

Exploring the Effect of Caregiver Burden among Alzheimer's Caregivers:  
A Test of The Stress Process Model

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ABSTRACT

The diagnosis of Alzheimer's disease (AD) is stressful for both patients and their family caregivers (FCG). As the disease progresses, the patient's memory, functioning status, and behavioral problems get worse, and the needs of the patient that must be addressed by family caregivers increase dramatically. This research examines the impact of the subjective burden with the objective stressors on FCG's depression and to determines which psychosocial resources can be used to either mediate or moderate this relationship.

I examine the baseline data that was collected from 670 family caregivers of Alzheimer's patients in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II clinical trial (REACH II), 2001–2004. The measurements used in the current study are caregivers' background and context factors, objective stressors, subjective burden, psychosocial resources, and symptoms of depression.

Three research questions will be investigated in this study: (1) How do the caregivers' background and context factors affect FCGs experiences of objective stressors and subjective burden during the caregiving process? (2) What is the relationship between the objective stressors and subjective burdens, and what impact, if any, do they have on FCGs' depressive symptoms? (3) How do psychosocial resources mediate and or moderate the relationship between the primary stressors and FCGs' depression experiences?

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GENERAL AUDIENCE ABSTRACT

The diagnosis of Alzheimer's disease (AD) is stressful for both patients and their family caregivers (FCG). In 2018, an estimated 5.7 million Americans have been diagnosed with Alzheimer's disease (Alzheimer's Association 2018). As the disease progresses, the patient's memory, functioning status, and behavioral problems get worse, and the needs of the patient that must be addressed by family caregivers increase dramatically. As Aneshensel, Carol S., Leonard I. Pearlin, Joseph T. Mullan, Steven H. Zarit, and Carol J. Whitlatch (1995) noted in their book *Profiles in Caregiving: The Unexpected Career*, the role of caregiving is generally an 'unexpected job' for FCGs (Aneshensel et al. 1995).

Based on Pearlin's stress process model (SPM), the primary goal of my thesis is to compare the impact of the subjective burden of caregiving with that of objective stressors on FCG's depression, and to determine whether psychosocial resources can either mediate or moderate this relationship. Objective stressors refer to the AD patient's memory and behavior problems, his or her cognitive impairment, self-care activities, and functional status. Subjective burden is the FCG's emotional response to objective stressors. Objective stressors and subjective burden are associated with each other, and they are primary stressors in the SPM. Psychosocial resources include FCG's religious coping, their positive experiences of caregiving, their social networks and whether they were satisfied with social support that they received from others.

The present study is important for two reasons. First, rather than focusing on subjective burden alone, the model examined how objective stressors (i.e. burden) influence mental health through their impact on subjective burden. Second, previous influential studies of the stressors

of caregiving either did not include the moderating effects of psychosocial resources (Pearlin et al., 1999), or included a limited number of resources and found that they did not play a significant role in how caregiving stress influences caregivers mental health (Aneshensel et al. 1995). In my thesis, I will explore both of the mediating and moderating effects of four types of psychosocial resources.

I examine the baseline data that was collected from 670 family caregivers of Alzheimer's patients from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) II clinical trial (REACH II), 2001–2004 (Schulz, Burgio, and Stevens 2006). The study participants target on FCGs who are vulnerable to the caregiving stressors. The purpose of the baseline data was to describe the AD patients' cognitive impairment and behavior problems at the initial stage of the REACH II study, the demands caused by the impairments imposed upon FCGs, the psychosocial resources adopted by FCGs to relieve the caregiving stress, and the consequences of the primary stressors on FCGs' daily lives. I will explore three research questions in the current study: (1) How do the caregivers' background and context factors affect FCGs experiences of objective stressors and subjective burden during the caregiving process? (2) What is the relationship between the objective stressors and subjective burdens, and what impact, if any, do they have on FCGs' depressive symptoms? (3) How do psychosocial resources mediate or moderate the relationship between the primary stressors and FCGs' depression experiences? The measurements used in the current study are caregivers' background and context factors, objective stressors, subjective burden, psychosocial resources, and symptoms of depression. Data analysis is primarily based on multiple linear regression. I will also use the post-hoc probing methods to specifically test the significance of the moderating test.

There are four key findings in the present study. First, caregivers' background and

context factors have some significant associations with objective stressors and subjective burden, but overall, their impact is minimal. Second, subjective burden has a stronger impact on depressive symptoms than all of the objective stressors do. Third, subjective burden undermines all four psychosocial resources tested in the current study. Fourth, the mediating and moderating effects of psychosocial resources have a negligible impact in the caregiving stress process.

Surprisingly, the effect of subjective burden on depressive symptoms among FCGs remained largely unchanged after all psychosocial resources were included in the model as mediators and moderators. In the mediational test, the effects of subjective burden on depression decreased by only 14 percent after all psychosocial resources were taken into account. Likewise, each of these psychosocial resources had only a negligible effect on moderating the impacts of stressors.

The study suggests that unless there is a full understanding of the effects of these stressors on caregivers' well-being, any interventions or preventive actions will be of limited utility. Future research should pay more attention to exploring the relationships between the subjective burden and objective stressors, and examining their different impacts on FCGs' depression experience. Additionally, the fact that none of the psychosocial resources have a buffering effect in the caregiving process suggests that there is little in the lives of caregivers that mitigates the deleterious effects of caregiving stress on Alzheimer's caregivers. Policy makers and mental health providers should consider the stress of caregiving, as reflected in both its objective and subjective aspects, as a major risk factor in the lives of those who care for family members with Alzheimer's disease. Those factors may play a causal role in caregivers' mental disorders and suicidal ideation.

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## CHAPTER 1: INTRODUCTION

### Problem Statement

Alzheimer's disease (AD) is an irreversible pathology that fundamentally affects patients' memory, self-care activities, and functioning status. The various manifestations of AD can generate needs and dependencies among patients that must be addressed by their family caregivers (FCGs). All of the actual demands that arise during the caregiving process are defined as objective stressors (Aneshensel et al. 1995, Pearlin et al. 1990). The direct assistance requests and the continuing attention required by AD patients negatively affect FCGs' mental health and increase their experience subjective burden. Subjective burden refers to FCGs' emotional response, which is triggered by these objective stressors.

The first goal of my thesis is to improve the understanding of the distinct effects between objective stressors and subjective burden during the caregiving process. It is a complex task for FCGs to provide care to a loved one who has been diagnosed with Alzheimer's disease. The demands imposed by Alzheimer's disease not only require FCGs to provide unlimited care, but also elicit their emotional responses. Subjective burden is one of the primary emotional responses generated during the caregiving process. With the current therapeutic intervention, researchers simply considered subjective burden as one type of manifested stressor and rarely distinguished its comparative impacts from objective stressors (Carretero et al. 2009, Ying et al. 2017). This measurement is problematic because it increases the difficulties of distinguishing which type of stressors are more problematic and which should be the focus of intervention.

The second goal of my thesis is to distinguish the effect of subjective burden and depression. It is essential to consider subjective burden as a primary predictor of depression rather than treat these two factors as a comorbid condition. Because of the confused

symptomatology between subjective burden and depression, most studies simply measure them as an interchangeable term to reflect FCGs' negative emotions (Berger et al. 2005, Clyburn et al. 2000, Nam and Park 2017). For example, some studies consider the notions of burden and depression as one type of psychological stress and evaluate these two factors together as one type of dependent outcome experienced by FCGs (Berger et al. 2005, Clyburn et al. 2000, Nam and Park 2017). One potential problem of this measurement is that it overlooks the potential causation between subjective burden and depression (O'Rourke 2004). Pinqart and Sörensen (2003) noted that subjective burden is an outcome that is explicitly caused by objective stressors. However, depression is a universal stress that is impacted by many other variables.

The third goal of my thesis is to test the mediational and moderating effects of four types of psychosocial resources: FCGs' religious coping, perceived positive aspects of caregiving, their social network, and satisfaction with social supports. None of these resources are expected to prevent, cure, or even slow the progress of Alzheimer's disease, but researchers are interested in their possible buffering effects during the caregiving process (Mittelman et al. 2004). A large number of intervention articles have been published over the past decades because of FCGs' overwhelming stressor experiences. However, these studies reported inconsistent results, sometimes with the different conclusions (Henry, Alisa, and Annette 2003, Koivisto et al. 2016, Pinqart and Sorensen 2006, Pusey and Richards 2001, Sörensen, Pinqart, and Duberstein 2002). In a meta-analysis of caregivers' coping and intervention, researchers found that psychosocial resources such as acceptance, problem-focused coping strategies, and social-emotional support are specifically beneficial for FCGs' mental health in decreasing depressive symptomatology (Gilhooly et al. 2016). However, the opposite was reported in a meta-analysis by Schoenmakers, Buntinx, and DeLepeleire (2010), who examined multiple types of

professional interventions targeted at FCGs of AD patients. These researchers found that none of the psychosocial resources had a significant impact on decreasing FCGs' subjective burden and depression.

The possible reasons for these opposing results are the theory behind caregiving research, the heterogeneous target populations investigated in different studies (Bourgeois, Schulz, and Burgio 1996), and the characteristics of different types of interventions (Sörensen, Pinquart, and Duberstein 2002). Apparently, the 'one size fits all' approach cannot be used to conduct this caregiving research (Knight, Lutzky, and Macofsky-Urban 1993). All of these inconsistencies inspired me to test the psychosocial resources more comprehensively.

#### Research Questions and Hypotheses

To design the model for the current study, I used *Profiles in Caregiving: The Unexpected Career* (Aneshensel et al. 1995) as the conceptual background for integrating Pearlin's Stress Process model (SPM). Based on this conceptual framework, the variables used in this research include caregivers' background and context factors, objective stressors, subjective burden, psychosocial resources, and depression. The detailed interpretation of each variable will be combined with its specific measurements in the following (methods) chapter. This thesis will compare subjective burden with the impact of all other objective stressors on FCGs' depression and evaluate whether there are any psychosocial resources mediate or moderate this relationship.

The following research questions, with their related hypotheses, will guide the statistical analyses in the following chapters:

RQ1: How do the caregivers' background and context factors impact FCGs' different experiences of objective stressors and subjective burden during the caregiving process?

H1: The caregivers' background and context factors, such as FCGs' age, gender, race and

ethnicity, education, income, employment status, and their relationship with care recipients, are directly related to FCGs' experiences of primary stressors.

RQ2: What is the relationship between objective stressors and subjective burdens, and what impact, if any, do they have on FCGs' depression experiences?

H2(1): FCGs who are experiencing more objective stressors are also more likely to report a higher level of subjective burden.

H2(2): Even though both objective stressors and subjective burden can affect FCGs' depression experiences, subjective burden, as the most problematic stressor, has the greatest impact on their experience with depression.

RQ3: How do psychosocial resources affect the relationship between the primary stressors and FCGs' experiences of depression?

H3(1): Psychosocial resources mediate the relationship between primary stressors and outcome of depression.

H3(2): The levels of the psychosocial resources experienced by FCGs will change the strength of relationship between primary stressors and depression.

#### Theoretical/Conceptual Framework

In 2018, an estimated 5.5 million people aged 65 or older are living with Alzheimer's disease (AD) (Alzheimer's Association 2018). This number will continue to rise as the baby boomer generation continues to age. When the setting of primary care changes from hospital to the home, family members take full responsibility for caregiving. Under the traditional expectation of FCGs, these people are the primary caregivers of loved ones afflicted with the disease.

Pearlin et al. (1990) first constructed the Stress Process Model (SPM) to identify

interactions among each domain of caregiving and proposed to evaluate the intensity of different stressors. The SPM consists of caregivers' background and context factors, primary stressors, secondary stressors, psychosocial resources, and outcomes. The framework in the current study is based on Pearlin's SPM to compare the impacts of different primary stressors on FCGs' depression and to explore possible psychosocial resources that either mediate or moderate this relationship. Both objective stressors and subjective burden are defined as primary stressors in the original SPM.

Considering the specific situations of persons with AD and their FCGs, stressors experienced by FCGs are closely related to caregiving's background and context factors such as age, race, gender, education, occupation, income, culture, characteristics of the person with AD, and their relationships (Pearlin et al. 1990). These factors are important because they reflect the disadvantages that exist in society. Inequalities stemming primarily from people's race, age, and gender could vary their family household income, education, and employment status. All of these factors combined in a unique way to affect FCGs' opportunities and resources during the caregiving process and ultimately led them to have a different experience of caregiving.

Pearlin (Aneshensel et al. 1995, Pearlin et al. 1990) proposed that stress proliferation includes both primary stressors and secondary stressors. Primary stressors refer to the direct needs that stem from a broad spectrum of care-related tasks. Typically, primary stressors can be separated into two categories, objective stressors and subjective stressors. Objective stressors include AD patients' cognitive impairments, behavioral problems and decreased function abilities (Aneshensel et al. 1995, Pearlin et al. 1990). When the cognitive status of a person with AD deteriorates over time, her functional impairments decrease simultaneously. For example, an individual with AD may require assistance in conducting basic activities of daily living, such as

dressing, bathing, eating and using the toilet. Even at the beginning stage of the disease, some patients may require assistance organizing a more complex activity, such as driving and managing finances. Studies suggested that people with cognitive impairment are also more likely to display problematic behaviors and are more likely to lose control of emotions and motivations (Harwood, Sultzer, and Wheatley 2000b). Compared with all other objective stressors, the problematic behavior of AD patients could significantly increase FCGs' subjective burden experienced. Researchers indicate that the problematic behaviors of AD patients include arguing, aggressive speaking, hurting themselves or others, engaging in embarrassing and dangerous behavior and destroying property (Johnson, Wackerbarth, and Schmitt 2001). All of these problematic behaviors required FCGs to provide a continuous monitoring with an unlimited time of care (Chiao, Wu, and Hsiao 2015, Gaugler, Kane, and Kane 2002, Park et al. 2017, Pinquart and Sörensen 2003, Van der Lee et al. 2014).

Ultimately, all of these complications will escalate the workload of FCGs' daily assistance and evoke their subjective burden towards the objective stressors. Because the strains and hardships exist all the time during the caregiving process, the level of subjective burden experienced by FCGs rarely, if ever, decreases (Papastavrou et al. 2007). Once the symptoms of Alzheimer's disease become noticeable, both individuals with AD and their FCGs begin to worry about the severe level of the disease (Cheah et al. 2012). The considerable experience of stressors and the overwhelming demands of caregiving usually force FCGs to give up their earlier preference of home care, and ultimately to transfer their caregiving role to a formal institution (Aneshensel et al. 1995). However, looking for assistance from a formal institution cannot help FCGs relieve the subjective burden significantly. Instead, FCGs continued to be

involved emotionally and remained engaged in the lives of their institutionalized relatives (Gaugler et al. 2010).

Secondary stressors represent role strains and intrapsychic strains that occur as a by-product of ongoing conditions encountered in caregiving (Aneshensel et al. 1995, Pearlin et al. 1990). The role strains of caregiving include disagreements with other family members on the distribution of care-related responsibilities. It also happens when FCGs face conflicts between care-related tasks and their current employment. FCGs of persons with dementia may specifically limit their time and energy for social engagements as compared with other caregivers. Some have to step away from their previous social networks in order to fulfill the caregiving role. Intrapsychic strain refers to the damage to FCGs' self-concepts that results from the enduring hardships of caregiving. Compared to secondary stressors, primary stressors are defined as hardships that directly stem from a broad spectrum of care-related tasks. Because the scope of my thesis is to specifically investigate the impacts of primary stressors on depression, the secondary stressors mentioned here will not be tested in the current research.

Theoretically, the original SPM model defined how coping and social support mediate the relationship between stressors and negative outcomes (Pearlin et al. 1990). Pearlin et al. (1990) considered psychosocial resources be the essential mediators mollified the stress experience among FCGs. That is, FCGs who received a higher level of psychosocial resources were expected to report a lower level of stress.

The outcomes of SPM include changes in both mental and physical health among FCGs as well as whether they choose to transfer their loved ones from home to a healthcare institution. Those outcomes are associated with caregivers' background and context factors, primary stressors, secondary stressors, and psychosocial resources.

## CHAPTER 2: LITERATURE REVIEW

This chapter will first introduce the Alzheimer's disease and the facts of AD patients' family caregivers. I will also highlight the variables in the current study and outline their conceptual components based on Pearlin's SPM.

### Alzheimer's Disease and Family Caregivers

The latest definition, published in 2018 by the Alzheimer's Association, explained that AD is "a continuum beginning with the initial brain changes that start years before the symptoms appear, continuing with years of symptoms that affect cognitive and physical function, and ending with severe Alzheimer's "(Alzheimer's Association 2018). A 2011 guideline also noted that Alzheimer's disease (AD) encompasses a continuum of difficulties that exist throughout each stage of the disease (Alzheimer's Association 2011). In general, initial changes in the brain have started before symptoms appear. As time passes, AD patients experience the significant impairments in both their cognitive and functional abilities. Ultimately, AD will cause an afflicted loved one to lose all sense of control in managing the activities of daily living, as well as their ability to walk and communicate.

In 2018, an estimated 5.5 million people who are aged 65 or older are living with Alzheimer's disease (Alzheimer's Association 2018), a number that is increasing as the baby boomer generation continues to age. Between 2010 and 2050, the number of AD patients will triple (Hebert et al. 2013). Most people with AD are aged 65 or older. Of these, three percent are aged 65 to 74, and 17 percent are aged 75 to 84. People aged 85 or older compose 37 percent of the population of people with Alzheimer's disease (Alzheimer's Association 2018).

As a result of this growing population living with AD, more and more family members are taking the role of primary caregiver and are providing a wide range of assistance to their

loved ones. Based on the latest Alzheimer's Association (2018) report, more than 16 million family members are providing an estimated 18.4 billion hours of unpaid care to their loved ones with AD. On average, these FCGs provide direct supervision or assistance totaling up to 171 hours per month, 6 hours a day. Among those FCGs, 42 percent provide daily care for up to 9 hours (Solway 2017). In addition, nearly 50 percent remained engaged in caregiving assistance to their loved ones for more than six years when AD patients living in a residential care facility (Kasper and Freedman 2015).

#### Pearlin's Stress Process Model

Pearlin's SPM was originally composed of four components: the background and contexts of the stress process, primary and secondary stressors, psychosocial resources and outcomes (Pearlin et al. 1990). This model was designed as a brief sketch to describe the comprehensive process of caregiving. Figure 1 presents the modified stress proliferation model that I adapted from the SPM and designed for the current study. The variables used in my research include caregivers' background and context factors, objective stressors, subjective burden, psychosocial resources and a depression outcome. My thesis is to compare the impact of subjective burden of caregiving with that of objective stressors on FCGs' depression and to determine whether psychosocial resources mediate or moderate this relationship.

*Caregivers' background and context factors.* As Pearlin (1990) explained, most researchers are interested in exploring questions about caregiving, which are strongly related to caregivers' background and context factors. From this background, I examine three main caregiving components: (1) demographic factors (e.g., age, gender, race); (2) socioeconomic status (e.g., education, occupation status, and yearly household income); and (3) caregiving relationship (e.g., the relationship with AD patients).

Gender differences are ‘unearned,’ ‘invisible,’ and ‘embedded in the social institution,’ which leads FCGs to have a varied caregiving experience (Calasanti and Kiecolt 2012). For example, the value of femininity embedded within the traditional family shaped women as the primary caregivers in households. However, it is not necessarily the case that women preemptively plan to take on the full responsibility for caregiving or are well-prepared themselves to serve as a primary FCG. The scholarly literature has consistently shown that female FCGs are more likely to experience high levels of psychiatric morbidity and poor physical health are affected more by their spouse’s identity change than male caregivers (Hayes, Boylstein, and Zimmerman 2009, Pinquart 2006, Swinkels et al. 2017, Yee and Schulz 2000). As Calasanti and King (2007) mentioned, even though female FCGs continuously report a higher level of burden and depression experience in the majority of published studies, concerns regarding the masculinity of male FCGs limits their ability to express negative emotions. In the same situation of caregiving, gender roles place male and female FCGs at risk for a different experience of caregiving, which in turn affects their emotional reactions.

In addition to gender, race and ethnicity among FCGs also affect the experience of caregiving. FCGs from minority groups have at their disposal different types of psychosocial resources during the caregiving process than their Caucasian counterparts. For example, African American FCGs are more likely to include God as a primary part of their informal support to mitigate the negative impacts of stressors. Roth et al. (2015) found that, different from their Caucasian counterparts, African American FCGs reported a higher level of positive attitudes towards caregiving and reported more benefits received from the caregiving process. However, Pinquart (2005) noted that minority FCGs commonly reported worse physical health and lower levels of life satisfaction than whites. For example, studies highlighted that Hispanic FCGs tend

to provide more help on care recipients' ADLs since they experienced more demanding of caregiving compared to white FCGs (Meyer et al. 2018). For people in the minority groups who might already experience some levels of health and health care disparities, the disadvantages accumulated over time could worsen their experience of caregiving.

The present study examined three commonly used quantitative indicators to examine FCGs' social economic status (SES): income, education, and employment status. Each of these factors is related to an FCG's personal, social, and economic resources. FCGs with higher SES are more likely to receive resources and opportunities from the professional healthcare institution or other formal care facilities. Alternately, FCGs with lower SES are more likely to receive support from other family members or friends. Paid employment could relieve a FCG's economic burden during the caregiving process. However, studies indicate that the conflicts between FCGs' work and their caregiving role increase their overall workload, which in turn increases their level of burden (Noyes et al. 2010, Pinquart and Sorensen 2011). To date, studies that have examined the specific relationship between FCGs' educational background and their stress experience are unclear. For example, several studies show that FCGs who are poorly educated are more likely to report a higher level of burden in their caregiving process (Kim et al. 2009, Sinforiani 2010). Kim et al. (2009) noted that a higher level of education could help FCGs adopt better skills for coping with stressors. However, a different perspective, illustrated by Hughes et al. (2014), suggested that highly educated FCGs could perceive the subjective burden differently, and lead him/her to be more likely to be affected by subjective burden. Most of the research related to FCGs' educational background combines with interventions. For instance, researchers have shown that FCGs with a lower educational background feel more ill-prepared to carry out their caregiving role and are less likely to benefit from formal interventions than their

more educated counterparts (Adelman et al. 2014, Conde-Sala et al. 2010, Kaufman et al. 2010).

The relationships between FCGs and AD patients are also taken into account. One national report shows that 25 percent of FCGs are members of the ‘sandwich generation,’ who need to provide care for both a parent with AD and children under age 18 (Alzheimer’s Association 2018). Conde-Sala et al. (2010) demonstrated that the feeling of guilt was the greatest risk factor in causing adult children to report a higher level of burden, especially when living separately from the parent with AD. In a meta-analysis, Pinquart and Sorensen (2011) evaluated 168 empirical studies and found a significant difference between spouses and adult children during the caregiving process. The authors found that spouse FCGs are expected to confront more stressors than adult children due to their attachment to care recipients, longer hours of providing care, and their own health issues.

In sum, it is essential to indicate that none of these caregivers’ background and context factors exists independently. They all interact with one another and affect the caregiving experience among each FCGs.

*Stress proliferation of the primary stressor.* The primary stressors are defined as hardships that directly stem from a broad spectrum of care-related tasks. In my thesis, primary stressors are separated into objective stressors and subjective burden. Objective stressors are based upon care recipients’ cognitive impairments, behavioral problems, and functional capabilities, as well as FCGs’ care-related tasks or direct supervision (Pearlin et al. 1990, Schulz and Martire 2004). Subjective burden is an FCG’s emotional reaction to the hardships encountered during the caregiving process (Pearlin et al. 1990). Typically, primary stressors not only include FCGs’ concrete assistances, but also their emotional responses (Aneshensel et al. 1995). In order to better measure the cost of caregiving, it is necessary to conduct research

specifically focused on the primary stressors and to test effects between objective stressors and subjective burden separately.

Different from other diseases, AD is an irreversible pathological process that affects a person's memory, language, problem-solving, self-care activities, and functioning abilities (Alzheimer's Association 2018). These impairments indicate a progressive decline in the cognitive abilities and eventually makes AD patients lose all sense of control of their lives. Although people with AD have different symptoms at each stage of the disease, the core syndromes are memory and intellectual impairments (Beydoun et al. 2014). Early clinical symptoms of Alzheimer's disease include difficulties in remembering recent events and experiencing more frequent confusion. This loss of memory is not the same as someone who occasionally forgets something but refers to people who do not remember things that they usually know (Kaup et al. 2015). AD not only causes a deficit in cognition but also underlies patients' higher rate of depressive syndromes (Harwood, Sultzer, and Wheatley 2000, Verhulsdonk et al. 2013). People with AD also are more likely to act in an agitated manner (Harwood, Sultzer, and Wheatley 2000). Ultimately, these complications increase the levels of FCGs' supervision and help with people care.

The internal feelings, attitudes and emotional reactions to the hardships experienced during the caregiving process are subjective stressors (Aneshensel et al. 1995, Montgomery, Gonyea, and Hooyman 1985, Pearlin et al. 1990). Subjective burden is used to measure the subjective stressor in this study. When the caregiving process becomes overwhelming, FCGs can express this burden through feelings of being stressed, angry, the experience of role strain, and diminished health. Subjective burden does not exist automatically by itself, but rather generate as one type of emotional reaction to objective stressors (Pearlin et al. 1990).

Based on the 2015 NAC/AARP's statistics, 46 percent of AD caregivers report a higher level of burden experience as compared to 38 percent of caregivers for patients without ADs (Alzheimer's Association 2018). This higher level of burden among FCGs is caused by the unmet needs embedded in their caring-related tasks (Park et al. 2015, Park et al. 2017, Van der Lee et al. 2014). Again, this result is anchored by previous studies that demonstrate that the experience of burden and depression among FCGs of loved ones with AD is much higher than that of other caregivers (Pinquart and Sörensen 2003, Pinquart 2004).

Even though the cognitive impairment of individuals with AD is the most apparent symptom of disease progression, its impact on FCGs' subjective burden is inconsistent. Pinquart and Sorensen (2003) noted in their meta-analysis that FCGs' burden and depression relates to multiple stressors and that there is a very weak positive correlation between the AD patients' cognitive impairments and FCGs' subjective burden experience. Van der Lee et al. (2014) conducted a systematic review of 17 studies using a multivariate model of the subjective burden in dementia and found that none of these studies present a significant relationship between the severity of AD patients' cognitive function and FCGs' mental health. Even though the results of these studies did not confirm that cognitive impairment among people with AD causes FCGs' burden and depression experience, the distinctive feature of the deterioration as the disease progresses increases the likelihood of other "contagious" effects (Van der Lee et al. 2014).

Because of the needs for continuous monitoring by FCGs, problematic behaviors of AD patients increase the burden experience more than other objective stressors (Chiao, Wu, and Hsiao 2015, Gaugler, Kane, and Kane 2002, Park et al. 2017, Pinquart and Sörensen 2003, Van der Lee et al. 2014). Ornstein and Gaugler (2012) examined the studies from 1990 to 2010 concerning the impacts of AD patients' problematic behavior and found that the problematic

behavior of AD patients has the greatest impact on an FCG's burden experience. Once the problematic behavior escalates, FCGs must be increasingly vigilant to keep the safe of care recipients. In this situation, FCGs must provide unlimited care, which in turn causes them to experience higher levels of stress.

FCGs' subjective burden is also highly dependent on AD patients' abilities to perform ADLs and IADLs. For example, many people need help from FCGs to complete ADLs. Even at the beginning stage of the disease, some people may need help organizing a complex activity, such as driving or managing bills. With the decline in patients' functional status, the need for FCGs to assist with ADLs and IADLs increases dramatically. Some studies have shown that the relationship between the ADL/IADL and FCGs' burden experience ranged from a moderate to strong level (Conde-Sala et al. 2010, Kim et al. 2012). In a cross-sectional sample of 866 AD patients and their FCGs that examined different indicators' impacts on FCGs' burden experience (Bergvall et al. 2011), the researchers found that both ADLs and IADLs are significantly associated with FCGs' burden experience. However, in another study of 1,133 AD patients and 1,133 FCGs, ADLs had no significant impact on FCGs' burden, while IADLs were the third highest risk factor for burden (Park et al. 2015).

In sum, objective stressors present a substantial impact on the subjective burden. Together, these two primary stressors ultimately influence FCGs' experience of depression.

*The depression outcome.* Although research on caregiving fluctuates widely, there is one consistent result: compared with non-caregiving individuals, FCGs of Alzheimer's patients always experience a higher level of stress and depression (Carek, Norman, and Barton 2010, Del-Pino-Casado et al. 2011, Joling et al. 2018, O'Dwyer et al. 2013, O'Dwyer et al. 2016). Based on the definition from the National Institute of Mental Health (NIMH 2018), depression is

a common and severe medical illness characterized by feelings of sadness, sleeplessness, hopelessness, guilt, and loss of interest or motivation. Depression is also the most critical risk factor contributing to an FCGs' mental health. Studies demonstrated that more than 30 percent of FCGs report a higher level of depressive symptoms during the caregiving process (Covinsky et al. 2003, Sallim et al. 2015).

Over the decades, FCGs' burden and depression were the most commonly used outcomes measures in caregiving research. However, the confusion of symptomatology between subjective burden and depression made it difficult for researchers to identify the relationship between these two, and they often simply measured them as a comorbidity outcome (O'Rourke 2004). For example, certain researchers review the notions of burden and depression together as one type of a psychological reaction related to the needs of people with AD and the caregiving process (Berger et al. 2005, Clyburn et al. 2000, Nam and Park 2017). Within this research, both subjective burden and depression have been treated as dependent outcomes and vary by the characteristics of the person with AD, the FCGs themselves, and the care-related tasks required. However, some researchers highlight that subjective burden as a significant predictor could potentially contribute to increasing FCGs' depressive symptoms during the caregiving process (Gallagher-Thompson and Powers 1997, Magaña et al. 2007, O'Rourke 2004, O'Rourke and Tuokko 2000, Phipps et al. 2005). In general, the results of these studies indicate that FCGs' depression is strongly related to the experience of subjective burden. Subjective burden has a more profound impact on FCGs' depression than any other stressor (Gallagher-Thompson and Powers 1997).

*Psychosocial Resources.* It is crucial for FCGs to adopt at least one type of resource to relieve their stress during the caregiving process. In the current study, I tested both mediational

and moderating effects of four types of psychosocial resources in the relationship between primary stressors and depression. These four psychosocial resources are religious coping, the positive aspects of caregiving, FCGs' social networks, and their satisfaction with social support.

The majority of caregiving research focuses on reports of negative aspects of the caregiving process. However, researchers indicate that positive aspects of caregiving accompany the negative side and can buffer negative effects of multiple stressors (de Labra et al. 2015). Lawton et al. (1991) defined the satisfaction of caregiving as when caregivers subjectively perceived gains from desirable aspects of caregiving. These 'rewards' refer to FCGs searching for positive meaning in caregiving and trying to identify it. Different from denying feelings of being overwhelmed, FCGs change their emotional reaction to multiple hardships during the caregiving process. These positive aspects include feelings of usefulness and being needed, appreciated, important, strong, and confident. All of these positive factors buffer FCGs' outlook on life and strengthen their relationships with care recipients (Ma et al. 2017). Researchers also have found that positive aspects of caregiving significantly decrease an FCGs' burden, depression, and anxiety (Abdollahpour, Nedjat, and Salimi 2018, Xue et al. 2018). More specifically, the positive aspects play a moderating effect between FCGs' burden and depression (Walker, Powers, and Bisconti 2016).

Another form of coping, religious coping, includes organizational religiosity (e.g., church attendance and religious involvement), non-organization religiosity (e.g., reading the Bible and praying), and subjective religiosity (e.g., internal reactions) (Nagpal et al. 2015). The present study focuses on FCGs' subjective religiosity is to explore their individual-focused coping strategies during the caregiving process. Most studies show that religious coping can positively affect FCGs' inherent resilience and limit the adverse impact of multiple stressors

(Jewell et al. 2016, Nagpal et al. 2015, Weisman de Mamani et al. 2014, Yoon et al. 2018). However, similar studies found the inconsistent results towards the effects of FCGs' religious coping strategies. For example, one study showed that neither religious coping nor religious practice could moderate the relationship between caregiving stress and depression (Rathier et al. 2015). Another study conducted by Merrit and McCallum (2013) illustrated that the religious coping could decrease FCGs' stress when the care recipients' behavior problems were taken into account. One possible explanation of this opposite result is the researcher focus on investigated whether FCGs choose to "work with God" or "work through God." As Rathier et al. (2015) mentioned, FCGs who selected to "work with God" were actively seeking to collaborate with God for problem-solving. While, working through God meant that the FCG was entirely depending on God and looking for a miracle through praying. Once the reality of the disease came up against with their expectations, FCGs working through God were more likely to experience a higher level of psychological distress. The questions of religious coping asked in the current study target FCGs who reported working with God on the problem-solving.

In the SPM, both Pearlin (1990) and Aneshensel et al. (1995) highlighted the effect of social support on decreasing FCGs' multiple stressors experiences. The first definition of social support dates back to 1976 and Sydney Cobb, who noted that social support is the information that leads a person to believe that he/she belongs to a social network, and people around them in this network are cared for, esteemed, encouraged, and valued each other. More recent research provides a broader definition of social support by including remote help through the internet and technological support (Kurz et al. 2016, Parker Oliver et al. 2017). Multiple studies demonstrate that social support could reduce FCGs' feelings of social isolation and reinforce their sense of self-esteem. Also, social support provides a way for FCGs to express their emotional reaction to

caregiving hardships and to the receipt of direct assistance from others (Dam et al. 2016, Ong et al. 2018). All of these resources can positively affect FCGs' adaption to caregiving and decrease their stress.

Research examining a social support refers to FCGs' feelings of belonging to the network and satisfaction with the protection they receive from that network. With this perspective, social support consists of two parts: FCGs' social networks and the satisfaction with social support (Dam et al. 2016). Despite a growing number of studies that explored the impacts of social support, questions about the relationship between these two are less understood. The diverse use of this terminology could potentially increase confusion concerning caregiving studies and misapplication in intervention strategies. To better understand the impact of social support, the current study highlights that social support is available, and that received aid by FCGs is satisfactory. In this study, I test the effect of social networks separated with satisfaction from social support, and evaluate the difference between these two constructs.

## CHAPTER 3: RESEARCH METHODS

This chapter introduces the participants and procedures in the REACH II dataset, and the specific measures, data description and data analysis I used for the current study.

### Participants and Procedure

My thesis investigates an archival dataset from the Resources for Enhancing Alzheimer's Caregiver Health (REACH II), 2001–2004. It is designed to evaluate multi-component intervention among family caregivers of Alzheimer's patients. The criteria for family caregivers in the REACH II study were people aged 21 or older, and who provided on average 4 hours of supervision or direct assistance per day for Alzheimer patients (Schulz, Burgio, and Stevens 2006). Only family caregivers completed six months in the caregiver role could participate. In addition, all of these FCGs had to report some mental or physical risk factors associated with hardships during caregiving. For example, researchers asked FCGs to evaluate within the past month, whether they ever felt stressed or overwhelmed, cried or felt they needed to cry, were angry or frustrated, had poorer health status than last year, or felt cut off from their family or friends. Only FCGs who reported at least two of risk factors were eligible for this study.

Study included baseline data and sixth months' follow-up data. During the six-month interim, FCGs were assigned to receive counseling from a trained counselor either in person or via telephone. This intervention was aimed at improving FCGs' problem-focused and emotion-focused coping strategies. The goals of the present study were accomplished by investigating the baseline data that examined FCGs' stress process before they received any kinds of intervention from a professional counselor. The investigators collected the baseline data through face-to-face interviews. There were 220 (34.21 percent) Caucasian, 221 (32.81 percent) African American, and 221 (32.81 percent) Hispanic FCGs. The REACH II data recruited FCGs evenly based on

race and ethnicity to create three distinct groups. Of the 670 family caregivers, 115 were male (17.16 percent), and 555 were female.

A quantitative research design was used to analyze the REACH II data in the current study. I used statistical methods to examine: (1) whether the caregivers' background and context factors affect FCGs experience of the primary stressors differently; (2) whether the effect of subjective burden over and above all other objective stressors has an impact on FCGs' depression; (3) and whether the four types of psychosocial resources could either mediate or moderate the relationship between the primary stressors and FCGs' depression experiences. Independent variables included caregivers' background and context factors and objective stressors. The caregivers' background and context factors included FCG's demographic information (e.g., age, gender, and race), socioeconomic status (e.g., education, income, and occupation status), and their relationship with AD patients. The objective stressors evaluated care recipients' cognitive impairment, problematic behaviors, and functioning status. All of these stressors, except for cognitive impairment, were evaluated and reported by FCGs.

## Measures

*Caregivers' background and context factors.* The majority of the caregivers' background and context factors were imputed in the SCREEN dataset in REACH II. To retrieve the most comprehensive information about FCGs, I merged the SCREEN dataset into the Baseline dataset. The caregivers' background and context factors included FCGs' race, gender, age, amount of education, employment status, yearly household income, and relationship with care recipients. The race for FCGs was separated into White/Caucasian, Black/African American, and Hispanic/Latino. FCG's education consisted of four categories: less than high school, high school, some college, and college or more. Employment status of FCGs was evaluated by

‘employed with pay’ and ‘not employed or working without pay.’ The criteria for coding employment status was dependent on whether FCGs had the chance or ability to receive payment from their employers. FCGs’ household income was yearly household income before taxes and included all of their income received from employment, social security, retirement accounts, or financial support from their children or other family members. In this study, the majority of FCGs are care recipients’ adult children or their spouse.

*Objective Stressors.* Objective stressors refer to levels of impairment among care recipients and actual demands that they placed on their FCGs. The conditions of these stressors were designated objectively and could triggered the emotional responses from FCGs. The core elements of the objective stressors consisted of care recipients’ cognitive impairments, problematic behaviors, functional abilities, and actual demands raised during the caregiving process. All the objective stressors were coded in the same direction with a higher value indicating a higher level of impairment among AD patients and a broader spectrum of care related demands on FCGs.

The Mini-Mental State Examination (MMSE) scale evaluated care recipients’ cognitive function by asking them questions about recall ability, short-term memory, orientation to time and place, and mathematical ability (Mitrushina and Satz 1991, Tombaugh and McIntyre 1992). This scale appears to be that most commonly used in the literature to collect information about the level of people with AD and their cognitive impairments (Baek et al. 2016, Mougias et al. 2018). The score range is from 0 to 30, with a score equal to or less than 24 representing a state of cognitive impairment. To keep the same direction of the other stressors, I reverse coded MMSE. In the current study, a higher score means worse cognitive status. Cronbach’s alpha for MMSE in this sample was 0.81.

The objective stressor of the behavior problems was evaluated by the Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992). This 24-item scale measured care recipient's memory-related problems (Cronbach's alpha = 0.70), depressive problems (Cronbach's alpha = 0.80), and disruptive problems (Cronbach's alpha = 0.70) exhibited in the past week. The scale of RMBPC has been approved with good validity to evaluate people with AD patients in different stages of the disease (Johnson, Wackerbarth, and Schmitt, 2001). FCGs were asked to report the frequency of a loved one's behavioral problems during the past week with a four-point scale range, ranging from 0 (never occurred) to 3 (daily or more often). The sum score was used to measure the presence of behavioral problems among persons with AD. A higher score referred to a very serious level of behavioral problems.

The scale of activities of ADL included seven items to assess the care recipient's ability to conduct some basic activities. The eight items in IADL scale assessed a care recipient's ability to conduct some of the more complex activities. People with AD patients at the beginning stage of the disease may only need FCGs to provide help with IADLs. With a progressive loss of autonomy, a person with AD may make more demands from their FCGs (Gauthier, Gélinas and Gauthier 1997). Both ADLs and IADLs are defined as objective stressors that helped measure functional disabilities caused by the disease. Cronbach's Alpha values for ADL and IADL were 0.85 and 0.78 respectively. The sum score of ADLs was used to predict whether the caregivers needed to perform basic tasks to care recipients. The range of ADLs was from 0 to 7, with a higher score indicating more needs for help with primary care tasks. The score of IADLs ranged from 0 to 8, with a higher score representing an intense need for the instrumental activity of daily living.

*Subjective Burden.* Subjective burden is defined as FCGs' internal responses evoked by their loved one with AD and his or her cognitive impairment, functional status, behavioral problems, and hardships experienced during the caregiving process (Aneshensel et al. 1995). In this study, the short version of the Zarit Subjective Burden was used to assess the degree of burden felt by FCGs. This 12-item questionnaire was used by multiple researchers for measuring FCGs' personal and role strains during the caregiving process (Hagell et al. 2017, Lin et al. 2017). The five-point scales ranged from 0 (never) to 4 (nearly always) with a higher number representing a serious burden. The sum score was to evaluate the level of burden experience among FCGs. The range for the scale is from 0 to 48. Using this baseline data, the short version of subjective burden had an overall 0.866 Cronbach's alpha value.

*Psychosocial Resources.* Of the psychological resources examined, two social support, the effects of FCGs' social networks and the satisfaction with social support. Two others examined individual coping strategies, the effects of FCGs' religious coping and their positive attitudes toward caregiving.

The social support questionnaire in REACH II data consisted of four categories with 15 items. This questionnaire was designed to assess FCGs' received social support, social network, negative interaction with others, and satisfaction with support (Cho, Ory, and Stevens 2016). Four items were derived from the Lubben Social Network Index to evaluate FCGs' social networks (Lubben 1988). Of these four items, three asked about the support that FCGs received from various social networks, including their relatives, friends, neighbors, or anyone other than care recipients. It is a six-point scale from 0 (none) to 5 (nine or more) to indicate the number of people in their networks. Another one item ranged from 0 (never) to 5 (very) and asked FCGs whether other people they knew were willing to communicate with them about making a

important decision. A sum score in this study evaluated FCGs' overall size of social network. Cronbach's alpha for these items based on this dataset was 0.718.

The satisfaction of social support among FCGs was measured using a four-item scale derived from the Satisfaction with Support scale (Krause 1995). Neal Krause (1995) developed this scale to determine whether respondents were feeling satisfied with the assistance they received from their social network. The scale ranged from 0 (not at all) to 3 (very), with a higher number indicating greater satisfaction with social support. Within these four items, three asked whether FCGs were satisfied with the tangible, emotional, and informational help from others. The last question asked FCGs to evaluate their overall satisfaction with supports they received from other family members, friends, or neighbors. Cronbach's alpha value for the network satisfaction was 0.800.

The rating scale of positive aspects of caregiving was based on the Measures of Positive Aspects (Lawton et al. 1991) and validated in REACH I (1995). This 11-item scale assessed FCGs' perception of benefits during the caregiving process. Responses ranged from 0 (disagree a lot) to 4 (agree a lot), with a higher sum score representing more positive attitudes. In this study, the items used to evaluate FCGs' positive aspects included the feelings of useful, good, needed, appreciated, important, strong, and confident, etc. This scale represented a very high Cronbach's alpha value of 0.919.

The religious/spiritual coping scale was derived from the Brief RCOPE scale. This scale was designed for evaluating positive and negative patterns of caregiver's religious coping (Pargament et al. 1998). In the current study, the positive aspect of caregivers' religious coping examined the spiritual connection with God and relief from FCGs' primary stressors during the caregiving process. A four-point scale ranged from 0 (not at all) to 3 (a great deal) was used to

evaluate the likelihood that FCGs felt a connectedness with God and went through hardships.

Scores summed across the three items represent the positive aspects of religious coping.

Cronbach's alpha value for this scale is 0.868.

*Depression.* Level of depression was measured by the Center for Epidemiological Studies Depression Scale (Radloff 1977). This is the most commonly used scale to evaluate the level of depression in the general population. A briefer 10-item version of depression evaluation was then explicitly developed to target older adults (Irwin, Artin and Oxman 1999). The REACH II data adopted this short version scale to evaluate FCGs' depression symptomatology in the past week. The response scale for each item was from 0 (rarely or none of the time) to 3 (most or almost all of the time). Total scores ranged from 0 to 30, with a higher score indicating an increased presence of depression symptoms. The Cronbach's alpha value was 0.850.

The validity of all of these measures has been demonstrated in multiple studies with very high alpha values. However, we cannot guarantee that all these measures can capture exactly what they are intended to measure. As in the psychosocial research area, it is impossible to know whether these measures are fulfilled measured what we want to measure. In addition, it is likely that these measures are different for men and women, whites and blacks, affluent and poor, etc. Based on the dataset I used in this study, it is not possible to determine whether FCGs with different race, age, and gender backgrounds have different responses to these measurements.

#### Pre-test Analysis

*Dealing with missing data.* I use listwise deletion to deal with missing data. The reason to adopt this methodology is that all of the missing in this study are missing completely at random. In other words, there are no trends for FCGs belonging to a specific group to be more or less

likely to answer or refuse to answer any specific question. In the data analysis, I excluded FCGs from the analysis that are missing data on any of the primary variables in the analysis.

*Test the multicollinearity.* It was essential to ensure that the independent variables in this study had no multicollinearity issues before I conducted any further regression analysis. It is problematic to estimate the regression coefficients if the predictors are strongly correlated with each other. In the current study, I used pair-wise correlations to compare the coefficient values of each pair of predictors. The rule of thumb to indicate a severe collinearity issue is a value of the correlation between two predictors a higher than 0.9 or lower than -0.9. The results of all the correlation coefficients among the variables have been listed in Table 1.3. As the table shows, none of them was higher than the standardized value. The correlation between social network and satisfaction of social support indicated the highest value of significant correlation ( $r=0.559$ ,  $p=0.000$ ), and the degree of this correlation was moderate. Thus, no multicollinearity issues affect the overall study instruments among independent variables in this study.

*Test the outliers and high influence points.* Before conducting the main regression analysis, I also tested if any outliers or high influence cases existed. Finding outliers allowed me to avoid any extreme value that would pull the estimated regression towards the potential outliers. I used studentized residuals to identify the outliers. The rule of thumb for this analysis was the observation of a value of studentized residuals over the range  $\pm 2$ . Eight FCGs showed a slightly higher value of the studentized residuals. These potential outliers were coded in the datasets with the ID numbers of 1005, 1105, 4146, 4165, 4207, 4261, 5048, 5199. FCGs with the ID 5048 presented the highest residual value of -2.53. Cook's Distance Method was then used to detect highly influential points and to re-determine these outliers. Any values of Cook's D near

one indicated the high influence cases. In Cook's Distance Test, none of these eight FCGs presented a Cook's D value higher than the standardized value.

#### Data Analysis of Main Testing

*Statistical methods to test research question 1.* How do the caregivers' background and context factors affect their experiences of objective stressors and subjective burden during the caregiving process? In this part of the analysis, FCGs' age, gender, race and ethnicity, education, income, employment status, and their relationship with care recipients are defined as independent variables to predict the objective stressors and the subjective burden respectively. Multiple regressions will examine FCGs' exposure to stressors on their caregivers' background and context factors. All independent variables are entered into the equations simultaneously. The results are displayed in the following results section. Unstandardized regression coefficients with the alpha value set at 0.05 were used for all analyses.

*Statistical methods to test research question 2.* What is the relationship between the objective stressors and subjective burdens, and what impact, if any, do they have on FCGs' depressive symptoms? The multiple linear regression was used for this part of the analysis. Because it provides a series of regression models by adding or removing variables from the models. More specifically, the following models will explain the statistical significance accounting for the models from the prior regression constant. The second research question examine the relationship between objective stressors, subjective burden and depression during the proliferation of stress. Hypothesis 2(1) explores the impact of objective stressors' impact on FCGs' subjective burden with the consideration of caregivers' background and context factors. In this analysis, Model 1 includes all of caregivers' background and context factors to explain their experience of the subjective burden. In the following step (Model 2), I add the variables of

objective stressors to test their impacts over and above caregivers' background and context factors on subjective burden. Hypothesis 2(2) considers how both objective stressors and subjective burden impact FCGs' experience with depression. In this analysis, the value of FCGs' experience with depression experience regresses on three types of independent variables: (1) caregivers' background and context factors; (2) objective stressors; and (3) subjective burden.

*Statistical methods to test research question 3.* How do psychosocial resources mediate and or moderate the relationship between the primary stressors and FCGs' depression experiences? The caregivers' background and context factors will always be considered and analyzed at the beginning of each of the following regressions. To directly present the mediational and moderating effects from stressors to depression, the controlling variables of caregivers' background and context factors will not be listed in the following tables. In the mediational test, a series of six regression models will test the effect of psychosocial resources. With the expectation that each psychosocial resource contributes to the relationship differently, the separate contribution of each resource will be tested one at a time and then their collective contribution will be considered. Model 1 establishes the caregivers' background and context factors combined with the objective stressors and the subjective burden impact on the dependent variable of depression without any psychosocial resources' impacts. Model 2 to Model 5 examine the effects of positive aspect, religious coping, social network, and the satisfaction of social support sequentially. Model 6 will present a considered impact of all psychosocial resources on depression collectively.

The moderating effects detect the interactions between stressors and psychosocial resources on changing the level of depression. The interaction between each stressor and psychosocial resource is assessed individually. For each regression, the interaction between two

factors (stressor\*psychosocial resource) will affect the strength from the independent variable (stressor) to the dependent variable (depression). In total, twenty different regressions will be tested in regressions. Only the interaction terms show a significant impact on depression is present in the following section. The results in both research questions two and three will estimate in the form of unstandardized measures and standardized measures. The unstandardized measures directly compare the value the coefficient deviates from zero. A higher value of the unstandardized coefficient represents a stronger interaction effect when all other component parts hold constant (Jaccard, Turrisi, and Jaccard 2003). The standardized measures can evaluate the proportion of variance in the dependent variables that are contributed uniquely by the interaction effect. In the current study, the values of the standardized measures will be calculated by computing the difference in squared multiple correlations for the primary effect model compared with the interaction model (Jaccard, Turrisi, and Jaccard 2003).

Post-hoc probing will then be used to examine the significant difference of the interaction terms. The moderating tests provide information about whether the interaction between the stressor and psychosocial resources is significant, but there is little information about the specific conditions in which the predictor (stressor) is significantly related to the outcome (depression) (Holmbeck 2002). For example, there is limited evidence to dictate whether any of the simple slopes are significantly different from zero or whether the slopes of any pair of simple regression equations significantly differ from one another (Aiken, West, and Reno 1991). The simple slope here refers to the slope of the regression of depression (outcome) on stressor (predictor) at a single value of the psychosocial resource (moderator). Post-hoc probing will be used in the current study to provide this information (Aiken, West, and Reno 1991, Holmbeck 2002).

The first step is to choose several representative values of the moderator to generate a

series of simple regression equations. It can also be interpreted that the slope of FCGs' depression on stressor differs depending on the value or the levels of the moderator. I calculated the impact of predicting depression from stressors at three different values of the psychosocial resources: a lower level, a medium level, and a higher level. A lower level of psychosocial resources can be represented by a resource that is one standard deviation below the mean of that resource. A medium level and a higher level of psychosocial resources can be represented by the mean and one standard deviation above the mean of psychosocial resources, respectively.

## CHAPTER 4: RESULT

### Data Description

All statistical analyses were conducted using by STATA v.14. The descriptive statistics listed in Table 1 include caregivers' background and context factors, primary stressors, psychosocial resources and depression experience. The distribution characteristics such as mean, standard deviation, and range are provided to indicate the level of FCGs' stressors, psychosocial resources, and depression.

In total, 670 FCGs participated in the baseline study. As Table 1(1) shows, a slight majority of FCGs are adult children of the person with AD (45.52 percent of all FCGs), followed by spouse (42.54 percent). Other caregivers include "Son-in-Law," "Daughter-in-Law," "Brother," "Sister," "Nephew," "Niece," "Grandson," "Granddaughter," "Stepdaughter," "other." Each of them have 2, 12, 1, 17, 1, 13, 7, 13, 2, 12 participants respectively. These other relatives together have been defined as "other relationship" in my study. The FCGs ranged in age from 22 to 90 years, with 59 percent age 35 years to 65 years and 39 percent age 65 years or older. About 83 percent are female which is consistent with the literature on caregiving. Race and ethnicity among FCGs are distributed evenly with 34.21 percent non-Hispanic White, 32.81 percent African-American, and 32.81 percent Hispanic. The majority of FCGs describe their yearly household income before taxes as between \$20,000 and \$49,999 (40.29 percent). About a third were lower in income (\$ 5000 to \$19,999) and 19.09 percent earned \$50,000 to \$99,999. Only 3.59 percent of FCGs reported a household income of less than \$5000, while 4.24 percent earned more than \$100,000. The education level for FCGs in this study are evenly distributed, with 31.26 percent reporting some training school after high school or some associate college degree. The FCGs with a high school education level only occupied 22.71 percent of the sample, and

19.6 percent received less than a high school education. FCGs with a college degree or more account for 26.44 percent of the study sample. This college degree differed from the 'some college degree' since it refers to the formal college education with a 4 or 5-year program. Most of the FCGs were currently not employed or working without pay (67.96 percent).

The assessment levels in Table 1.2 indicate the FCGs' evaluations of multiple primary stressors experience, psychosocial resources, and depression. The primary objective stressors were measured by MMSE, RMBPC, ADL, and IADL. The mean score for MMSE among AD patients is 16.721 (SD=7.687) within the range 0 to 29. To keep the same direction as all other stressors, I reverse coded MMSE, with higher scores indicating a worse cognitive status. Thus, the cognitive impairment among AD patients in the present study has an average impairment in the moderate range. Based on the previous literature, the highest risk objective stressor is AD patients' problematic behavior. The average value of AD patients' behavior problems reported for the past week before the interview is 22.739 (SD=10.156) within the range 0 to 58. The objective stressors are also measured by the ADL and IADL. AD patients in this sample needed help with a mean of 4.03 (SD=2.414) on ADL items and a mean of 6.583 (SD=1.869) on IADL items. Both of these stressors are higher than the midpoints of their range. The Zarit Burden Interview measures the subjective burden with a mean of 18.829 (SD= 9.871) within the range 0-46.

There are four types of psychosocial resources in this study. Two of them are individual-coping strategies and the other two are collaborated-coping strategies. The scale of positive aspect in the individual-coping strategies shows a mean value of 31.007 (SD=10.924). Compared to the scale range from 0 to 44, many of the FCGs hold positive attitudes toward the caregiving process and maintain a sense of being in control of their own lives. The range for religious

coping in this study is 0 to 9, and the mean value of this scale is 6.825 (SD=2.639). In social assets, the average of the responses yields a mean of 10.981 (SD=3.958, range=0-20) and 6.671 (SD=3.627, range=0-12) for social network and satisfaction with social support respectively. This indicates that FCGs generally connected with their social network and feel satisfied with the social support they received from others. Depression as an outcome variable has been evaluated by the CES-D scale. The mean level of depression among FCGs (CES-D) is 9.965 (SD=6.456) in the range of 0 to 30.

#### Research Question 1 and Hypothesis 1 Test

The stressors generated during the caregiving process are shaped by FCGs' age, gender, race, education, occupation status, yearly household income, and their relationship with AD patients. The first research question examined the primary stressors under the impacts of caregivers' background and context factors. As Table 2 indicates, problem behaviors (RMBPC) among AD patients are less likely to be reported by African American FCGs compared with their white counterparts ( $r = -3.015$ ). Additionally, both African American ( $r = 1.954$ ) and Hispanic FCGs ( $r = 2.123$ ) reported a higher stressors experience on care recipients' cognitive impairment than did Whites. The higher levels of AD patients' cognitive impairments ( $r = -2.75$ ), problem behaviors ( $r = -2.166$ ), and the assistance on activity of daily living ( $r = -0.858$ ) shows a more serious impact on adult child caregivers than on spouses. FCGs with an older age ( $r = -0.112$ ), male ( $r = -2.725$ ), and African American ( $r = -4.096$ ) report comparatively lower rates of exposure to the subjective burden than their counterparts. Education level among FCGs is positively related to their subjective burden experience ( $r = 0.525$ ). In sum, except for the instrumental activities of daily living (IADL), all remaining stressors depend upon at least one of the FCGs' social contextual factors.

## Research Question 2 and Hypothesis 2 (1)(2) Test

The second research question consists of two hypotheses. The first hypothesis is to evaluate the relationship between the objective stressors and subjective burden with the consideration of caregivers' background and context factors. The results of Model 1 in Table 3.1 show that 12 percent of the variance of FCGs' subjective burden experience can be explained by caregivers' background and context factors [ $F(10, 547) = 7.74, p < 0.000, R^2 = 0.120$ ]. In the second model, I added objective stressors into the regression. The result of Model 2 indicates that combining caregivers' background factors with objective stressors predicts FCGs' subjective burden experience [ $F(14, 543) = 11.69, p < 0.000, R^2 = 0.232$ ]. The  $R^2$  in Model 2 suggests that the set of independent variables can account up for to 23.2 percent of the variability in the subjective burden. As an illustration, an additional 11.2 percent of variability in FCGs' subjective burden is due to the inclusion of the objective stressors.

The second hypothesis evaluates the outcome of FCGs' depression experience based on three types of independent variables: (1) caregivers' background and context factors; (2) objective stressors; and (3) subjective burden. As Table 3.2 shows, the social contextual factors were examined first in the regression, followed by the objective stressors and the subjective burden. Although Model 1 shows a statistically significant impact on FCGs' depression experience, those predictors only contribute to 4.8 percent of the variance [ $F(10, 547) = 2.78, p = 0.0024, R^2 = 0.048$ ]. As Model 2 shows, the overall  $R^2$  increased by 8.7 percent once the objective stressors were added into the regression [ $F(14, 543) = 6.03, p < 0.000, R^2 = 0.1346$ ]. The  $R^2$  reached highest value when the subjective burden was taken into account [ $F(15, 542) = 23.89, p < 0.000, R^2 = 0.398$ ]. The change in  $R^2$  from Model 1 to Model 3 shows that subjective burden, compared with all other variables tested in this study,

contributes most strongly to increasing FCGs' experience of depression ( $\Delta R = 0.2635, p < 0.000$ ). In Table 2, problem behavior of care recipients (RMBPC) as the most risk objective stressor indicates the strongest impact on FCGs' depression ( $r=0.187, p<0.000$ ). However, its value drops significantly once subjective burden is taken into account. As we can see in the Table 3, the coefficient of RMBPC dropped to the value of 0.06 ( $p=0.011$ ) compared with the coefficient of subjective burden, 0.379 ( $p<0.000$ ). These results are consistent with the conclusion in hypothesis 2(2). Even though both objective stressors and subjective burden are primary stressors generated during the caregiving process, the subjective burden is the most problematic factor compare with the objective stressors in increasing FCGs' depression experiences.

#### Research Question 3 and Hypothesis 3 (1)(2) Test

Table 4.1 presents the results that access to psychosocial resources mediate the relationship of primary stressors to depression. In this test, FCGs' depression was first regressed on the social contextual factors, followed by the objective stressors, and then the subjective burden. As Table 4.1 shows, both AD patient's problem behavior (RMBPC) and FCGs' subjective burden significantly impact FCGs' depression experiences. The coefficient of RMBPC on depression does not fluctuate much even when the psychosocial resources variables were added into the regression.

From Model 2 to Model 5, the effects of positive aspect, religious coping, social network, and satisfaction with social support were entered into the regression sequentially. I conducted these different regressions to assess whether the relationship between primary stressors and depression varied based on the different resources. In Model 2, FCGs' positive aspects of caregiving contributed to decreasing the level of depression in a nonsignificant way ( $r=0.037,$

p=0.122). Model 3 reveals that religious coping could significantly decrease FCGs' level of depression ( $r=-0.401$ ,  $p=0.000$ ). However, it also shows that this resource can only decrease FCGs' subjective burden by 2.7 percent (from  $r=0.379$ ,  $p<0.000$  to  $r=0.367$ ,  $p=0.000$ ). The impact of social network over and above all other psychosocial resources on decreasing FCGs' depression experience was significant ( $r=-0.630$ ,  $p=0.000$ ) and reduced the coefficient of subjective burden from 0.379 ( $p=0.000$ ) to 0.347 ( $p=0.000$ ). The satisfaction of social network creased FCGs' subjective burden by 10.5 percent (from  $r=0.379$ ,  $p<0.000$  to  $r=0.339$ ,  $p=0.000$ ) and made a modest contribution to decreasing depression outcome ( $r=-0.410$ ,  $p=0.000$ ). Model 6 presents the analysis that assesses the combined effects from these four types of psychosocial resources. It shows that all of these hypothesized mediators reduced the subjective burden's coefficient only from 0.379 to 0.325, which is less than 15 percent.

In short, subjective burden is the factor more likely to increase FCGs' depression, no matter whether they have any psychosocial resources or not. A comparison of the  $R^2$  from Model 1 to Model 5 indicates that the social network plays a relatively more powerful effect than any other psychosocial resources on predicting depression [ $F(16, 541) = 26.80, p < 0.000, R^2 = 0.442$ ]. The  $R^2$  for combined effects (including all of these psychosocial resources into the regression [ $F(19, 538) = 24.50, p < 0.000, R^2 = 0.464$ ]) is higher than each of them tested individually.

The moderating tests refer to the degree to which psychosocial resources varied the relationship between primary stressors and depression (Aneshensel et al. 1995). More specifically, the impacts of stressors on depression could be different for FCGs who adopt different levels of resources. Moderating effects have been detected through the interactions term between stressors and psychosocial resources. In total, twenty regressions were tested in the

current study, and only the interaction terms present a significant impact on depression. The results were listed in the formats of statistical tables and figures. In these analyses, four interaction terms indicated a significant association with FCGs' depression. As Table 4.2 shows, the significant interaction terms ( $p < 0.05$ ) are, 1) Social Network interacting with AD patients' cognitive impairments (MMSE), 2) Satisfaction with Social Support interacting with AD patients' problematic behaviors (RMBPC), 3) Religious Coping interacting with AD patients' daily decencies (IADL), and 4) Positive Aspects interacting with Burden.

Post-hoc probing methods were used to test whether any of the simple slopes were significantly different from zero. As Table 4.3 indicates, none of the slope related to MMSE test was significant. Similar to the IADL test, the result of the post-hoc probing test indicated only that higher level of religious coping significantly moderated the relationship between FCGs' IADL and depression. The other two tests, care recipients' problem behavior (RMBPC) and FCGs' burden, present significantly different impacts within the different levels of satisfaction of social support and positive aspect, respectively. For FCGs with a higher level of satisfaction of social support, they are more likely to experience a lower level of depression caused by RMBPC [ $F(13, 554) = 13.53, p < 0.000, R^2 = 0.241$ ]. The positive aspect of caregiving also plays an important role in decreasing the effect of subjective burden on FCGs' depression [ $F(13, 589) = 29.55, p < 0.000, R^2 = 0.395$ ]. It is important to highlight that the positive aspect of caregiving is the only factor that presents a significant interaction effect with subjective burden. For every one unit that the FCGs' positive aspect toward caregiving increases, the slope of the subjective burden on depression is predicted to decrease by 0.004. However, the moderating effect of the interaction term between the positive aspect and the subjective burden is fragile.

Although each of these psychosocial resources somehow moderates the relationship between the primary stressors and depression, the main effects of these interaction terms were found to be very small with coefficients ranging from -0.005 ( $p=0.006$ ) to -0.119 ( $p=0.016$ ). Additionally, the proportion of variance in the depression outcome accounted for by the interaction terms is very small. The strength of the interaction effect can be calculated by computing the R square difference from the “main-effect-only” model to the interaction model. In the current study, the R square changed from 0.005 to 0.007. In other words, the interaction effect only accounted for 0.7 percent maximum of the variance in the FCGs’ depression outcome in the sample data. In Figure 2, each of these psychosocial resources was assigned into one of three categories to reflect FCGs’ adoption of a low, moderate, and high level of psychosocial resources. Figure 2 shows the difference between the nonsignificant slope (dotted line) and the significant slope (solid line).

## CHAPTER 5: CONCLUSION

The first research question posed in this thesis is whether the FCGs' background and contextual factors are associated with their experience of primary stressors. I tested the effects of objective stressors and subjective burden in the context of demographic factors (e.g., age, gender, and race); socioeconomic status (e.g., education, occupation status, and yearly household income); and caregiving relationship (e.g., the relationship with AD patients). The findings indicated that each of these factors has one or more significant effects on the FCGs' experience of primary stressors.

My findings may not apply for all FCGs. The FCGs eligible for this study were those who reported some risk factors caused by caregiving. These risk factors could be the FCGs' emotional and/or physical stressors generated during the caregiving process. Some FCGs may underreport their risk factors or not be willing to express their stress experiences to the investigators and these FCGs were not included in the study. This underreport issue is not randomly distributed among the FCGs population. For example, male FCGs may be less likely to express their hardships of caregiving compared with female FCGs. However, because the primary goal of the REACH II study is to improve mental health status among FCGs of Alzheimer's patients, it is reasonable for the investigators to select only participants who are willing to express their internal feelings and report some levels of stress experience. The results generated from this study, therefore, do not represent FCGs who are not willing to express their hardship experience or underreport their stress feelings.

How big is this problem? One question in the screening form in the REACH II dataset presents the proportion of participants who reported caregiving stressors versus those who did

not. In total, the researchers randomly selected 995 FCGs. Of these participants, only 82 FCGs reported that they do not experience the stressors caused by the caregiving. With this information, it is safe to say that the results generated from this study reflect the general FCGs population and not only FCGs who are vulnerable.

The result of the gender issues in the current study is consistent with other studies (Hayes, Boylstein, and Zimmerman 2009, Pinqart 2006, Swinkels et al. 2017, Yee and Schulz 2000) in which male FCGs reported less subjective burden compared with female FCGs. Also, younger FCGs are less likely to suffer from subjective burden than older FCGs. The relationship between FCGs' race and their experiences of stressors suggest that African American FCGs are less likely to report the subjective burden and AD patients' problem behaviors than their white counterparts. In this study, adult children generally encounter somewhat higher levels of stress on objective stressors, such as AD patients' cognitive impairment, problematic behaviors, and activities of daily living, perhaps because the majority of adult child caregivers are members of the 'sandwich generation.' They are balancing their careers as well as young children or adolescents who also need support (Pinqart and Sorensen 2011). In the current study, adult child FCGs reported a higher level of stress experiences than spouse FCGs related to a broad spectrum of care related tasks.

Social economic status (SES) is a theoretical concept that represents people's social position (Conger and Donnellan 2007). SES characteristics among FCGs shaped their perceptions of stressors and the responsibilities of caregiving (Etter et al. 2008). In the current study, well-educated FCGs are more likely to report a higher level of burden experience. It is possible that those FCGs are more likely to be overestimating the potential negative impacts caused by a progressive disease and anticipating the difficulties of managing it. Some studies

indicate that FCGs with higher education are more likely to adopt interventions to overcome tangible hardships generated during the caregiving process (Kim et al. 2009, Sinforiani 2010). However, the benefits of these interventions might only help relief objective stressors instead of emotional stress. The results in the current study showed that FCGs with more education are less likely to experience stressors caused by the direct assistance with daily living. But they suffer high levels of emotional stress related caregiving. FCGs' yearly household income and employment status did not have a statistically significant effect on their subjective burden experience. These insignificant associations might be due to the suppressed effects caused by the full range of social contextual factors tested simultaneously in the multiple linear regression. Each of these factors present a significant effect when I tested their effect on FCGs' stressors independently. Because none of these demographic factors could exist independently during the caregiving process, it is more appropriate to examine all of these factors simultaneously in this research.

In sum, all of these contextual factors were interrelated, and each one had a unique association with FCGs' caregiving experiences.

Multiple studies targeting caregiving and FCGs' stress experience focused on three major factors: (a) factors related to the care recipients' cognitive impairment, problematic behaviors, and functioning status (Aneshensel et al. 1995, Park et al. 2017, Pearlin et al. 1990), (b) factors associated with the specific caregiving-related tasks or direct supervision (Aneshensel et al. 1995, Pearlin et al. 1990), and (c) factors contributing to FCGs' mental, physical, and financial strains (George and Gwyther 1986).

Pearlin et al. (1990) noted that one reason to apply the stress process model was to try to understand inconsistent results in caregiving research. Their goal was to identify the interactions

between each of the domains of caregiving and to evaluate a comprehensive process of stress proliferation. Even though many studies on the FCGs of Alzheimer's patients' stress have been published within the last three decades, the results and conclusions derived from each of the domains fluctuated widely.

I designed my thesis project to look at the most fundamental effects of these primary stressors and examine their different impact on FCGs' depression experience. Instead of reviewing the overall stress proliferation, I am more curious about the impacts of the primary stressors. In the comprehensive SPM, we consider the primary stressors as the onset of overall stress proliferation. It is necessary to pay more attention to exploring the relationships between the subjective burden and objective stressors and to evaluate if there are any psychosocial resources can either mediate or moderate their impacts on depression. In the current study, I explored the objective stressors and their effect on subjective burden. I also examined how these two stressors combined together to define FCGs' different depression experiences.

AD patients' cognitive and functional degeneration have been treated as a catalyst to reinforce FCGs' stress experiences during the caregiving process. Even though the trajectory of Alzheimer's disease begins with a decline in AD patients' cognitive abilities, there is no significant effect of the care recipient's cognitive ability on FCGs' subjective burden experience. As Aneshnsel et al (1995) noted in their research, the constraint of MMSE measurement might make it difficult to find the effects of care recipients' cognitive impairment. When the measure of cognitive ability (the MMSE) is at its maximum, it is not possible to observe any further deterioration in the patient's cognitive condition. (Aneshnsel et al. 1995). In the current study, the results related to care recipients' problematic behaviors were consistent with other studies. The non-cognitive features of Alzheimer's disease such as psychotic symptoms, depression, and

behavioral problems created the most demanding tasks, which required FCGs to spend more time on caregiving and led them to experience a higher level of subjective burden (Chiao, Wu, and Hsiao 2015, Gaugler, Kane, and Kane 2002, Park et al. 2017, Pinquart and Sörensen 2003, Van der Lee et al. 2014). In sum, the objective stressors matter to the overall stress proliferation process in large part because these conditions generate subjective burden. Subjective burden is the most important risk factor associated with FCGs' depression experience. This study did not find significant impacts of patients' cognitive impairment and daily dependencies, but the causal links between these objective stressors and subjective burden are critical elements in the process of stress proliferation.

The result of research question 2 also indicated that depression is a common experience among female and low household income FCGs. Adult child FCGs reported a higher level of depression only when both the objective stressors and the subjective burden are taken into account. The level of depression is related to the progression of both objective stressors and subjective burden. When all variables were considered collectively, subjective burden was sufficient for examining the major relationship between primary stressors and depression. In this study, subjective burden directly magnifies the impact of objective stressors and increases FCGs' depression experience. Ultimately, all of these primary stressors indirectly redefine the circumstances of caregiving and exacerbate FCGs' emotional stress.

In research question 3, I examined whether psychosocial resources could either mediate or moderate the relationship between primary stressors and depression. The results indicated that none of these resources presented a strong buffering effect. Instead, they exhibited a weak to moderate mitigation of the consequences of FCGs' depression. Correspondingly, those FCGs

who are lacking certain types of resources are more susceptible to the impacts of the hardships of caregiving.

Three psychosocial resources presented a significant impact on mediating the relationship between the primary stressors and FCGs' depression outcome. Both social network and the satisfaction of social support had a moderate effect of decreasing the impact of primary stressors on depression. This finding corresponds to other studies showing that social support provides an opportunity for FCGs to receive both emotional and instrumental assistance from others (Dam et al. 2016). FCGs' satisfaction with social support contributes the most to decreasing the effect of burden on depression compared with all other psychosocial resources. This result also indicated that satisfaction with social support could help FCGs stave off or avert the negative effect of burden.

Religious coping also negatively related to FCGs' depression. FCGs who actively seek to collaborate with God for problem-solving are less likely to have a higher level of psychological distress (Rathier et al. 2015). Although the positive aspects of religious coping did not present any indirect effect on the mediational test, it exhibited a moderating effect on changing the relationship between FCGs' subjective burden and depression. This finding corresponded to the research of De Labra et al. (2015), who found that when FCGs hold a positive attitude toward caregiving, their stressors' experience was lower. Abdollahpour, Nedjat, and Salimi (2018) also reported that the positive attitude towards caregiving plays a buffering effect between FCGs' subjective burden and depression. Consequently, we might see that religious coping, positive aspect, social network, and satisfaction with social support tend to alleviate the impacts of FCGs' subjective burden on depression at a small degree. It is possible that those resources only affect

stress proliferation when they direct effects on depression instead of being a mediator or moderator in the stress proliferation process.

In sum, subjective burden among FCGs is the strongest risk factor for depression compared to all other stressors. The result of the present study reconfirms this distinction as pivotal to the understanding of the effects of primary stressors in the stress proliferation process. As the results in the current study show, overall psychosocial resources did not shift the impacts of the primary stressors on FCGs' depression. In the mediational test, the effect of subjective burden on depression only decreased by 14 percent when all psychosocial resources were taken into account. Likewise, each of these psychosocial resources appear to exert only a minor effect in modifying the impacts of primary stressors on depression.

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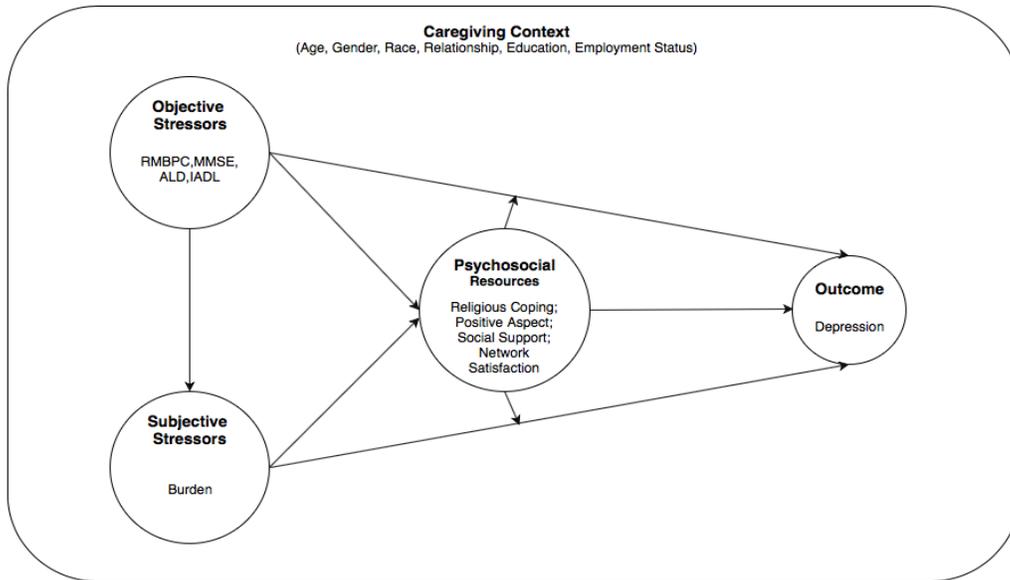
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Figure 1 Modified Stress Proliferation Model



Note: RMBPC=Revised Memory and Behavior Problem Checklist; MMSE=Mini-Mental State Examination; ADL = activity of daily living; IADL = instrumental activities of daily living

*Table 1 Caregivers' Social Contextual Factors and Assessment Levels*  
*Table 1.1 Caregivers' Social Contextual Factors*

Caregiver characteristics	Mean	SD	Range	N (%) (N=670)
<b>Relationship to CR<sup>a</sup></b>				
Spouse	0.4254	0.495	0-1	285 (42.54%)
Adult Child	0.455	0.498	0-1	305 (45.52%)
Other	0.119	0.324	0-1	80 (11.94%)
Age	60.570	13.30	22-90	670
<b>Gender</b>				
Male	0.172	0.377	0-1	115 (17.16%)
Female	0.828	0.377	0-1	555 (82.84%)
<b>Race and Ethnic</b>				
African-American	0.328	0.469	0-1	211 (32.81%)
Hispanic	0.328	0.469	0-1	211 (32.81%)
Non-Hispanic White	0.342	0.475	0-1	220 (34.21%)
<b>Education</b>				
Less than high school	0.196	0.397	0-1	126 (19.60%)
High School	0.227	0.419	0-1	146 (22.71%)
Some college	0.313	0.464	0-1	201 (31.26%)
College or more	0.264	0.441	0-1	170 (26.44%)
<b>Employment Status</b>				
Employed with Pay	0.320	0.467	0-1	206 (32.04%)
Not employed or Working without pay	0.679	0.467	0-1	437 (67.96%)
<b>Yearly Household Income</b>				
Less than \$5000	0.036	0.186	0-1	22 (3.59%)
\$5000-\$19,999	0.328	0.470	0-1	201 (32.79%)
\$20,000-\$49,999	0.402	0.490	0-1	247 (40.29%)
\$50,000-\$99,999	0.191	0.393	0-1	117 (19.09%)
\$100,000 or more	0.042	0.202	0-1	26 (4.24%)

<sup>a</sup> CR=Care Recipients

Table 1.2 Caregivers' Assessment for The Primary Variables

Caregivers' Assessment	Mean	SD	Range
RMBCP <sup>b</sup>	22.739	10.156	0-58
MMSE <sup>c</sup>	16.721	7.687	0-29
ADL <sup>d</sup>	4.03	2.414	0-7
IADL <sup>e</sup>	6.583	1.869	0-8
Burden	18.829	9.871	0-46
Religious Coping	6.825	2.639	0-9
Positive Aspect	31.007	10.924	1-44
Social Network	10.981	3.958	0-20
Satisfaction with Social Support	6.671	3.627	0-12
CES-D <sup>f</sup>	9.965	6.456	0-30

<sup>b</sup> RMBCP=Revised Memory and Behavior Problem Checklist; <sup>c</sup> MMSE=Mini-Mental State Examination; <sup>d</sup> ADL = activity of daily living; <sup>e</sup> IADL = instrumental activities of daily living; <sup>f</sup> CES-D = Center for Epidemiological Studies–Depression

Table 1.3 Correlation for The Primary Predictors

Correlation	RMBPC	MMSE	ADL	IADL	Burden	Religious Coping	Positive Aspect	Social Network	Network Satisfaction
RMBPC	1.000								
MMSE	0.102*	1.000							
ADL	0.079	0.466***	1.000						
IADL	0.149***	0.197***	0.332***	1.000					
Burden	0.380***	-0.034	0.045	0.089*	1.000				
Religious Coping	-0.072	0.030	0.026	-0.012	-0.180***	1.000			
Positive Aspect	-0.114**	0.002**	0.087*	-0.016	-0.417***	0.322***	1.000		
Social Network	-0.070	0.121**	-0.093*	0.019	-0.176***	0.166***	0.050	1.000	
Satisfaction with Social Support	-0.131**	0.046	-0.080	0.025	-0.316***	0.163***	0.183***	0.559***	1.000

\*p ≤ 0.05. \*\*p ≤ 0.01. \*\*\*p ≤ 0.001

Note: Correlation between predictors and outcome.

Correlation	RMBPC	MMSE	ADL	IADL	Burden	Religious Coping	Positive Aspect	Social Network	Network Satisfaction
Depression	0.290***	-0.008	0.077	0.031	0.587***	-0.232***	-0.271***	-0.318***	-0.352***

Table 2 Social Contextual Factors Impact on Family Caregivers' Primary Stressors Experience

Predictors	Unstandardized Regression Coefficients				
	Objective Stressors				Subjective Stressors
	RMBCP <sup>b</sup>	MMSE <sup>c</sup>	ADL <sup>d</sup>	IADL <sup>e</sup>	Burden
Relationship to CR <sup>a</sup>					
Spouse	-2.116* (1.216)	-2.75*** (0.848)	-.858** (0.291)	-0.134 (0.211)	-0.683 (1.144)
Other Relationships	-0.975 (0.480)	0.406 (0.673)	0.001 (0.865)	0.0491 (0.837)	-1.933 (1.297)
Age	-0.068 (0.043)	0.036 (0.031)	0.002 (0.011)	-0.006 (0.007)	-0.112** (0.041)
Gender (Male)	0.647 (1.129)	0.976 (0.787)	0.136 (0.270)	-0.054 (0.196)	-2.725* (1.062)
Race and Ethnic					
African-American	-3.015** (1.124)	1.954* (0.783)	-0.040 (0.269)	-0.349 (0.195)	-4.096*** (1.057)
Hispanic	0.495 (1.126)	2.123* (0.848)	-0.029 (0.269)	-0.328 (0.211)	-0.868 (1.143)
Education (in years)	0.057 (0.167)	-0.192 (0.116)	-0.066 (0.039)	-0.009 (0.029)	0.525*** (0.157)
Income	0.084 (0.197)	-0.089 (0.137)	-0.024 (0.472)	-0.017 (0.034)	0.167 (0.187)
Employment Status					
Employed with Pay	0.429 (1.071)	0.165 (0.747)	-0.329 (0.256)	-0.158 (0.186)	0.487 (1.007)
R <sup>2</sup>	0.050**	0.071***	0.033*	0.011	0.120***

Excluded caregivers who did not answer all the items above, n=558.

\*p ≤ 0.05. \*\*p ≤ 0.01. \*\*\*p ≤ 0.001.

<sup>a</sup> CR=Care Recipients; <sup>b</sup> RMBCP=Revised Memory and Behavior Problem Checklist; <sup>c</sup> MMSE=Mini-Mental State Examination; <sup>d</sup> ADL = activity of daily living; <sup>e</sup> IADL = instrumental activities of daily living

*Table 3 Structural Foundation of Stress Proliferation*  
*Table 3.1 The Impact of Objective Stressors on Subjective Burden*

Predictors	The Impact of Objective Stressors on Subjective Stressor	
	<i>Model 1</i>	<i>Model 2</i>
Relationship to CR <sup>a</sup>		
Spouse	-0.682 (1.143)	-0.119 (1.087)
Other Relationships	-1.933 (0.137)	-1.515 (0.215)
Age	-0.112** (0.041)	-0.086* (0.039)
Gender (Male)	-2.725* (1.06)	-2.867** (0.998)
Race and Ethnic		
African-American	-4.095*** (1.057)	-2.897** (1.009)
Hispanic	-0.868 (1.143)	-0.832 (1.083)
Education (in years)	0.525 *** (0.157)	0.497*** (0.148)
Employment Status		
Employment with Pay	0.487 (1.007)	0.401 (0.947)
Income	0.167 (0.186)	0.134 (0.174)
Objective Stressors		
RMBCP <sup>b</sup>		0.335*** (0.038)
MMSE <sup>c</sup>		-0.091 (0.060)
ADL <sup>d</sup>		0.121 (0.182)
IADL <sup>e</sup>		0.016 (0.232)
Constant	20.807***	12.365***
<i>R</i> <sup>2</sup>	0.120	0.232

Excluded caregivers who did not answer all the items above, n=558.

\* $p \leq 0.05$ . \*\* $p \leq 0.01$ . \*\*\* $p \leq 0.001$ .

<sup>a</sup> CR=Care Recipients; <sup>b</sup> RMBCP=Revised Memory and Behavior Problem Checklist; <sup>c</sup> MMSE=Mini-Mental State Examination; <sup>d</sup> ADL = activity of daily living; <sup>e</sup> IADL = instrumental activities of daily living

Unstandardized regression coefficients are presented with standard errors in parentheses.

Table 3.2 The Impact of Overall Stressors on Depression

Predictors	The Impact of Overall Stressors on Depression		
	Model 1	Model 2	Model 3
Relationship to CR <sup>a</sup>			
Spouse	1.254 (0.769)	1.673* (0.746)	1.718** (0.623)
Other Relationships	-0.619 (0.478)	-2.966 (0.724)	0.277 (0.693)
Age	-0.038 (0.027)	-0.025 (0.027)	0.008 (0.022)
Gender (Male)	-2.788*** (0.715)	-2.898*** (0.685)	-1.811** (0.576)
Race and Ethnic			
African-American	-1.128 (0.711)	-0.519 (0.692)	0.578 (0.582)
Hispanic	-1.120 (0.769)	-0.155 (0.744)	0.159 (0.621)
Education (in years)	0.192 (0.106)	0.185 (0.101)	-0.003 (0.086)
Employment Status			
Employment with Pay	0.569 (0.678)	0.543 (0.650)	0.392 (0.543)
Income	-0.288* (0.125)	-0.307* (0.120)	-0.358*** (0.010)
Objective Stressors			
RMBCP <sup>b</sup>		0.187*** (0.026)	0.060* (0.023)
MMSE <sup>c</sup>		-0.055 (0.041)	-0.020 (0.035)
ADL <sup>d</sup>		0.235 (0.125)	0.189 (0.104)
IADL <sup>e</sup>		-0.201 (0.159)	-0.207 (0.133)
Subjective Stressors			
Burden			0.379*** (0.025)
Constant	11.418*	7.464**	2.780***
R <sup>2</sup>	0.048	0.135	0.398

Excluded caregivers who did not answer all the items above, n=558.

\*p ≤ 0.05. \*\*p ≤ 0.01. \*\*\*p ≤ 0.001.

<sup>a</sup> CR=Care Recipients; <sup>b</sup> RMBCP=Revised Memory and Behavior Problem Checklist; <sup>c</sup> MMSE=Mini-Mental State Examination; <sup>d</sup> ADL = activity of daily living; <sup>e</sup> IADL = instrumental activities of daily living  
Unstandardized regression coefficients are presented with standard errors in parentheses.

Table 4 The Meditational and Moderating Effects of Regression

Table 4.1 The Meditational Effect of Psychosocial resources

Predictors	The Meditational Effect of Psychosocial Resources					
	Model 1	Model 2	Model 3	Model 4	Model 5	Model 6
Objective Stressors						
RMBCP <sup>b</sup>	0.060*	0.060**	0.060**	0.068**	0.061**	0.067**
	(0.023)	(0.023)	(0.023)	(0.02)	(0.023)	(0.022)
MMSE <sup>c</sup>	-0.020	-0.018	-0.028	-0.042	-0.025	-0.045
	(0.035)	(0.035)	(0.034)	(0.034)	(0.034)	(0.033)
ADL <sup>d</sup>	0.189	0.201	0.206	0.180	0.165	0.182
	(0.104)	(0.104)	(0.102)	(0.101)	(0.102)	(0.099)
IADL <sup>e</sup>	-0.207	-0.219	-0.199	-0.187	-0.183	-0.173
	(0.133)	(0.133)	(0.131)	(0.130)	(0.130)	(0.126)
Subjective Stressors						
Burden	0.379***	0.364***	0.367***	0.347***	0.339***	0.325***
	(0.025)	(0.026)	(0.024)	(0.024)	(0.025)	(0.026)
Psychosocial Resources						
Positive Aspect		-0.037				-0.0009
		(0.024)				(0.024)
Religious Coping			-0.401***			-0.308***
			(0.085)			(0.086)
Social Network				-0.630***		-0.478***
				(0.096)		(0.103)
Satisfaction with Social Support					-0.410***	-0.214*
					(0.082)	(0.088)
Constant	2.780***	4.579	6.056**	6.325**	5.677**	9.552***
R <sup>2</sup>	0.398	0.401	0.422	0.442	0.425	0.464

N=558.

\*p ≤ 0.05. \*\*p ≤ 0.01. \*\*\*p ≤ 0.001.

<sup>b</sup> RMBCP=Revised Memory and Behavior Problem Checklist; <sup>c</sup> MMSE=Mini-Mental State Examination; <sup>d</sup> ADL = activity of daily living;

<sup>e</sup> IADL = instrumental activities of daily living

Table 4.2 The Moderating Effects of Psychosocial Resources

Predictors	The Moderating Effects of Psychosocial Resources			
	<i>Test</i> RMBPC	<i>Test</i> MMSE	<i>Test</i> IADL	<i>Test</i> Burden
Objective Stressors				
RMBPC	0.247*** (0.048)			
MMSE		0.180 (0.099)		
IADL			0.843 (0.353)	
Subjective Stressors				0.525*** (0.062)
Burden				
Psychosocial Resources				
Positive Aspect				0.059 (0.047)
Religious Coping			0.123 (0.338)	
Social Network		-0.250 (0.158)		
Satisfaction with Social Support	-0.289 (0.167)			
Interaction				
Positive Aspect × Burden				-0.004* (0.002)
Religious Coping × IADL			-0.112* (0.049)	
Social Network × MMSE		-0.018** (0.008)		
Satisfaction with Social Support × RMBPC	-0.013* (0.006)			
Constant	8.983***	13.847**	10.985***	1.758
<i>R</i> <sup>2</sup>	0.241	0.155	0.108	0.395

Only significant interactions were presented in this table.

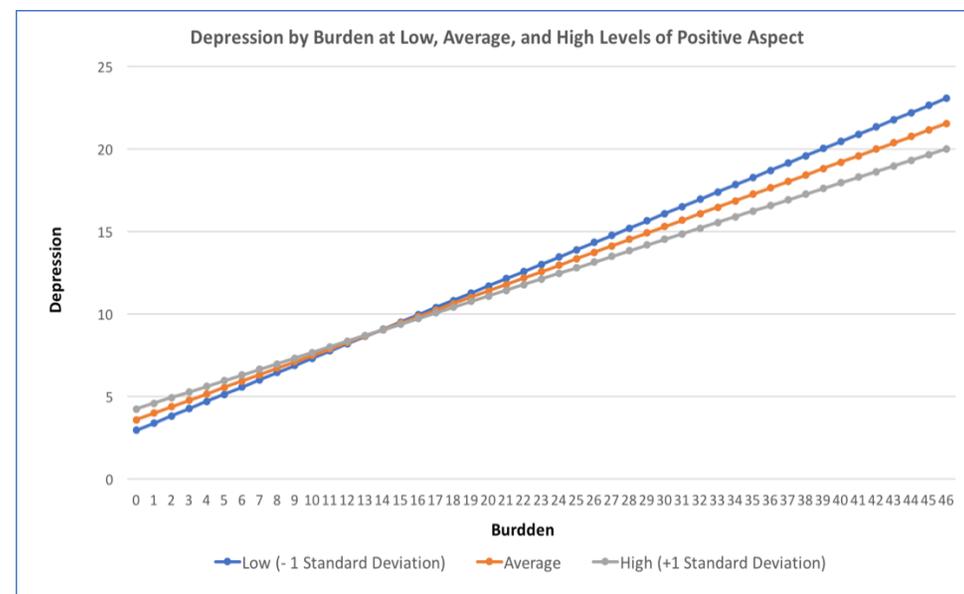
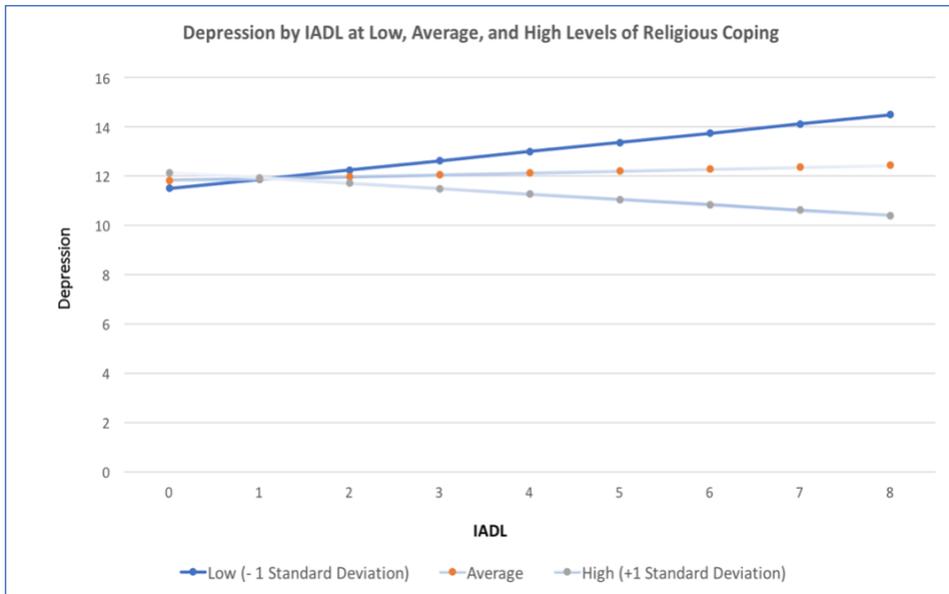
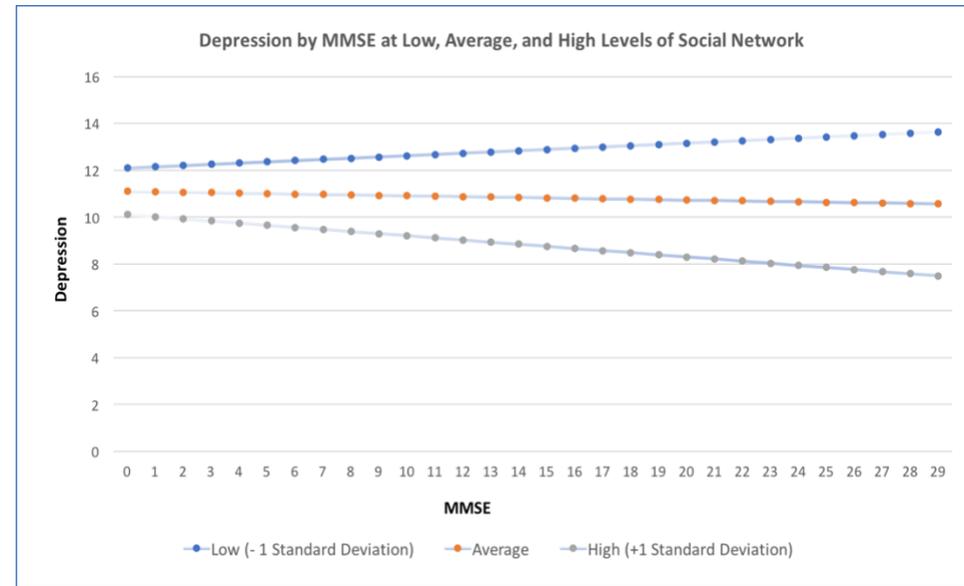
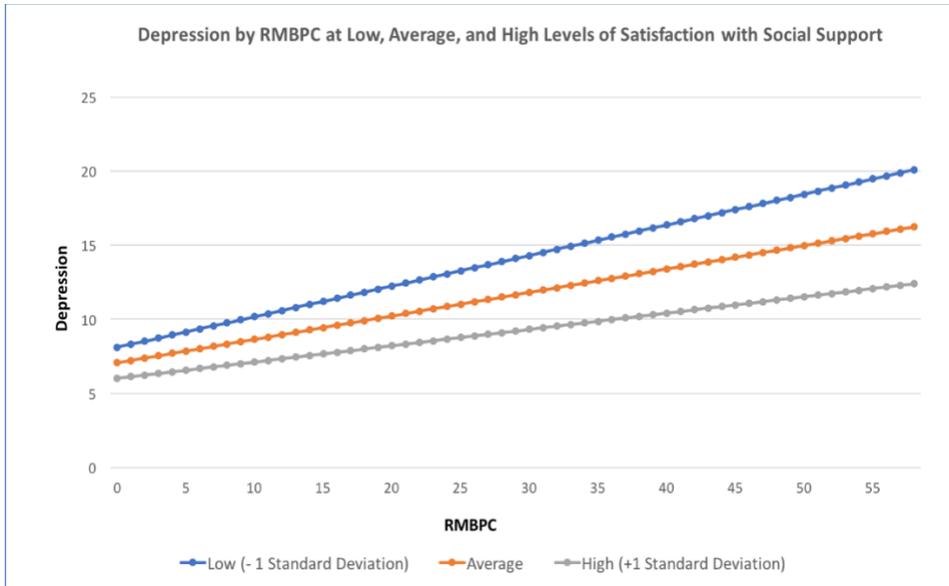
\* $p \leq 0.05$ . \*\* $p \leq 0.01$ . \*\*\* $p \leq 0.001$ .

RMBPC=Revised Memory and Behavior Problem Checklist; IADL = instrumental activities of daily living

Table 4.3 The Post-Hoc Probing Test of the Moderating Effects

		Slope	Std. Err.	t	P> t	[95% Conf. Interval]	
RMBPC	Lower Satisfaction with Social Support	0.207	0.033	6.35	0.000	0.143	0.270
	Medium level Satisfaction with Social Support	0.158	0.024	6.59	0.000	0.111	0.206
	Higher Satisfaction with Social Support	0.110	0.034	3.22	0.001	0.043	0.177
MMSE	Lower Social Network	0.053	0.048	1.110	0.266	-0.041	0.148
	Medium level Social Network	-0.018	0.034	-0.530	0.595	-0.086	0.049
	Higher Social Network	-0.090	0.048	-1.880	0.061	-0.184	0.004
IADL	Lower Religious Coping	0.374	0.182	2.060	0.040	0.017	0.730
	Medium level Religious Coping	0.078	0.137	0.570	0.570	-0.191	0.346
	Higher Religious Coping	-0.218	0.195	-1.120	0.264	-0.602	0.165
Burden	Lower Positive Aspect	0.438	0.031	14.06	0.000	0.376	0.499
	Medium Level Positive Aspect	0.390	0.024	16.16	0.000	0.343	0.437
	Higher Positive Aspect	0.342	0.032	10.62	0.000	0.279	0.406

Figure 2 The Moderating Effects of Psychosocial Resources



## Appendix A IRB Approval Letter



**Office of Research Compliance**  
Institutional Review Board  
North End Center, Suite 4120  
300 Turner Street NW  
Blacksburg, Virginia 24061  
540/231-3732 Fax 540/231-0959  
email [irb@vt.edu](mailto:irb@vt.edu)  
website <http://www.irb.vt.edu>

### MEMORANDUM

**DATE:** August 15, 2018  
**TO:** Michael D Hughes, Yuxin Zhao  
**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires January 29, 2021)  
**PROTOCOL TITLE:** Exploring the Effect of Burden among Alzheimer's Caregivers: A Test of The Stress Process Model  
**IRB NUMBER:** 18-728

Effective August 15, 2018, the Virginia Tech Institution Review Board (IRB) approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at: <http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

### PROTOCOL INFORMATION:

Approved As: **Exempt, under 45 CFR 46.101(b) category(ies) 4**  
Protocol Approval Date: **August 15, 2018**  
Protocol Expiration Date: **N/A**  
Continuing Review Due Date\*: **N/A**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

### FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

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