators to question if strain may vary depending on gender. Compounded by possible personal perceptions regarding their caregiver role, males may necessitate further exploration of adaptation to caregiving. These findings are congruent with similar studies in the United States.

[H4] Age, ethnicity, and gender are all predictors of resilience, accounting for 23% of the variance in this study.



A significant positive correlation was found between age and resilience scores in this study consistent with the regression analysis showing a significant influence of age on resilience in this study. Moreover, findings from this study are similar to another study suggesting that resilience increased with age (Wagnild, 2009). In a study seeking to examine the relationship between resilience and forgiveness, age and gender along with forgiveness scores, self-rated resilience and health status explained about 28.1%, of the variance in resilience among 497 randomly selected planned community dwelling older adults (Wagnild, 2009).

Gender bias may exist with the Resilience Scale since it was developed exclusively with women (Wagnild, 1993). Data confirms that the Resilience Scale has been utilized with more women than men (1,110 females and 650 males) (Wagnild, 2009). To further substantiate the discussion that the Resilience Scale may be biased regarding gender, a cross-sectional study examining resilience as a response to a stressful life event regardless of the specific type of life event in older adults found no association with gender and high resilience without using the Resilience Scale to evaluate resilience (Hardy, Concato, & Gill, 2004).

Although 23% of the variance in resilience is accounted for in this study, 77% of the variance in resilience may be related to extraneous variables. There was no correlation between Resilience Scale scores and Caregiver Strain Index scores.

#### *Serendipitous Findings*

Looking at individual items of analysis of Caregiver Strain Index [CSI] and Resilience Scale [RS] revealed relevant clinical findings. In examining the CSI, 56% of

study participants found caring for their ADRD family member to be inconvenient with 61% responding that it was confining. The researcher observed the tone of voice, and hesitancy to respond, as well as body language to this question that many caregivers were reluctant to reply “yes”, possibly because they did not want to be identified as verbalizing a negative connotation affiliated with caring for their family member with ADRD.

Caregivers in this study, mainly (85%), responded that there had been emotional adjustments as well as family adjustments (76%) resulting in changes in personal plans (78%). These findings are consistent with other studies (Covinsky & Yaffe, 2004, Prigerson, 2003), which describe the emotional changes caregivers experience resulting from altering personal plans as well as making family adjustments. Additionally, caregivers found the behavior of family members to be upsetting (84%). Equally upsetting to caregivers was the change in the family member with ADRD from their previous self (82%). Several participants reflected on the significant decline in mental and functional ability of their family member with ADRD by elaborating on the personal and professional accomplishments of their family member with ADRD. This elaboration at the conclusion of data collection left an impression with the researcher that the caregiver felt the need to distinguish the mental and sometimes physical aptitude of the family member with ADRD.

Only 26% of caregivers reported a financial strain associated with caring for their family member with ADRD with 57% of caregivers reporting individual incomes greater than \$45,000. Despite the high income level of caregivers, the researcher questions if they were reluctant to admit to experiencing financial strain. If the item had addressed

the potential for financial strain, the percentage may have been higher. Many study participants expressed problems with the wording of Item #13 due to the word “completely” being in the phrase. This may have contributed to only 54% of study participants responding positively to this item.

In analyzing the RS, the researcher examined the responses by grouping the study participants responses in the following categories from 1 to 3 associated with low resilience, 4 neutral, 5 moderate resilience and 6 and 7, high resilience (Wagnild, 1993). These groupings are consistent with scoring for this scale (Wagnild, 1993). Seventy-eight percent of study participants responded highly as being able to follow through with plans. Overall, participants responded positively to factors associated with self-reliance, a core concept indicative of resilience (Wagnild, 1990) with 89% stating they usually manage one way or another; 88% stating they are able to depend on themselves more than anyone else; and 91% stating that if they had to, they can be on their own.

Caregivers responded highly to feeling proud of their own individual life accomplishments (87%) as well as expressing that their lives had meaning (94%). Both of these responses reveal that participants in this study expressed feelings of purpose in life and valued their individual contributions to life. This is descriptive of another core concept of resilience, meaningfulness (Wagnild, 1990).

All of the caregivers responded at the moderate to high level of resilience as being able to get through difficult times because of previous experiences with 83% responding in the high resilience range. The ability to consider a broader range of experience, which may assist with modulating extreme responses to adversity, is associated with,

equanimity, another core concept of resilience (Wagnild, 1990). The majority (90%) of the participants identified themselves as being resilient. All (100%) of the caregivers described themselves as being someone that others could rely on in an emergency.

Several participants verbally indicated issues with the wording and meaning of item #17, which states “My belief in myself gets me through hard times.” Reservations centered on the phrase “... belief in myself...” with participants further attributing their perseverance to religious and spiritual beliefs. The researcher noted the association of relying on spiritual and religious affiliation was not affiliated with ethnicity as investigations have reported in the past (Picot, Debanne, Namazi, & Wykle, 1997).

### Theoretical Framework

The theoretical framework guiding this study was The Family Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1991). It is a family theory used extensively in health care research to examine adaptation to a stressful event; thus, appropriate for examining resilience in urban dwelling African-American and Caucasian caregivers of family members with ADRD. This theory is useful in evaluating resilience in family caregivers. The perceived stressor of caring for a family member with ADRD is the adverse or stressful event that the family as a unit or as individuals experience resulting in a positive outcome of adaptation, resilience. Resilience may be influenced by caregiver strain, memory and functional status of the family member with ADRD, and sociodemographic variables.

The results in this study are mixed in respect to supporting the theoretical framework that caregivers of ADRD family members adapt to caring for their family member. African-American family caregivers collectively demonstrated higher resilience scores in this study in comparison to Caucasian family caregivers. Caregiver strain nor memory and functional status of the family member with ADRD influenced resilience in this investigation.

The demographic variables of ethnicity, age, and gender were identified as predictors of resilience in this study. However, age was the only demographic variable that significantly influenced caregiver strain. While this information does not fully validate the theoretical framework utilized in this study, it does add to the model providing information regarding sociodemographical information about caregivers of family members with ADRD who may be at risk for maladaptation.

Social support was not measured and may account for some of the variance in resilience in this study. The literature has identified that familial and peer relationships are an integral factor in decreasing stress levels in caregivers of ADRD family members (Wilks & Croom, 2008). Differences in the availability of support persons between African-American and Caucasian caregivers of family members with ADRD exist with African-American caregivers identifying fewer support persons over a five year time period (Clay, Roth, Wadley & Haley, 2008).

## Implications for Research, Policy, and Practice

### *Research*

In conducting studies that describe African-American caregivers of family members with ADRD, it will be important to integrate their perceptions of resilience. The results from this study demonstrate that African-American caregivers, especially African-American females, of family members with ADRD are resilient. This finding may be attributed to cultural values and gender role theory. Not understanding their personal perspective or views of resilience may result in developing false assumptions of African-American female caregivers of family members with ADRD.

### *Policy*

The majority of the caregivers were middle-class and college graduates. Approximately half of them expressed concern about the financial strain associated with caring for their family member with ADRD as well as having to make work adjustments. These results call attention to the ever increasing demand for evaluation of municipal programs, services, and agencies that assist caregivers in maintaining their family members with ADRD in the community. Further appraisal concerning the effect of the Family Medical Leave Act (FMLA) on caregivers decreased productivity and lost wages is also needed. Lobbyists may utilize results to justify additional funding for community resources.

### *Practice*

The results could provide clinicians with evidence for assessment and treatment decisions as well as patient educational material. African-American females are more

likely to verbally express positive emotions regarding caring for a family member with ADRD (Roff et. al., 2004). Therefore, they may collectively be viewed as resilient.

Ultimately, nurse practitioners may be the initial health care professionals many caregivers of family members with ADRD confide in. Therefore, nurse practitioners need to believe in an individual's ability to identify new strengths, while nurturing resilience in all patients. Allowing time to express feelings about stressors related to caring for their family member with ADRD is therapeutic and should be integrated into primary care visits.

### Recommendations

This study found that there was a difference in resilience in urban dwelling African-American and Caucasian caregivers of family members with ADRD. Recommendations for further research designed to explore and describe the perceptions of resilience in caregivers of family members with ADRD include the following:

1. Qualitative exploration of the constructs for items on the Resilience Scale in males and African-Americans.
2. Replicate the study with a larger more diverse sample collecting data from other regions in the United States and more diverse populations. Extending the study to other urban regions and being more inclusive of male family caregivers and other underrepresented groups would strengthen external validity.
3. To conduct a comparative descriptive qualitative study that delineates the 21<sup>st</sup> century perceptions of caregivers of family members with ADRD. This study

would update the literature to delineate the process of caring for a family member with ADRD now in comparison to 20 years ago.

4. The study should be designed to qualitatively explore the appropriateness of the concepts and language on the Resilience Scale in male family caregivers.

### Limitations

The following limitations were identified in this study:

1. The collection of data from a metropolitan region limits external validity. All of the subjects in this study resided in a large metropolitan area. The findings can only be generalized to similar samples in the metropolitan Washington, DC area with caution. Family caregivers from rural regions may reveal different results possibly as a result of receiving care in a less densely populated area.
2. Providing two methods of collecting data that the participant selected, either via telephone or in person, was utilized to gain trust and obtain information from an extremely busy population, has limitations. Subjects may have stated what they thought the investigator wanted to hear.
3. Using network sampling versus random sampling has limitations. Because an advantage of network sampling is that the researcher may gain access to difficult populations, participants tend to refer others who are similar in demographics as well as experiences (Burns & Grove, 2001).



4. Utilizing the DCBC, a religious entity may present bias. Participants may have been influenced by religious affiliations. Religious affiliation of subjects was not investigated in this study.

### Conclusion

The primary purpose of this study was to evaluate resilience in urban dwelling African-American caregivers of family members with ADRD and their Caucasian counterparts. The literature supports the existence of differences in characteristics of African-American and Caucasian caregivers of family members with ADRD. This study supports the observation that there is a difference in resilience between African-American and Caucasian caregivers of family members with ADRD.

In light of this, no difference in resilience was found between African-American and Caucasian caregivers of family members in this study when caregiver strain as well as memory or functional status of the family member with ADRD were taken into consideration. Age, ethnicity, and gender were all found to be predictors of resilience in this study. The duration of caring for a family member with ADRD in the community is lengthy and characterized by increased memory loss and decreased function of the individual diagnosed with ADRD. This places a tremendous amount of strain on the family unit, particularly the specific family member or members who provide care to the individual. Further investigation of resilience among male and ethnically diverse family caregivers is needed.



**The Catholic University of America**  
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### **Informed Consent Form**

**Name of Study:** Resilience in African-American and Caucasian Caregivers of Family Members with Alzheimer's Disease and Related Dementia (ADRD)

**Investigator:** Kimberly D. Battle, MSN, RN  
Doctoral Student  
Telephone: (202)494-1994  
Email: [73battle@cua.edu](mailto:73battle@cua.edu)

**Supervisor:** Sister Mary Elizabeth O'Brien, Ph.D., RN, FAAN, AHN  
Telephone: (202)319-6459

**Description and Purpose of the Study:** I understand that I am being asked to participate in this research study. I understand that the purpose of this study is to compare and describe resilience in African-American and Caucasian caregivers of family members with Alzheimer's Disease and Related Dementia. Resilience is a personality trait that assists one in coping with stress and encourages adaptation. This study is being done in the Washington, DC area with volunteer caregivers who will be contacted through churches as well as by word of mouth in their communities. I understand that this study is being carried out to fulfill partial requirements for a Doctor of Philosophy in Nursing degree at The Catholic University of America School of Nursing.

**Description of Procedures:** I am being asked to participate in this study because I am involved in the care of my family member who has ADRD. The researcher has discussed the study and reviewed the informed consent with me. I will be asked by phone or personal interview to complete questionnaires about myself, the degree of dementia in my family member, and to describe any strain that is associated with caring for my family member with ADRD. This may be done at a mutually agreed upon time in my home or other setting or via telephone. This whole process should last about 45 to 60 minutes. At the end of the session, I will be offered a \$10.00 gift card as a token of appreciation for my time.

**Foreseeable Risk, Inconveniences, or Discomforts:** The risks and discomforts associated with

this study are minimal. I understand that participation in this study is voluntary. I understand I may ask to stop the completion of the questionnaires at any time and contact Kimberly Battle,

MSN, RN who will provide me with support.

**Benefits That May Occur:** Although my participation may not benefit me directly, I understand that my participation in this study has potential to provide a deeper understanding of resilience in urban dwelling caregivers of family members with ADRD. Additionally, results may also assist health care workers with developing skills to promote resilience and positive health outcomes in caregivers.

**Confidentiality of Subject Identity/Records:** I understand that the questions asked do not identify me by name. I understand that my responses will be secured in a locked file cabinet accessible by the investigator only. I understand that all information provided by me in relation to this study will be confidential to the extent that it is legally possible. I understand that my research records may be subpoenaed by court order or may be inspected by federal regulatory authorities. I understand that all of the information obtained will be presented in group form.

**Supplies/Storage of Study Tools:** I understand that all study materials will be stored under lock and key for five years at a secured location controlled by the investigator, at which time they will be destroyed. Identifying data, such as my name and informed consent form, will be kept separate from the questionnaires. Only the investigator will have access to these questionnaires and/or consents.

**Termination of Participation:** I understand that participation in this study is voluntary. I understand that I may refuse to participate and can withdraw my consent at any time during the study without penalty or loss of benefits to which we may be entitled.

I understand that any information obtained because of my participation in this research will be kept confidential to the extent legally possible.

I have had the opportunity to ask any questions about the research and my participation in the research, and these questions have been answered to my satisfaction.

I understand that I will receive a signed copy of this consent form.

I volunteer to participate in this study.

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Participant's Signature

---

Date

---

Investigator's Signature

---

Date

Any complaints or comments about your participation in this research project should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, DC 20064; Telephone: (202) 319-5218.

**Family Caregiver's Profile Form**Caregiver's Gender ☐ Male ☐ Female      Number of years caring for relative \_\_\_\_\_

Caregiver's Age in Years: \_\_\_\_\_

Caregiver's Ethnicity: ☐ Black      ☐ White      ☐ Other

Relationship of Caregiver to relative: ☐ wife ☐ husband ☐ sister ☐ brother ☐ cousin  
☐ daughter ☐ son ☐ niece ☐ nephew ☐ uncle ☐ aunt ☐ stepmother  
☐ stepfather ☐ other \_\_\_\_\_

Annual Income of Caregiver:

☐ \$0.00 - \$15,000    ☐ \$15,001 - \$30,000    ☐ \$30,001 to \$45,000    ☐ greater than \$45,001

Caregiver's Highest Level of Education

☐ Grade School      ☐ High School      ☐ GED      ☐ Trade School    ☐ College  
☐ Other \_\_\_\_\_

Employment Status (Please check all that apply)

☐ Full-Time (greater than or equal to 30 hours per week)  
☐ Part-Time (less than or equal to 29 hours per week)  
☐ Retired      ☐ Unemployed      ☐ Disabled

Number of Hours a Day Providing Care for Relative \_\_\_\_\_

Number of Years Providing Care for Family Member \_\_\_\_\_

Number of people in family, relationship, and age living in the same home with caregiver and  
 ADRD patient.

Individual (Adult or Child)	Relationship	Age

**Family Caregiver's Profile Form**  
(continued)

Other people who may assist with ADRD family member's care and the number of minutes or hours they assist

Individual	Minutes/Hours They Assist	Compensated/Voluntary

Have you received any respite care in the past year? ☐ Yes ☐ No

Who provided respite care for you?

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---

Amount of time away from family member every day \_\_\_\_\_

How would you describe your health?

☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor

Do you or have you ever seen a doctor for any of the following conditions:

☐ Hypertension ☐ Insomnia ☐ Cancer ☐ Stroke ☐ Heart Attack ☐ Diabetes

☐ Depression ☐ Anxiety ☐ Other \_\_\_\_\_

Family Member with ADRD Gender: ☐ Male ☐ Female

Family Member's Age in Years: \_\_\_\_\_

## Appendix C

Participant # \_\_\_\_\_

### Resilience Scale

Please read the following statements. To the right of each you will find seven numbers, ranging from "1" (Strongly Disagree) on the left to "7" (Strongly Agree) on the right. Circle the number which best indicates your feelings about that statement. For example, if you strongly disagree with a statement, circle "1". If you are neutral, circle "4", and if you strongly agree, circle "7", etc.

	Strongly Disagree					Strongly Agree	
1. When I make plans, I follow through with them.	1	2	3	4	5	6	7
2. I usually manage one way or another.	1	2	3	4	5	6	7
3. I am able to depend on myself more than anyone else.	1	2	3	4	5	6	7
4. Keeping interested in things is important to me.	1	2	3	4	5	6	7
5. I can be on my own if I have to.	1	2	3	4	5	6	7
6. I feel proud that I have accomplished things in life	1	2	3	4	5	6	7
7. I usually take things in stride	1	2	3	4	5	6	7
8. I am friends with myself.	1	2	3	4	5	6	7
9. I feel that I can handle many things at a time.	1	2	3	4	5	6	7
10. I am determined.	1	2	3	4	5	6	7
11. I seldom wonder what the point of it all is.	1	2	3	4	5	6	7
12. I take things one day at a time.	1	2	3	4	5	6	7
13. I can get through difficult times because I've experienced difficulty before.	1	2	3	4	5	6	7
14. I have self-discipline.	1	2	3	4	5	6	7
15. I keep interested in things.	1	2	3	4	5	6	7
16. I can usually find something to laugh about.	1	2	3	4	5	6	7
17. My belief in myself gets me through hard times.	1	2	3	4	5	6	7
18. In an emergency, I'm someone people can generally rely on.	1	2	3	4	5	6	7
19. I can usually look at a situation in a number of ways.	1	2	3	4	5	6	7

## Resilience Scale

	Strongly Disagree				Strongly Agree		
20. Sometimes I make myself do things whether I want to or not.	1	2	3	4	5	6	7
21. My life has meaning.	1	2	3	4	5	6	7
22. I do not dwell on things that I can't do anything about.	1	2	3	4	5	6	7
23. When I'm in a difficult situation, I can usually find my way out of it.	1	2	3	4	5	6	7
24. I have enough energy to do what I have To do	1	2	3	4	5	6	7
25. It's okay if there are people who don't like me.	1	2	3	4	5	6	7
26. I am resilient.	1	2	3	4	5	6	7

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**The Catholic University of America**

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**Invitation to Participate in a Research Study**

As a nurse practitioner providing care for elderly citizens in the metropolitan Washington, D.C. area, I have become familiar with the various hardships and stressors family caregivers experience in providing care for their loved one with Alzheimer's Disease and/or Related Dementia (ADRD). As a student pursuing my PhD from The Catholic University of America School of Nursing, I became interested in researching these experiences. Currently, I am seeking participants who are age 18 and older and the primary caregiver for a family member with Alzheimer's Disease or Related Dementia (ADRD).

The purpose of this study is to describe and compare resilience in urban dwelling Caucasian and African-American caregivers of family members with ADRD. Your participation directly or indirectly by referring someone you know who is a caregiver of a family member with ADRD to this study may assist other caregivers and their family members with ADRD by providing knowledge about the similarities and differences that exist in caring for a loved one with ADRD. You may be eligible for a gift card for participating in this study. For consideration, please call Kimberly Battle at (202) 494-1994.

Thank You,

Kimberly Battle

Appendix E

Recruitment Flyer (Adapted for Print)

Caregivers of Family Members with Alzheimer's Disease or Dementia Research  
Study

Are you the caregiver of a family member with Alzheimer's Disease or Dementia?

Age 18 and older?

Interested in helping others understand what it is like to care for a family member  
with Alzheimer's Disease or Dementia?

For more information:

Contact Kimberly Battle, RN @ 202-494-1994

Doctoral Student

The Catholic University of America

(You may be eligible for a \$10.00 gift card as a token of thanks for participating in  
this research study.)

**Blessed Dementia Scale (ADL) [C2A]**  
(Information on subjects with dementia provided by informant)

1. Memory and performance of everyday activities: On the left, rate subjects' LOSS of ability to do the tasks listed below. For each score of 0.5 or 1, indicate on the right whether reason is physical (P), mental (M), or both (B).

None	Some	Severe		P	M	B	N/A
0.0	0.5	1.0	A. perform household tasks	0	1	2	9
0.0	0.5	1.0	B. cope with small sums of money	0	1	2	9
0.0	0.5	1.0	C. remember a short list of items (e. g. , shopping list)	0	1	2	9
0.0	0.5	1.0	D. find way about indoors (home or other familiar locations)	0	1	2	9
0.0	0.5	1.0	E. find way around familiar streets	0	1	2	9
0.0	0.5	1.0	F. grasp situations or explanations	0	1	2	9
0.0	0.5	1.0	G. recall recent events	0	1	2	9
0.0	0.5	1.0	H. Tendency to dwell in the past	0	1	2	9

(Score: 0 =none; 0.5 = sometimes; 1 = frequently)

2. Habits

A. EATING

- 0 = Feeds self without assistance
- 1 = Feeds self with minor assistance
- 2 = Feeds self with much assistance
- 3 = Has to be fed

B. DRESSING

- 0 = Unaided
- 1 = Occasionally misplaces buttons, etc., requires minor help
- 2 = Wrong sequences, forgets items, requires much assistance
- 3 = Unable to dress

C. TOILET

- 0 = Clean, cares for self at toilet
- 1 = Occasional incontinence, or needs to be reminded
- 2 = Frequent incontinence, or needs much assistance
- 3 = Little or no control

3. TOTAL SCORE OF ALL ITEMS (Maximum Score of 17):

--	--	--

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CAREGIVER STRAIN INDEX

I am going to read a list of things which other people have found to be difficult in helping out after somebody comes home from the hospital. Would you tell me whether any of these apply to you? (GIVE EXAMPLES)

Yes = 1; No = 0

Sleep is disturbed (e.g., because <insert name> is in and out of bed or wanders around at night): 1 or 0

It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help): 1 or 0

It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required): 1 or 0

It is confining (e.g., helping restricts free time or cannot go visiting): 1 or 0

There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy): 1 or 0

There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation): 1 or 0

There have been other demands on my time (e.g., from other family members): 1 or 0

There have been emotional adjustments (e.g., because of severe arguments): 1 or 0

Some behavior is upsetting (e.g., because of incontinence; <insert name> has trouble remembering things; or <insert name> accuses people of taking things): 1 or 0

It is upsetting to find <insert name> has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be): 1 or 0

There have been work adjustments (e.g., because of having to take time off): 1 or 0

It is a financial strain: 1 or 0

Feeling completely overwhelmed (e.g., because of worry about <insert name>; concerns about how you will manage): 1 or 0

Total Score (count yes responses):

Robinson, G. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38(3): 344-348. Copyright (c) The Gerontological Society of America. All Rights Reserved. Reprinted with permission. Permission is hereby granted to reproduce this material for non-for-profit educational purposes only, provided **The Hartford Institute for Geriatric Nursing, Division of Nursing, New York University** is cited as the source.

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