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Alzheimer's Disease Caregiver Burden: Does Resilience Matter?

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To the Graduate Council:

I am submitting herewith a dissertation written by Cathy B Scott entitled "Alzheimer's Disease Caregiver Burden: Does Resilience Matter?." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Social Work.

David R. Dupper, Major Professor

We have read this dissertation and recommend its acceptance:

Bill Nugent, Becky Fields, Sherry Cummings

Accepted for the Council:
Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

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Alzheimer’s Disease Caregiver Burden: Does Resilience Matter?

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Cathy B. Scott
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DEDICATION

This dissertation is dedicated to my dear mother, the late Mary Brawley, for her enduring love and support in my life. She always offered comforting words and encouragement. Because of the legacy of determination she instilled in me, I was able to pursue and accomplish my dream. This day, I know her spirit is with me.

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Abstract

Caring for an individual with Alzheimer's disease is especially challenging and impacts every aspect of the lives of the informal caregivers. Informal caregiving is defined as unpaid care provided by family or friends to people with a chronic illness or disability (Young & Newman, 2002). Caregiver burden involves the physical, psychological, social and emotional problems experienced by a caregiver of an impaired loved one (Gwyther & George, 2006). Alzheimer's disease caregivers report more depression than their caregiving and non-caregiving peers, experience increased physical decline, and often experience financial challenges. Evidence suggests Alzheimer's disease caregiver burden is a result of both care recipient and caregiver factors. Pearlin et al's Stress Process model (1990) is widely used to examine triggers in caregiver burden. The model consists of antecedents, stressors, and outcomes. Few studies have examined moderators in the burden process in Alzheimer's disease caregiving. Whether resilience accounts for variance in outcomes associated with caregiver burden is not addressed in the literature. Data from a convenience sample of Alzheimer's disease caregivers (N=111) were examined for the purpose of exploring the moderating effect of resilience on the relationship between stressors and caregiver burden predictors. RESULTS: Resilience did not moderate the relationship between the caregiver stressors and caregiver burden. However, results indicated a relationship between resilience and caregiver burden. Specifically, as resilience increases, caregiver burden decreased. This finding highlights the importance of Alzheimer's caregivers and implementing support and interventions that will increase their resilience.

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CHAPTER I - INTRODUCTION

According to the U.S. Census Bureau (2006), there are over 303 million people living in America today. The U.S. population is diverse in race, gender, ethnicity, and age. The total U.S. population is growing at a steady pace; however, it pales in comparison to growth trends in its aging population. The percentage of Americans over 65 has tripled since 1900. As recent as 2003, the Census Bureau reported the aging population to be 12% of the total population. More alarming is the fact that the aging population is on the threshold of a boom. After the first baby boomers turn 65 in 2011, the number of individuals over age 65 are is expected to increase to approximately 72 million by the year 2030, an increase from 35 million reported in 2000 (U.S. Census Bureau, 2006). The rapid growth of the aging population has medical, social, and financial implications for all. Similar statistics for Alzheimer's disease exist. There are more than 5 million individuals living with Alzheimer's disease today. The number of Alzheimer's disease diagnoses is expected to triple in the coming decades. For this reason, the graying America population is receiving increased attention. For instance, CSWE has incorporated a gerontology focus in its annual program meeting. Medicare is undergoing a major overhaul. Innovative social programs such as home and community-based waivers are being developed to meet the needs of America's elders.

Technological and medical advances along with healthier lifestyles are major factors in the increasing aging population. In the early 1900s, the average life expectancy was 44 years of age. Today, individuals reaching age 65 have an average life expectancy of an additional 18.5 years (U.S. Dept. of Health and Human Services, 2005). Although overall health status has improved for older adults, many continue to fall prey to chronic diseases. The Department of

Health and Human Services (2005) notes common disorders that plague older Americans. Among those listed are hypertension, arthritis, diabetes, heart disease, and cancer, with heart disease being the most deadly. At first glance, this list appears to be comprehensive; however, it does not include diseases that lead to cognitive impairments. Specifically, Alzheimer's type dementia is a condition that ravages the independent functioning of aging individuals and inevitably leads to death and impedes every aspect of the lives of informal caregivers.

Statement of the Problem

Dementia is progressive brain deterioration that leads to a loss or decline in memory and cognitive and intellectual abilities which leads to an inability to perform activities of daily living (Alzheimer's Association 2010). Approximately 5 million older people suffer from some form of dementia (Alzheimer's Association, 2010). There are various forms of dementia. Vascular dementia, often due to a series of mini strokes, is a result of decreased blood flow to the brain. Parkinson's disease is a movement impairment that is often accompanied by cognitive impairment. Also, hallucinations, muscle rigidity and tremors are common to Parkinson's disease. Lewbody dementia is a pattern of cognitive and functional decline where alertness and severity fluctuate. Alzheimer's type dementia is the most common form of dementia. Fifty to seventy percent of all cases of dementia are characterized as Alzheimer's disease (Alzheimer's Association, 2007). Hallmark symptoms of Alzheimer's disease are difficulty remembering names and recent events, apathy, impaired judgment, disorientation and confusion.

Alzheimer's disease is a form of dementia that cripples the cognitive and physical aspects of a person's life. According to the National Alzheimer's Association (2007), an estimated 5 million Americans are diagnosed with Alzheimer's disease. More disturbing is that this figure is expected to increase to over 11 million by 2050 (Alzheimer's Association, 2007). Alzheimer's disease is most often characterized as early, middle, or late stage. Indicators of early to middle stages of Alzheimer’s disease include mild cognitive impairment, memory lapses and forgetting familiar names, words, or locations. The middle stage of Alzheimer’s disease is characterized by increased memory lapses, decreased knowledge of recent/current events and a decreased capacity to perform mental arithmetic tasks such as managing finances or paying bills (Alzheimer’s Association, 2010).

The progression of Alzheimer’s disease and the duration of each stage vary in each individual. Irrespective of the rate of progression, individuals experience increased memory impairment and changes in personality and behavior. Physical immobility, non-communication, and death are inevitable in the final stage of Alzheimer’s disease (Alzheimer’s Association, 2007). In addition to the physical effects of Alzheimer’s disease, the emotional effects of the disease are identified. Shua-Haim (2001) studied Alzheimer’s disease caregivers and care recipients and found that more than half of the care recipients scored < 5 on the Geriatric Depression Scale (Yesavage, 1982), a score that suggest that depression is present.

Throughout the progression of the disease, Alzheimer’s disease caregivers are essential in the lives of individuals with dementia. Caregivers are important in the daily lives of Alzheimer’s patients because they provide consistent care in a comfortable and familiar environment, both of which are necessary in providing care for individuals diagnosed with Alzheimer’s disease (Alzheimer’s Association, 2007). In addition to caring for the physical and emotional needs of a loved one with Alzheimer’s disease, caregivers are often responsible for their financial needs.

It is estimated that the economic value of informal dementia caregiving is approximately $257 billion. If it were not for informal caregivers, the cost of long-term care would skyrocket even more (Schumacher, 2006). In light of the already burgeoning health care budget and the documented burden of informal caregivers (Weinberger, et al, 1993, Guk-Hee, 2002), policy makers and practitioners are seeking ways to better support informal dementia caregivers. Home and community-based programs and other nursing home alternatives are on the rise. Current trends toward a community-based health care system suggest that informal caregivers will provide most of the care. Even with support from home and community-based social programs, many caregivers succumb to caregiver burden and opt for nursing home placement or experience other negative outcomes. For this reason, social service professionals, researchers, program directors and elected officials are focusing more attention on the needs of caregivers. Research grants, tax credits, Choices Act, and other support programs are examples of efforts being made to support caregivers (Gleckman, 2007, Mui, 2001).

Though informal community-based care is preferred over institutional care, providing care for dementia patients can be an extremely burdensome task (Suh et al., 2005). For instance, when providing care, Alzheimer's dementia caregivers are responsible for completing daily activities for their loved ones as well as themselves. Many times, Alzheimer's caregivers provide constant supervision (Fredman et al, 2010, Ory et al, 1999), redirect problematic behaviors (Teri et al, 1992), and assist with bathing, dressing, and toileting. The caregiver burden literature is overflowing with research that identifies risk factors of dementia caregiver burden. These factors are found within two major categories, caregiver and care recipient variables. The research literature attests to the fact that as a result of caregiver burden, care recipient and caregiver outcomes are less than optimal. Alzheimer's disease caregivers are more likely to develop chronic physical diseases and depression than non-caregivers (Bertrand et al., 2006) and make difficult financial decisions. Caregivers may quit work, reduce to part-time employment or purchase formal caregiver services to meet the needs of their demented loved one, all of which are financially taxing (National Alliance for Caregiving, 2004). Many caregivers find themselves totally absorbed in their caregiving role. Consequences of caregiver burden for the care recipient results, many times, in nursing home placement (Buhr et al, 2006), a setting that some find less desirable when compared to community-based care.

While it is important to understand the impact of dementia caregiving, it is also important to understand that it is rare that the relationship between predictors and caregiver burden is a direct path. Moderator variables are those that change the strength of the relationship (Baron & Kenny, 1986). Specifically, the moderator variable interacts with the independent variable so that its association with the outcome variable is stronger or weaker. See figure below (Bennet, 2000, Wu & Zumbo, 2008).

An understanding of the stress process of caregiver burden, factors associated with caregiver burden and variables that influence the relationship between these will serve as a base for future research, strengthen intervention, and inform policy development. Using Pearlin et al's (1990) Stress Process model as a theoretical framework, this study seeks to add to the existing research new information on the potentially moderating effects of caregiver resilience in the burden process of Alzheimer's disease caregivers.

This study is significant to the profession of social work in a number of ways. The social work profession has its roots in values and goals that are committed to serving individuals in need and helping individuals reach their fullest potential. Likewise, the purpose of this study is to extend knowledge that will support and help caregivers to take care of themselves in their daily journey of tending to their loved ones. Also, this study is significant to the social work profession in that it forwards a strengths perspective to analyzing caregiver burden. To study the extent of resilience in Alzheimer's disease caregivers and their ability to withstand adversity, social workers are able to transition from an assessment and the development of a plan of care that is based on the identification of problems and/or deficits to one that identifies the strengths of the caregiver that are in turn used as a foundation to problem solving.

Building on the current Alzheimer's disease caregiver literature, this study seeks to identify whether the personal resilience in the caregiver circumvents the effects of caregiver stressors. In general, the objective of this study is to examine the interaction effect of resilience on the relationship between stressor variables and caregiver burden. Specific research questions and hypotheses are described in the Chapter 3.

CHAPTER 2- REVIEW OF THE LITERATURE

Alzheimer's Disease Caregivers

Informal caregiving is defined as unpaid care provided by family or friends to people with a chronic illness or disability (Young & Newman, 2002). Schumacher (2006) extends the definition of informal caregiving in a manner that speaks directly to the overwhelming burden caregivers experience on a daily basis. Overwhelming caregiver burden is a result of providing care that goes beyond what is considered "normal" care or help that is provided within families (Schumacher, 2006). Informal caregivers have the awesome task of tending to the unmet needs of their loved ones. A spouse caring for his/her husband diagnosed with Alzheimer's disease, assisting with bathing, feeding, and dressing is an example of an informal caregiver. According to recent estimates, there are approximately 44 million informal caregivers in the United States today (Caregiver Alliance, 2004). Research studies address caregiver issues for HIV/AIDS and stroke patients as well as special needs caregivers; however, a plethora of studies highlight Alzheimer's dementia caregiver issues.

There are approximately 5 million American households caring for someone diagnosed with Alzheimer's disease or a related dementia (National Alliance for Caregiving, 2004). Alzheimer's dementia caregivers provide 75% of the care required by the estimated 5 million individuals who are stricken with Alzheimer's disease (Schulz & Martire, 2004, Family Caregiver Alliance, 2004). With current trends moving towards community-based health care, the number of caregivers and hours providing care is expected to increase as will the caregiver burden associated with Alzheimer's dementia caregiving.

Along with providing assistance with activities of daily living (i.e. personal hygiene, dressing, grooming, and meal preparation), caregivers often have the responsibility of managing instrumental activities such as money management, transportation, and household maintenance (Lawton, 1969). To perform such tasks alone is daunting. When coupled with the daily activities of their own lives, reports of burden, distress, and burnout emerge. Inasmuch as informal caregiving for a frail elder is burdensome, caring for someone with Alzheimer's disease includes the above-mentioned tasks and is often complicated by care recipient behavior problems, insomnia, and caregiver strenuous physical responsibilities.

For instance, Ory et al (1999) used national family caregiving data and analyzed the responses from Alzheimer's dementia caregivers and non-dementia caregiver peers (N= 1509). Findings indicated that Alzheimer's dementia caregivers experienced greater negative impacts than their non-dementia caregiving peers. These included providing more care hours per week, more assistance with activities of daily living, and challenges balancing their own lives including employment. A more recent study reporting similar findings also found that Alzheimer's disease caregivers provided more hours of care than caregiving peers (Bertrand, 2006). In addition, Alzheimer's disease caregivers reported more perceived stress and experienced more behavior problems than their caregiving peers.

The results of these studies demonstrate the extent of the association between burden and Alzheimer's dementia caregiving. Alzheimer's dementia caregiving has far-reaching effects. For instance, while providing assistance with basic daily living skills (Ory, 1999), many Alzheimer's disease caregivers struggle with problematic behaviors such as sleeplessness, physical aggression, and wandering and experience a host of other negative outcomes (Schumacher, 2006, Bertrand, 2006). The fallout of these behaviors can result in total exhaustion for the caregiver, which can affect their work attendance and performance, family dynamics, and their own personal health (Teri et al, 1992, Drinka, Smith, & Drinka, 1987).

Before proceeding to discuss the aspects of Alzheimer's disease caregiver burden, a theoretical framework for caregiver burden will be described.

Theoretical Perspectives

Various theories are used to understand caregiver burden. For instance, social exchange theorists (Hooyman & Kiyak, 2002) argue that equitable exchange minimizes informal caregiver burden. It is the opinion that when care recipients return kindness or gratitude for the aid they are receiving, balance is created and caregivers will experience more satisfaction and less caregiver burden. Carpenter (2001) used The Attachment Theory to explain caregiver burden. She posits that emotionally secure relationships between the caregiver and the care recipients lessens caregiver burden (2001). Pearlin *et al*'s (1990) stress process framework provides a comprehensive understanding of caregiver burden. This widely used model consists of the five domains: (1) Socio-demographics and social context, (2) Stressors, (3) Moderators, (4) Outcomes. The model is described below.

Socio-demographic factors- Caregiver and care recipient age, gender, race, and living arrangements are included. The caregiver's employment status and education level are often included as well. Demographics are applicable because the extent of burden is often a result of a caregiver's gender, race, etc. (Pearlin et al, 1990).

Stressors- These are the conditions or experiences of caregiving that are problematic and can prevent a caregiver's efforts and fatigue them. Stressors may be primary or secondary. Primary stressors encompass objective indicators such as care recipient cognitive status, problem behaviors, and functional dependencies. An example of a primary stressor in the life of an Alzheimer's dementia caregiver would be wandering that requires 24-hour supervision or memory impairment that causes the care recipient to be disoriented to person or place. These are measured by the severity of the cognitive impairment or the number of behavioral challenges caregivers face daily. Primary stressors are also subjective in nature. For instance, a caregiver's perceived overload or the meaning they attach to caregiving (Montenko, 1989) may be included as a stressor.

Secondary stressors are those that are related to roles and activities outside of the caregiving situation. An example of secondary stressors includes additional roles such as wife, parent or responsibilities of employment that require extra energy to complete in addition to the care they are providing. It is noteworthy that the term secondary in no way implies that these stressors are any less impacting or important than primary stressors. They are termed secondary because they are not related directly to the care recipient's illness (Family Caregiver Alliance, 2004). Secondary stressors are every bit as influential in caregiver burden as primary stressors. In fact, primary stressors often spill over and complicate other areas of the caregiver's life. For instance, if a care recipient wakes several times during the night, it is likely that the caregiver's sleep is disturbed also. This sequence of events is likely to lead to difficulties functioning adequately at work the next day (Family Caregiver Alliance, 2004). Also, the time an adult child spends providing care for their parent takes time away from their role as a spouse and hampers their ability to fulfill responsibilities of their own (Anhensel, Pearlin, & Schuler, 1993).

Moderators- Variables that change the strength or lessen the impact of stressors in the relationship between two variables are moderators. These are also helpful in explaining why people react to similar situations differently.

Outcomes- Outcomes are changes in the health and well-being of the caregiver as a result of the impact of the stressors. Outcomes can include measures of burden, depression, and physical health, and placement of care recipient in the nursing home (See Figure 1).

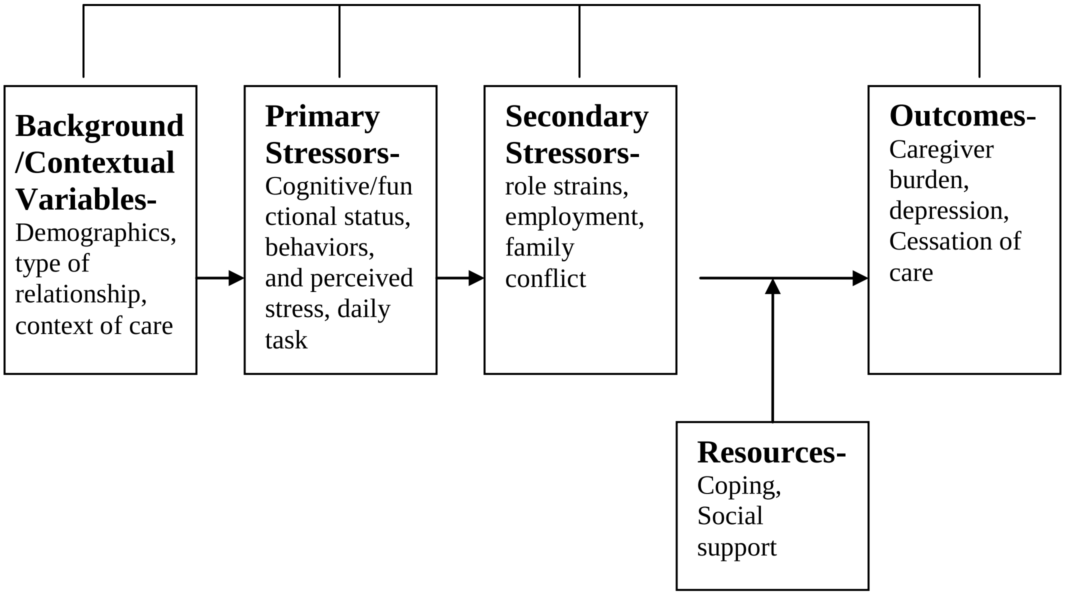

Figure 1- The Stress Process Model (Pearlin et al, 1990)

<u>Caregiver Burden in Alzheimer's Disease Caregivers</u>

As early as the 1960's, the majority of elders diagnosed with Alzheimer's disease were cared for in the community (Kay et al, 1964, Bergman, 1975). For reasons such as respect and revere for the community's elders, guilt, concern over quality of care, and costs, caregivers often maintain their care recipients in the home. To provide the level of care that is often needed, caregivers can become socially isolated, suffer from a loss of freedom, and are physically worn out, all of which encompass caregiver burden (Clyburn, 2000, Vitaliano et al, 1991).

Caregiver burden is defined as the negative consequences one experiences while caring for an adult with a debilitating condition (Hargrave, 2006, Gwyther & George, 2006) and is characterized and measured objectively or subjectively. Objective caregiver burden is related to the specific task performed by the caregiver to or for the care recipient where as subjective caregiver burden involves the meaning and appraisals of the caregiving role by the Alzheimer's disease caregiver (Jones, 1996). Its effects stretch across physical, psychological, and economic aspects of a caregivers' life. Studies documenting the physical decline and depression in caregivers associated with caregiver burden are summarized below.

Caregiver Depression. Earlier caregiver research indicates reports of depression among Alzheimer's disease caregivers. Eighty-seven percent of the caregivers in a study conducted Drinka, Smith, & Drinka, (1987) reported depression. Also, caregiver depression was found to be associated with caregiver burden (1987). Several factors are noted to contribute to depression in Alzheimer's disease caregivers. Caregiver recipient variables such as greater functional dependence, depression and increased cognitive impairment are identified as risk factors to caregiver depression (Shua-Haim, 2001). A caregiver's perception of a lack of control over their lives also contributed to depression in Alzheimer's disease caregivers. More recent studies confirm the prevalence of depression in Alzheimer's caregivers and highlight the need for awareness and intervention in this area.

The extent to which perceived suffering in the care recipient effected caregiver depression and the use of antidepressant medications was examined (Shulz, McGinnis, Zhang, Martire, Hebert, Beach, Zdaniuk, Czaja, & Belle, 2008). Data (N=1222) from the Resources for Enhancing Alzheimer's Caregiver Health study REACH (Gitlin, Belle, & Burgio et al (2003) was used for the analysis. Demographic data, functional impairment (Katz, Ford, & Moskowitz, 1963), cognitive impairment (Folstein, Folstein, & McHugh, 1975) and behaviors (Teri, Truax, Logsdon, et al, 1992) were collected and analyzed. Depression was the outcome variable and was measured using the CES-D (Radloff, 1977). Caregivers were randomly assigned to a control or treatment group. The treatment group received a social intervention while caregivers in the control group received their usual support. Findings in this study indicated moderate levels of caregiver depression. The mean depression score was 15.4% (SD=11.5). A score greater than 16 on the CES-D indicates a risk factor for clinical depression. Specifically, younger Alzheimer's caregivers were more depressed than their older caregiver peers as was caregivers with a high school education or less. Caregivers providing more hours of care and caring for recipients with greater dependence in activities of daily living also reported higher levels of depression. Caregivers also rated their care recipient's level of suffering. From their own perspective, caregivers reported that care recipients exhibited anxiety, sadness, and depression. Findings in this study underscore the importance of a caregiver's perception of their love ones. Many times it is the caregiver's reaction to a situation rather than the incident itself that causes distress.

Roth, Ackerman, Okonkwo, & Burgio (2008) used REACH data to examine factors of the CES-D across multiple ethnic groups. Data from 1222 Alzheimer's caregivers were analyzed. In particular, CES-D data were subjected to confirmatory factor analysis. Findings indicated that factor loadings provided excellent fit for the observed data. That is, the CES-D measured depression across ethnic caregiver groups with minimal item-loading differences. Further results indicated Hispanic caregivers reporting the highest level of depression (55%) followed by white caregivers (41%). Of the ethnic groups analyzed, African American caregivers reported the lowest level of depression (31%). Findings in this study are consistent with previous research (Schulz et al, 2008) and highlight the scope of depression among Alzheimer's disease caregivers. Understanding the unique experience of caregiving influenced by one's ethnic group, culture, etc is important and enables practitioners to individualize services. How different ethnic groups respond to depression has implications for practice as well. For instance, if depression or other mental illness is attached to shame or stigma, individuals may resist treatment or support.

Eisdorfer's (2003) examined the effectiveness of a technology-based therapeutic intervention on Alzheimer's caregiver depression. Data from a REACH study research site were used in this study. Two hundred twenty-five Alzheimer's caregivers participated in the study at this site. The therapeutic intervention was based on Brief Strategic Family Therapy. The intervention took place over 12 months and consisted of weekly sessions initially and titrated to monthly sessions by the final 6 months. The Center for Epidemiologic Studies Depression scale (CES-D) (Radloff, 1977) was used to measure levels of depression. At the onset of the study, 50% of the participating Alzheimer's caregivers reported CES-D scores of 16 or above, indicating high levels of depressive symptoms among informal dementia caregivers. At the 6 and 12-month follow-ups, caregivers receiving therapeutic intervention with enhanced computer technology reported decreased depression rates.

Summary

Research substantiates depression in Alzheimer's disease caregivers. When compared, Alzheimer's disease caregivers were more depressed than the general population, non-caregiving peers, and formal care providers (Takahasi, et al., 2005). Signs of depression in Alzheimer's caregivers include periods of sadness, loss of energy, irritability and difficulty concentrating. As a result of depression, Alzheimer's caregivers are at greater risk for chronic illness such as heart disease or diabetes, even death (Shulz, 1999). The fall out of depression has negative implications for the caregiver as well as the care recipient. If the Alzheimer's disease caregivers falls prey to depression, chances are that they may become unable to carry out their caregiver duties. If no other caregiver is available to steps in, Alzheimer's care recipients are likely placed in a nursing home.

Caregiver and care recipient variables are shown to influence rates of depression in Alzheimer's disease caregivers. Specifically identified are care recipient depression, cognitive impairment and problematic behavior and increased functional decline in care recipients. Caregiver age, gender, and education are identified as contributors as well. For instance, being younger, white or Hispanic, and having lower level of education are correlated with Alzheimer's caregiver depression. Also, the more time a caregiver devotes to providing care, the greater the rate of depression (Family Caregiver Alliance, 2004).

The strength of Alzheimer's disease caregiver research lies in the use of a valid and reliable measure of depression. Also, nationally representative data were used in Alzheimer's disease caregiver depression research. A large and representative sample increases the generalizability of the findings to the general population of Alzheimer's caregivers. Taken together, findings from these studies speak to the importance of identifying depression in caregivers and warn of the potentially unfavorable outcome for Alzheimer's disease caregivers.

Compromised Physical Health. Considering the effects of caregiver burden on the psychological well-being of informal dementia caregivers, its harmful effect on the physical well being of dementia caregivers is no surprise; however, fewer studies were found examining the physical effects of Alzheimer's disease caregiving than those documenting the psychological effects. Alzheimer's disease caregiving is regarded as a chronically stressful process that has negative physical health consequences (Mannion, 2008). Poor health of caregivers may be attributed to the effects of the physical exertion that aggravates already diagnosed chronic conditions, negative changes in the caregiver's diet and exercise, and the physiological effects of psychological distresses experience by caregivers (Pinquart & Sorensen, 2004). For instance; Keicolt-Glaser et al (1996) found significant differences in the immune systems of Alzheimer's caregivers when compared to non-caregiving peers. This and other physical effects of Alzheimer's caregiving are attributed to caregivers spending much of their time and energy attending to the needs of their loved ones while neglecting their own health care. Many physicians fail to recognize the failing health of informal caregivers. Due to failing health, caregivers are often considered as the "forgotten patient" (Levine, 2003). The physical well-being of the Alzheimer's caregiver is in such a downward spiral, medical professionals are embarking on a multi-disciplinary initiative to identify, better support, and treat the failing physical health of Alzheimer's disease caregivers (Levine, 2003).

Mounting evidence suggests the relationship between mental health stress and poor health outcomes. In fact, stress and poor health habits are shown to stimulate physiological activity that leads to negative outcomes such as hyperglycemia and higher blood pressure. If these conditions are prolonged, the risk for negative coronary and diabetic reactivity increases (Vitaliano, Young, & Zhang, 2004, Lee Colditz, Berkman, & Kawachi, 2003).

Mausback, Rabinowitz, Patterson, & Grant (2007) conducted a study to examine the impact of Alzheimer's related depressive and distress symptoms on time to developing a diagnosis of cardiovascular disease. A sample of 643 Alzheimer's caregivers originally recruited as a part of the larger REACH study was followed over an 18-month period. At baseline, Alzheimer's disease caregivers were free from a cardiovascular diagnosis. The caregivers were assessed again at 6, 12, and 18 months. The caregivers answered questions regarding their physical health and medication by confirming any diagnosis they had previously received. Questions regarding smoking and high blood pressure were also asked. Participating caregivers were also asked to rate their health on a scale ranging from poor to excellent and to compare their health to others. Depression in the caregiver was measured using the CES-D depression scale (Radloff, 1976). The frequency of care recipient behaviors was rated using the Revised Memory and Behavior Problem Checklist (Teri et al, 1992). After 18 months, 32 participants reported a new diagnosis of cardiovascular disease. The average time to onset was 400 days. After controlling for socio-demographics and health factors (smoking, high blood pressure), higher depression and behavior frequency scores were significantly related to time to cardiovascular diagnosis. Findings in this study have practice implications. To lessen the impact of depression and behaviors, unmanaged behaviors and mental health support to address depression should be priority in the plan of care. Without efforts to identify risk factors that hasten the physical decline of Alzheimer's disease caregivers, the community-based care received by those living with Alzheimer's disease will be compromised, which is not in the best interest of the care recipient or the caregiver (Buhr, et al, 2006, Gray, 2003).

Compared to their non-caregiving peers, Alzheimer's disease caregivers are in worse physical health. They use over-the-counter medicines more often, suffer from sleeplessness and report misusing alcohol (National Alliance for Caregivers, 2004). Because of the time absorbed in providing care, many caregivers report limited participation in preventive health behaviors such as doctor visits, wholesome diet, or exercise. In fact, when clinically examined, caregiving husbands had elevated blood pressure labs compared to their non-caregiving peers (Moritz, et al, 1992). It is also posited that, due to unhealthy behaviors and caregiving stress, informal dementia caregivers are at increased risk for mortality (Shulz & Beach, 1999).

Other studies examining the physical impact of Alzheimer's disease caregiving are presented according to two primary methods used to measure the physical health of caregivers: self-report or objective health measures. Self-report measures are surveys completed by the study participants regarding their health. Objective health measures involved clinical results from tests administered in a clinical setting.

Empirical Studies Using Self-report Measures. Fredman, Doros, Cauley, Hillier, & Hochberg (2010) interviewed 246 Alzheimer's caregivers and followed for one year. Baseline data were drawn and one year later, follow-up interviews were conducted. Fredman et al followed caregivers to determine the association between caregiving and metabolic indicators. Walking speed was used as the outcome variable because it is influenced by metabolic syndrome and increases the risk of disability and mortality. Metabolic health indicators were identified as hypertension, diabetes, high cholesterol, and the use of medication. The total score for metabolic indicators ranged from 0-3. Walking speed was determined by the number of seconds it took respondents to walk a 3-meter course at their usual pace. Change in walking speed was calculated as the difference between walking speed at baseline and follow-up. Findings indicated that stressful indicators combined with multiple metabolic syndrome indicators resulted in greater walking speed declines. Specifically, the walking speed of Alzheimer's disease caregivers with 3-4 metabolic indicators declined more than any other respondents. Change in walking speed may seem minute; however, in light of the physical exertion that is often associated with caregiving, adequate gait speed and quality are important.

More than a decade ago, Fuller-Jonap and Haley (1995) studied a small group of husband Alzheimer's disease caregivers and a comparison group (N=30). Sample participants were recruited primarily through a research center on aging at a major university and a data bank of persons over 65. Study findings evidenced greater reports of respiratory symptoms and poorer health habits in study participants when compared to controls. Specifically, caregivers reported more difficulty sleeping and using over-the-counter medicines more frequently. No significant differences were found in self-rated health and the usage of psychotropic medications.

A more recent study yielded similar results. The National Alliance of Caregivers (2004) reported on the declining physical well-being of Alzheimer's disease caregivers. Particularly, compared to non-caregivers, Alzheimer's caregivers (N=1247), perceived their health to be worse than their counterparts (Family Alliance, 2004, Patterson & Grant, 2003). To gain a better perspective of how Alzheimer's caregivers rate their health, AARP surveyed 1247 informal caregivers. Fifteen percent of the informal caregivers rated their health as worse than prior to providing care. Four in 10 reported worse physical health, while the remaining 41% reported a slight decline in their physical health since providing care. Findings also indicated that caregivers providing extensive hours of care (i.e. more than 40 hours) are twice as likely to report poor health. According to results from the Level of Burden Scale, 50% of the caregiving participants reported increased use and even misuse of alcohol and prescription drugs as well as decreased participation in preventive health care maintenance. Putting the care recipient's needs first and the lack of time and energy was reported as factors contributing to this decline (Caregiving in the U.S., 2004).

Further evidence indicates that caregiver burden can result in a change in healthy behaviors in Alzheimer's disease caregivers. Specifically, Alzheimer's disease caregivers are less likely to participate in healthy behaviors. Failing to take time away from caregiving, lack of adequate rest, and forgetting to take prescribed medications attributed to unhealthy physical well-being in informal caregivers. The inability to maintain an exercise routine and increased vulnerability to increased consumption of alcohol and smoking (Fredman et al, 1997) were also identified as correlates of physical burden in informal dementia caregiving.

Son, Erno, Shea, Fernia, Zarit, & Stephens (2007) completed comprehensive interviews with 234 Alzheimer’s disease caregivers. Data were collected included both objective and subjective stressors and three dimensions of health (self-rated health, negative health behaviors, and greater use of health care services). Caregivers were asked to rate their current health compared to 2 years prior and with the health of their peers. Caregivers were also asked to note the frequency of lack of sleep, exercise and poor nutrition and the use of alcohol. Findings indicate that the care recipient’s behaviors resulted in caregivers taking poor care of themselves and was associated with health care expenditures.

Markowitz et al (2003) examined the physical health quality of life in informal dementia caregivers. Markowitz et al indicated that Alzheimer’s disease caregiver burden had substantial effects of the health related quality of life. Data for this study were drawn from an original consumer-based representative sample. Questionnaires were subsequently mailed to self-identified Alzheimer’s disease caregivers in the sample, yielding a sample of 2477 participants. The purpose of the survey was to investigate the relationship of health related quality of life to the burden of caring for patients with Alzheimer’s disease. Mental and physical well-being were measured using the SF-12. An average score of the SF-12 is 50. Scores above or below 50 indicate scores above or below that of the general population. Problem behaviors in the care recipient were recorded using The Revised Memory and Behavior Checklist (Teri et al, 1992). The Physical Self-Maintenance and Instrumental Activities of Daily Living scale was used to measure ADLs. Study results indicated that caregiver burden; particularly behaviors associated with care recipient behaviors, had substantial effects on the health related quality of life of Alzheimer’s caregivers. These results are synonymous with previous research that links caregiver burden and negative outcomes (Son et al, 2007).

Empirical Studies Using Objective Health Measures. Objective health measures are used to evaluate the effects of informal caregiving through investigating immune and metabolic functioning and other clinical means of testing differences (Schulz, O'Brein, Bookwala, & Fleissner, 1995). Research studies show that Alzheimer's caregivers have more compromised immune systems than non-caregivers (Redwine et al, 2004). To determine the effects of informal caregiving on immune function, Keicolt-Glaser et al (1996) conducted a study comparing 32 Alzheimer's disease caregivers to 32 sex and age matched controls. Participants were recruited from local dementia evaluation centers in area hospitals, Alzheimer's disease support groups, newsletters and respite care programs. Controls were recruited through newspapers, church and social organizations, and referrals from other participants. Researchers used influenza vaccinations to test the effects of chronic stress in caregivers on their immune functioning. Experimental and control group participants had similar influenza vaccine histories. All had received the flu virus vaccine in the previous year. Health related data was collected to assess the possibility of confounding variables. No significant differences were found at baseline. Blood samples were drawn prior to the flu vaccines, 25-35 days afterwards, and again two weeks later.

Findings indicated that although caregivers and non-caregivers had comparable baseline pre-vaccine antibody titers, caregivers responded less often after vaccinations, indicating slower immune responses to influenza vaccines. Caregivers were less likely to show a significant increase in antibody titers four weeks after vaccines. These differences were magnified in older subjects. Analysis of psychosocial data revealed that caregivers reported significantly higher levels of depression symptoms and exhibited differences in sleep and exercise.

The sample size in the study limits the generalizability of these findings; however, the implications are great. If the physical health of Alzheimer's disease caregivers continuously declines, mortality risks increase (Shulz & Beach, 1999). Because informal caregivers are the backbone of community-based care, the economic cost of their demise would be great. If the physical health of Alzheimer's disease caregivers continues to decline and they were unable to provide, more care recipients would require placement in a long-term care facility. To that end, health care cost would increase as would nursing home utilization for the care recipients.

Moritz, Kasl, and Ostfeld (1992) gathered data using both objective and self-reported measures to further investigate the health consequences of living with a cognitively impaired spouse. Different than the previous study, these researchers analyzed blood pressure. The sample (N=318), was drawn from the Yale Health and Aging Project, a study funded by the National Institute on Aging. The original sample was a probability sample of 2,812 community-dwelling men and women over age 65. No information was provided regarding the process of identifying caregiver status. Study participants were interviewed face-to-face in their homes. In this study, Moritz et al analyzed blood pressure in two ways. First, they examined separately the mean systolic and diastolic levels, from their perspective, the most sensitive means to examine as an impact of chronic stress. Secondly, the researchers dichotomized blood pressure levels according to current practice. That is, individuals were considered hypertensive with an average systolic pressure ≥ 140, average diastolic pressure ≥ 90 or taking anti-hypertensive medications. Self-rated health measures were measured by the response to the following questions: 1) Have there been any changes in your health over the past year? 2) How would you rate your health at the present time? 3) How is your health today as compared to when you were 40? The number of hospitalizations, amount of alcohol consumption, rate of smoking, and psychotropic drug use were measured as outcome variables as well. Results indicated that the blood pressure of caregiving men not taking antihypertensive medications increased as the care recipient's cognitive functioning decreased. The impact on wife caregivers is less conclusive; results indicated a marginally significant association. Other conclusions were as follows: Caregiving husbands were three times more likely to report declines in their health status than non-caregiving peers. None of the other health behaviors measured in this sample were related to the cognitive functioning of the care recipient.

Alzheimer's disease caregivers are at increased risk for decreased physiological function that could lead to mortality (Schulz & Beach, 1999). To test this hypothesis, Schulz and Beach conducted an ancillary study to the Cardiovascular Health Study (CHS). Data used were drawn from the Health Care Financing Administration Medicare Enrollment list. The final sample for the CHES consisted of 392 caregivers and 427 non-caregiver controls. Original CHS data was used to provide information regarding caregiver status, socio-demographics, and physical health information. For the purpose of the CHES, physical health status was measured by three categories of physical health: 1) prevalence of at least one major disease; 2) no prevalent disease, but one disease indicator; or 3) no prevalent disease or disease indicator.

Caregiver strain measures were derived from the participant's response to the following question: "How much of a mental or emotional strain is it on you to provide help directly or arrange for help for this activity?" Response options were "no strain," "some strain," or "a lot of strain." Mortality was confirmed through the reviews of obituaries, medical records, and death certificates. Fifty-six percent of the caregivers reported caregiver strain. Contrary to previous research, fewer caregivers reported prevalent diseases compared to their non-caregiving controls. Cox regression analysis was used to analyze the effects of these variables on mortality of informal caregivers. After controlling for socio-demographic factors (i.e. age, race, education, stressful life events, and previous physical health status), study findings conclude that participants who were providing care and experiencing caregiver strain had mortality risk that was 63% higher than non-caregivers. Those who were providing care and did not report strain did not have elevated mortality risks.

Summary

Unsupported caregiver burden can and will lead to the demise of Alzheimer's disease caregivers. This body of research studies has implications for research and practice with Alzheimer's caregivers. It highlights the importance of encouraging routine examinations along with the use of supportive services that promote healthier living. The strength of this literature lies in the use of objective measures. As a result, bias is decreased. By using a nationally representative sample the study results are likely to represent the total population of Alzheimer's disease caregivers. Most measures used throughout this literature were valid and reliable. A number of studies used control groups. Collectively, evidence from these studies suggests an empirical correlation between Alzheimer's caregiving and declining physical health of the informal caregiver.

Limitations within this body of knowledge are the use of self-report measures and convenience sampling. Because of potentially biased self- reports, results of such analyses should be interpreted with caution. Self-reports measures potentially yield an inaccurate relationship between caregiving and physical health. Convenience sampling limits the representativeness of the sample participants and the generalizability of study findings to the general population.

Predictors of Caregiver Burden

Efforts to decrease or alleviate a problem begin with identifying the root cause of the problem. Anything otherwise is merely taking a band-aid approach to the problem. Alzheimer's caregiver burden is no different. Identifying root causes of Alzheimer's caregiver burden is essential to lessen the deleterious effects of Alzheimer's disease caregiving. A review of the research literature found substantial research dedicated to the purpose of identifying risk factors in caregiver burden. Throughout the literature, causes or risk factors of Alzheimer's caregiver are primarily characterized as care recipient or caregiver variables that contribute to Alzheimer's caregiver burden. Studies are presented below.

Care-recipient Variables

Behavioral Disturbances. Disruptive behaviors can include, but are not limited to insomnia, destruction of property, aggression toward self or others or agitation. It is rare that the manifestation of Alzheimer's disease is discussed without discussion of behavior problems (Teri et al, 1992). Disruptive behaviors were identified as a predictor of Alzheimer's disease caregiver burden in a study conducted by Kang (2006). Kang used data from the National Long Term Caregiver Survey to examined predictors of Alzheimer's disease caregiver burden. Differences in the effects of behaviors between spouse and adult child caregivers were analyzed. Socio-demographic information was gathered which included caregiver age, gender, employment status, living arrangements, and race. Care recipient cognitive function and disruptive behaviors were measured, as was caregiver demand, perceived overload and family dynamics. Contrary to previous studies (Cantor, 1983, Miller et al, 1991) no statistically significant differences in caregiver burden were found between spouse and adult child caregivers. This is likely due to the lack of a valid and reliable measure of caregiver burden to accurately measure caregiver burden in the Alzheimer's disease caregivers.

Disruptive behaviors were statistically correlated to caregiver burden in both spouse and adult child caregivers. Specifically, study results indicated a moderate correlation between disruptive behaviors and caregiver's perceived overload. Further, disruptive behaviors and the social and emotional limitations on the caregiver's life were statistically significant predictors of caregiver burden. Family dynamics, namely family disagreements were also found to influence caregiver stress. This study provides insight into the burden experienced by adult child and spouse caregivers. Findings also shed light on how behavior problems can complicate the caregiver role. Methodological limitations, however, warrant the cautious interpretation of the results.

Rinaldi et al (2005) extended the research of the empirical relationship between caregiver burden and care recipient problem behaviors. Participants for this study were recruited from Geriatric Clinics participating in an ongoing study of the Italian Society of Gerontology and Geriatrics. Four hundred nineteen caregiver dyads were enrolled in the study. The cognitive function and functional independence of care recipients were evaluated. Caregiver burden, anxiety, distress related to behaviors, and depression was also measured. Caregivers were placed in either the Higher Burden Distress Depression Anxiety group (HBDDA) or Lower Burden Distress Depression Anxiety group (LBDDA) depending on their behavior, anxiety, and distress scores. Severe limitations in activities of daily living, agitation, abnormal motor behaviors and nighttime behaviors were significantly associated with the high burden and anxiety that were measured in the HBDDA group.

Ingersoll-Dayton & Raschick (2004) examined specific care recipient behaviors and their association to Alzheimer's caregiver burden. Data from the National Long-Term Care Survey were used (N=441). Behaviors were categorized as problem behaviors and helping behaviors. Problem behaviors included excessive demands, repetitive behaviors and motor problems while helping behaviors were identified as the assistance and companionship provided by the care recipient. In this study, greater financial hardship, functional dependence of the care recipient, and more hours providing care equaled higher caregiver burden. Consistent with previous research, results indicated that problem behaviors and caregiver burden were significantly associated. Other findings highlight gender differences in caregiver burden.

Functional Abilities. To further explain caregiver burden in Alzheimer's disease caregivers, MiYoung (2008) tested a three-stage model to examine predictors of Alzheimer's disease caregiver burden (N=83). Path analysis was used to analyze the variable relationships. Findings indicated that patient cognitive impairment and functional dependence of the care recipient and wandering were directly associated with caregiver burden.

Razani (2007) investigated the relationship between caregiver burden and the care recipient's functional abilities. A sub-sample of 34 caregiver dyads drawn from a larger sample completed a battery of testing that included measures of activities of daily living (ADL's) and cognitive functioning. Dementia status in the care recipients was predetermined. Both performance-based and informant-based measures were used to measure the functional abilities of the care recipient as well as valid and reliable instruments to measure ADL's and memory. The results of this study indicated that there is a correlation between care recipient level of function and caregiver burden. Specifically, informant (caregiver-rated) measure of function was significantly associated with caregiver burden, more so than the performance-based measure. Caregivers for lower functioning care recipients reported greater feelings of depression, hostility, and poor emotional well-being. These caregivers also reported more restriction on their time and greater physical problems. The findings in this study speak to the importance of caregiver assessment when working with the caregiver dyad, however, it also important to understand how a caregiver's level of burden may influence their judgment.

Cognitive Impairment. Alzheimer's disease involves the progressive deterioration of one's cognitive and functional abilities (Alzheimer's Association, 2007). As a result, a strong association between cognitive impairment and caregiver burden is expected; however, research findings are inconclusive. Germain et al (2009) used longitudinal data to determine care recipient characteristics that most predicted caregiver burden. Care recipients and their caregivers were analyzed. Cognitive impairment was measured using the Mini-Mental State Examination, a screening tool used to measure cognitive impairment (Folstein, Folstein, & McHugh, 1975), Clinical Dementia Rating Scale was also used to measure cognitive impairment (Hughes et al, 1982), and the Alzheimer Disease Assessment Scale-Cognitive Section (Rosen et al, 1984). Functional abilities (Lawton & Brody, 1969) and behaviors (Cummings et al, 1994) were also measured. Results of this study found that behaviors, not cognitive impairment, are the most significant predictors of caregiver burden.

Bruce et al (2008) examined and confirmed mild cognitive impairment (MCI) to be associated with caregiver burden. Fifty-one individuals diagnosed with MCI and their caregivers participated in the study. Care recipients underwent a battery of evaluations to assess cognitive impairment and depression. Caregivers completed the Zarit Burden Interview as a measure of caregiver burden and the Revised Memory Behavior Checklist, to document the frequency of care recipient behaviors. Results of this study indicated that 30% of the caregivers reported caregiver burden. Also, a high level of cognitive impairment in the care recipient and higher frequency of caregiver reported behaviors were statistically significant predictors of caregiver burden.

Other research in the literature supports the relationship between cognitive impairment and caregiver burden. For instance, Lieberman & Fisher (1995) examined the impact of

Alzheimer’s disease on 97 caregivers and found that the more severe the cognitive impairment, the lower the caregiver well-being and greater the symptoms of anxiety and depression and burden. While examining the relationship between cognitive impairment and caregiver burden, a study conducted by Bruce et al (2008) yielded similar findings. Cognitive impairment was measured using the Mini-Mental State Exam (Folstein et al, 1975). Caregiver burden was measured using the Zarit Burden Interview (Zarit et al, 1985). Of fifty-one dementia caregivers, 30% reported caregiver burden. In this sample, increased burden was associated with a longer course of cognitive symptoms, behavior and mood variations, and cognitive impairments.

Contrary to these findings, Allegri et al (2006) examined factors associated with caregiver burden in eighty-two Alzheimer’s disease caregivers. Sample participants were drawn from a hospital memory clinic. The Mini-Mental State Examination and the Clinical Dementia Rating scale were used to measure cognitive functioning (Folstein et al, 1975, Hughes et al, 1982). Other patient variables measured included neuropsychiatric behaviors such as delusions, hallucinations, agitation, bed-time behaviors and eating behaviors. Caregiver data gathered included demographic items such as gender, age, duration of care, and time spent caregiving and a measure of burden (Zarit, et al, 1985). As reported in other studies, patient behaviors were the best predictor of caregiver burden. Specifically, neuropsychiatric behaviors identified as predictors were hallucinations, anxious behavior, delusions, and restlessness. Cognitive impairment was not found to be a statistically significant predictor of and caregiver burden nor was there an association between depression and apathy.

Taken together, the previous research studies demonstrate that care recipient characteristics greatly influence caregiver burden (Torti et al, 2004). Each variable represents a unique contribution to caregiver burden. Of the variables documented, it appears that care recipient disruptive behaviors have the greatest negative impact in the lives of Alzheimer's caregivers and has implications in research examining potential moderators in the relationship between cognitive impairment and Alzheimer's disease caregiver burden.

Caregiver Variables

Evidence points to the significant role caregiver characteristics play in the development of Alzheimer's caregiver burden. Caregiver characteristics that influence caregiver burden are sometimes simply related to who the caregiver is or the relation of the caregiver to the care recipient. Extensive research suggests that simple demographics often distinguish highly burdened caregivers from low burdened caregivers (Rinaldi, 2004, Torti, Takano & Arai, 2005). The National Center on Caregiving posits several caregiver factors that are associated with caregiver burden. Gender and the relationship between the caregiver dyad are identified as influences in caregiver burden. Also evidenced is the fact that a caregiver's perception of various aspects of caregiving is associated with caregiver burden.

Gender. More so than not, female caregivers fare worse than their male caregiving counterparts. Specifically, female caregivers experience higher levels of depression, anxiety and lower levels of well- being (Family Caregiver Alliance, 2004). Rinaldi (2004) examined 419 individuals and their caregivers. Study participants were recruited from Geriatric Clinics belonging to a Brain Aging Study Group. Dementia in the study participants was determined using the DSM-IV. The Caregiver Burden Inventory (CBI) (Novak & Guest, 1989), a widely used valid and reliable measure of burden, was used to measure caregiver burden. Findings from this study identified behavioral disturbances in the care recipient as a distinguishing factor in informal caregiver burden. Gender was significantly associated with caregiver burden. Specifically, female caregivers reported increased caregiver burden. Age and co-residence were also identified as factors leading to caregiver burden. As this sample is likely an over representation of participants and families seeking assistance and willing to participate, the findings should be interpreted with caution. Limitations, notwithstanding, the findings of this study speak to the individualized needs of caregivers when intervening to reduce caregiver burden.

Gender differences were also examined in a study conducted by Ingersoll-Dayton & Raschick (2004). The purpose of this study was to examine gender differences related to problem behaviors. Data for this study were drawn from the National Long Term Care Survey. The sample and consisted of 441 husband and wife caregivers. Ingersoll-Dayton & Raschick hypothesized that husband caregivers would report less frequent behaviors than wife caregivers and that problem behaviors would be less burdensome for husband caregivers. Caregiver burden was measured using an index of questions constructed by the researchers. Scores ranged from 4-16 with higher scores indicating higher burden. Consistent with previous research, wife caregivers experienced greater burden than did husband caregivers. Specifically, repetitious questions, clinging and swearing behaviors were reported as more burdensome to wife caregivers. Findings in this study also highlight the unique experience of caregiving relative to gender, however; the findings should be interpreted with caution because of limited measurement validity.

Takano & Arai (2005) also examined gender differences in early-onset Alzheimer's caregivers. Twenty-four participants and their caregivers were interviewed. Caregiver burden and depression of the caregivers were measured using widely used, valid and reliable measurement tools, the Zarit Burden Inventory (Zarit, 1980) and the Beck Depression Inventory (1987). Findings of this study are consistent with previous studies in that females are more likely to experience caregiver burden. Contrary to previous studies, behavior disturbances were not identified as a strong influence on dementia caregiver burden. This is likely due to the differences in cognitive functioning of this study's participants compared to previous studies. Findings should be interpreted with caution as the small sample size limits the generalizability of the study findings to the entire population of dementia caregivers.

Relationship Type. Although evidence is presented with inconsistencies, in some instances, there are differences in the level of burden experienced by spouse caregivers compared to adult child caregivers. The results of these studies are varied. Raschick & Ingersoll-Dayton (2004) examined a four-category caregiver sample that consisted of husband and wife spouse caregivers as well as male and female adult child caregivers. The subsample caregivers (N=978) were examined for differences in terms of the cost and rewards of dementia caregiving. The data for these caregivers were drawn from the 1999 National Long Term Caregiver Survey. Based on previous literature, it was hypothesized that spouse caregivers would report more cost in caregiving and adult child caregivers would experience more rewards. Control variables used were financial hardship, employment, functional dependency, and problem behaviors. The outcome variables were operationalized as rewards and costs. A 4-item scale related to burdens often experienced by caregivers measured costs. Higher scores indicated greater costs. Findings indicate that spouse caregivers experienced more caregiving cost than did adult child caregivers and adult child caregivers experienced more rewards than spouse caregivers. This is likely a result of the spouse receiving less help from the care recipient and living with the care recipient. Study results related to gender differences were consistent with previous research in that female caregivers experienced more costs than did male caregivers.

Kang's (2006) results differed somewhat. Using nationally representative data, spouse and adult child caregivers were examined to determine differences in the burden each group experienced and to identify salient predictors of burden. The subsample in this study consisted of 956 caregivers that included husband, wife, son and daughter caregivers. The outcome variable was a single self-related measure of caregiver strain. Data was also drawn regarding socio-demographic factors of the study participants, stressors, and family dynamics. Findings suggest common predictors of caregiver burden in both groups. For both spouse and adult child caregivers, disruptive behaviors, perceived overload, family dynamics, and limitations on life were predictors of caregiver burden. Caregiver age and race were unique predictors for adult child caregivers. Contrary to previous studies (Raschick & Ingersoll-Dayton, 2004, Miller et al., 1991), Kang found no statistically significant differences between spouse and adult child caregivers. The contrast in the findings is likely related to the measures of burden used in the studies. No valid and reliable measure of caregiver burden was used. While each of these studies is presented with apparent measurement error, findings are helpful in understanding the unique experience of burden each caregiver has on individual caregivers.

Deimling et al (1991) conducted a study that examined stress differences in spouse and adult child caregivers of dementia patients. One hundred eighty caregivers were assessed in terms of their caregiver burden and perceived health status. Data were also used to determine differences in caregivers with shared or separate residences. Caregiver burden was operationalized as a multi-dimensional variable. Perceived health was measured by a self-rated measure of physical and emotional health. An eight-item questionnaire was used to measure the caregiver's strain and a 5-item measure was used to assess the activity restriction of the caregiver. Cognitive impairment in the care recipient was measured by a 5 item measured developed by Poulshock & Deimling (1984). Participants in this study, as measured by this item, were only mildly impaired. Contrary to the previous study, findings indicated that adult-child caregivers experienced more burden than spouse caregivers, but less health declines and activity restriction.. The increased burden experienced by the adult child caregiver is due to the demands caregiving has imposed on their life and the social restrictions they are experiencing.

Subjective Perceptions. While the research literature points to the demographic variables that are associated with caregiver burden, individual caregiver perceptions and meaning of the caregiver impact burden levels as well. For instance, Kang (2006) found that an increased perception of overload was strongly associated with caregiver burden. A more recent study conducted by Andren & Elmstahl (2008) examined the relationship between a caregiver's perceived health, their sense of coherence and caregiver burden. Sense of coherence describes a personality characteristic that involves: 1) the perception that the stress factor is capable of being grasped, 2) being motivated, 3) being available. Sense of coherence is shown to be related to physical and psychological outcomes. That is, the stronger the sense of coherence, the more likely the person is able to cope with stressful situations. One hundred thirty (N=130) care recipients and their caregivers participated in the study. Demographic data were collected. The Sense of Coherence scale (Antonovsky, 1987) was used to quantify sense of coherence. The Nottingham Health Profile Scale (Hunt & Wiklund, 1987) was used to measure perceived health. The Berger Scale (1980) measured cognitive impairment. Each scale demonstrated good psychometric properties. Findings in this study indicated a significant relationship between sense of coherence and caregiver burden. Specifically, caregivers with a stronger sense of coherence were better able to manage difficult situations and were less anxious, hostile.

Andren & Elmstahl (2005) also explored factors associated with satisfaction and burden. One hundred fifty-three dementia caregivers were interviewed. Background demographics were collected. Functional and social dependency as well as cognitive impairment was measured using valid and reliable measures (Katz, 1963, Berger, 1980). Caregiver's level of satisfaction was assessed using the Carer's Assessment of Satisfaction Index (Nolan et al, 1996). The Caregiver Burden Scale measured subjective caregiver burden. Findings in this study found that burden and satisfaction can co-exist. That is, dementia caregivers can report moderate levels of burden and still experience satisfaction. Specific to the findings in this study, caregiver burden scores and perceived health did not influence the degree of satisfaction in the study participants. Taken together, the findings in these studies highlight the importance of recognizing of the caregiver's perspective and appraisal of their caregiving role.

Caregiver Knowledge of Alzheimer's Disease. Alzheimer's type dementia is a cruel and complicated disease. It is cruel because of its effect on the human brain and the body. It is complicated because its knowledge base is broad. To grasp a total understanding of Alzheimer's disease, it helps to have general as well as clinical knowledge and have awareness of its prevalence. A general understanding consist of basic knowledge about the disease and its stages, while clinical knowledge involves having an understanding of changes in the body functions over the course of the disease (Graham et al, 1997). Alzheimer's disease caregivers who lack understanding about Alzheimer's disease may not function at an optimal level and be at risk for caregiver burden (Diekman et al, 1988).

Knowledge of Alzheimer's disease is not included in Pearlin et al's (1990) Stress Process model as a predictor of caregiver burden. Absence of this information, however, does not preclude its potential relevance to caregiver burden. Thorough knowledge of Alzheimer's disease is associated with better decision-making in Alzheimer’s disease caregivers (Werner, 2000) and lower levels of depression (Olinger et al, 1987). Researchers have assessed Alzheimer’s disease knowledge and caregivers were found to have moderate levels of knowledge, particularly if they were associated with the local Alzheimer’s Association (Graham, Ballard, & Sham, 1997, Werner, 2001). To date, the relationship between Alzheimer’s disease knowledge and caregiver burden has not been examined. Because of its association with better decision-making and lower depression, it stands to reason that greater knowledge or the lack of knowledge of Alzheimer’s disease will have an effect of Alzheimer’s disease caregiver burden.

Moderators in Alzheimer’s Caregiver Burden

The relationship between predictors and caregiver burden is most often non-linear. The relationship is complicated by a combination of circumstances, experiences and resources (Pearlin et al, 1990). Negative consequences are so great in Alzheimer’s caregiving, it is important to examine variables that further explain the causal relationship between independent and outcome variables. In the development of the Stress Process model (Pearlin et al, 1999), coping, characterized as behaviors and practices used in response to life’s problems, was identified as a mediator in relationship between stressors and caregiver burden. Although the term mediator was used, they appear to be describing a moderating effect of coping in the relationship between caregiver stressors and caregiver burden (Morano, 2003, Holmbeck, 1997). According to Baron & Kenny (1986), the terms “mediator” and “moderator” have been used interchangeable in research even though the terms offer two distinct explanations of empirical relationships. Moderator variables are ones that affect the relationship between two variables in such a way that the impact of the predictor variables is dependent on the level of the moderator.

Mediator variables explain how the effect occurs. Several studies have examined moderators in caregiver research.

Haley, Roth, Coleton, Ford, West, Collins, & Isobe, (1996) examined appraisals, coping, and social supports as moderators of Alzheimer's disease caregiver burden. Caregivers for this study were recruited a larger study at the Memory Disorders clinic at the University of Alabama at Birmingham. To be eligible for the study, caregivers had to be providing community-based care, related to the care recipient by blood or marriage, and live within a specified radius of the clinic. The sample consisted of 123 white caregivers and 74 black caregivers. Demographic information of the caregivers was gathered, which included race, age, gender, marital and employment status. Socioeconomic status data was collected and categorized using grouped categories of income and the Nam-Powers Index of Occupational Status (Nam & Terrie, 1988). An inventory of social supports was measured using The Social Support Questionnaire Short Form (Sarason, Sarason, & Pierce, 1987). Care recipient's level of cognitive impairment and behaviors were measured (Folstein, Folstein, & McHugh, 1975). The results of this study indicated that the effects of caregiver stressors were moderated by social support, caregiver coping mechanisms, and appraisals.

Appraisal and coping were tested as moderators of the relationship between care recipient problematic behaviors and caregiver strain and gain in a study of 204 Alzheimer's disease caregivers (Morano, 2003). Alzheimer's caregivers were recruited from support groups in the southeast Florida area. Self-reported questionnaires were used to document basic demographic information for each caregiver (gender, age, relationship to the patient, income), coping styles, mastery and strain in caregiving. Moderating variables in this study were coping and mastery. Coping methods (problem-focused and emotional-focused) were measured using scales developed by (Pearlin et al, 1990) to measure how well the caregivers managed their caregiving situation, kept the care recipient preoccupied, and the meaning and appraisal they attached to the caregiving situation. The reliability of these measures were documented as α= .60 and .78. Mastery and gain were measured using scales developed by Pearlin et al, (1990) also. These scales quantified the caregiver's personal growth and their ability to deal with the situation. Caregiver strain was operationalized as depression and somatic complaints. The short form of the CES-D (Shrout & Yeager, 1991) was used to measure depression. The Bradford Somatic Inventory (Mumford et al., 1991) was used to measure somatic complaints. This 21-item scale documented physical complaints such as headaches. Findings in this study indicated that the caregiver's appraisal of satisfaction moderated the negative effects of problem behaviors.

Several lessons are learned from this study. First, both strain and gain both influence caregiver outcomes and should be examined. The meaning or appraisal attached to the problem behaviors experienced by Alzheimer's caregivers is just as much an influence on outcomes as the behaviors themselves. Finally, findings in this study underscore the importance of approaching caregiver burden from a strengths perspective.

Not all caregivers experience the negative effects of caregiver stressors. It is hypothesized that it is due to a caregiver's sense of mastery. Personal mastery references a caregiver's belief that he or she has control of his/her circumstance and future (Younger, 1991, & Pearlin et al, 1990). Mausbach, Patterson, von Kanel, Mills, Ancoli-Israil, Dimsdale & Grant (2006) examined the moderating effects of personal mastery of caregiver stressors on the psychiatric morbidity. Seventy-nine spouse Alzheimer's disease caregivers participated in the study. The outcome variable psychiatric morbidity was measured using the Brief Symptoms Inventory (Derogatis & Melisaratos, 1983). Stressors were identified as problem behaviors and caregiver burden (Pearlin et al, 1990). Personal mastery was the moderating variables and was measured with a scale developed by Pearlin & Schooler (1978). The initial analyses suggested the potential moderating effect of personal mastery on the relationship between problem behaviors and psychiatric morbidity. Post hoc analyses indicated that when mastery was low, the relationship between problem behaviors and psychiatric morbidity was significant. When mastery was high, no statistically significant relationship was found between problem behaviors and psychiatric morbidity. Specifically, this study demonstrates that certain levels of personal mastery may protect caregivers from the negative effects of caregiving. Findings in this study further support the assessment of caregiver strengths and the analysis of strengths as moderating variables.

Fatigue is a distressing symptom that often results in a reduced quality of life and the lack of motivation to engage in routine physical activities. As a result of the physical and psychological demands of Alzheimer's disease caregiving, many caregivers experience fatigue. In fact, according to Nygard (1988), 75% of caregivers reported fatigue. Roepke, Mausbach, Kanel, Ancoli-Israel, Harmell, Dimsdale, Aschbacher, Mills, Patterson, & Grant (2009) posited personal mastery as a moderator in the relationship between caregiving status and fatigue. Fatigue in Alzheimer's caregivers versus non-caregivers was examined in reference to their levels of mastery. Seventy-three (73) Alzheimer's caregivers and 41 non-caregiving controls participated in the study. Fatigue was measured using the 30-item Multidimensional Fatigue Symptom Inventory (Stein et al, 1998). This scale assessed the extent to which the participants felt "pooped", "tense", "heavy all over: or "lively". Mastery was measured using the Personal Mastery Scale (Pearlin & Schooler, 1978). Results indicated that Alzheimer's disease caregivers had worse fatigue than non-caregivers. Personal mastery alone did not have a relationship with fatigue; however, the caregiving status x mastery interaction had a statistically significant relationship with fatigue. Specifically, Alzheimer's caregivers with higher mastery felt generally less fatigued and had a greater sense of energy and vigor regardless of their caregiving status.

Summary

The developmental process of Alzheimer's disease caregiver burden is an association of care recipient and caregiver factors. Disruptive behaviors, functional dependence, and cognitive impairment in the care recipient are all identified as stressors in the caregiving experience. Caregiver variables are associated with caregiver burden also. Specifically, white female, spouse caregivers at the average age of forty-eight are more likely to report high caregiver burden (National Alliance of Caregivers, 2004). Even the subjective perceptions and the meaning attached to the caregiver situation lead to caregiver burden. Knowledge of Alzheimer's disease is shown to be important in the lives of Alzheimer's caregivers. Its relationship to several aspects of caregiving has been examined; however, the extent of its relationship with caregiver burden is unknown. Thus, research implications exists for research examining the relationship between Alzheimer's disease knowledge and caregiver burden

Research evidences the relationship between various caregiver stressors and caregiver burden. The literature also documents that this relationship is influenced by moderator variables (Mausbach et al, 2006, 2009, Morano, 2003). Specifically, caregivers with a greater sense of personal mastery and coping skills are able to resist the effects of stressors and experience less burden, depression, and/or fatigue. Of the studies that have examined moderators, none has examined the moderating effect of resilience on the in caregiver burden.

Resilience

By and large, caregiver research studies have primarily focused on the negative aspects of caregiving. In contrast, other studies have identified positive gain and rewards that are acquired through informal caregiving (Monteko, 1989). Many caregivers persevere and provide care for their loved ones until death in spite of the burden they experience. This fact suggests the presence of resilience (Gaughler, et al. 2007). Although resilience appears to be significant in Alzheimer's caregiving and may account for differences in outcomes over time, research is limited in this area. Why do some caregivers withstand the enormous task of caregiving to the end and others end care prior to death and opt for nursing home placement? Is resilience a moderator in the relationship between caregiver stressors and caregiver burden?

One who endures in the face of adversity is considered resilient (Garity, 1997, Conrad & Greene, 2002, Richardson, 2002, Rutter, 1999, Werner & Smith, 1992). A plethora of risk and resilience literature exists in children's research literature, but is limited in the field of Gerontology. Resilience research, as previously documented, has important implications for gerontology. By examining resilience in caregivers, we will understand if personal attributes or support network in some way contribute to the ability of caregivers to withstand the awesome task of caregiving until the death of the care recipient or lessen caregiver burden. Resilience research can also serve as foundation for effective interventions and increased support. Such knowledge will enable social workers to work alongside informal dementia caregivers and equip them at the onset of the client-worker relationship with the skills and resources needed to maintain the community-dwelling status of their loved one. The next section of the review summarizes research literature conceptualizing the construct of resilience. Subsequent sections summarize how the term resilience has been operationalized and measured. Finally, this review concludes with a summarization of research studies of resilience and its operationalization in studies of informal dementia caregivers. This review will conclude with research and practice implications related to the resilience of dementia caregivers.

What Is Resilience?

Resilience is generally described as the ability to bounce back from or successfully adapt regardless of adverse conditions (Norman, 2000). More specifically, resilience involves personality factors or a support network of family, friends and/or social services that enable one to sustain functioning amidst the presence of major life stressors (Masten, Best, Garmezy, 1990). Resilience has been characterized as a personality trait (Werner, 1992, Beardlee & Podersky), while others describe resilience as a dynamic process (Masten, 2001 Rutter, 1987, 1988, 2006). The contention of the latter position is that resilience involves the interplay of two conditions: protective factors and the presence of vulnerabilities or risks and overtime an individual becomes resilient. Risk factors are characterized as a life circumstance or conditions that increase the vulnerability of individuals (Rutter, 1987, Greene, 2000). Personal characteristics, family and community support that moderate the effects of the vulnerabilities are considered protective factors (Norman, 2000, p. 3). The attribute-process conceptualization debate of resilience spans the research literature. The lack of consensus in the conceptualization of the construct of resilience is thought to be one of the most salient and problematic issues in research literature (Luthar, Cichetti, and Becker, 2000).

Resilience Research

Studies investigating successful adaptation in the face of adversity began as early as 1970. Early studies of children of mothers with schizophrenia played a significant role in the emergence of childhood resilience as an empirical topic. Evidence that many of these children thrived despite their high-risk status led to increasing empirical efforts to understand individual variations in response to adversity (Garmezy, 1974, Luthar, Cicchetti, & Becker, 2000). Groundbreaking studies in the early 1980s led to the expansion of resilience research to include multiple adverse conditions such as socioeconomic disadvantages, poverty and violence (Werner & Smith, 1992, Beegley & Cicchetti, 1994, & Luthar, 1999). Resilience research is rooted in the psychology and child development literatures, but is being applied across multiple domains (i.e. mental health and family therapy).

Inquiry into resilience has emerged in three waves (Richardson, 2002, p. 310). The first wave, characteristic of early research, identified resilience as personality traits that led to positive outcome in spite of adversity (Werner, 1992). The second wave of inquiry focused on processes such as life experiences, counseling or some other intervention that led to resilience (Rutter, 1987, Masten, 2001). The underlying assumption here is that irrespective of one's personality traits; coping methods can be acquired to deal with life's challenges. The first two waves of resilience research begged further questions: What and where is the energy source that motivates resilient reintegration (Richardson, 2002, p. 309)? Research consistent with the third wave of inquiry seeks to help clients discover the force that drives reintegration. Resilience research, albeit having inconsistencies in conceptualization, represents a paradigmatic shift toward a strengths perspective rather than a continued focus on pathology and helplessness. As inquiry of resilience research is expanding into caregiver literature, understanding how the construct of resilience has been defined is necessary. The following sections of the review will present resilience research as characterized by resilience as an attribute or a process that leads to a positive outcome.

Resilience As an Attribute**.** Early research on resilience focused its attention on the observable phenomenon of children who succeeded in life despite their being at risk for problems and psychopathology (Broyles, 2005). Werner and Smith (1992) conducted a landmark study of a birth cohort beginning in 1955 in Kauai, Hawaii. The principle goals of this investigation were to document the course of the pregnancies and their outcomes from birth to age forty. Long-term consequences of pre-natal trauma, parental psychopathology, poverty and other adverse rearing conditions were examined.

As the study progressed, however, individuals who had become successful in spite of their exposure to adverse conditions piqued the interest of the researchers. Approximately 30% of the cohort encountered biological and psychological risk factors. They grew up in chronic poverty, lived in family environments troubled with discord, and experienced parental alcoholism and mental illness. Two-thirds of the children exposed to risk factors developed learning and behavior problems, had delinquent school records, mental health records, and teenage pregnancy. Surprisingly, seventy-two members of the cohort managed to successfully cope in spite of adversity they faced. The lives of these individuals contrasted with those who developed serious problems. They were able to escape the same psychopathologies their counterparts had fallen prey to.

Many characteristics in individuals and families were found to contribute to their positive adaptation. Differences in children considered resilient were noted as early as infancy. They were considered “good-natured,” affectionate, cuddly, and easy to deal with. These children also had sharper communication and self-help skills than their peers. Other characteristics that distinguished resilient children from their peers included high self-esteem, internal locus of control, and self-reliance. A higher level of tolerance and autonomy were also among distinguishing qualities. Emotional support outside their own families and participation in extracurricular activities played an important part in their successful adaptation. Thus, from Werner and Smith's perspective, resilience is a personal attribute that contributes to positive adaptation.

Resilience has also played a significant role in the successful adaptation of adolescent children of parents with affective disorders (Beardlee & Podorefsky, 1988). Beardlee and Podorefsky hypothesized that children of parents with major affective disorders have a sense of self-understanding that assisted in their positive adaptation albeit challenging situations and as a result were considered resilient. Participants for this study were drawn from a large sample of families with clinically affective illnesses and a random sample of subjects from a prepaid health plan. Sample participants were initially interviewed using the Schedule of Affective Disorders and Schizophrenia scores to characterize parental psychopathology.

The Garmezy Child Inventory (Finkleman & Garmezy 1979) was used to score adaptive functioning and the Rochester Adaptive Behavior Inventory (Jones, 1977) for behavioral issues. At the follow-up interview, behavioral functioning and self-understanding were examined. The shortened version of the Diagnostic Interview for Children and Adolescents as well as questions related to their awareness, experiences and understanding of their parent's illness were used. Individuals who successfully adapted irrespective of adverse conditions were considered resilient. Results indicated that in spite of living with parents with major affective disorders these youth adapted and became intelligent, hard-working, and vibrant individuals. Findings indicate that self-understanding played a major role in positive adaptation in spite life adversity. Some of the sample participants assumed a caretaker role and provided stability and cohesiveness to others later in life. Having close confiding relationships and external support were reported as instrumental factors. Superior IQ scores, having exceptional talents, inner resources, higher economic levels than their family of origin, and close relational ties were noted as common characteristics in resilient individuals.

While much of the research literature consists of studies conducted in the lives of young children, resilience research of the aging population is emerging. From a grounded theory approach, Wagnild and Young, (1990, 1993) examined adjustment patterns of 24 older adult women after a major loss. Resilience was defined as a personality characteristic that moderates the negative effects of stress and promotes adaptation. Audiotaped interviews were conducted with the sample participants. Participants were asked to recall a major loss in their life. Five questions were asked related to the loss. The questions referenced the identification of the loss, their response to the loss, and how they managed that loss. Sample participants were also asked how they managed difficult times in general as well as how they perceived their lives at that time of the interview. Five major themes were drawn from this study:

- Equanimity- balanced perspective of one’s life and experiences.
- Perseverance- the act of persistence despite adversity or discouragement
- Self-reliance- a belief in oneself and one’s capabilities
- Meaningfulness- the realization that life has purpose and valuing one’s contribution.
- Existential aloneness- each person’s life path is unique with shared experiences and those you must face alone.

The participants in this study were able to restore balance and continue to live as though they had purpose in life. Data from this study were used develop the Resilience Scale (Wagnild & Young, 1990). Details of this study are found in the measures of resilience section of this review. It should be noted here that in subsequent studies, Wagnild & Young (1993) defined resilience as a positive personality characteristic that enhances individual adaptation. Conclusions drawn from these studies show resilience to be a multidimensional construct that includes two factors: personal competence and acceptance of self and life. Also, in older adults, resilience is significantly correlated with health-promoting behaviors, life satisfaction, and morale (Wagnild, 2003). Considering the buffering effects of resilience in the lives of young children reared in adverse conditions and older adults dealing with issues of loss of independence, by extrapolation, it seems that resilience could serve as a protective factor in the lives of Alzheimer's disease caregivers in their sometimes demanding journey.

Resilience As a Process. Some warn against defining resilience as an attribute. Resilience as a personal attribute could inadvertently breed perceptions of inadequacy for some, leading them to think that they lack what it takes to be overcome or withstand adversity (Masten, 2001). Further, Masten argues that even though previous research has labeled resilient children as somewhat remarkable, however; she posits an ordinariness to resilience. Resilience, according to Masten, is the common phenomenon that results from the operation of the basic human adaptation system, nothing extraordinary. Masten insists that illuminating the process of resilience leads to strength awareness and better informs interventions (Masten, Best, & Garmezy, 1990).

Resilience as a process is synonymous to what Richardson (2002) characterizes as a second wave of inquiry into resilience. This expanded characterization of resilience was instrumental in an effort to discover the process through which one becomes resilient. Here, resilience is defined as the process of individuals coping with adversities that result in positive outcomes (Jacelon, 1997, Dyer, 1997, Richardson, 2002). The process of resilience is described as a cycle of disruptive and re-integrative experiences that results in a positive outcome or the interplay of risk and protective factors (Richardson, 2003, Rutter, 1987). The process of resilience encompasses the following elements: 1) overcoming stress or adversity depends on the experiences following the risk exposure; 2) individual traits, alone, do not equate to resilience; and 3) personal agency or coping strategies may have a mediating influence leading to resilience (Rutter, 2007).

Flach (1988) describes a framework that depicts the process of resilience as a cycle of disruption and reintegration. The cycle is characterized as a disruption in one's normal routine followed by reintegration to a more stable level of functioning. Richardson (2002) extends Flach's framework into a four-step model of the resilience process. According to Richardson, the process of resilience involves adversity, a form of change, and the opportunity to identify and strengthen resilience qualities and reintegration. Richardson posits a bio-psycho-spiritual homeostasis in which individuals have adapted physically, mentally, and spiritually to a circumstance, good or bad. This homeostatic state is then affected by life's disruptions then the process of reintegration begins and ends in one of four outcomes: 1) resilient reintegration-reintegration with gain; 2) reintegration back to homeostasis- this is the avoidance of disruptions to heal or "just get through;" 3) reintegration to loss- the individual gives up some motivation, loss or drive because of life prompts or disruptions; and finally 4) dysfunctional reintegration occurs when people resort to other substances, destructive behaviors or other means to deal with life prompts (p. 311).

Rutter (1979) conducted one of the earliest studies depicting resilience as a process. In a series of epidemiological studies situated in inner-city London and the rural Isle of Wight, Rutter examined psychopathology in adolescents and adults of those reporting abuse. Abuse was hypothesized to be associated with increased risks for psychiatric disorder. It was also hypothesized that a significant minority of the sample would show no evidence of psychiatric disorder and would be classified as resilient.

The sample consisted of a birth cohort born between 1953 and 1955 living on the Isle of Wight. Eligible children were identified from local education and health authority records. The final sample, minus children with behavior issues at the onset of the study, consisted of 571 adolescents. A comparison group was randomly selected and used for the analysis. Psychopathology was assessed through interviews with parents, children, and teacher reports.

Rutter found that over their life span and through interacting with external support systems and other influences, one quarter of the children were resilient, adversity notwithstanding. High self-esteem, easy temperament, and being female were personality traits identified as protective factors leading to resilience. Other protective factors found to be predictors of resilience were parental, peer, and partner relationships. The quality of these relationships was also independently associated with resilience. Rutter posits that resilience and vulnerability are at opposite ends of a continuum and the individual response to adversity is mediated by protective factors. To that end, he argues, in isolation, protective factors have no effect, but through the interplay with interactive processes over time is resilience developed (Rutter, 2006, 1987, 1985).

Rutter uses findings from the Isle of Wight follow-up study to support the fact that resilience is not a function of personal traits alone, but rather a process across the life span that involves relationship development. The follow-up study was conducted between 1998 and 2000 (Collishaw et al, 2007). The objective of this study was to examine the study participants who reported abuse and examine the extent of their resilience and to identify factors that distinguished resilience and non-resilient individuals with experiences of abuse. It was hypothesized that abuse would be associated with increased risks for psychiatric disorders and that a significant minority of abused individuals would show no evidence of psychiatric disorder and be classified as resilient.

Participants of the original study were currently between the ages of 42 and 46. Death, refusals, and intellectual impairment were among reasons given for attrition. The final follow-up sample included 378 of the original participants. A majority of the sample was interviewed in person; the others were interviewed by telephone, and mailed questionnaires. Childhood abuse experiences were defined by using retrospective reports of the abuse the adults experienced as a child. They were asked about the degree of sexual contact, frequency, and the age and relationship of the perpetrator. Adult psychopathology was assessed using the Schedule for Affective Disorders and Schizophrenia-Lifetime version (SADS-L) (Harrington, Hill, Rutter, Fudge, Zollolillo, & Weissman, 1988). The participants were also asked about their perceptions of the parenting they received as children. Areas of adult functioning (i.e. work, marriage/cohabitation, friendships, social contacts, day-to-day coping) were assessed using the Adult Personality Functioning Assessment (Hill, Harington, Fudge, Rutter, & Pickles, 1989). Other aspects of daily functioning such as relationships, personality and health were assessed via self-report questionnaires. Data was also gathered regarding any criminal history as well.

Findings indicate that 55% percent of the individuals reporting abuse in childhood (N=44) were diagnosed with at least one Axis I disorder during adulthood compared to 36% of non-abused individuals. Consistent with the hypothesis, fourteen of the abused sample participants reported no psychopathology over their adult life compared to an unspecified number of non-abused participants. These individuals were classified as resilient. Having strong peer relationships in adolescence and adulthood as well as at least one caring parent rather than personal traits (gender, IQ) were associated with resilience.

To infuse a resilience perspective in social work practice, Norman (2002) posited that resilience is “not a fixed attribute of individuals, but rather a process of interaction between environmental and personal factors” (p. 4). For example, in practice with older individuals, Gutheil and Congress (Norman, 2000) present a process of resilience enhancement that involves a practitioner/client dyad who work together to identify indicators of strengths and resilience in the client, identify areas of mastery and those which cannot be controlled, identify informal and formal supports and tap into new areas of strengths. Kaplan (Norman, 2000) describes resilience enhancement interventions with African American women. She too describes the process of resilience as beginning with identifying the presenting problems, gathering background information, identifying the client’s vulnerabilities and protective factors and resilience characteristics, then proceeds into a therapeutic treatment phase.

As presented, resilience, as a process appears to be indicative of journey that encompasses protective characteristics and the interaction with a network of family, friends and external relationships, both of which are associated with resilience. Indication that this process has been applied with Alzheimer’s disease caregivers is lacking. Perhaps a similar perspective can be taken in intervention with Alzheimer’s disease caregiver to promote resilience. For instance, if a caregiver lacks the personal stamina that results in a resilient caregiver, relationship-building efforts such as listening and a strengths-based assessment may result in resilient Alzheimer’s disease caregivers.

Summary

Throughout the resilience research literature, the construct of resilience is broadly defined and is lacking consensus in its conceptualizations. As shown, resilience has been considered as an individual attribute. That is, having personal resources that lead to a positive adaptation amidst adverse conditions. In contrast, others speak of the developmental process of resilience. In this instance, a cycle of events and reintegration occur resulting in a resilient person (Richardon, 2002, Rutter, 2006). Variances in conceptualizations notwithstanding, there are common threads (Tedeschi & Kilmer, 2006, Greene, 2002, Jacelon, 1997).

Similarities in conceptualizations of resilience as an attribute are evident in three distinct dimensions. First, exposure to stressors and a degree of adversity are necessary in evaluating resilience. Individual attributes such as self-efficacy, intelligence, easy temperament, and perseverance are factors that have contributed to positive adaptation. External factors such as relationship ties, positive school climate, and supportive neighborhood lead to positive outcomes as well. Finally, exposure to stressors and the level of adversity are important, as they are necessary factors in evaluating resilience.

Consensus among those who conceptualize resilience as a process is not as distinct. Proponents of this perspective recognize the influence of individual attributes, but posit more so a process that begins with attributes and via coping mechanisms (i.e. intervention or a supportive network) positive outcomes are the result (Masten, 2001, Caplan, 2000). It is suggested that the process of resilience begins with the interplay of risk and protective factors, while others posit a cyclical process that begins with a bio-psychosocial balance in life (Flach, 1988, Richardson, 2002). Those who studied resilience in children assert that the process of resilience manifest in later years. For example, Werner & Smith (1992) speculate that children who were high-risk in earlier years recovered later in life. Masten (2001) posits resilience as nothing extraordinary at all, but a common phenomenon beginning with the ordinary human adaptive processes. Differences notwithstanding, there is consensus that the process leading to a resilient individual involves interplay among significant variables (i.e. protective factors, risk factors, homeostasis).

Resilience has been and continues to be defined broadly and varies in contexts, however, specific to social work practice, Greene's (2003) summarization of key assumptions of resilience is theoretically based and is an appropriate conceptualization for practice. As described below, Greene's compilation appears to capture resilience both as an attribute and the process of resilience. According to Greene (2002), resilience is a biopsychosocial and spiritual phenomenon that:

- involves a transactional dynamic process of person-environment exchanges
- occurs across the life course with individuals, families, and communities experiencing unique paths of development
- is linked to life stress and people's unique coping capacity
- involves competence in daily functioning
- may be on a continuum–a polar opposite to risk
- may be interactive, having an effect in combination with risk factors
- is enhanced through connection or relatedness with others
- is influenced by diversity including ethnicity, race, gender, age, sexual orientation, economic status, religious affiliation, and physical and mental ability

Researchers have traditionally argued one perspective over another. Some posit the construct as a personal characteristic while others maintain the process of building resilience.

Because empirical research exists to support both perspectives-some more robust than others- it seems that one perspective could build on another. For example, an initial assessment can be used to explore personal resilience. From there subsequent assessment and support could focus on enhancing or building skills that promote resilience.

Measures of Resilience

Traditional psychosocial assessments have focused primarily on problems, emotional concerns, deficits, and functional difficulties. In recent years there has been shift in the literature toward understanding personal resource, strengths and resilience. Strengths-based assessments and measures create a sense of accomplishment and enhance the individual's ability to deal with adverse circumstances. To that end, assessing from a strengths perspective promotes further personal, social, and academic performance. Thus, assessing resilience is an important approach to assessing strengths. Therefore, a search in the resilience literature to understand how resilience has been measured is necessary. Summarized below are studies outlining how resilience is measured.

A three-step approach to assessing resilience is suggested to measure resilience (Tedeschi & Kilmer, 2005). Commonly noted in the literature is the fact that inherent to resilience is the presence of protective factors that buffer against adversity. As a result, one noted approach to measuring resilience is to use validated instruments to assess specific factors that are related to resilience. For example, a warm family environment is associated with resilience; therefore, one could use a scale that measures family relationships such as the Family Environment Scale (Moos & Moos, 1994). Likewise, personal attributes such as self-efficacy have been linked to resilience. Thus, scales measuring these and other correlates of resilience may be used as self-report measures. Finally, Tedeschi & Kilmer suggest the use of intake or evaluative questions to reflect potential protective factors related to resilience. One or the other of these methods has been used throughout the resilience research literature. Primarily, measures of protective factors are used throughout the literature.

Earlier studies of resilience failed to utilize a structured, validated and reliable measure of resilience (Werner, 1992, Rutter, 1987) or measures of protective factors. Their approach to identifying resilient individuals involved tracking children from adverse conditions over time to examine how they adapted. Children who were deemed successful in spite of life challenges were considered resilient. This approach was recently used in a study of dementia caregivers (Ross et al, 2003). More recently, several measures of resilience have been developed; however, only three major scales are consistently used throughout the resilience research literature (i.e. The Resilience Scale, The Resilience Scale for Adults, and the New Connor-Davidson Resilience Scale). Research studies outlining their use, psychometric properties and application are presented below.

The Resilience Scale (RS) (Wagnild & Young, 1990) was developed to identify individual resilience. The Resilience Scale measures resilience as a personality characteristic that enhances successful adaptation. The scale consists of two factors: personal competence and acceptance of self and life. The development of the RS was the result of qualitative methods in which 24 women were asked to describe how they managed self-identified loss. Based on narratives, the following interrelated components were identified as constituting resilience (equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness).

The RS has been used in several studies. Preliminary data was used to support internal consistency, construct and concurrent validity. Wagnild & Young (1993) initiated this study to establish the validity and reliability of the RS in a larger sample. The scale was tested in a sample of 810 older adults with a mailed survey packet that included demographic information, the RS, and instruments to assess concurrent validity. Results indicated good internal consistency (.76-.91) and consistent reliability. Support for concurrent validity was shown by high correlations of the RS with well-established measures of constructs linked with resilience and outcomes of resilience such as depression, life satisfaction, morale, and health. The RS proved to be an instrument that could be used as a measure of personal characteristics and positive contributions an individual brings to the difficult life event (Wagnild & Young, 1993). The RS is and has been more widely used than other measures of resilience. It has been applied across multiple settings and populations.

Interested in a tool that could be used to measure resilience in adults, Friborg, Hjemdal, Rosenvinge, Marinussen, and Flaten (2006) developed the Resilience Scale for Adults (RSA). Two basic assumptions were instrumental in the development of this scale: 1) some form of stress has to precede the development of resilience; and 2) positive characteristics, coherent and stable family environment, and supportive social networks are all protective factors. The scale is comprised of five factors: personal strength, social competence, structured style, family cohesion, and social resources. Although this scale has limited use, it has previously demonstrated good psychometric properties. Alpha reliability of the individual factors ranged from .68 - .87 and .88 for the total (2006). A more recent study was initiated to explore the predictive validity of the instrument (2006). Eighty-four individuals were randomized into low or high groups of stress, and selected to a low or high resilience groups according to their scores on the RSA. Resilience Scale scores were reported prior to the procedure to examine whether resilience factors were protective.

Findings indicate the association between high resilience scores and lower stress scores. This supports the notion that protective factors, as measured by the RSA, may be generally helpful amidst stress events. Based on the assumptions above and its subscales, it is apparent that the RSA measures personal attributes as well as external protective factors. This conclusion speaks to Rutter's (1985) argument that suggests that identifying protective factors are important; however, understanding the process through which these factors result in resilience is more conclusive.

Recognizing the lack of a widely used, well-validated measure of resilience, Connor and Davidson, (2003) created the Connor-Davidson Resilience Scale (CDRSC). This is a self-report measure that consists of 25 items. The CDRSC measures resilience as a measure of successful stress-coping ability and is typically applied in clinical settings. The following study was conducted to validate and ensure the reliability of the CDRSC. Scale content was drawn from research literature on hardiness, strategy development, and personal control and commitment. Each item is scored on a 5-point likert scale with higher scores indicating greater resilience. The scale was administered to a community sample group, and to psychiatric and primary outpatients randomly selected through random-digit dialing. Good internal consistency was reported with a Cronbach Alpha of .89. Test-retest reliability was assessed in twenty-four subjects resulting in a score of .87. Findings indicate that the Connor-Davidson Resilience scale demonstrates good psychometric properties while effectively distinguishing between those with higher or lower resilience.

Summary

Previously mentioned scales have been applied in adult populations. Each one demonstrates good psychometric properties and has been used with various populations.

Compared to other measures of resilience; however, the Resilience Scale has received stronger ratings and is more widely used (Wagnild & Young, 2003). Approaches to operationalizing resilience also vary. In previous studies, resilience is measured as a function of successful stress and coping (Connor & Davidson, 2003), adjustment and coherence (Friborg et al, 2006), or personality characteristics that enhance adaptation (Wagnild & Young, 2003). Limited studies have measured resilience as a process. Of the studies identified, the findings were anecdotal (Norman, 2000) or used a grounded theory approach to identify themes associated with resilience (Ross, Holliman, & Dixon, 2003). Valid and reliable measures of resilience were not used in studies examining resilience as a process.

Resilience is potentially an important issue is assessing Alzheimer's caregivers. Identifying an appropriate measure of resilience has implications for understanding the personality and will of the caregiver in the face of adversity. Correctly measuring resilience in Alzheimer's disease caregivers will lay a foundation in the interventions and support caregivers are due.

Resilience and Alzheimer's Disease Caregivers

Caregivers assist the lives of many. Individuals afflicted with medical complications, cognitive impairment or developmental delays rely on the physical and social support of informal caregivers. Though they are very much needed, informal caregivers, particularly Alzheimer's disease caregivers suffer physically and emotionally. The plight of caregivers is receiving increasing attention. In fact, a wealth of research literature is devoted to the experience of informal caregivers. Much of the caregiver literature is deficit-focused. That is, it reveals the negative impact of providing care.

During the late 1980s however, a paradigmatic shift occurred toward interest in strengths and wellness factors. This provoked more research of strengths and the well-being of caregivers. There was increasing interest in negative and positive aspects of the caregiving experience. While it is important to have an understanding of the emotional, physical, and financial impact of caregiving as well as the rewards of caregiving, likewise it is equally important to be apprised of factors that are associated with a caregiver's ability to persevere the midst of the complex task of providing care.

Be it individual attributes, effective coping mechanisms, or a strong support network, resilience in Alzheimer's disease caregivers has great implications for policy and intervention when care recipient outcomes are considered. To gain understanding of the contribution of resilience in the lives of Alzheimer's disease caregivers, a literature search was conducted. To date, few resilience studies have been conducted within the Alzheimer's disease caregiver literature. The next section of the literature review focuses on research that has been conducted on Alzheimer's caregivers and resilience. Four resilience studies were identified and summarized below.

Garity (1997) conducted one of the earliest studies of resilience in Alzheimer's disease caregivers. Garity examined the relationships among stress level, learning style, resilience factors, and ways of coping among Alzheimer's caregivers. Depicting resilience as a characteristic, Garity sought to describe the relationships among stress, learning styles, and resilience factors in order to recommend more specified educational interventions for caregiver support groups. Building on Wagnild & Young's (1993) definition of resilience, Garity conceptualized resilience as a personality characteristic that moderates the negative effects of stress and promotes adaptation.

The Resilience Scale (Wagnild & Young, 1993) was used to measure resilience. Higher scores reflect higher resilience. Other validated measures were used to measure learning style, coping mechanisms, and caregiver burden. Seventy-six participants from Alzheimer's Associations in Eastern Massachusetts support groups were evaluated. Results indicated moderately high scores of resilience. Resilience Scale factors: personal competence and acceptance of life suggest personal characteristics such as self-reliance, independence, determination, mastery, adaptability and balance (Wagnild & Young, 1993).

Resilience was positively correlated with coping mechanisms such as distancing and organized problem-solving. The results suggest that individuals who have the above-mentioned personality characteristics use coping strategies to draw on the positive aspects of caregiving, refusing to let the situation overwhelm them. Moreover, these individuals were task-oriented, developed a plan of action with alternative solutions and followed through with that plan.

This study points to the significance of individual characteristics that are associated with resilience. The ability to recognize these characteristics is helpful in forecasting caregiver outcomes. Insight into resilience characteristics will be instrumental in the development and implementation of support and education groups. Understanding the diversity of learning, coping styles and their correlations with resilience could potentially result in individually tailored interventions.

While the findings of this study provide useful information, caution should be taken when interpreting the results of this study. The cross-sectional study design limits the generalizability of these findings in that the relationship indicated in these findings may be not generalize to caregivers beyond these study parameters. Sampling methods limits the findings in that it is likely not representative of the caregiver populations. It is probably more appropriate to say that there is an association between resilience and coping for Alzheimer's disease caregivers seeking support through Massachusetts Alzheimer's support groups. Also, as sample size is directly associated with statistical power, the study findings may not be indicative of the true relationship indicated between study variables.

Ross, Holliman, & Dixon (2003) present findings from an exploratory study of Alzheimer's disease caregivers. The purpose of this study was to identify common themes, activities and characteristics associated with resilient caregivers. This purposive sample consisted of twenty-three Alzheimer's disease caregivers recruited from the Center for Intergenerational Services Research. Sample participants agreed to and participated in face-to-face interviews. They were asked questions from the Caregiver Resilience Instrument (Ross, Holliman, & Dixon, 2003). Interviews responses were compiled and analyzed for common themes.

This survey instrument is a one-page questionnaire with four items. It was designed to collect information regarding the following: 1) a brief description of the caregiver role; 2) the most difficult aspect of providing care; 3) the caregiver's perception of any benefits gain as a result of their role; and 4) any coping mechanisms that were used to manage stress. Findings from this study reveal the following indicators thought to be associated with resilient caregivers: distancing themselves from the caregiver role, number of years of being a caregiver, participating in physical exercise, hobbies, religion, humor, and having a good support system.

The findings of this study suggest a relationship between personal characteristics and coping behaviors and resilience. Findings from this study should be interpreted with caution. The small purposive sample limits the generalizability of the findings beyond sample participants and is not likely representative of the larger caregiver population. The small sample size also limits our ability to conclude a true relationship between common characteristics and resilience. Also, the lack of psychometric properties of the survey instrument limits our ability to conclude that the variables were measured correctly. Future research may be enhanced by the use of a validated and reliable instrument to measure resilience to identify characteristics associated with resilience.

Family support is important in Alzheimer's disease caregiving and can be influential in resilience (Gonzales-Sanders, 2007). This is found to be the case in the Latino culture as it relates to Alzheimer's caregiving. Within Latino cultural values, strong identification with and bonding to nuclear and extended families is ever present. *Familismo*, as it is called, involves strong feelings of loyalty, reciprocity, and solidarity among members of the same family (Marin & Marin, 1991, p. 12). Gonzalez-Sanders (2007) hypothesized that Latino family caregivers reporting greater *familismo* would report higher resilience scores compared to Latino family caregivers reporting lower **familismo** factors. To test the hypothesis, Gonzalez-Sanders examined a snowball sample of 60 Latino Alzheimer's disease caregivers. Sample participants were recruited from community agencies in Connecticut and Massachusetts. Face-to- face interviews were used to collect the following: participant demographic characteristics, familismo, and resilience. Resilience was measured using the Resilience Scale (Wagnild & Young, 1993). The hypothesis was supported in that higher *familismo* scored correlated with higher resilience scores.

The cross-sectional study design warrants the caution when interpreting these findings. Examining the relationship between study variables cross-sectionally provide an analysis at one point in time. As a result, a causal relationship cannot be established. A majority of the sample was low-income, unemployed, and had low education attainment. Thus, sample bias limits generalizability to all social classes of Latino family caregivers. Finally, face-to-face interviews also present a limitation in the findings of this study in that sample participants may not respond authentically, but respond in such a way to please the interviewer.

Recently, Gaughler, Kane, and Newcomer (2007) examined the relationship between resilience, perceived demands, and institutionalization. The purpose of this study was to ascertain whether resilience influenced transitions from providing in-home care to placing the care recipient in the nursing home. It was hypothesized that Alzheimer's caregivers with low resilience and high caregiver demands were more likely to end in-home care and place their loved one in a nursing home.

Gaughler et al. defined resilience as successful adaptation, competence, and positive functioning in the face of stressful experiences. Resilience, according to the authors encompasses the following: resilience as overcoming odds-- positive outcomes despite negative circumstances; resilience as stress resistance, sustained competence or positive development while experiencing continual stress; resilience as recovery-- recovery from negative life experience or trauma. *Low resilience* was operationalized as high perceived burden and *high resilience* as low perceived burden. The 7-item version of the Zarit Burden Scale (Zarit, 1980) was used to measure of burden, while covariates (context of care, care recipient mental status, and resources) were measured using the Folstein Mini-Mental State Examination and a gathered list of resources used during the past six months.

Data were drawn from the Medicare Alzheimer's Disease Demonstration project that consisted of 1979 caregivers. The caregivers were assessed over a three-year period. Fifteen hundred sample participants were lost to attrition. The final sample consisted of 466. Analyses results indicated that being female and caring for longer periods of time were associated with resilience. The test of the hypothesis was partially supported when compared to high-resilience caregivers because low resilience caregivers were more likely to end in-home informal dementia caregiving. Contrary to the hypothesis, low resilience caregivers were less likely to experience the death of a care recipient during the study period.

This study contributes to the literature in that study findings reinforce the need to recognize the diversity in caregivers' ability to endure the challenges of caregiving. The results of this study also indicate a cultural significance in resilience, as Caucasian caregivers were more likely to indicate low resilience than were non-Caucasian caregivers. Finally, as more community-based services become available, findings from this study indicate the importance of identifying resilience factors that will predict the onset of transitions to nursing home placements. While study findings provide useful information relative to resilience and nursing home placement, resilience was not measured using a validated and reliable measure of resilience. Thus, study findings should be interpreted with caution.

Summary

Taken together, resilience studies are helpful in identifying individual characteristics empirically associated with resilient caregivers. Findings from these studies also highlight the importance of external support systems for caregivers such as community-based services. Also, findings suggest that increased attention should be given to diversity in culture, learning and coping styles. Identifying attributes linked with resilience provides insight to other variables that are related to the ability to withstand the adversity of caregiving and its relationship to commitment to continue in-home care. Moreover, findings from Gaughler et al.'s study (2007) pointed to the contribution of external supports to resilience. However, the impact of specific programs or interventions on resilience enhancement is not known. Receiving formal services from a community-based program could provide support needed that could result in a resilient caregiver. Finally, further investigations of these factors could provide more insight to why some caregivers adapt successfully to their caregiver roles and others terminate care and place their loved ones in the nursing home.

Against these strengths, however, there are gaps in this body of knowledge. It is clear that resilience is an important issue to caregiving. A dearth of studies related to resilience and dementia caregivers limit our knowledge of the true relationship between resilience and the sustainability of Alzheimer's caregivers. Gaughler (2007) indicates that Alzheimer's caregivers who report low resilience are more likely to end in-home care and place loved ones in the nursing home. A limitation that causes the findings to be interpreted with caution is that a valid and reliable measure of resilience was not used.

Other studies (Garity, 1997, Ross, Holliman, & Dixon, 2003, Gonzales-Sanders, 2005) utilized a more optimal measure of resilience and pointed to factors related to resilience, but a number of factors limit the power of study findings. The use of a convenience sample recruited from service agencies are likely an over representation of Alzheimer's caregivers willing to participate in research studies. Small sample also limit the generalizability of study findings within sample parameters. Finally, cross-sectional study designs impede the ability to conclude a cause and effect relationship between resilience and study variables.

Future research in this area would benefit from a study of resilience in Alzheimer's caregivers that utilize a valid and reliable measure of resilience. A study of resilience in caregivers and their decisions to institutionalize utilizing a comparison group would also add to caregiver literature. Studies examining the process of resilience among informal dementia caregivers are non-existent. A longitudinal examination of resilience in Alzheimer's caregivers over time would provide a picture of a true cause and effect relationship between resilience and the decision to institutionalize as well as identify the relationship between personal and external factors related to resilience.

A review of the resilience literature suggests two salient conceptualizations of resilience: resilience as an attribute or a process. Identifying personal characteristics associated with resilience is important. This information provides insight into the strengths and resources a caregiver has as well as their potential, ability, and will to care for their loved one in the home until death. Likewise, it is equally important to identify processes (support group, education intervention, building a support network) through which resilience is developed, this is especially important for those individuals not considered resilient based on an inherent personal characteristic.

What We Know and Remaining Questions

The objective of this review was to summarize the Alzheimer's caregiver burden research literature. Specifically, research studies identifying components of the stress process in Alzheimer's disease caregivers were examined. For starters, the literature highlights the importance of informal caregivers in the daily lives of Alzheimer's disease patients. Vital role, notwithstanding, caregivers are burdened and consistently report depression. Moreover, caregivers report declining physical and emotional health that complicates their caregiving role.

Further evidenced in the caregiver research literature is a profile of the Alzheimer's disease caregiver. According to the National Alliance for Caregiving (2004) and the Alzheimer's Association (2010), being white, middle age, and a female are quintessential variables of the typical and most burdened caregivers. The Stress Process model (Pearlin et al, 1990) is widely used in the literature to identify and explain the relationship between predictors and caregiver burden. Research reveals that both caregiver and care recipient characteristics influence the development of Alzheimer’s disease caregiver burden. Caregiver variables include socio-demographic variables such as age, gender, and race. Care recipient behavior problems are also identified as a salient predictor of caregiver burden. Research studies examining care recipient cognitive impairment as a predictor in caregiver burden yielded inconclusive findings.

The Alzheimer’s disease caregiver literature supports the fact that the relationship between stressors and caregiver burden is not a direct path. Third variables often mediate or moderate the relationship between caregiver stressors and burden. In previous studies, these concepts have been used interchangeably; however, each one has a unique effect in the relationship between two variables. The effects of a mediating variable is one in which the effect of one variable on another is through a third variable. The third variable is the link between the cause and effect (Wu & Zumbo, 2008, Bennett, 2000). A moderator variable is a third variable that modifies the strength or direction of the relationship between one variable and another (Wu & Zumbo, 2008). In early caregiver research, Pearlin et al, (1990) examined coping as mediating variable in the stress process in informal caregivers. Based on the described effects of coping in the stress process model and conceptualizations of recent moderator and mediator variables (Pearlin, 1990), it appears that the researchers were describing the moderating effect of coping rather than a mediating one. In addition to coping, personal mastery and caregiver appraisals are identified as moderators in the Alzheimer’s disease caregiver experience.

Alzheimer’s disease caregiver literature also shows that caregiver burden is but one aspect of the Alzheimer’s disease caregiver experience. In the midst of challenging times, research attests to rewards and gains and well-being in Alzheimer’s disease caregiving

(Monteko, 1989, Cohen, Colantoni, & Vernich, 2002). Resilience was examined and is identified as a protective factor that enables individuals to withstand adversity in their lives (Rutter, 1999).

Resilience is shown to be a protective factor in challenging times in the lives of children mostly, but has also been examined across other age groups as well. Limited studies have examined resilience in Alzheimer's disease caregivers. Of the studies identified, caregivers are said to be resilient if they exercise the following amidst caregiving, distancing from the caregiver role, providing care for a number of years, and participating in physical exercise, hobbies, religion, use of humor, and having a good support system (Ross, Holliman, & Dixon, 2006). Resilience is also shown to be associated with the learning and coping styles of Alzheimer's caregivers (Garity, 1999).

Caregivers considered resilient were shown to be less likely to place their loved ones in the nursing home and were more likely to continue providing care until death (Gaughler, 2008). Previous research identifies resilience as a buffer against poor outcomes in other populations. However, examination of the moderating influence of resilience in caregiver burden is lacking. Thus the question remains; is Alzheimer's disease caregiver burden moderated by resilience?

Understanding the influence of resilience in the lives of Alzheimer's disease caregivers will serve as a foundation for future resilience research within the caregiver and aging bodies of literature. Strengths-based intervention in social work practice will support the paradigm shift to the assessment of assets rather than deficits. If resilience is indeed identified as a moderator of burden in Alzheimer's disease caregivers, it follows that resilience enhancing support and education programs could be developed to strengthen a caregiver's ability to maintain the community-dwelling status of their loved ones.

Chapter 3-Research Proposal Methodology

Amid the documented challenges informal Alzheimer's caregivers face, further investigation of variables that may moderate the impact of predictors on caregiver burden is advantageous. This study will examine factors associated with caregiver burden in informal dementia caregivers. The proposed study extends the current caregiver literature by using the Stress Process Model (Pearlin et al, 1990) to examine the relationship between background and contextual variables, caregiver and care recipient variables and caregiver burden. More specifically, this study will examine the moderating influence of resilience in the relationship between predictor variables and caregiver burden in Alzheimer's disease caregivers.

Although psychological resources are identified as factors that decrease one's risk for caregiver burden (Morcyz, 1985, Zarit et al, 1980, Vitaliano, Russo, Young, Teri, & Maiuro, 1991), few studies have examined the effects of resilience in the lives of Alzheimer's disease caregivers. Findings from this study will advance the understanding of resilience in Alzheimer's disease caregivers. Its findings will also serve as a foundation for increased resilience research in the aging research literature, caregiver assessments and service provision.

Using Pearlin et al's (1990) Stress Process model as a theoretical framework, this study seeks to add to the existing research new information relative to the interaction effects of caregiver resilience in the burden process of dementia caregivers. The focus of this study is significant to the social work profession because it is consistent with its foundational values and goals committed to serving those in need. The objectives of this study and the proposed research model (The Resilience-moderated Burden model) are described below (See Figure 2).

1. To examine the relationship between stressors (i.e. caregiver knowledge of Alzheimer's disease, care recipient problem behaviors, functional dependence) and caregiver burden in informal dementia caregivers.
2. To determine the interaction effect of resilience on the relationship between stressors and caregiver burden.

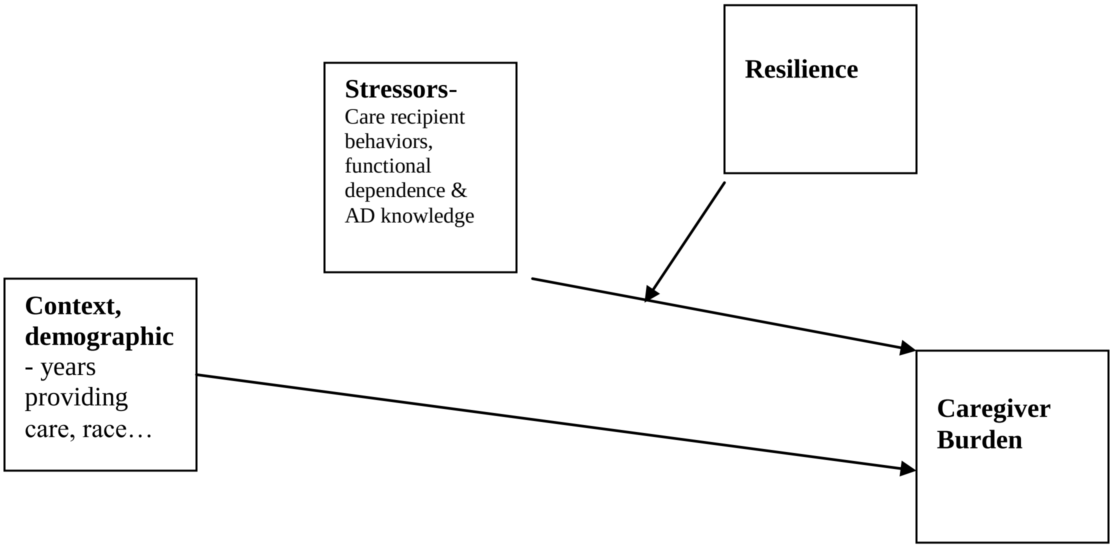

Figure 2 – The Resilience-Moderated Burden Model

Conceptualizations

Operational definitions of the constructs used throughout this study are provided below. Definitions used in this study were drawn from a review of the Alzheimer's disease caregiver and resilience research literature.

- Knowledge of Alzheimer's Disease- caregiver's level of knowledge of Alzheimer's disease that include the stages, cause, medical treatments, and prognosis (Werner, 2001, Kuhn, King, & Fulton, 2005).
- Functional dependence- a comprehensive functional assessment of the care recipient consists of both activities of daily living and instrumental activities of daily living. Functional dependence is the inability to perform basic self-care activities and have increased dependence on others to complete these daily tasks (Gallo et al, 2006, Pearlin, 1990).
- Care recipient behavior problems-Behaviors are common in individuals diagnosed with Alzheimer's disease. Behaviors are depressive, disruptive, or memory-related and can include repeated questions, destroying property, aggressiveness, and/or sadness (Teri et al, 1992, Rabins, 1994).
- Resilience- Resilience is conceptualized as a personal attribute the enables an individual to bounce back from or successfully adapt regardless of adverse conditions (Norman, 2000, Greene, 2000). It is also considered a dynamic process that involves an individual's exposure to risks and their protective factors that interact over time to produce resilience. Due to the cross-sectional nature of this research and the lack of a valid and reliable measure of the process of resilience, resilience will be measured as a personal attribute.

- Caregiver burden- Caregiver burden refers to a person's emotional response to the demands that are associated with caregiving. Caregiver burden can be either objective or subjective (Pinquart & Sorensen, 2003). Objective caregiver burden is associated with the task or activities of providing care. Subjective caregiver burden is the emotional reaction (i.e. worry, anxiety, fatigue) of the caregiver to their role.
- Alzheimer's disease caregiver- An unpaid individual (blood relative or fictive kin) who provides assistance with and is responsible for the physical, emotional, and often financial support of another person who is diagnosed with Alzheimer's disease and is unable to care for themselves due to an illness (National Alliance for Caregiving, 2004).
- Care recipient- the individual diagnosed with Alzheimer's disease who is receiving assistance from the informal dementia caregiver with activities of daily living such as personal care, meals, medication compliance, and supervision (Family Caregiving Alliance, 2004). See Table 1.

Methodology and Study Design

The debilitating effects of Alzheimer's disease on both the care recipient and the caregiver are the basis of extensive research. Specifically, the consequences of Alzheimer's caregiver burden are widely examined in the research literature. In an attempt to gain an understanding of the development of Alzheimer's caregiver burden predictors of Alzheimer's caregivers burden are identified. The research literature indicates that caregiver and care recipient variables, also called stressors, both contribute to Alzheimer's caregiver burden. Few studies have identified moderators on the effects of predictors on Alzheimer's caregiver burden (Pearlin et al, 1990).

This study seeks add to the Alzheimer’s caregiver literature by examining the interaction effect of resilience on the relationship between stressors and caregiver burden. A cross-sectional study design with an exploratory purpose will be used to conduct this study. This study design is appropriate for this study because its findings will provide insight into a relatively new area of research. The findings from this study will lay a foundation in understanding the relationship between resilience and Alzheimer’s caregiver burden (Rubin & Babbie, 2005). Quantitative methods are appropriate for this study because numbers and attributes will be used to record variation in survey data. Quantitative data will be used to test the stated hypotheses and answer the following research questions (Rubin & Babbie, 2005).

Table 1: Conceptualizations of the Stress Process and Resilience-Moderated Models

Stress Process Model (Pearlin et al, 1990)	**Resilience-moderated Burden Model**	**Measurement Tools Used in Proposed model**
Background/contextual demographics- Key characteristics of the caregiver such as age, gender, relationship to the care recipient, and length of time providing care	**Background/contextual demographics**- Caregiver age, race, gender, relationship to care recipient and length of time providing care	Biographical information sheet
Stressors- Conditions, experiences, and activities that impede the efforts and exhaust caregivers. Stressors can be primary (directly related to the caregiver situation) or secondary (roles or activities outside the caregiving situation).	**Stressors**- Functional independence of the care recipient, problem-behaviors of the care recipient, and caregiver knowledge of Alzheimer's disease	• Functional independence: Katz Index of ADLs (Katz & Stround, 1989), Lawton Scale of IADLs (Lawton & Brody, 1969) • Problem behaviors: Revised Memory and Behavior Problems Checklist (RMBPC), (Teri et al, 1992) • Caregiver Knowledge of Alzheimer's disease (KAML-C) (Kuhn et al, 2005).
Mediators/Moderators- Extraneous variables that further explain the relationship between stressors and the outcome. Mediators/moderators may change the direction or strength of the relationship.	**Moderator**- Resilience	Resilience- The Resilience Scale (Wagnild & Young, 1993).
Outcome- The well-being of individuals that can include physical and mental, and their ability to sustain themselves.	**Outcome**- Caregiver Burden	Caregiver burden- Caregiver Burden Inventory (Novak & Guest, 1989)

Research Questions

1. Does resilience moderate the relationship between caregiver Alzheimer's disease knowledge and caregiver burden?
2. Does resilience moderate the relationship between care recipient independence in activities of daily living and caregiver burden?
3. Does resilience moderate the relationship between care recipient independence in instrumental activities of living and caregiver burden?
4. Does resilience moderate the relationship between reported behavior frequency and caregiver burden?
5. Does resilience moderate the relationship between a caregiver's reaction (as measured by the subscale on the RMPBC) to behavior frequency and caregiver burden?

Hypotheses**:**

1. Controlling for care recipient behaviors and functional dependence, the interaction of caregiver knowledge of Alzheimer's disease and resilience moderates the relationship between caregiver Alzheimer's knowledge and caregiver burden.
2. Controlling for Alzheimer's disease knowledge and care recipient behaviors, the interaction of activities of daily living and resilience moderated the relationship between activities of daily living and caregiver burden.
3. Controlling for caregiver knowledge of Alzheimer's disease and functional independence, the interaction of instrumental activities of daily living and resilience moderates the relationship between behavior frequency and caregiver burden.

4. Controlling for caregiver knowledge of Alzheimer’s disease, functional independence, caregiver reaction to behavior frequency, the interaction of behavior frequency and resilience moderates the relationship between behavior frequency and caregiver burden.
5. Controlling for caregiver knowledge of Alzheimer’s disease, functional independence, and behavior frequency, the interaction of caregiver reaction to behavior frequency and resilience moderates caregiver burden.

Sample

Convenience sampling was used in this study. Convenience sampling is used in social research because it is an economical means of exploratory research (Rubin & Babbie, 2005, Schutt, 2006). Convenience sampling is appropriate for the proposed study because it seeks to explore a relatively new research area in the Alzheimer’s caregiver literature. Limitations notwithstanding, convenience sample is also appropriate for this study because it will provide preliminary estimates of the statistical correlation between resilience and Alzheimer’s caregiver burden (Schutt, 2006, Rubin & Babbie, 2005).

The sample for this study was recruited in Chattanooga, Tennessee from local agencies providing services to Alzheimer’s caregivers of community dwelling care recipients. A description of each agency is provided below. To be included in this study, the self-identified Alzheimer’s caregivers must be providing daily care for an individual who is diagnosed with Alzheimer’s disease. The diagnosis may have come from a physician or psychological testing. Alzheimer’s caregiver of care recipients residing in a facility will be excluded from this study. Also, the focus of this study is on informal Alzheimer’s caregivers, thus professional caregivers will be excluded from this study.

The sample size for this study was estimated using the Sample Power, a statistical program that is used to calculate sample sizes. Data entered into the Sample Power calculations included three sets of independent variables. Set A consisted of 11 variables that represented demographic and predictor variables. Set B consisted of 1 independent variable that represented the target variable. The interaction set included 4 variables. Sample size calculations included the documented R^2 values of Germain et al's (2009) work examining the influence of care recipient's functional abilities on caregiver burden ($R^2= .35$), Kang's (2006) identification of predictor variables in caregiver burden ($R^2= .52$) and Gaughler's study of resilience as a predictor variable in caregiver burden and institutionalization ($R^2= .62$). Critical alpha level was set $\alpha= .05$. Sample Power calculations estimated a sample of at least 100 study participants is needed to detect an interaction effect and have power.

Agency Description

The regional Alzheimer's Association serves 10 counties in Southeast Tennessee. The mission of the Alzheimer's Association is to eliminate Alzheimer's disease through research. Also, individuals diagnosed with Alzheimer's disease and their families are supported through caregiver support groups, referrals, and education. Currently, the regional Alzheimer's Association database consists of approximately 250 caregivers in 10 Southeast Tennessee counties.

Alexian Brothers Community Services (ABCS) is a community-based adult day care whose purpose is to serve Chattanooga area elders who are medically frail and/or diagnosed with Alzheimer's disease. ABCS is approved to serve a maximum of 320 participants and families. Its current census is approximately 304. ABCS enables its participants to remain in their communities through a system of managed care. ABCS services include medical, nursing, nutrition, social services, and rehabilitation services.

Alexian Brothers Valley Residence (ABVR) is a residential facility for individuals diagnosed with Alzheimer's disease. A staff especially trained to care for individuals diagnosed with Alzheimer's disease cares for residents. In addition to residential living, ABVR offers adult day services to approximately 50 community-dwelling Alzheimer's suffers and caregivers. While at ABVR residents and adult day attendees enjoy a comfortable environment, recreational programming, and supervision.

The University of Tennessee IRB approval was obtained prior to conducting research. Letters of support will be received from each agency and attached to the IRB approval application. Upon approval, invitation notices were posted [APPENDIX A] and recruitment began. During the study period, time periods were identified for Alzheimer's caregivers to complete packets on site. It was stressed to study participants that involvement in the study was voluntary and they may withdraw at any time. Study participants signed and returned an informed consent form that was attached to the front of the survey packet. Informed consent forms will be kept in a locked office on the campus of the University of Tennessee. To ensure the confidentiality of each study participant, no identifying information was included in the survey packets; however, participants were asked to provide a return address separate from the survey packets in order to receive their gift cards. Once the gift cards were mailed, the identifying information of the caregiver was shredded.

Data Collection

Quantitative methods were used to collect demographic and survey data from five survey measures [APPENDIX A]. Survey packets included a cover letter, consent agreement, and the measurement instruments. The doctoral candidate conducting this research was responsible for the recruiting and data collection. Invitation fliers and notification in the agency newsletters were used to recruit caregivers. The notices included the purpose of the study, the date and time by which the surveys should be completed. The notices were posted at each agency [APPENDIX A]. Prior to data collection, the researcher met with agency representative to determine a date and time data were to be collected. The surveys were self-administered on site. It took approximately 25 minutes for the caregivers to compete the surveys. In the event Alzheimer's caregivers are unable to complete the survey packets on site, the survey packets were available for pick up and drop off. Return envelopes were included for those caregivers who wanted to return by mail. Each caregiver who completed the survey packets received a $10.00 Wal-Mart gift card in appreciation for their time.

Reliability and Validity

To ensure measurement validity and reliability, previously tested valid and reliable measures will be used to measure the independent and outcome variables. Also, alpha coefficient for each measure was obtained to check the measures for internal consistency. Multivariate analysis is used to strengthen internal validity.

Survey Instruments [APPENDIX B]

Each study participant completed a biographical information sheet of basic demographics such as age, gender, race, etc (Q1-Q8). Demographic information was used to provide descriptive statistics of the individuals participating in the study [APPENDIX B-1]. The following survey instruments will be used to test the research hypotheses:

1. Alzheimer's caregiver knowledge was measured using the Knowledge about Memory Loss and Care (KAML-C) (Kuhn et al, 2005). The KAML-C is a 15-item that was

developed to assess the knowledge of Alzheimer's caregivers. The KAML-C tests the knowledge of Alzheimer's caregivers in the following areas: medical information, caregiving, and legal and financial planning. The KAML-C exhibited moderate internal consistency in this study, α= .56. The KAML-C is appropriate for use in cross-sectional studies and it was specifically designed to test the knowledge in informal caregivers. Sample question: The best way is to enable someone with memory loss to understand you is to… Each question has 4-5 answers to choose from. Higher scores indicate higher Alzheimer's disease knowledge [APPENDIX B-2]. Permission to use this measure was received [APPENDIX C].

2. Functional dependence in the care recipient encompasses both activities of daily living (ADL's) and instrumental activities of daily living (IADL's) (Gallo, 2006). Activities of daily living include basic activities such as bathing, dressing, and toileting. Instrumental activities of daily living include more complex activities such as money management and housekeeping. The Stress Process Model asserts that the more dependent the care recipient is, the greater the burden in the caregiver (Pearlin et al, 1990). Care recipient functional independence was measured using the Katz Index of Independence in Activities of Daily Living scale (Katz & Stroud, 1989). The Katz Index of ADL is an index measuring six categories of daily functioning: bathing, dressing, toileting, transferring, continence, and feeding. Questions are scored as independent or dependent. Independent receives score of 1 and dependent receives score of 0. A score of 6 indicates independent function, 4 indicate moderate functional dependence, and a score of 2 or below indicates severe functional dependence. Sample item: "Bathing: Bathes self independently or needs help in bathing only a single part of the body…" or Needs help

with bathing more than one part of the body, getting in or out of the tub/shower. Requires total bathing". The Katz Index of ADL exhibited good internal consistency with a score of α = .78. The Katz Index of ADL was chosen because of its widespread use in assessing older adults and its brevity [APPENDIX B-3]. Compared to basic activities of daily living, instrumental activities of daily living (IADL) include more complex functions. IADL include executive functions such as money management, shopping, cooking, and transportation. Most times, IADL skills decline before ADL skills limiting the individual's ability to continue community based living without caregiver support (Graf, 2008). In this proposed study, IADL was measured using the Lawton Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969). The Lawton Scale of IADL assesses eight domains of daily function and contains 31 items. The items are scored as 0= unable to perform, 1= needs assistance, or 3= independent. Higher scores indicate greater independence and lower scores indicate greater dependence. Item example: Plans, prepares and serves adequate meals independently. The Lawton IADL is valid and reliable and is widely used is research. Cronbach alpha in this study was α= .82. Administration time of the Lawton IADL is approximately 10-15 minutes [APPENDIX B-4].

3. The Stress Process Model identifies care recipient problem behaviors as an impetus in Alzheimer's caregiver burden. Specifically, Pearlin *et al* (1990) assert that problematic behaviors in the care recipient and the vigilance of the caregiver to ensure the care recipient does not harm himself or others makes problem behaviors a formidable stressor (Pearlin et al, 1990). The 24-item Revised Memory and Behavior Problems Checklist (RMBPC) was used to measure care recipient behaviors in this study (Teri et al, 1992).

The RMBPC consists of a total score with 3 subscales. Subscale domains consist of memory-related, depressive, and disruptive behaviors. This scale was chosen for the following reasons: its items are consistent with the behaviors described in the Stress Process Model as a driving stressor in caregiver burden and the RMBPC rates the caregiver's reaction to the care recipient's problem behaviors. An example of an item is "Engaging in behavior that is potentially dangerous to self or others". Possible scores range from 0= never, 1= not in the past week, 2= 1-2 times in the last week, 3= 3-6 times in the last week, 4= daily or more often, or 9= don't know. Caregiver reactions are rated based on how much the behaviors upset the caregiver. Possible scores range from 0= not at all, 1= a little, 2= moderately, 3= very much, 4= extremely, and 9= don't know. The RMBPC demonstrates good psychometric properties. It is shown to be valid and reliable in patients and caregivers. Reliability in this study was α= .92 for patient behaviors and α= .93 for caregiver reactions (Teri et al, 1992). Scoring is continuous with higher scores indicating higher frequencies of disturbing behaviors. The RMBPC was designed for use in research settings to collect data at one point in time. Thus, it is appropriate for cross-sectional research. It is an easy-to-use, self-report measure that can be completed in approximately 10-15 minutes (Teri et al, 1992) [APPENDIX B-5]. Permission to use this scale has been requested [APPENDIX C].

4. A groundbreaking resilience study (Werner & Smith, 1992) identified resilience characteristics as the contributing factor in a child's ability to successfully endure the hardship of an impoverished environment. Pearlin et al (1990) posit that mediating or moderating variables can explain the relationship between stressors and caregiver burden. The interaction effect of resilience will be examined. Resilience will be measured using

the Resilience Scale RS (Wagnild & Young, 1993). The Resilience Scale is a 25 –item measure is scored on a 7-point Likert scale (1= strongly disagree to 7= strongly agree). Sample question: “When in difficult situations, I can usually find a way out.” Scores on the RS range from 25-175. Higher scores indicate greater resilience. The RS has two subscales, Personal Competence and Acceptance of Self and Life. Reliability and validity has been tested in a sample of women and older adults in previous studies. Cronbach alpha in this study was α = .94 [APPENDIX B-6]. Permission to use this scale was received [APPENDIX C].

5. Caregiver burden will be measured using the Caregiver Burden Inventory (CBI) (Norvak & Guest, 1988). The CBI is a 24-item a global measure of burden capturing both the objective and subjective aspects of caregiver burden. The measure consists of five subscales: time dependence, developmental, physical, social, and emotional burden. Responses range from 0(not at all disruptive) to 4 (very disruptive). This measure was chosen because of its focus on the caregiver’s subjective perceptions. The CBI is scored continuously with higher scores indicating greater subjective caregiver burden. Cronbach alpha for this study was α= .90 [APPENDIX B-7].

Data Analysis Plan

Quantitative methods will be used to collect data. Pre-analysis data screening will be completed. Pre-analysis data screening is essential to ensure the accuracy of the data and to identify patterns of missing data to avoid systematic bias in reporting study results (Newton & Rudestam, 2005). The pre-analysis data screening will include a missing values analysis and a visual examination for outliers. Assumptions of normality, linearity, and homogeneity of variances will also be tested.

SPSS (PASW) version 18 will be used to analyze the data. Descriptive statistics will be conducted for frequency distributions and measures of dispersion including the mean, and standard deviation of the measures. Tests of the hypotheses are described below.

1. Controlling for functional independence (ADLs, iADL), behavior frequency and caregiver reaction to behavior frequency, the relationship between caregiver Alzheimer's knowledge will be moderated by interaction of Alzheimer' knowledge and resilience.

   Independent variable: Caregiver's knowledge of Alzheimer's disease (r_Ak)

   Interaction variable: resilience (Res) and Alzheimer's knowledge (r-Ak)

   Dependent variable: caregiver burden (CBI)

   Statistical test: Multiple linear regression

2. Controlling for behavior frequency, caregiver reaction to behavior frequency, Alzheimer's knowledge, and instrumental activities of daily living, the relationship between independence in activities of daily living and caregiver burden will be moderated by resilience.

   Independent variable: activities of daily living (ADls)

   Interaction variable: resilience (Res) and activities of daily living (ADls)

   Dependent variable: caregiver burden

   Statistical test: Linear multiple regression

3. Controlling for activities of daily living, Alzheimer's knowledge, behavior frequency and caregiver reaction to behavior frequency, the relationship between independence in instrumental activities of daily living and caregiver burden will be moderated by resilience.

   Independent variable: instrumental activities of daily living (iADl)

Interaction variable: Resilience (Res) and Instrumental Activities of daily living (iADls)

Dependent variable: Caregiver burden

Statistical test: Linear multiple regression

4. Controlling for Alzheimer's knowledge, activities of daily living, instrumental activities of daily living and caregiver reaction to behavior frequency, the relationship between behavior frequency will be moderated by resilience.

   Independent variable: Behavior frequency (Bf)

   Interaction variable: Resilience (Res) and Behavior frequency (Bf)

   Dependent variable: Caregiver burden

   Statistical test: Linear multiple regression

5. Controlling for Alzheimer's knowledge, instrumental activities of daily living, activities of daily living and behavior frequency, the relationship between caregiver reaction to behavior frequency and caregiver burden will be moderated by resilience.

   Independent variable: Reaction to behavior frequency (rBf)

   Interaction variable: Resilience (Res) and Reaction to behavior frequency (rBf)

   Dependent variable: Caregiver burden

   Statistical test: Linear multiple regression

Chapter 4- Data Analysis

Chapter 4 details the research methodology used to conduct this study. Operationalization of the dependent variable is defined and the processes of the pre-analysis data screening are discussed. This chapter also includes details of the distribution of the survey packets and the responses received. Data analysis results along with the limitations of this study are presented.

Dependent Variable

The dependent variable was operationalized as a continuous variable representing caregiver burden. Caregiver burden was measured using the Caregiver Burden Inventory (CBI). The CBI has five domains that measure time dependence and the developmental, physical, social and emotional aspects of caregiver burden. Caregiver burden will be as a total caregiver burden indicator.

Data Collection

Once the IRB approval was received, three hundred survey packets were distributed to Alzheimer's disease caregivers associated with service agencies in Chattanooga, Tennessee. Seventeen (17) individuals informed the researcher of their care recipient's death at least one or more years ago and did not participate in the study. One (1) caregiver refused to participate and returned a blank survey. One hundred seventy-two survey packets were not returned. The final sample consisted of (n=111) one hundred eleven completed survey packets, approximately a 37% return response.

Pre-Analysis Data Screening

Pre-screening the data is important for several reasons. Pre-screening the data is used to examine the basic assumptions of statistical testing. Pre-analysis data screening also helps to identify patterns of missing data, identifies outliers and ensures the overall accuracy of the data. Pre-analysis screening included an examination of the distribution of each variable in the study. Results of the screening indicated no problems with five of the variables in the analysis. A visual examination of the histogram and box plots of five independent variables (Alzheimer's knowledge, activities of daily living, instrumental activities of daily living, behavior frequency, caregiver's reaction to behavior frequency) indicated no problems with outliers and a distribution of cases that span the range of scores [APPENDIX D]. An examination of resilience scores indicated no outliers; however, an examination of the histogram indicated a restricted range of scores. Scores in the resilience distribution were truncated at the higher end of the distribution (see Graph 1). The restricted range of data limits the generalizability of findings in this study to individuals reporting high resilience. Restricted range is also a threat to statistical conclusion validity (Cohen & Cohen, 2003).

Missing Variables Analysis. Avoiding missing values is important in order to increase the statistical power of the findings and reduce bias. A missing data analysis of the caregiver-resilience data was conducted. The missing values analysis revealed no item missing more than ten percent of values. Pairwise deletion was used to maintain the sample size and avoid skewing the data [APPENDIX D-1].

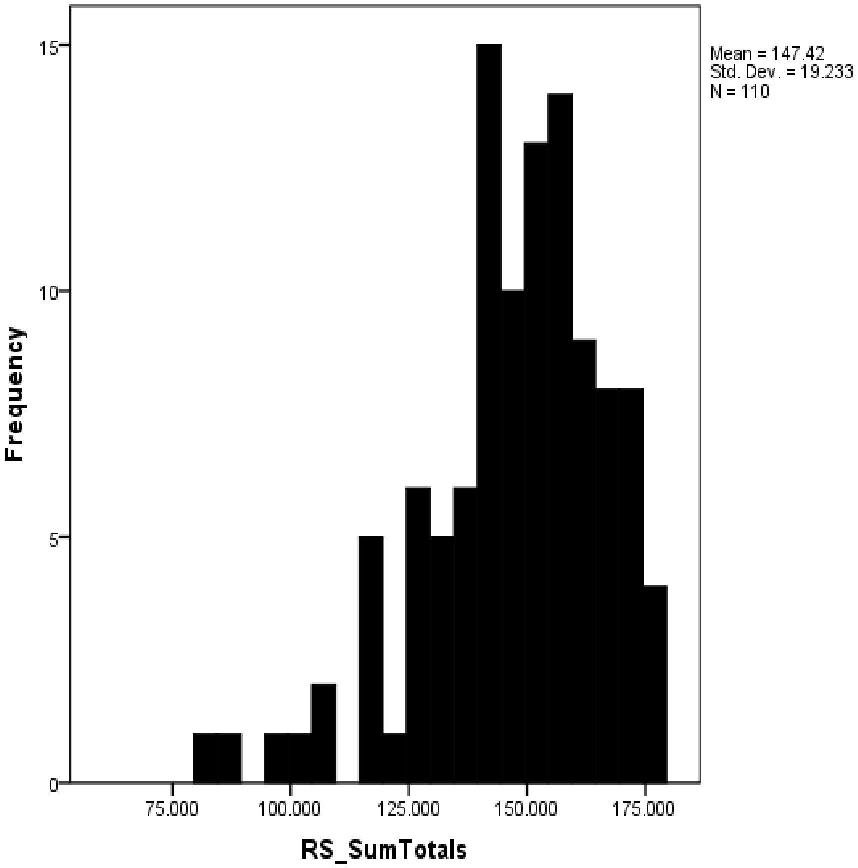

Figure 3- Resilience Scale Distribution of Scores

Descriptive Statistics

To be eligible for this study the caregiver participant had to be providing care to an individual diagnosed with Alzheimer's disease. The final sample in this study included (n=111) Alzheimer's disease caregivers. Demographic data were collected that included age, gender, race, co-reside or not, employment status and the number of years the caregiver has been providing care.

In the final sample (n=111), ages ranged between 25-89 years old, with a mean age of sixty-three (SD = 11). The sample consisted of both male and female caregivers. Eighty-nine (80.2%) of the caregivers were female, while twenty-two (19.8%) were male. Fifty-seven

(51.4%) of the participating caregivers were white, while fifty-two (46.8 %) were black. Two caregivers (1.8 %) were classified as other. The majority of the caregivers were related to the care recipient. Forty caregivers (36 %) identified themselves as spouse caregivers and sixty-six (59.5%) as adult child caregivers. Five caregivers were identified as other (4.5%). Thirty-two (28.8%) of the Alzheimer's disease caregivers participating in this study were full-time employees. Twenty-eight percent (28.8%) were unemployed, while only 10 (9%) worked part-time. Thirty-seven (33.3%) of the caregivers were retired. The average number of years providing care was five (5), with the maximum number of years providing care being fifteen (Table 2).

Table 2- Descriptive Statistics of Alzheimer's Disease Caregivers

Descriptive Statistics	**Mean**	**SD**
Age	63	11
Years Providing Care	4.5 yrs.	3
Frequency/Percentage		
Gender		
Male	22 (20%)	
Female	89 (80%)	
Race		
White	57 (51%)	
Black	52 (47%)	
Other	2 (2%)	
Relationship		
Spouse	40 (36%)	
Adult child	66 (60%)	
Other	5 (4.5%)	
Employment		
Full-time	32 (29%)	
Part-time	10 (9%)	
Retired	37 (33%)	
Unemployed	32 (29%)	

Alzheimer's disease knowledge was measured using the KAML-C (Kuhn, 2005). Scores range from 0-15. Higher scores indicate higher knowledge. Alzheimer's caregivers in this study had a mean AD knowledge score of 8.62, with a SD of 2.56. Care recipient functional independence was measured using the Katz Scale of Activities of Daily Living and the Scale of Instrumental Activities of Daily Living. Scores on the Katz Scale of ADLs range from 0-6. Scores on the Lawton & Brodaty Instrumental Activities of Daily Living range from 0-8. Higher scores equal higher independence. The average functional independence score for this sample in ADLs was 2.74 (SD= 2.13). The average score on the Lawton & Brodaty IADL scale was 1.59 (SD=1.64). The occurrence of behaviors in the care recipient was measured. Behavior frequencies ranged from 0-96 occurrences. Mean behavior frequency for this sample was 40.18. Overall, the Alzheimer's disease caregivers exhibited high resilience. The range of possible score on the Resilience Scale is between 0-175. Resilience scores in this study ranged from 82-175. The average resilience score was 146.

Table 3- Summary Statistics of the Study Variables

Independent Variables(range of scores)	**Mean**	**SD**
Caregiver Knowledge of AD	8.6	2.5
KAML-C (15)		
Functional Independence		
ADL(s) (0-6)	2.7	2
iADL(s) (0-8)	1.6	1.6
Behaviors	40	20
Frequency (0-96)		
Caregiver Reaction to (0-96)	26	20
Moderator Variable		
Resilience (0-175)	146	23.7
Dependent Variable		
Subjective Caregiver Burden (0-100)	41.4	17.5

N= 111

Comparison of Means

Independent samples t-test results indicated a statistically significant difference in Alzheimer's disease knowledge between black and white Alzheimer's caregivers (p<.001). Specifically, white caregivers had greater Alzheimer's knowledge than their black caregiving peers. No statistically significant difference was found between black and white caregivers in resilience or caregiver burden. Male and female Alzheimer's disease caregivers did not differ in Alzheimer's knowledge, resilience or caregiver burden. One-way Analysis of Variance results indicated no statistically significant differences between spouse, adult child and other relative caregivers in Alzheimer's knowledge, resilience or caregiver burden. For simple correlations between the variables in this study, see the simple correlations chart below, (Table 4).

Multiple Regression

Multiple regression involves multiple independent variables and one dependent variable. Multiple regression is a statistical analysis used to examine the relationship between multiple independent variables and a single dependent variable (Keith, 2006). The independent variables can be any level of measurement, while the dependent variable must be continuously distributed. Also, multiple regression is appropriate for analysis in experimental or non-experimental research (p. 17, 2006). Another benefit to using multiple regression is statistical control.

Multiple regression was chosen for this study because of its usefulness in examining the impact of continuous independent variables on the dependent variable, an advantage not available using the Analysis of Variance (ANOVA). Results of the test of the hypotheses are described below.

Assumptions of Statistical Testing. Statistical tests are built on a foundation of assumptions that permit the test to function correctly (Newton & Rudestam, 1999).

When assumptions are not met, study findings may not be trustworthy resulting in a Type I or Type II error (Osborn & Waters, 2002). Assumptions necessary to test a hypothesis in multiple regression include normality of the distribution of residuals, equality of variances, and independence of observations. Nonnormality and inequality of variances can lead to incorrect significance tests and confidence intervals (Keith, 2006).

Homoscedasticity or equality of variances refers to constant variances in the population (Osborne & Waters, 2002). When variances are not equal across all levels of the independent variables, heteroscedasticity increases and can lead to distortions and erroneous statistical findings. Marked heteroscedasticity increases the chance of a Type I error.

Normality was examined by visually examining the histogram of the standardized residuals and Normal P-P Plot [APPENDIX D]. An examination of the residuals did not indicate a problem with normality. Also, an examination of the scatterplot of the standardized residuals and the predicted values did not indicate a problem with homoscedasticity [APPENDIX D]. Finally, an examination of bivariate scatterplot suggested a linear relationship between the variables. The largest Cook's D value was .265 indicating no influential outliers. Multicollinearity was not a problem.

Table 4- Bivariate Correlations

Correlations

		CBiTotal	R_AKSums	ADlSums	iADlSums	BfSums	rBfSums	RS_SumTotals
CBiTotal	Pearson Correlation	1	-.276**	-.075	-.165	.388**	.444**	-.320**
	Sig. (2-tailed)		.004	.435	.085	.000	.000	.001
	N	110	110	110	110	110	110	110
r_AKSums	Pearson Correlation	-.276**	1	.039	.046	-.110	-.127	-.141
	Sig. (2-tailed)	.004		.684	.637	.255	.185	.140
	N	110	110	110	110	110	110	110
ADlSums	Pearson Correlation	-.075	.039	1	.576**	-.096	-.087	.051
	Sig. (2-tailed)	.435	.684		.000	.319	.366	.598
	N	110	110	110	110	110	110	110
iADlSums	Pearson Correlation	-.165	.046	.576**	1	-.151	-.060	-.115
	Sig. (2-tailed)	.085	.637	.000		.116	.537	.230
	N	110	110	110	110	110	110	110
BfSums	Pearson Correlation	.388**	-.110	-.096	-.151	1	.743**	-.086
	Sig. (2-tailed)	.000	.255	.319	.116		.000	.372
	N	110	110	110	110	110	110	110
rBfSums	Pearson Correlation	.444**	-.127	-.087	-.060	.743**	1	-.171
	Sig. (2-tailed)	.000	.185	.366	.537	.000		.073
	N	110	110	110	110	110	110	110
RS_SumTotals	Pearson Correlation	-.320**	-.141	.051	-.115	-.086	-.171	1
	Sig. (2-tailed)	.001	.140	.598	.230	.372	.073	
	N	110	110	110	110	110	110	110

**. Correlation is significant at the 0.01 level (2-tailed).

Results of the Test of the Hypotheses

Five research questions guided this research. Generally, each question concerned the moderating effect of resilience on the relationship between caregiver stressors and caregiver burden. Each research question and hypothesis is restated below.

To examine the possible moderating effect of resilience, variables were entered into the regression model as follows (Table 4): five independent variables were entered in model 1. The moderator variable, resilience, was added in model 2. Model 3 consisted of the five interaction variables. Results indicated a statistically significant relationship between stressors and Alzheimer's caregiver burden (Model 1) [R^2= .270, F= 7.680, p= 000]. When resilience was added to the model (Model 2), a statistically significant change was indicated [ΔR^2= .102, F= 16.801, p= .000]. Model 3 results indicated that resilience did not moderate the relationship between caregiver stressors and caregiver burden [R^2 = .417, F= 1.524, ΔR^2 = .045, p= .189]. Results for each test of the hypothesis testing are described below.

Table 5- Model Summary Table

Model Summary[d]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.519[a]	.270	.235	15.020554	.270	7.680	5	104	.000
2	.610[b]	.372	.336	13.994966	.102	16.801	1	103	.000
3	.646[c]	.417	.352	13.820347	.045	1.524	5	98	.189

1. **Does resilience moderate the relationship between caregiver Alzheimer's disease knowledge and caregiver burden?**

   Hypothesis #1- *Controlling for care recipient behaviors and functional dependence, resilience has a statistically significant moderating effect on the relationship between caregiver Alzheimer's knowledge and caregiver burden.*

   This hypothesis was not supported. Results indicated no statistically significant moderating effect of resilience on the relationship between caregiver Alzheimer's knowledge and caregiver burden [b= -.392, *t*= .183, *p*= .855].

2. **Does resilience moderate the relationship between care recipient independence in activities of daily living and caregiver burden?**

   Hypothesis #2- *Controlling for Alzheimer's disease knowledge, behavior frequency, reaction to behavior frequency and instrumental activities of daily living, resilience moderates the relationship between activities of daily living and caregiver burden.*

   No statistically significant moderating effect of resilience was found [b= .792, *t*= .404, *p*= .687].

3. **Does resilience moderate the relationship between care recipient independence in instrumental activities of living and caregiver burden?**

   Hypothesis #3- *Controlling for caregiver knowledge of Alzheimer's disease, activities of daily living, behavior frequency and caregiver reaction to behavior frequency, resilience moderates the relationship between instrumental activities of daily living and caregiver burden.*

   This hypothesis was not supported. Unstandardized regression coefficients did not indicate a statistically significant moderating effect of resilience on the relationship between instrumental activities of daily living and caregiver burden. Specifically stated (*b*= 3.362 , *t*= 1.621, *p*= .108).

4. **Does resilience moderate the relationship between behavior frequency and caregiver burden?**

Hypothesis #4- *Controlling for caregiver knowledge of Alzheimer's disease, activities of daily living, instrumental activities of daily living and caregiver reaction to behavior frequency, resilience moderates the relationship between behavior frequency and caregiver burden.*

There was no statistically significant moderating effect of resilience on the relationship between behavior frequency and caregiver burden [b= 1.199, *t*= .402, *p*= .689].

5. Does resilience moderate the relationship between caregiver reaction to behavior frequency and caregiver burden?

Controlling for caregiver knowledge of Alzheimer's disease, activities of daily living, instrumental activities of daily living and behavior frequency, resilience moderates the relationship between caregiver reaction to behavior frequency and caregiver burden.

This hypothesis was not supported. The results of the analysis yielded the following regression coefficient, [b= -4.163, t= -1.707, p= .091].

Table 6- Results of Multiple Regression Analysis

Interaction Variables	**B**	**Beta*(b)***	*T*	***p***
Alzheimer's Knowledge/Res	-.392	-.016	-.183	.855
Activities of Daily Living/Res	.793	.046	.404	.687
Instrumental Activities of Daily Living /Res	3.362	.262	1.621	.108
Behaviors/Res	1.199	.065	.402	.689
Caregiver reaction to behaviors/Resilience	-4.163	-.207	-1.707	.091
R²=.417 F(11, 99)= 7.281, p=.189				

In summary, the overall model indicated a linear relationship between at least one caregiver stressor and caregiver burden. The relationship between caregiver stressors (Alzheimer's knowledge, activities of daily living, and instrumental activities of daily living, behavior frequency, and reaction to behavior frequency) and caregiver burden were not moderated by resilience. Post hoc findings indicated a statistically significant relationship between resilience and caregiver burden. Resilience, controlling for covariates, accounted for approximately 10.2% of the variance in caregiver burden scores. Specifically, the regression coefficient indicated that as resilience increased, caregiver burden decreased, [b= -.299, t = -4.099, p < .001].

Limitations of the Study

Statistically significant correlations were found between caregiver Alzheimer's knowledge, instrumental activities of daily living and the caregiver's reaction to behavior frequency and caregiver burden (Table 4). Resilience did not moderate the relationships between caregiver stressors and caregiver burden; however, results indicated a statistically significant relationship between resilience and caregiver burden. There are a number of limitations in this study. First, convenience, not random, sampling was used to recruit Alzheimer's caregivers for this study. Convenience sampling is frequently used in social research because it is more economical than sampling designs and it is more feasible with certain populations (Rubbin & Babbie, 2005). Because a convenience sample consists of individuals who are easier to access, they are not representative of the general population from which they are drawn. Due to a lack of representativeness of the convenience sample, the generalizability of the study findings is limited. Thus, findings in this study are not generalizable to the general population of Alzheimer's disease caregivers.

Findings in this study may also have been influenced by sample bias. Because sample participants were recruited through social service agencies, the sample may be an over-representation of Alzheimer's disease caregivers who have the capability and willingness to participant in research, and therefore likely an underrepresentation of caregivers who are not connected to the local support group or formal services. By extrapolation, one could assume that caregivers who are not receiving assistance from formal service providers are likely more burdened. Thus, mean caregiver burden scores in this study may be an under estimate of the general population of Alzheimer's disease caregivers. Response bias may affect the results in that the data was self-reported by the caregivers. Self-report data depends on the respondents understanding of what is being asked and their honest response. This too could bias study findings.

The small sample size in this study limits the findings in several ways. Small samples limit the statistical power and increase the chance of making a Type II error. The failure to find statistically significant interactions in the hypothesis tests could have occurred due to the small sample size and therefore low statistical power. The truncated range of resilience scores could have contributed to this failure to detect statistically significant interactions. As a result of the small sample size in this study, caregiver stressor and caregiver burden scores of the Alzheimer's disease caregivers may not be a true reflection of those in the general population of Alzheimer’s disease caregivers. In future research, the sample size should be increased by increasing the sampling frame to other agencies and the population of Alzheimer’s disease caregivers in the general recruiting area. Also, offering a larger monetary incentive may improve the sample size. Purposive sampling should be used to obtain scores from persons with low resilience. This may serve to give a wider range of resilience scores than was obtained in the current study. Because Alzheimer’s disease caregiving requires several hours of commitment, the effort and length of time necessary to participate might also be minimized. Also, in future research a predetermined plan for follow-up should be developed to encourage the caregivers to respond. Research has shown that a follow-up mailing is an effective means of increasing return rates of mailed surveys (Rubbin & Babbie, 2005).

Chapter 5- Discussion and Conclusion

Informal Alzheimer's disease caregivers are essential in maintaining the daily function and safety of their care recipients in their homes and communities; however, this is a daunting task. As shown, caring for the Alzheimer's disease care recipient requires a daily sacrifice of time and physical energy. In fact, caregivers spend forty or more hours per week providing care to their loved ones (Ory, 1999). In many instances, Alzheimer's caregivers provide care while balancing both care recipient and the demands in their own life. Consequently, Alzheimer's caregivers experience interrupted sleep, confinement and limited social outlets. Thus it follows that Alzheimer's caregiving chips away at the physical and emotional health of the Alzheimer's disease caregiver. Yet, even with these challenges, many Alzheimer's disease caregivers continue providing care. The staying power that Alzheimer's disease caregivers display in the midst of providing care is analogous to what is defined as resilience (Norman, 2000). The purpose of this study was to examine the potential moderating effect of resilience on the relationship between caregiver stressors and Alzheimer's caregiver burden.

Limitations and Implications for Future Research

The overall model fit in this study was not significant. The interaction of resilience with the caregiver stressors accounted for only 4.5% of the variance in caregiver burden. Model summary results indicated no statistically significant moderating effect of resilience on the relationship between caregiver stressors and caregiver burden. Hierarchical regression analysis was used to test the interaction of resilience with caregiver stressors and its moderating influence on caregiver burden. The hypotheses in this study were not adequately tested due to the following methodological limitations.

As previously stated, this sample size was not sufficient to detect a statistically significant interaction effect of resilience. The demands of the Alzheimer's disease caregiver likely contribute to the small sample size in the current study. For instance, many caregivers spend more than forty hours a week providing care and have to balance the daily responsibilities of their loved ones along with their own (Ory, 1999, Family Caregiver Alliance, 2004). Given the time and energy exerted while providing care, participating in a research study is likely a low priority. It follows that Alzheimer's disease caregivers will be a complicated population to sample. To obtain a larger sample of Alzheimer's disease caregivers, future research could expand the sampling frame from just social service agencies to the general population. Broader more rigorous sampling should be extended to local churches and physician offices as well as advertisement in the local newspaper to yield a larger sample of caregivers. In addition to broader sampling methods, follow-up reminder notices and large monetary incentives will likely result in a larger sample.

The power to detect the interaction effect of resilience was complicated by a restricted range of resilience scores (interaction variable). Specifically, the examination of the resilience scores indicated scores that were concentrated at the higher end of the distribution, with no scores at the lower end. According to Cohen & Cohen (2003), the power to detect interactions is dependent on the distributions of the predictor variable and is hampered when the variable's distribution of scores is skewed. Due to the sparse data on the lower end of the resilience distribution, the findings in this study are only generalizable to Alzheimer's disease caregivers who have high resilience.

Having a strong external support system (i.e. being connected to external support systems) is associated with increased resilience (Ross, Holliman & Dixon, Greene, 2002). To that end, it is not surprising that the caregivers in this study reported high resilience. Contrary to sampling methods in the current study, purposive sampling targeting Alzheimer's caregivers not affiliated with social service agencies should be used in future research to obtain a broader cross-section of Alzheimer's disease caregivers. Purposive sampling methods will likely produce data that is representative of the Resilience Scale's range of scores.

A convenience sample of Alzheimer's disease caregivers recruited from social service agencies was used in this study. The use of convenience sampling resulted in the over sampling of Alzheimer's caregivers associated with social service agencies. Because these caregivers were readily available, this sample is not representative of the general population of Alzheimer's caregivers. As a result, the findings in this study are not generalizable to Alzheimer's disease caregivers beyond this study. Therefore, the findings in this study tell very little about resilience and the reduction of caregiver burden of Alzheimer's disease caregivers not affiliated with support agencies. Future research should employ random sampling, sampling of caregivers beyond service agencies and/or a replication of this study to increase generalizability.

A cross-sectional study design was used to examine the Resilience-Moderated Burden model. Post-hoc analysis indicates a linear relationship between resilience and caregiver burden in that as resilience increases, caregiver burden decreases. Causal inferences cannot be made with certainty because of the use of the cross-section examination. The use of the cross-sectional study design threatens the internal validity of the causal relationship of the variables because of the examination at one point in time and the lack of control for other plausible causes of Alzheimer's disease caregiver burden (Rubbin & Babbie, 2005).

Does resilience matter in the experienced burden of Alzheimer's disease caregivers? At first glance, no. Contrary to prediction, resilience did not moderate the effects of the stressors on caregiver burden; however, post hoc findings indicate a statistically significant relationship between resilience and caregiver burden, such that as resilience increases, caregiver burden decreases. This finding shows promise and has important implications for policy, practice and social work education.

Implications for Practice and Policy

Caregivers are essential in the lives of Alzheimer's disease care recipients. Yet, caregivers experience ill-effecting burden related to the care they provide. This fact alone underscores the needed focus on the sustainability of Alzheimer's disease caregivers. The negative relationship between resilience and caregiver burden evidenced in this study indicates that enhancing a caregiver's resilience shows promise in reducing caregiver burden. A reduction in caregiver burden increases the likelihood that Alzheimer's disease caregivers will continue providing care and are less likely to place their loved ones in the nursing home (Gaughler, 2007). Traditionally, support services have primarily focused on the individual living with Alzheimer's disease, maybe obtaining a brief measure of caregiver burden (Mui, 2001). In light of the resilience- caregiver burden relationship indicated in this study, implications for social work practice include recognizing Alzheimer's caregivers as essential to the well-being of the care recipient. The social work practitioner should also have an understanding of resilience and its significance in Alzheimer's disease caregiving. Practitioners should examine resilience in caregivers using a valid and reliable measure of resilience such as the one used in this study (Wagnild & Young, 1990).

Previous research that lends support for burden-reducing intervention such as peer support groups or psycho-educational programs is limited (Martin-Carrasco et al, 2009). In fact, none were identified that encompassed a focus on resilience. Supportive services that received the greatest support were psycho-educational programs that cover specific information (p. 490). Give the findings of this study, supportive interventions designed to enhance characteristics and external supports that lead to increased resilience should be implemented. If no resilience-increasing intervention or support program exists, practice would be enhanced by the development and validation of an intervention that can be implemented to increase resilience.

The lack of resilience-enhancing interventions has implications for policy. If no resilience- enhancing services exist, social practitioners should advocate on behalf of Alzheimer's caregivers and collaborate with agency administrators to develop processes for the implementation of resilience- enhancing interventions. On a broader scale, practitioners should implore legislators to increase funding to support Alzheimer's disease caregivers and their need for interventions that will lead to increased resilience.

Implications for Social Work Education

Previous research evidences the difference resilience has made in the lives of various populations (Beardles & Poderfsky, 1988, Wagnild & Young, 1993, Collishaw et al, 2007). Similarly, results of this study indicate that increased resilience reduces caregiver burden in this study's sample of Alzheimer's disease caregivers. Together, the purpose of social work education to promote knowledge that results in human well-being and the resilience related finding in this study have implications for social work education. Specifically, social work education will foster an understanding of resilience conceptualizations that include personality characteristic and the process of resilience development that involves interplay of vulnerabilities and protective factors. Also, social work students will understand resilience theory as a cycle of disruptive and re-integrative experiences that lead to resilience. Finally, resilience research, particularly resilience and Alzheimer's disease caregivers research, will serve as a guide in understanding of the approaches to examining resilience in various populations.

Closing Thoughts

During my doctoral education, I became the primary caregiver for my mother. It was then that I became more sensitive to the needs of caregivers. Albeit education and experience, caregiving for me was exhausting and emotionally draining. I needed answers to questions and help to navigate the maze of medical information I had received. I wanted others near me, simply because it was comforting. Considering my personal experience and the responses of the Alzheimer's caregivers who participated in this study, a couple of thoughts remain and are basis for future Alzheimer's caregiver research: 1) If engaged, most caregivers want to share their story and 2) Alzheimer's caregivers who were willing to participate in the research did so because they are searching for answers to their questions and looking for ways to improve the quality of their lives and the lives of their loved one suffering from Alzheimer's disease.

Moreover, supporting, educating, and/or compensating informal caregivers can be a key factor in increasing the quality of life in individuals living with Alzheimer's disease. Also, supporting caregivers can aide in decreasing the burgeoning long term care budget. Currently, more than 80% of those receiving long-term care do so at home (Gleckman, 2007, p. 18) and it is posited that if the aged and disabled are maintained in the home Alzheimer's disease care recipients' receive improved care and money is saved (p. 18). A benefit that is impossible without informal caregivers.

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APPENDIX

APPENDIX A
Documents

Agency Letter

December 9, 2009

Cathy B. Scott
8491 Keystone Circle
Chattanooga, TN 37421

Agency name
Agency Director
Agency address.
Chattanooga, TN 37405

Dear,

I am conducting research that involves informal Alzheimer's dementia caregivers. As your agency provides services to informal Alzheimer's dementia caregivers providing community-based care, I am requesting permission to recruit participants for my study at your agency. If permission is granted, I would appreciate your response in writing or electronically. Enclosed you will find the study description. The objectives of the study are included. Specific tasks that are asked of the caregivers are outlined as well. Feel free to contact me with further questions. My contact information is 423-432-5081 or cscott17@utk.edu.

Cordially,

Cathy B. Scott, MSW
Doctoral Student
College of Social Work
University of Tennessee
Knoxville, TN 37996

A2-Study Description
Project Title: Burden in Informal Alzheimer’s Caregivers: Does resilience matter?

INTRODUCTION

Informal Alzheimer’s caregivers are invited to participate in a research study. The purpose of this study is to examine factors associated with informal Alzheimer’s caregiver burden. Also, resilience, as measured by a valid and reliable resilience survey, will be examined as a moderator in caregiver burden.

INFORMATION ABOUT PARTICIPANT’S INVOLVEMENT IN THE STUDY

Participants who accept the invitation to participate in the research study will be invited to one of the participating agencies to complete a survey packet. The packet will be an envelope that will include a pencil, a consent form, and five survey instruments. Based on the time documented developer of each survey; it will take approximately 50 minutes to complete the survey packets. Upon completing the packets, study participants will be asked to put the packets in a designated place. Cathy Scott, MSW will be available at each session while the caregivers complete the packets. Cathy Scott has a Master’s degree in Social Work. She has 10 years of experience working with caregivers and care recipients.

RISKS

Caregivers participating will experience minimal risk while participating in this study. The anticipated risk is no greater than those encountered in daily life or those experienced during routine physical or psychological testing.

BENEFITS

Caregivers will benefit from this study in that they will have the opportunity to assist in the advancement of knowledge in informal caregiver research.

CONFIDENTIALITY

Information collected during this study will be kept confidential. The information collected will only be available to the researcher conducting the study and overseeing doctoral committee members. No link or identifying information will be made between the participant and the information collected.

COMPENSATION

Upon completion of the survey packets, study participants will receive a $10.00 Wal-Mart gift card as a token of appreciation for their time.

CONTACT

If you have questions regarding this study, feel free to contact the researcher, Cathy Scott, MSW at 423-432-5081. If you have questions about your rights, contact the Office of Research Compliance Officer at the University of Tennessee, Knoxville, TN at 865-974-3466.

PARTICIPATION

Your participation in this study is voluntary; you may decline participation or withdraw your participation at any time. If you choose to withdraw from the study at any time, you may do so without penalty. If you withdraw from the study, your data will be destroyed. Return of the completed survey packet and consent forms signifies your consent to participate.

A3- Invitation Notices

YOU ARE INVITED TO PARTICIPATE

IN

RESEARCH ABOUT

CAREGIVERS!

Purpose: (1) To examine the relationship between stressors and caregiver burden
(2) To examine the influence of resilience on the relationship between stressors and caregiver burden.

What do you do: Take approximately 50-55 minutes to answer survey questions.

Where: Alexian Brothers Community Services PACE

When: April, 2010
April, 2010
Survey packets can also be picked up and returned at PACE on these dates. A drop box will be placed at the East and West side sign-in desks.

YOUR HELP IS GREATLY NEEDED!

For questions call: 423-432-5081

Participation in the study is voluntary. You may withdraw at any time without penalty. Data collected will be kept confidential and locked in the office of the researcher. Only the research and advisors will have access to the data. Completing the survey packets will serve as your consent to participate. Each caregiver completing the survey packets will receive a $10.00 gift card as appreciation for their time.

YOU ARE INVITED TO PARTICIPATE

IN
RESEARCH ABOUT

CAREGIVERS!

Purpose: (1) To examine the relationship between stressors and caregiver burden
(2) To examine the influence of resilience on the relationship between stressors and caregiver burden.

What do you do: Take approximately 40 minutes to answer survey questions.

Where: Alexian Brothers Valley Residence

When: April 2010
April, 2010
Survey packets can also be picked up and returned at ABVR on these dates. A drop box will be placed at the front office.

YOUR HELP IS GREATLY NEEDED!

For questions contact:

Cathy Scott, MSW
cscott17@utk.edu
University of Tennessee
College of Social Work
423-432-5081

Participation in the study is voluntary. You may withdraw at any time without penalty. Data collected will be kept confidential and locked in the office of the researcher. Only the research and advisors will have access to the data. Completing the survey packets will serve as your consent to participate. Each caregiver completing the survey packets will receive a $10.00 gift card as appreciation for their time.

YOU ARE INVITED TO PARTICIPATE

IN

RESEARCH ABOUT

CAREGIVERS!

Purpose: (1) To examine the relationship between stressors and caregiver burden
(2) To examine the influence of resilience on the relationship between stressors and caregiver burden.

What do you do: Take approximately 40 minutes to answer survey questions.

Where: Southeast Alzheimer's Association Support Groups

When: April meetings
Survey packets may be completed on site or taken and returned by mail.

YOUR HELP IS GREATLY NEEDED!

For questions contact:

Cathy Scott, MSW
cscott17@utk.edu
University of Tennessee
College of Social Work
423-432-5081

Participation in the study is voluntary. You may withdraw at any time without penalty. Data collected will be kept confidential and locked in the office of the researcher. Only the research and advisors will have access to the data. Completing the survey packets will serve as your consent to participate. Each caregiver completing the survey packets will receive a $10.00 gift card as appreciation for their time.

A4- Informed Consent Statement for Informal Alzheimer's Disease caregivers
Project Title: Alzheimer's disease caregiver burden: Does resilience matter?

Introduction- Informal Alzheimer's disease caregivers are invited to participate in a research study. The purpose of this study is to explore the relationship between caregiver stressors and caregiver burden and to examine the effects of resilience on that relationship.

Participant Involvement in the Study- Your participation is this study is voluntary. You may withdraw at any time without penalty. Your participation in this study involves approximately 45 minutes of your time. You will be asked to complete five survey instruments. The survey instruments include questions about your knowledge of Alzheimer's disease, the functional abilities of the care recipient, and any caregiver burden you are experiencing.

Risks- Risks in this study may include discomfort in answering questions related to your role as a caregiver, coercion to participate in the study or breach of confidentiality. Protection against these risks includes the freedom to withdraw from the study if you become distressed while answering questions. The number of a social worker or counselor will also be provided for additional support. To protect your anonymity, no personal information will be collected. A secured drop box will available for completed surveys. Agency staff members who may become aware of your participation in the study are bound by the agency confidentiality policies.

Benefits and Compensation- The benefits of participating in this study would be the opportunity to participate in research that will enhance the assessment and support provided to Alzheimer's disease caregivers. Participants will receive a $10.00 Walmart gift card after completing the surveys.

Confidentiality- The information collected as a part of this study will be kept confidential. Completed surveys will be kept in the locked office of the supervising faculty member on the University of Tennessee campus. Data collected will be kept on a password-protected computer.

When you turn the page and begin answering questions, you are consenting to participate in this study. Thank you for your participation.

APPENDIX B
QUANTITATIVE DATA INSTRUMENTS

B1- Project Title: Burden in Alzheimer's disease caregivers: Does resilience matter?

Biographical Information Sheet

1. What is your age?_______

2. Gender:
a. Male
b. Female

3. What is your race?
a. White
b. Black
c. Other

4. What is your relationship to the care recipient?
a. Spouse
b. Adult child
c. Other: ___________________

5. Do you live with the care recipient?
a. Yes
b. No

6. Are you employed?
a. Full-time
b. Part-time
c. Retired
d. Unemployed

7. Approximately how long have you been providing care?
____

B-2- **Burden in alzheimer's disease caregivers: Does resilience matter?**
Measuring the Caregiver's Knowledge of Alzheimer's Disease
Knowledge about Memory Loss and Care (KAML-C), Kuhn et al (2005)

1. Which of the following is the most common cause of memory loss in people over age 65?
    a. Alzheimer's disease
    b. Senility
    c. Hardening of the arteries
    d. Forgetfulness
2. Which of the following conditions may resemble Alzheimer's disease?
    a. Major depression
    b. Anemia
    c. Thyroid disorder
    d. Parkinson's disease
    e. All of the above
3. Genetic testing for Alzheimer's disease is currently:
    a. A reliable way of predicting if symptoms will develop later in life
    b. Useful only as a research tool
    c. A definitive means of diagnosis after the onset of symptoms
    d. An accurate means of diagnosis in most cases
    e. Approved for home use by the government
4. A symptom of Alzheimer's disease usually NOT seen in the early stage:
    a. Disorientation to time and place
    b. Word finding difficulty
    c. Aggressive behaviors
    d. Memory loss
    e. Difficulty with calculations
5. Giving reminders such as the date and place to persons with memory loss disease will:
    a. Improve memory for a time
    b. Improve orientation for a time
    c. Not change memory or orientation
    d. Increase confusion
    e. Be useful temporarily but will have no lasting effect on memory or orientation
6. The BEST way to enable someone with memory loss to understand you is to:
    a. Explain your reasoning
    b. Write out a detailed note
    c. Repeat yourself until the point is made
    d. Give brief and simple instructions
    e. Speak in a quiet tone
7. Which of the following is NOT likely to be a problem for a person in the early stage of memory loss who is living alone?
    a. Forgetting to turn off the stove
    b. Making travel plans
    c. Managing money
    d. Remembering to take medications
    e. Getting dressed in the morning
8. Which of the following is NOT HELPFUL for persons with memory loss in completing tasks?
    a. Breaking tasks down into small steps
    b. Encouragement to try harder
    c. Repeating old familiar skills
    d. Having others assist them as needed
    e. Companionship

9. The BEST way for persons in the early stages of memory loss to ensure that their rights and personal preferences will be protected in the future is to:
    a. Sign a living will for health and financial decisions
    b. Complete Durable Powers of Attorney for Property and Health Care
    c. Have a legal guardian appointed
    d. Have a loved one speak up in their behalf as needed
    e. Transfer their assets into the name of a loved one
10. In regard to financial affairs, persons with memory loss can:
    a. Be persuaded of the need for a legal guardian
    b. Usually be trusted to manage their income and assets
    c. Be exploited if safeguards are not put in place
    d. Be responsible for paying their bills if in the early stage of the disease
    e. Make transactions after thorough consultation
11. Medicare covers which one of the following for persons with Alzheimer's disease?
    a. Doctor's visits on an out-patient basis
    b. Nursing home care on a long-term basis
    c. Adult day care
    d. Companion services at home
    e. Medication
12. Most persons with Alzheimer's disease live:
    a. In nursing homes
    b. In retirement communities
    c. In their own homes
    d. With their adult children
    e. In assisted living facilities
13. Primary caregivers of persons with Alzheimer's disease suffer from major depression:
    a. At the same rate as the general population
    b. At a lower rate than the general population
    c. At a much higher rate than the general population
    d. At a slightly higher rate than the general population
    e. At a much lower rate than the general population
14. For a married person with Alzheimer's disease to qualify for Medicaid in order to pay the cost of nursing home care, the:
    a. Spouse is required to spend down their liquid assets to $2000
    b. Spouse must sell their residence and all assets
    c. Spouse is entitled to keep a certain level of income and assets
    d. Spouse may transfer most assets to their children
    e. Spouse must file for bankruptcy or divorce
15. Those LEAST likely to be primary caregiver of persons with Alzheimer's disease are:
    a. Their sons
    b. Their daughters
    c. Their daughters-in-law
    d. Their husbands
    e. Their wives

B-3 **Burden in alzheimer's disease caregivers: Does resilience make a difference?**

Measuring the Functional Independence of Activities of Daily Living

Katz Index of Independence (Katz & Stroud, 1989) &
Lawton Scale of Instrumental Activities of Daily Living (Lawton & Brody, 1969)

ACTIVITIES	**INDEPENDENCE** 1 pt.	**DEPENDENCE** 0pts
1. Bathing	Yes_____	No_____
2. Dressing	Yes_____	No_____
3. Toileting	Yes_____	No_____
4. Transferring	Yes_____	No_____
5. Continence	Yes_____	No_____
6. Feeding	Yes_____	No_____

Total Points: _____

High patient independent = 6
Moderate patient dependence= 4
Patient very dependent = 0

B-4 **INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE**

Lawton & Brody (1969)

1. Ability to use telephone
   a. Operates telephone, looks up number and dial
   b. Dials a few well-known numbers
   c. Answers telephone but does not dial
   d. Does not use telephone at all
2. Shopping
   a. Takes care of all shopping needs
   b. Shops independently for small purchases
   c. Needs to be accompanied for shopping trips
   d. Completely unable to shop
3. Food Preparation
   a. Plans, prepares and serves adequate meals independently
   b. Prepares adequate meals if supplied with ingredients
   c. Prepares meals but does not maintain adequate diet
   d. Needs to have meals prepared and served
4. Housekeeping
   a. Maintains house alone or with occasional help
   b. Performs light daily task (dishes, making bed)
   c. Performs light daily task but can’t maintain cleanliness
   d. Needs help with all task
   e. Does not do any housekeeping
5. Laundry
   a. Does personal laundry completely
   b. Rinses small items
   c. All laundry must be done by others
6. Transportation
   a. Travels independently in public transportation or own car
   b. Arranges own transportation
   c. Travels when arranged by others
   d. Limited travel with others
   e. Does not travel at all
7. Responsibility for own medications
   a. Responsible for taking medications correct (dosage and time)
   b. Takes responsibility if medications is prepared in advance
   c. Is not capable of dispensing own medications
8. Ability to handle finances
   a. Manages financial matters independently, collects and keeps track of income
   b. Managed day-to-day purchases, but needs help with banking and major purchases
   c. Incapable of handling money

B-5-**Caregiver Burden in Informal Dementia Caregivers: Does resilience make a difference?**

Measuring care recipient disruptive behaviors (Revised Memory and Behavior Problems Checklist (Teri et al, 1992)

The following is a list of problems patients sometimes has. Please indicate if any of these problems have occurred during the past week. If so, how much as this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

<u>Frequency Ratings</u>:	<u>Reaction Ratings</u>
0 = never occurred	0= not at all
1= not in the past week	1= a little
2= 1-2 times in the past week	2= moderately
3= 3-6 times in the past week	3= very much
4= daily or more often	4= extremely
9= don’t know/not applicable	9= not applicable

Behavior	**Frequency**	**Reaction**
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing things	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you and other family members up at night	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
13. Engaging in behavior that is dangerous to self of others	0 1 2 3 4 9	0 1 2 3 4 9
14. Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future.	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20. Commenting about death of self or others	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or a burden	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining	0 1 2 3 4 9	0 1 2 3 4 9

B-6- **Caregiver Burden in Informal Dementia Caregivers: Does resilience make a difference?**

Measuring resilience in informal dementia caregivers

Resilience Scale (Wagnild & Young, 1993)

Personal Competence	**Disagree**						**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 my 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
Acceptance of Self and Life							
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 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
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

B-7- **Caregiver Burden in Informal Dementia Caregivers: Does resilience make a difference?**

Measuring caregiver burden

Caregiver Burden Inventory (Novak & Guest, 1989)

Ratings:
0- not at all descriptive
1- somewhat descriptive
2-descriptive
3- somewhat descriptive
4- very descriptive

Please circle the number that best reflects your experience.

Time Dependence Burden Score

1. My care receiver needs my help to perform daily tasks. 0 1 2 3 4
2. My care receiver is dependent on me. 0 1 2 3 4
3. I have to watch my care receiver constantly. 0 1 2 3 4
4. I have to help my care receiver with many basic functions. 0 1 2 3 4
5. I don't have a minute's break from my caregiving chores. 0 1 2 3 4

Developmental Burden Score

1. I feel that I am missing out on life. 0 1 2 3 4
2. I wish I could escape from this situation. 0 1 2 3 4
3. My social life has suffered. 0 1 2 3 4
4. I feel emotionally drained because of caring for my care receiver. 0 1 2 3 4
5. I expected that things would be different at this point in my life. 0 1 2 3 4

Physical Burden Score

1. I'm not getting enough sleep. 0 1 2 3 4
2. My health has suffered. 0 1 2 3 4
3. Caregiving has made me physically weak. 0 1 2 3 4
4. I'm physically tired. 0 1 2 3 4

Social Burden Score

1. I don't get along with other family. 0 1 2 3 4
2. My caregiving efforts aren't appreciated by others in my family. 0 1 2 3 4
3. I've had problems with my marriage. 0 1 2 3 4
4. I don't do as good a job at work as I used to. 0 1 2 3 4
5. I feel resentful of others relatives who could but do not help. 0 1 2 3 4

Emotional Burden Score

1. I feel embarrassed over my care receiver's behavior. 0 1 2 3 4
2. I feel ashamed of my care receiver. 0 1 2 3 4
3. I resent my care receiver. 0 1 2 3 4
4. I feel uncomfortable when I have friends over. 0 1 2 3 4
5. I feel angry about my interactions with my care receiver. 0 1 2 3 4

APPENDIX C

Permissions to Use Survey Measures

Permission to use the Knowledge about Memory Loss and Care (KAML-C) scale

Mr. Scott and Ms. Scott:
It's a pleasure to have a fellow social worker using something we've created.

Dan

Daniel Kuhn, MSW | Director, Professional Training Institute, Alzheimer's Association - Greater Illinois Chapter, 8430 W. Bryn Mawr, Suite 800, Chicago, IL 60631 Tel: 847-324-0391 Fax: 773-444-0930

Check out our upcoming professional training & education programs: www.alz.org/illinois

.

Our vision is a world without Alzheimer's

Permission to The Caregiver Burden Inventory (Novak & Guest, 1989)

Hello Cathy: Yes, you may use the CBI with our permission. Best wishes. Mark Novak

On Dec 1, 2009, at 12:01 PM, Scott, Cathy B wrote:

> Dr. Novak,
>
> I am a PhD candidate at the University of Tennessee in the College of Social Work. I will be conducting a study examining resilience and caregiver burden in Alzheimer's disease caregivers. I would like to use the Caregiver Burden Inventory as the outcome measure for caregiver burden. Thank you in advance for your cooperation. I look forward to your response.
>
> Cathy Scott, MSW

Sorry for delay
You have my permission.
Best of luck.

****

Linda Teri, Ph.D.
Professor and Chair
Dept. Psychosocial and Community Health
Director, Northwest Research Group on Aging
University of Washington
School of Nursing
campus box: 358733
Seattle, WA 98195

phone: 206-543-0715
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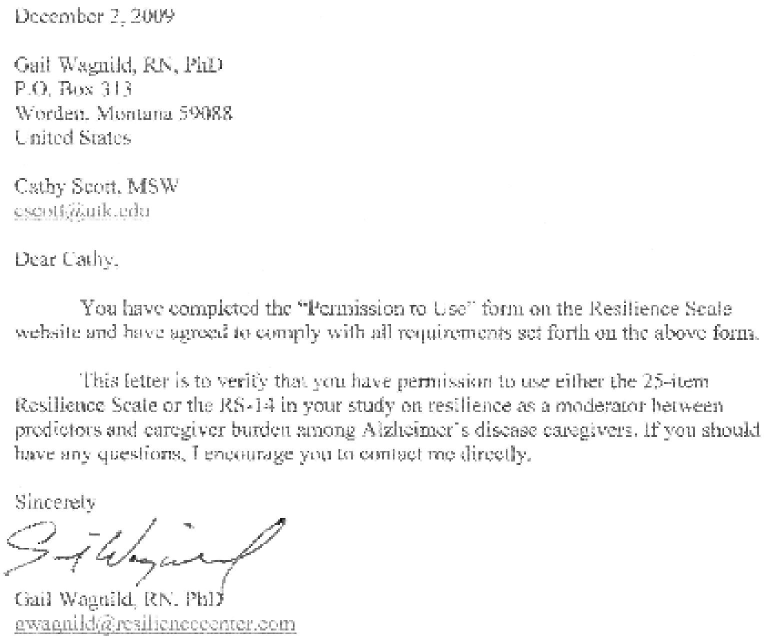


December 2, 2009

Gail Wagnild, RN, PhD
P.O. Box 313
Worden, Montana 59088
United States

Cathy Scott, MSW
cscott@uik.edu

Dear Cathy,

You have completed the "Permission to Use" form on the Resilience Scale website and have agreed to comply with all requirements set forth on the above form.

This letter is to verify that you have permission to use either the 25-item Resilience Scale or the RS-14 in your study on resilience as a moderator between predictors and caregiver burden among Alzheimer's disease caregivers. If you should have any questions, I encourage you to contact me directly.

Sincerely

Gail Wagnild, RN, PhD
gwagnild@resiliencecenter.com

APPENDIX D
Pre-analysis Data Screening Charts & Graphs

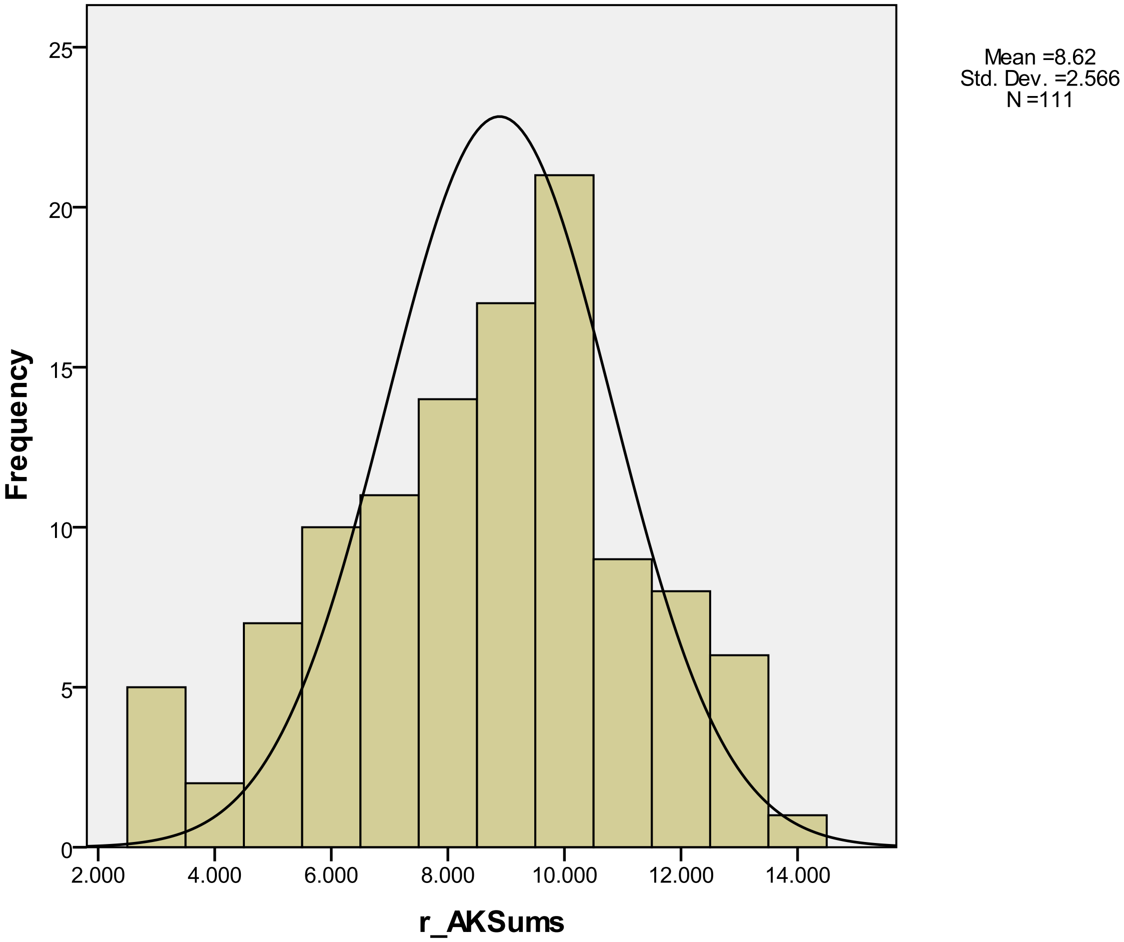
D-1 .Caregiver Alzheimer's knowledge

a. Case Processing Summary-Alzheimer's Knowledge

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
r_AKSums	111	100.0%	0	.0%	111	100.0%

b. Alzheimer's Knowledge Descriptives

			Statistic	Std. Error
r_AKSums	Mean		8.62162	.243525
	95% Confidence Interval for Mean	Lower Bound	8.13901	
		Upper Bound	9.10423	
	5% Trimmed Mean		8.67518	
	Median		9.00000	
	Variance		6.583	
	Std. Deviation		2.565697	
	Minimum		3.000	
	Maximum		14.000	
	Range		11.000	
	Interquartile Range		3.000	
	Skewness		-.276	.229
	Kurtosis		-.401	.455



c. The Alzheimer's Knowledge Distribution of Scores

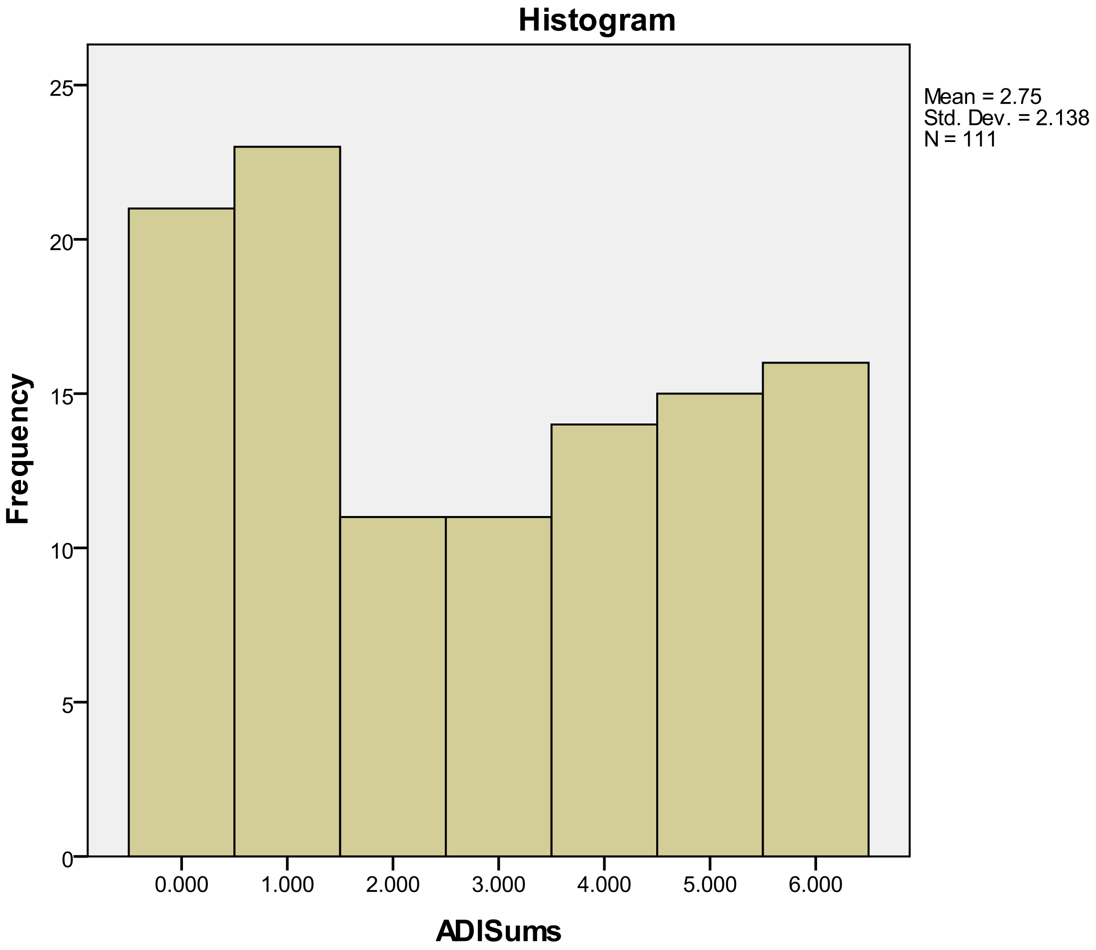
D-2 Activities of Daily Living

a.Case Processing Summary- Activities of Daily Living

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
ADlSums	111	100.0%	0	.0%	111	100.0%

b. Activities of Daily Living Descriptives

			Statistic	Std. Error
ADlSums	Mean		2.74775	.202955
	95% Confidence Interval for Mean	Lower Bound	2.34554	
		Upper Bound	3.14996	
	5% Trimmed Mean		2.71972	
	Median		3.00000	
	Variance		4.572	
	Std. Deviation		2.138260	
	Minimum		.000	
	Maximum		6.000	
	Range		6.000	
	Interquartile Range		4.000	
	Skewness		.176	.229
	Kurtosis		-1.419	.455



c.The Activities of Daily Living Distribution of Scores

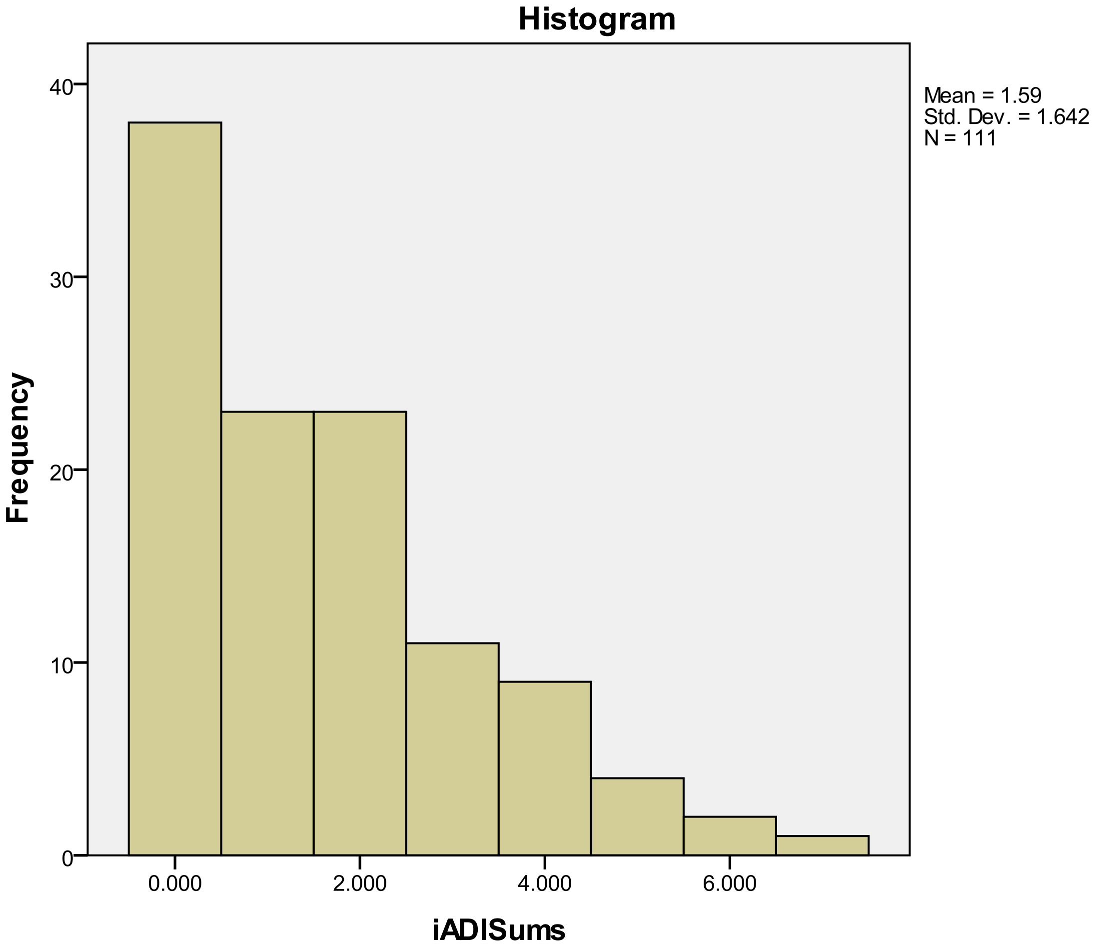
D-3 Instrumental Activities of Daily Living

a.Case Processing Summary- Instrumental Activities of Daily Living

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
iADlSums	111	100.0%	0	.0%	111	100.0%

b.Instrumental Activities of Daily Living Descriptives

			Statistic	Std. Error
iADlSums	Mean		1.59459	.155899
	95% Confidence Interval for Mean	Lower Bound	1.28564	
		Upper Bound	1.90355	
	5% Trimmed Mean		1.45395	
	Median		1.00000	
	Variance		2.698	
	Std. Deviation		1.642495	
	Minimum		.000	
	Maximum		7.000	
	Range		7.000	
	Interquartile Range		2.000	
	Skewness		1.014	.229
	Kurtosis		.529	.455



c. The Instrumental Activities of Daily Living Distribution of Scores

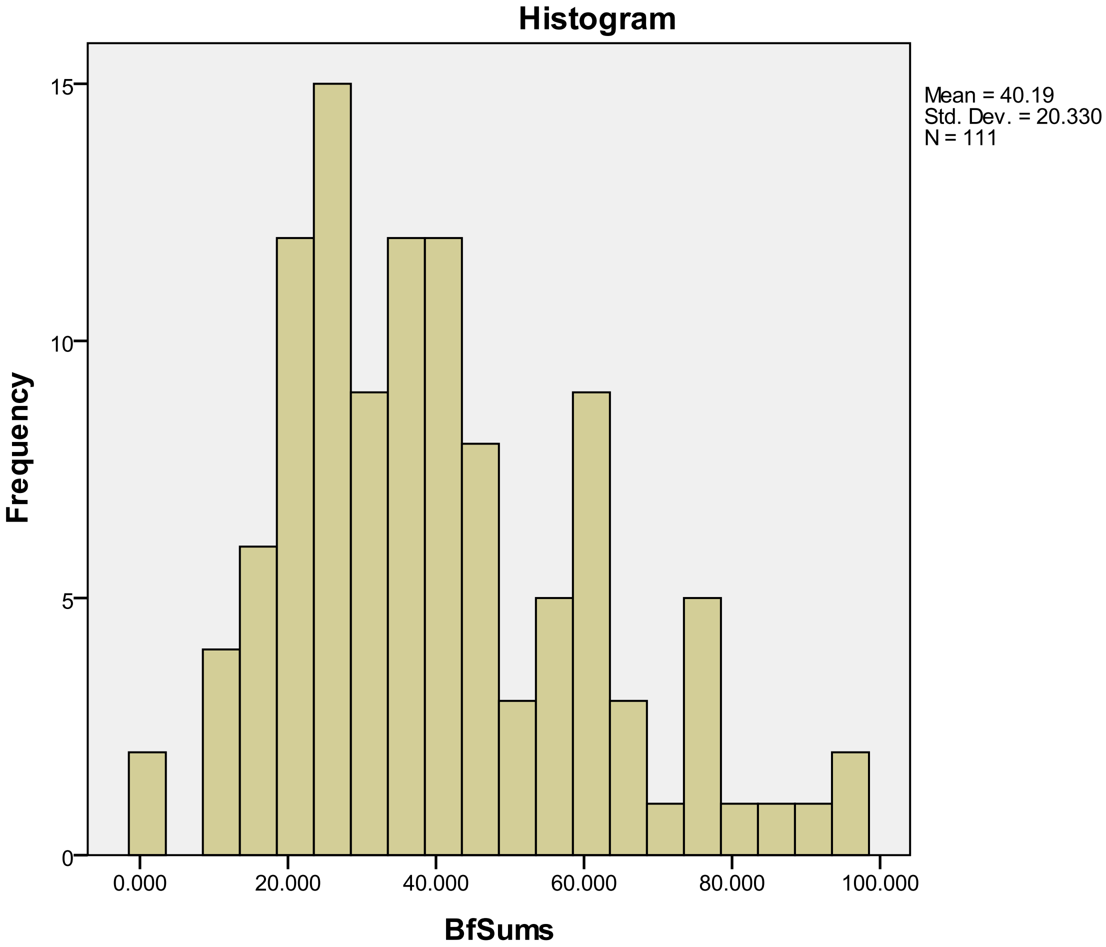
D-4 Behavior Frequency

a. Case Processing Summary- Behavior Frequency

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
BfSums	111	100.0%	0	.0%	111	100.0%

b. Behavior Frequency Descriptives

			Statistic	Std. Error
BfSums	Mean		40.18919	1.929618
	95% Confidence Interval for Mean	Lower Bound	36.36514	
		Upper Bound	44.01324	
	5% Trimmed Mean		39.27878	
	Median		36.00000	
	Variance		413.300	
	Std. Deviation		20.329787	
	Minimum		1.000	
	Maximum		96.000	
	Range		95.000	
	Interquartile Range		29.000	
	Skewness		.700	.229
	Kurtosis		.107	.455



c. **Behavior Frequency Distribution of Scores**

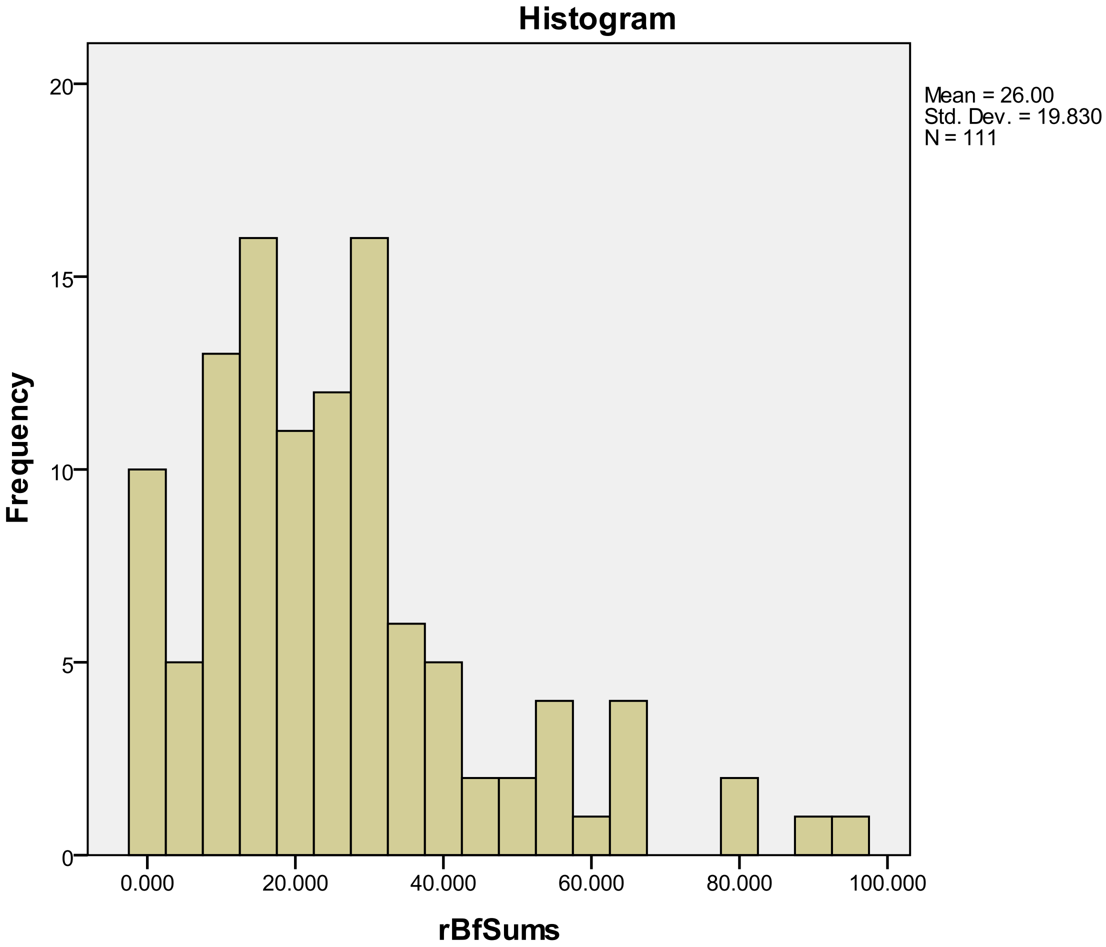
D-5 Caregiver reaction to Behavior Frequency

a. Case Processing Summary-Caregiver Reaction to Behavior Frequency

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
rBfSums	111	100.0%	0	.0%	111	100.0%

b. Caregiver reaction to Behavior Frequency Descriptives

			Statistic	Std. Error
rBfSums	Mean		26.00000	1.882155
	95% Confidence Interval for Mean	Lower Bound	22.27001	
		Upper Bound	29.72999	
	5% Trimmed Mean		24.38138	
	Median		23.00000	
	Variance		393.218	
	Std. Deviation		19.829730	
	Minimum		.000	
	Maximum		96.000	
	Range		96.000	
	Interquartile Range		21.000	
	Skewness		1.274	.229
	Kurtosis		1.842	.455



c. Reaction of Behavior Frequency Distribution of Scores

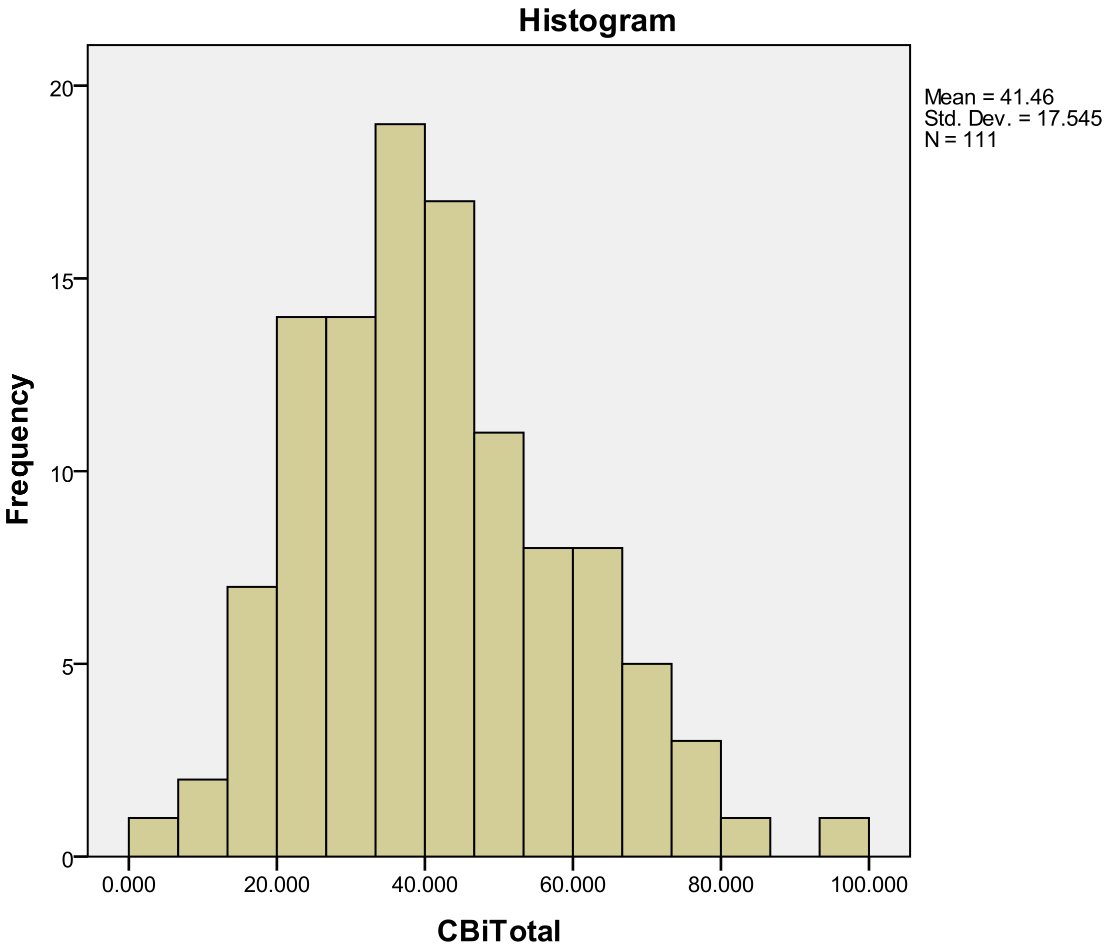
D-6 Caregiver Burden

a. Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
CBiTotal	111	100.0%	0	.0%	111	100.0%

b. Descriptives

			Statistic	Std. Error
CBiTotal	Mean		41.46171	1.665330
	95% Confidence Interval for Mean	Lower Bound	38.16142	
		Upper Bound	44.76200	
	5% Trimmed Mean		40.97910	
	Median		39.50000	
	Variance		307.839	
	Std. Deviation		17.545337	
	Minimum		.000	
	Maximum		96.000	
	Range		96.000	
	Interquartile Range		24.000	
	Skewness		.460	.229
	Kurtosis		.094	.455



c. Caregiver Burden Distribution of Scores

D-7 Missing Variables-Alzheimer's Knowledge

Univariate Statistics

	N	Mean	Std. Deviation	Missing		No. of Extremes[b]	
				Count	Percent	Low	High
Ak1	108	1.93	1.358	3	2.7	0	0
Ak2	110	3.42	1.763	1	.9	0	0
Ak3	107	2.10	1.046	4	3.6	0	0
Ak4	110	2.85	1.124	1	.9	0	10
Ak5	110	4.41	.998	1	.9	6	0
Ak6	111	4.03	.803	0	.0	.	.
Ak7	110	4.57	.943	1	.9	.	.
Ak8	110	2.31	.955	1	.9	.	.
Ak9	110	2.03	.735	1	.9	.	.
Ak10	111	2.73	.774	0	.0	.	.
Ak11	108	2.06	1.534	3	2.7	0	0
Ak12	108	2.88	1.419	3	2.7	0	0
Ak13	110	3.18	.593	1	.9	.	.
Ak14	108	2.07	1.125	3	2.7	0	0
Ak15	110	2.00	1.149	1	.9	0	0

a. . indicates that the inter-quartile range (IQR) is zero.

b. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-8 Missing Variables- Activities of Daily Living

Univariate Statistics

	N	Mean	Std. Deviation	Missing		No. of Extremes[a]	
				Count	Percent	Low	High
Adl1	111	.31	.629	0	.0	0	1
Adl2	111	.38	.487	0	.0	0	0
Adl3	111	.54	.501	0	.0	0	0
Adl4	105	.50	.606	6	5.4	0	1
Adl5	111	.45	.518	0	.0	0	0
Adl6	111	.78	.594	0	.0	0	2

a. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-9 Missing Variables-Instrumental Activities of Daily Living

Univariate Statistics

				Missing		No. of Extremes[b]	
	N	Mean	Std. Deviation	Count	Percent	Low	High
iAdl1	111	3.23	.924	0	.0	6	0
iAdl2	111	3.59	.610	0	.0	1	0
iAdl3	111	3.91	.438	0	.0	.	.
iAdl4	111	4.05	1.205	0	.0	0	0
iAdl5	111	2.86	.658	0	.0	.	.
iAdl6	111	3.71	.888	0	.0	5	0
iAdl7	111	2.87	.450	0	.0	.	.
iAdl8	111	2.86	.444	0	.0	.	.

a. . indicates that the inter-quartile range (IQR) is zero.

b. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-10 Missing Variables-Behavior Frequency

Univariate Statistics

				Missing		No. of Extremes[a]	
	N	Mean	Std. Deviation	Count	Percent	Low	High
Bf1	110	3.15	1.621	1	.9	0	2
Bf2	111	3.34	1.474	0	.0	13	2
Bf3	110	2.82	1.516	1	.9	0	1
Bf4	111	2.84	1.576	0	.0	0	1
Bf5	111	3.35	1.714	0	.0	15	4
Bf6	111	2.83	2.475	0	.0	0	10
Bf7	110	3.34	2.130	1	.9	0	8
Bf8	111	1.46	2.358	0	.0	0	7
Bf9	110	1.93	1.999	1	.9	0	4
Bf10	111	2.51	2.638	0	.0	0	0
Bf11	111	1.79	2.670	0	.0	0	10
Bf12	110	2.45	1.690	1	.9	0	2
Bf13	111	1.42	2.139	0	.0	0	5
Bf14	111	.82	1.927	0	.0	0	14
Bf15	111	.86	1.806	0	.0	0	14
Bf16	109	1.40	1.801	2	1.8	0	2
Bf17	108	2.10	1.594	3	2.7	0	1
Bf18	109	1.51	2.030	2	1.8	0	4
Bf19	109	1.46	1.903	2	1.8	0	3
Bf20	109	1.27	1.793	2	1.8	0	2
Bf21	110	1.25	1.892	1	.9	0	3
Bf22	110	1.44	1.942	1	.9	0	3
Bf23	110	1.12	2.044	1	.9	0	19
Bf24	110	1.92	1.714	1	.9	0	0

a. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-11 Missing Variables-Reaction to Behavior Frequency

Univariate Statistics

	N	Mean	Std. Deviation	Missing		No. of Extremes[b]	
				Count	Percent	Low	High
rB1	110	1.69	1.723	1	.9	0	3
rB2	110	1.42	1.404	1	.9	0	1
rB3	108	1.31	1.650	3	2.7	0	2
rB4	110	1.53	1.566	1	.9	0	1
rB5	109	1.17	1.636	2	1.8	0	2
rB6	110	1.16	2.061	1	.9	0	19
rB7	110	1.40	2.073	1	.9	0	5
rB8	108	1.60	2.714	3	2.7	0	10
rB9	109	1.48	1.975	2	1.8	0	4
rB10	109	2.27	2.798	2	1.8	0	0
rB11	110	1.74	2.856	1	.9	0	12
rB12	108	1.79	1.865	3	2.7	0	3
rB13	108	1.51	2.098	3	2.7	0	3
rB14	109	1.06	2.298	2	1.8	.	.
rB15	108	1.08	2.110	3	2.7	0	4
rB16	106	1.40	1.744	5	4.5	0	1
rB17	108	1.87	1.565	3	2.7	0	1
rB18	106	1.27	1.754	5	4.5	0	2
rB19	107	1.40	1.942	4	3.6	0	3
rB20	106	1.23	2.067	5	4.5	0	4
rB21	107	1.17	1.988	4	3.6	0	4
rB22	107	1.24	1.774	4	3.6	0	2
rB23	107	.94	1.852	4	3.6	0	15
rB24	107	1.74	1.819	4	3.6	0	1

a. . indicates that the inter-quartile range (IQR) is zero.

b. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-12 Missing Variables-Resilience

Univariate Statistics

	N	Mean	Std. Deviation	Missing		No. of Extremes[a]	
				Count	Percent	Low	High
RS1pc	108	5.81	1.269	3	2.7	3	0
RS2pc	108	6.34	.909	3	2.7	7	0
RS3pc	110	6.15	1.326	1	.9	10	0
RS4pc	110	6.12	1.232	1	.9	9	0
RS5pc	109	6.21	1.233	2	1.8	12	0
RS6pc	109	6.24	1.088	2	1.8	10	0
RS7pc	109	5.74	1.364	2	1.8	2	0
RS8pc	110	6.12	1.232	1	.9	10	0
RS9pc	110	5.83	1.233	1	.9	3	0
RS10pc	110	6.28	1.059	1	.9	7	0
RS11pc	110	5.05	2.013	1	.9	0	0
RS12pc	108	5.91	1.437	3	2.7	4	0
RS13pc	109	5.94	1.307	2	1.8	3	0
RS14pc	109	5.81	1.182	2	1.8	1	0
RS15pc	108	6.00	1.184	3	2.7	2	0
RS16a	110	6.01	1.267	1	.9	3	0
RS17a	109	5.80	1.311	2	1.8	2	0
RS18a	110	6.13	1.068	1	.9	9	0
RS19a	110	5.84	1.216	1	.9	1	0
RS20a	110	6.25	.971	1	.9	8	0
RS21a	110	6.35	1.145	1	.9	8	0
RS22a	110	5.59	1.558	1	.9	6	0
RS23a	110	5.88	1.115	1	.9	1	0
RS24a	110	5.15	1.675	1	.9	0	0
RS25a	110	5.65	1.548	1	.9	6	0

a. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

D-13 Missing Variables-Caregiver Burden

Univariate Statistics

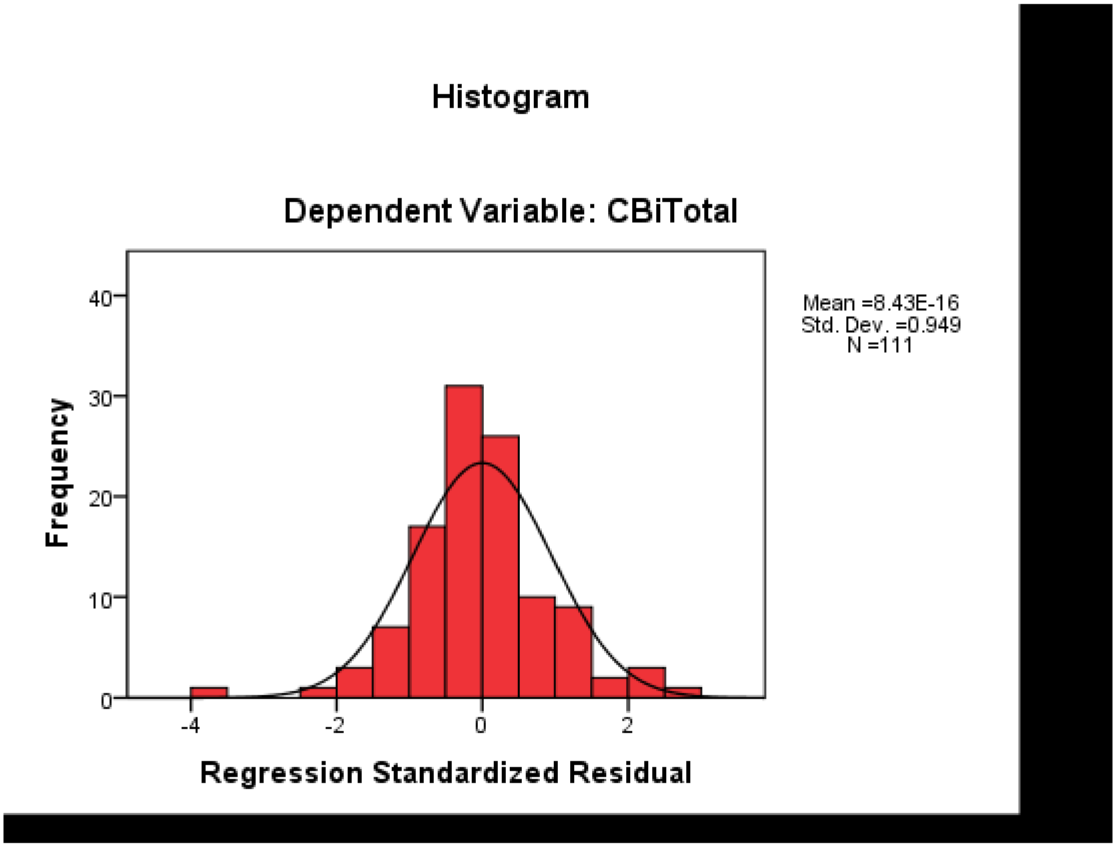
	N	Mean	Std. Deviation	Missing		No. of Extremes[b]	
				Count	Percent	Low	High
CBI1td	109	3.21	.982	2	1.8	6	0
CBI2td	110	3.45	.895	1	.9	4	0
CBI3td	109	2.77	1.214	2	1.8	0	0
CBI4td	110	2.97	1.113	1	.9	0	0
CBI5td	110	1.88	1.217	1	.9	0	0
CBI1db	109	1.67	1.291	2	1.8	0	0
CBI2db	110	1.74	1.209	1	.9	0	10
CBI3db	109	2.15	1.346	2	1.8	0	0
CBI4db	110	2.17	1.240	1	.9	0	0
CBI5db	109	2.42	1.396	2	1.8	0	0
CBI1pb	110	2.26	1.268	1	.9	0	0
CBI2pb	110	1.71	1.343	1	.9	0	0
CBI3pb	110	1.55	1.275	1	.9	0	0
CBI4pb	110	2.23	1.345	1	.9	0	0
CBI1sb	110	1.05	1.266	1	.9	0	0
CBI2sb	110	1.20	1.537	1	.9	0	1
CBI3sb	106	.67	1.357	5	4.5	0	8
CBI4sb	103	.66	1.081	8	7.2	0	8
CBI5sb	110	1.35	1.424	1	.9	0	0
CBI1eb	110	.94	1.086	1	.9	0	0
CBI2eb	110	.38	.790	1	.9	.	.
CBI3eb	110	.45	.934	1	.9	.	.
CBI4eb	108	.56	.988	3	2.7	0	6
CBI5eb	109	.82	1.156	2	1.8	0	0

a. . indicates that the inter-quartile range (IQR) is zero.

b. Number of cases outside the range (Q1 - 1.5*IQR, Q3 + 1.5*IQR).

APPENDIX E
Multiple Regression Assumption Graphs & Charts

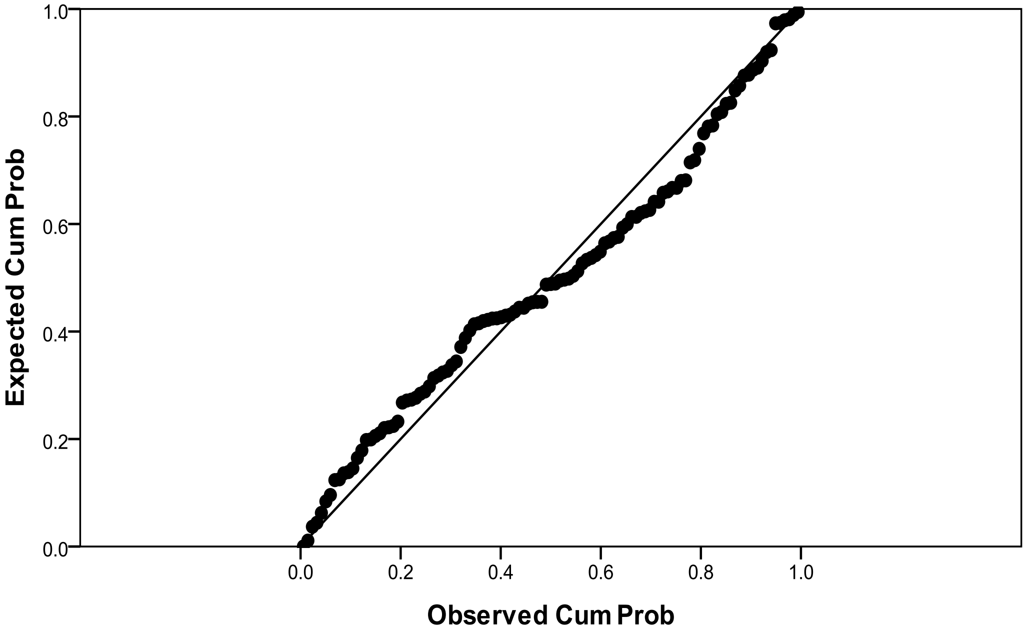
E-1 Histogram of Residuals



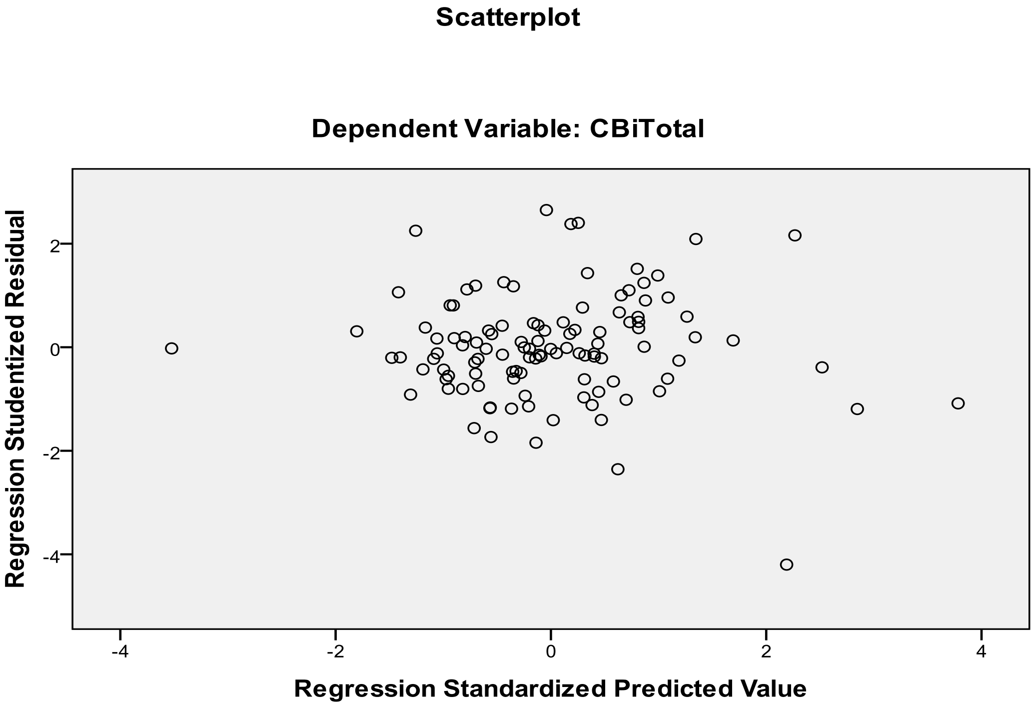
E-2 Graph of the Equality of Variance

Plot of standardized residuals versus z-predicted

Dependent Variable: CBiTotal



E-3 Equality of Variance



APPENDIX F
Multiple Regression Analysis Tables

F-1 Coefficients Table

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	44.678	6.408		6.972	.000
	r_AKSums	-1.448	.563	-.217	-2.570	.012
	ADlSums	.502	.826	.063	.608	.545
	iADlSums	-1.669	1.103	-.157	-1.513	.133
	BfSums	.076	.107	.090	.709	.480
	rBfSums	.299	.109	.346	2.735	.007
2	(Constant)	93.064	13.228		7.035	.000
	r_AKSums	-1.810	.532	-.272	-3.400	.001
	ADlSums	.937	.777	.117	1.205	.231
	iADlSums	-2.405	1.043	-.227	-2.305	.023
	BfSums	.090	.100	.106	.898	.371
	rBfSums	.233	.103	.270	2.263	.026
	RS_SumTotals	-.299	.073	-.335	-4.099	.000
3	(Constant)	88.722	15.065		5.889	.000
	r_AKSums	-1.798	.549	-.270	-3.275	.001
	ADlSums	.863	.781	.107	1.104	.272
	iADlSums	-2.704	1.042	-.255	-2.596	.011
	BfSums	.051	.111	.060	.458	.648
	rBfSums	.289	.110	.334	2.639	.010
	RS_SumTotals	-.267	.080	-.299	-3.326	.001
	rAkRes	-.392	2.141	-.016	-.183	.855
	AdlRes	.792	1.960	.037	.404	.687
	iAdlRes	3.362	2.074	.141	1.621	.108
	BfRes	1.199	2.983	.060	.402	.689
	rBfRes	-4.163	2.438	-.231	-1.707	.091

a. Dependent Variable: CBiTotal

F-2 Residual Statistics Table

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	-1.05915	86.15060	41.46171	10.636658	111
Std. Predicted Value	-3.998	4.201	.000	1.000	111
Standard Error of Predicted Value	1.441	13.060	2.891	1.641	111
Adjusted Predicted Value	-6.46609	97.18129	41.60795	11.512400	111
Residual	-56.253761	39.535858	.000000	13.953507	111
Std. Residual	-3.939	2.768	.000	.977	111
Stud. Residual	-4.221	2.861	-.005	1.010	111
Deleted Residual	-64.595039	42.238556	-.146238	14.972975	111
Stud. Deleted Residual	-4.610	2.966	-.006	1.034	111
Mahal. Distance	.129	90.991	4.955	10.791	111
Cook's Distance	.000	.440	.013	.047	111
Centered Leverage Value	.001	.827	.045	.098	111

a. Dependent Variable: CBiTotal

Vita

Cathy Scott, MSW received her Bachelors in Social Work from the University of Alabama in Birmingham, Alabama and her Master's in Social Work from Alabama A & M University, Huntsville, Alabama. Cathy has been a social work practitioner in a number of social work venues including the developmentally delayed, at-risk youth and infant and toddlers with special needs; however, her passion is working with senior adults. Cathy has ten years of social work experience with individuals living with Alzheimer's disease and their caregivers.