

IMPACT OF A PSYCHOEDUCATIONAL INTERVENTION
ON DEMENTIA CAREGIVING

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by
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University of Missouri-Kansas City, 2011

ABSTRACT

Of the 65.7 million caregivers in the United States (U.S.), approximately 14.9 million caregivers provide unpaid care for a person diagnosed with dementia. Most, about 80%, of this care is provided in the home and community settings. Past studies have shown positive results with psychoeducational interventions on caregiver health and stress. This study examined the impact of a psychoeducational intervention, the Family Series Workshop, on levels of coping, caregiving competence, and stress among caregivers ($N = 35$) of community-dwelling individuals with dementia. The Stress Process Model served as the conceptual framework. A non-controlled, pretest-posttest research design was employed. Caregivers were recruited for this study from three sites in a Midwestern metropolitan area: two churches and a hospital. Data were collected with paper/pencil questionnaires at baseline (Time 1) and post-intervention (Time 2). Using paired t -tests with random effect, caregiving competence significantly increased ($p = 0.036$) from Time 1 ($M = 11.6$ points) to Time 2 ($M = 14.6$ points). Although, caregiver's coping and stress did not change significantly, scores improved for coping

from Time 1 ($M = 58.6$ points) to Time 2 ($M = 72.6$ points) and stress from Time 1 ($M = 20.7$ points) to Time 2 ($M = 21.2$ points). Regression analysis was also used to examine the relationship between coping, caregiving competence, and stress. A significant association was found concerning the mediator coping and its association with caregiving competence ($p < 0.001$) and stress ($p = 0.008$). Caregiver competence was significantly correlated with stress ($p = 0.046$). Findings from this study provide empirical support that the Family Series Workshop may have positive effects on one's competency when providing care for a person with dementia. Furthermore, findings indicate that coping and stress are important components of the caregiving process. The next step in this program of research is to conduct a controlled study with a larger sample size to further examine the efficacy of the intervention.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Nursing have examined a dissertation titled “Impact of a Psychoeducational Intervention on Dementia Caregiving,” presented by Sarah Mariano Llanque, candidate for the Doctor of Philosophy degree, and certify that in their opinion it is worthy of acceptance.

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DEDICATION

For caregivers

CHAPTER 1

INTRODUCTION

More than 65.7 million adults, 29% of the United States (U.S.) population, provide care for an ill or disabled family member or friend during any given year (National Alliance for Caregiving and AARP, 2009). About a third of these caregivers are over the age of 50 and are predominantly female (National Alliance for Caregiving and AARP, 2009). The older adult population is the fastest growing group in the U.S. (U.S. Census Bureau, n.d.). Eighty percent of older adults have at least one chronic health condition, and 50% have two or more chronic conditions (Administration on Aging, 2010). Many older adults become debilitated due to their chronic illnesses and require late life caregiving assistance by a spouse, relative, or friend (Administration on Aging, 2010). Other individuals may require formal long-term care, which might include assistance with activities of daily living (ADLs) such as dressing, bathing, and toileting (Centers for Medicare & Medicaid Services, 2009). The number of older adults in the population has grown and continues to grow (Talley & Crews, 2007). Therefore, the issues surrounding caregiving of older adults have gained national attention (Centers for Disease Control and Prevention, 2010; National Alliance for Caregiving and AARP, 2009; National Family Caregivers Association, 2010).

Caregiving

The term *caregiver* refers to anyone who provides assistance and support to family members or acquaintances that have physical, psychological, or developmental needs (Family Caregiver Alliance, 2006a; National Library of Medicine, 2010). This unpaid care is equivalent to an estimated value of \$306 billion dollars annually in the

U.S. (Family Caregiver Alliance, 2006b). Approximately 43.5 million adult caregivers in the U.S. provide unpaid care to an elderly person over 50 years old (National Alliance for Caregiving and AARP, 2009). Recipients of care (care receivers) live in both community and institutional settings, such as nursing homes (Kart & Kinney, 2001). However, the majority (55%) of adult care receivers live in their home in the community, while less than 10% live in a nursing home or in an assisted living facility (National Alliance for Caregiving and AARP, 2009). Care receivers typically suffer from a chronic illness or disabling condition, requiring ongoing assistance with everyday tasks in order to function daily (Family Caregiver Alliance, 2006a; Kiecolt-Glaser et al., 2003).

Dementia

Dementia is a common chronic illness that negatively impacts the care receiver, the caregiver, as well as their families and friends. Dementia is characterized by the loss of or decline in memory and other cognitive abilities to the point of interfering in the ability to manage daily tasks and relationships (Albert et al., 2011; Jack et al., 2011; McKhann et al., 2011; National Institute of Neurological Disorders and Stroke [NINDS], 2010). Information transfer at the synaptic cleft fails as a result of damaged brain cells (neurons; Albert et al., 2011; McKhann et al., 2011; National Institute on Aging [NIA] and National Institutes of Health [NIH], 2008). Brain morphology of persons with advanced Alzheimer's shows widespread dead and dying neurons with dramatic cortical atrophy (NINDS, 2010). Memory loss, confusion of time or place, loss of executive function, and inevitable decline in performing activities of daily living often occur due to these physiological changes in brain tissue (Jack et al., 2011; McKhann et al., 2011; NINDS, 2010).

There are many types of dementias (NINDS, 2010; McKhann et al., 2011); however, the most common types are Alzheimer's disease (AD; 60% to 80%), vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, and Parkinson's disease dementia (NINDS, 2010). The life expectancy for individuals with dementia is anywhere from three to 20 years or more, depending on the type or types of dementia diagnosed (Alzheimer's Association, 2011). For example, life expectancy for persons with AD is eight to 10 years after initial diagnosis (NINDS, 2010). Since AD is the most common type of dementia, it is worth expounding on the pathophysiology of the disease as it relates to caregiving.

Alzheimer's Disease

As the most common type of dementia, AD currently affects 5.4 million people in the U.S. (Alzheimer's Association, 2011). This decline leads to cognitive deficits initially and later related physical decline in persons diagnosed with the disease (NIA and NIH, 2008). The progression of the disease may occur in different ways, but the most common symptom in the early stage of the disease is diminished short-term memory (NIA and NIH, 2008). For example, difficulty remembering names and the details of recent events are often early clinical symptoms of AD. Early disinterest in activities and depression may also occur (Alzheimer's Association, 2011).

As damage to neurons spreads, individuals often experience other difficulties such as a decrease in their communication skills, ability to make sound judgments, and disruptions in their sleep routine (NIA and NIH, 2008). Social behavior can also be affected (Melillo & Houde, 2010). Individuals can make rude or inappropriate remarks to friends, family members, or strangers (Alzheimer's Association, 2009). The later

stages of the disease manifest disorientation, impaired judgment, behavior changes, difficulty swallowing, and ambulation difficulties (NINDS, 2010). The risk of exhaustion and sleep deprivation increases to the point at which many caregivers *yield* their role as a caregiver to another—either transferring responsibilities to others such as a paid caregiver in the home or arranging for the institutional placement of the care receiver (Pearlin, Mullan, Semple, & Skaff, 1990).

Stress

The demands of caregiving increase as the disease progresses, placing caregivers at high risk for caregiver overload (or burnout) and poor health outcomes such as slow wound healing and lower immune system function resulting from the overwhelming demands of caring for a person with AD (Kiecolt-Glaser et al., 2003). As the disease progresses, many caregivers are not prepared for dealing with the neuropsychiatric symptoms, which often occur in the middle stages of dementia (Melillo & Houde, 2010). Approximately 60% to 80% of persons with dementia experience some type of neuropsychiatric symptom (Yaffe, 2007). These symptoms include agitation, resistance to care, emotional lability, delusions, hallucinations, repetitive vocalizations, wandering, depression, anger, and paranoia (Melillo & Houde, 2010). As the pathological course of dementia progresses, caregivers must continually monitor the care receiver (Stephens, Kinney, & Ogrocki, 1991). Pearlin et al. (1990) state that when efforts of the caregiver to satisfy daily and instrumental needs are met with resistance on the part of the care receiver, an increase in stress for the caregiver is more likely to result. The demands placed on the caregiver are associated with increased morbidity, stress, depression, as

well as a higher cost of care and reduced quality of life for the care receiver (Pearlin et al., 1990).

Primary versus Secondary Stressors

Stressors associated with caregiving are classified as either *primary* or *secondary* (Pearlin et al., 1990). *Primary stressors* stem directly from the needs of the care receiver and the nature and magnitude of the care demanded by these needs (Pearlin et al., 1990). Primary stressors include the declining cognitive status of the care receiver, problematic behaviors exhibited by the care receiver, ADLs, instrumental activities of daily living (IADLs), dependencies of the care receiver, caregiver overload, as well as relational deprivation of the caregiver due to the cognitive decline of the care receiver (Pearlin et al., 1990).

Primary stressors can lead to other problems and hardships called *secondary stressors* (Pearlin et al., 1990). These stressors include family conflict, job-caregiving conflict, economic problems, and restrictions of the caregiver's social life (Pearlin et al., 1990). Conditions, experiences, and activities that create stress in caregivers are those that threaten them, thwart their efforts, and fatigue them (Pearlin et al., 1990).

Effects of Chronic Stress

Chronic stress from caring for a person with dementia can accelerate the age-related decline of the immune response, resulting in an intensified risk for chronic illnesses (Kiecolt-Glaser et al., 2003). Not only do caregivers exposed to chronic stress exhibit poorer immune responses to viral challenges and experience slower rates of wound healing, but they also are at increased risk for developing mild hypertension and coronary artery disease (Grant et al., 2002; Kiecolt-Glaser et al., 2003). Exposure to

chronic stressors can also lead to caregiver overload and depression (Vitaliano et al., 2002). Caregivers have reported poorer perceived health and higher incidence of chronic illnesses than non-caregivers (Pruchno & Potashnik, 1989; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

Caregivers who reported higher levels of preparedness for caregiving experienced lower levels of caregiver strain (Archbold, Stewart, Greenlick, & Harvath, 1990; Schumacher, Stewart, & Archbold, 2007; Schumacher et al., 2008). For caregivers, high levels of perceived social support also predicted better-reported health status (Monahan & Hooker, 1995) and lower metabolic and cardiovascular risk (Vitaliano et al., 2002). However, many family caregivers are not prepared for the caregiver role (Schumacher, Beck, & Marren, 2006) and may not have received training or education about what to expect as AD progresses, nor how to deliver care related to dementia (Alzheimer's Association, 2011).

Caregiver Interventions

Interventions aimed at addressing the needs of caregivers of individuals with dementia could have an important positive impact on the caregiver, the care receiver, and society in general (Family Caregiver Alliance, 2006b; Schulz, 2000). Tailored caregiver support interventions have been found to reduce levels of stress, increase positive aspects of care, and decrease premature institutionalization of the care receiver (Belle et al., 2002; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Sörensen, Pinquart, & Duberstein, 2002). Providing education and support for caregivers has been shown to improve or maintain the quality of life among individuals with dementia and help caregivers cope with stressors (Belle et al., 2006; Gallagher-Thompson et al., 2003;

Ostwald et al., 1999). Tailored caregiver support interventions also enable the care receiver to safely remain in their own homes for longer periods of time, reducing social and economic costs (Arno, Levine, & Memmott, 1999).

Psychoeducational Interventions

Psychoeducational programs provide skill-building education to those who are diagnosed with a mental illness, such as dementia (Goldberg-Arnold, Fristad, & Gavazzi, 1999). Psychoeducational interventions can also be used with caregivers of persons with dementia. Psychoeducational programs enable caregivers to effectively cope with the problems and challenges associated with the disease process (Goldberg-Arnold et al., 1999). Both the care receiver and caregiver's own strengths, resources, and coping skills are reinforced in order to minimize crises and stress; this approach promotes the caregiver's own health and wellbeing on a long-term basis (Goldberg-Arnold et al., 1999). Psychoeducational programs have been shown to be highly beneficial for caregivers and care receivers (Goldberg-Arnold et al., 1999). Past studies have shown that increased knowledge about dementia and the use of positive coping skills significantly diminished the daily struggles with the illness (i.e., dementia; Goldberg-Arnold et al., 1999). The knowledge and enhancement of such coping skills helped caregiver-care receiver dyads to live with the disease process (Goldberg-Arnold et al., 1999).

Studies have shown that multifamily psychoeducational intervention groups reduced caregiver stress, which resulted in improve family and child functioning (Goldberg-Arnold et al., 1999). Belle et al. (2006) revealed that persons caring for patients with dementia who participated in a multicomponent caregiver intervention that

included psychoeducational interventions along with respite and counseling had lower rates of depression and an improved quality of life. Past studies strongly support the notion that the more understanding and knowledge the caregiver or family members have of the patient's illness, the better they will be able to care for themselves.

Significance of the Study

A growing number of psychoeducational interventions have undergone randomized controlled trials and have been found to significantly improve caregiver wellbeing, thereby reducing caregivers' levels of clinical depression (Belle et al., 2006; Schulz et al., 2002; Sørensen et al., 2002). Psychoeducational interventions differ in the specific format and manner in which components of information are presented to participants (Sørensen et al., 2002). Most psychoeducational programs are short-term, closed to outside participants once they begin, and not tailored to individual caregiver needs (Cummings, 1997; McCallion & Toseland, 1996). There is a need to evaluate the outcomes of other psychoeducational interventions that are tailored for and inclusive of caregivers of persons with dementia. Building on the findings of past studies, the aim of this dissertation was to evaluate the impact of a new psychoeducational intervention program called the Family Series Workshop, which was tailored for caregivers of persons with dementia.

Purpose

The purpose of this dissertation was to examine the impact of the Family Series Workshop on caregiver's coping, caregiving competence, and stress levels. The Family Series Workshop is a six-session, psychoeducational intervention that addresses common challenges of caregiving and provides vital information to help caregivers improve care

for the person with dementia. This grass-roots intervention had not been formally evaluated previously for efficacy with this population. A non-controlled, pretest-posttest research design was used to examine the impact of the intervention on coping, caregiving competence, and stress levels. The study sample consisted of informal, non-paid, adult caregivers of persons with dementia in the Midwestern region of the U.S.

Research Aim and Questions

The aim of this dissertation research was to examine the impact of the Family Series Workshop, a psychoeducational intervention, among caregivers of persons with dementia. *Coping* was hypothesized as the mediator that would result in enhanced caregiving competence and lower stress.

The research addressed two questions:

1. What is the impact of the Family Series Workshop psychoeducational intervention on the coping, caregiving competence, and stress levels of dementia caregivers from pre- to post-intervention?
2. What is the relationship between coping, caregiving competence, and stress among caregivers attending the Family Series Workshop psychoeducational intervention?

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter begins by presenting information regarding the rationale for utilizing psychoeducational interventions. A review of literature of the key concepts--coping, caregiving competence/knowledge, and stress--related to the conceptual framework follows. This chapter concludes with a discussion of the conceptual framework used to guide this intervention. The Stress Process Model (SPM) of Alzheimer's caregiving served as the conceptual framework for this dissertation (Pearlin et al., 1990).

Coping

Past research has regarded coping as a response to life's problems (Pearlin et al., 1990). Effective coping, in relation to the Stress Process Model, enables caregivers to confront and manage stressors that can result from their caregiving situation (Pearlin et al., 1990). In the Stress Process Model, coping serves as a mediator (Pearlin et al., 1990). Coping buffers caregivers from the intensity of certain stressors, which they experience (Pearlin et al., 1990). More specifically, coping reduces perceived threats and enables caregivers to manage their circumstances, reducing caregiver stress (Pearlin et al., 1990). Psychoeducational interventions may have the potential to impact caregiver's coping skills. However, few psychoeducational studies were found that examined the concept of caregiver coping. The following psychoeducational intervention studies examined coping as an outcome variable.

Chiverton and Caine (1989) assessed outcomes of a psychoeducational program using a quasi-experimental research design. This program evaluated the coping skills of spousal caregivers' of persons with AD using the *Health Specific Family Coping Index*

(Choi, Josten, & Christensen, 1983). The intervention included three home visits, each about two hours long, by a registered nurse. The intervention consisted of didactic and group discussion regarding disease process, communication skills, behavioral management techniques, basic strategies about ADLs, and community resources (Chiverton & Caine, 1989). Learning about how the disease is diagnosed, as well as the disease process, can help persons with dementia and their caregivers reframe the way they view their situation, which can have a positive effect on their ability to cope with dementia (Nolan, Grant, & Keady, 1996). Past studies have shown that the cognitive strategy of reframing has been associated with improved psychological well-being (Aldwin & Revenson, 1987; Carver et al., 1993; Ducharme, Lévesque, Lachance, Giroux, Legault, & Prévaille, 2005).

A registered nurse completed the *Health Specific Family Coping Index* to assess coping outcomes in caregivers prior to the intervention and at the end of the four-week intervention period (Chiverton & Caine, 1989). Results showed that the treatment group ($n = 14$) had improved coping scores, which increased from a mean score of 30.60 points ($SD = 4.39$) to 32.80 points ($SD = 4.47$). The control group ($n = 15$) had a mean change of 28.90 points ($SD = 3.19$) to 29.15 ($SD = 3.24$) post-intervention. A t -test was performed on the pre- and post-intervention total coping score of the intervention and control groups. Spousal caregivers in both the intervention and control groups showed a significant improvement in coping ($t = 4.09, p < 0.004$). A psychoeducational intervention may improve spousal caregiver's ability to cope with the daily demands of caregiving. Significant changes in three coping sub-categories of the *Health Specific*

Family Coping Index included therapeutic competence ($t = 2.85, p < 0.01$), knowledge ($t = 4.01, p < 0.001$), and emotional competence ($t = 2.35, p < 0.03$).

The *Coping with Caregiving* intervention, previously described in the Caregiver Stress section of this chapter, also evaluated coping in caregivers of persons with dementia (Gallagher-Thompson et al., 2003). Caregivers in the treatment group received cognitive-behavioral mood management skills, relaxation and cognitive appraisal techniques, and communication skills (Gallagher-Thompson et al., 2003). The relationship between positive interactions and mood in the care receiver was identified (Gallagher-Thompson et al., 2003). Caregivers learned to reward themselves in caregiving accomplishments throughout the study (Gallagher-Thompson et al., 2003). Findings from this intervention revealed a significant increase in use of adaptive coping strategies (Gallagher-Thompson et al., 2003).

The Coping with Caregiving study outcomes showed a decrease in the use of negative coping strategies in caregivers in the comparison group. Coping was evaluated by using the 57-item, *Revised Ways of Coping Checklist* (Gallagher-Thompson et al., 2003; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985). A subscale of this instrument is the *Positive Coping* subscale, which was used to evaluate this intervention (Gallagher-Thompson et al., 2003). This subscale showed a significant intervention effect, $F(1,179) = 4.95, p = 0.05$. Negative interactions of the caregiver and care receiver dyads were significantly decreased in the treatment group, $F(1,179) = 5.21, p = 0.05$ (Gallagher-Thompson et al., 2003). The findings indicated that participants in the treatment group increased their use of positive coping strategies more than those in the comparison group (Gallagher-Thompson et al., 2003; Vitaliano et al., 1985).

The *Taking Care of Myself* psychoeducational intervention, also evaluated coping strategies of caregivers of persons with dementia (Ducharme et al., 2005). The *Carers' Assessment of Managing Index* was utilized to evaluate caregiver's coping levels (Nolan et al., 1996). Caregivers gained competence dealing with health care staff when measured from baseline (two weeks prior to the intervention start date) to post-intervention (10 weeks after the start of the intervention; Ducharme et al., 2005). Caregivers were also able to cope with perceived challenges of the caregiver role (Ducharme et al., 2005). Both the treatment and comparison groups showed a significant increase in the use of cognitive reframing, a coping strategy (Ducharme et al., 2005).

There is inconclusive evidence that coping levels increase through psychoeducational interventions. Based on past research (Chiverton & Caine, 1989; Ducharme et al., 2005; Gallagher-Thompson et al., 2003), findings from coping outcomes provide researchers with a basis for developing future studies. Psychoeducational interventions may be helpful to increase caregiver coping skills, which may help caregivers manage the stressors associated with caregiving (Gallagher-Thompson et al., 2003).

Knowledge and Caregiving Competence

Knowledge

Knowledge is defined as facts, information, and skills acquired by a person through experience or education (Oxford University Press, 2010). Caregivers who receive knowledge in the form of information and advice, as well as support, can achieve satisfactory outcomes for themselves and the care receivers (Nolan et al., 1996). Other studies showed that knowledge and skill building enabled caregivers to better carry out

sophisticated tasks for persons with dementia (Ostwald et al., 1999). Only two psychoeducational intervention studies (Chiverton & Caine, 1989; Munro, 2005) have measured caregiver knowledge in the past two decades (1989 to 2010) to the knowledge of the investigator. Both studies used different scales to evaluate caregiver knowledge. These scales are the *Alzheimer's Disease Knowledge Test* (Dieckmann, Zarit, Zarit, & Gatz, 1988; Morano & Bravo, 2002) and the knowledge domain of (part of a coping instrument; Chiverton & Caine, 1989).

Chiverton and Caine's (1989) study assessed caregiver knowledge in caregivers of persons with AD. The study included content about managing behavioral problems in persons with AD, finding home and community-based services, and information to assist families in keeping the care receiver at home (Chiverton & Caine, 1989). Caregiver knowledge was evaluated with a specific subscale of the *Health Specific Family Coping Index* (Chiverton & Caine, 1989). The treatment group showed the greatest significant increase in the knowledge domain ($t = 4.01, p < 0.001$; Chiverton & Caine, 1989).

A quasi-experimental pilot study by Morano and Bravo (2002) tested a psychoeducational intervention for Hispanic caregivers of persons with AD. This study evaluated caregiver knowledge of the progression and treatment of AD using the *Alzheimer's Disease Knowledge Test* (Dieckmann et al., 1988; Morano & Bravo, 2002). The intervention included a 20-hour psychoeducational program, which met on five consecutive mornings from 9 a.m. to 1 p.m. (Morano & Bravo, 2002). Outcomes showed a significant improvement on the *Alzheimer's Disease Knowledge Test* (Morano & Bravo, 2002; Dieckmann et al., 1988). The caregivers scored significantly lower on the pretest, $t(38) = 2.51, p < 0.05$, than on the posttest, $t(19) = 3.23, p < 0.05$ (Morano &

Bravo, 2002). Caregiver's knowledge was significantly improved after the implementation of the intervention (Morano & Bravo, 2002).

Caregiving Competence

Competence is defined as the ability to do something successfully or efficiently (Oxford University Press, 2010). This concept has been rarely measured among dementia caregivers. However, Marilyn M. Skaff and colleagues developed and tested the *Caregiving Competence Scale* with dementia caregivers in order to measure the concept of caregiving competence in caregivers (Pearlin et al., 1990). This scale revealed good internal consistency ($\alpha = 0.74$) and validity. One past study called the *Savvy Caregiver Intervention*, utilized the *Caregiving Competence Scale* in measuring caregiver competence with dementia caregivers (Hepburn, Lewis, Sherman, & Tornatore, 2003).

The Savvy Caregiver psychoeducational intervention study (Hepburn et al., 2003) assessed caregiving competence in caregivers of persons with dementia using the *Caregiving Competence Scale*. The study findings revealed that competence did not significantly increase from baseline on their pretest score, 2.48 points, to their posttest score 2.47 points ($p = 0.941$; Hepburn et al., 2003). Researchers were not prepared for this finding. Although the researchers do not specifically discuss this result in further detail, past studies have shown that adult caregivers and spousal caregivers in shared households experience similar levels of stress (Deimling, Bass, Townsend, & Noelker, 1989). In the Savvy Caregiver psychoeducational intervention study, caregiving daughters tended to rate the program as slightly less relevant to them than did caregiving spouses (Hepburn et al., 2003). In spite of these findings, the researchers concluded that competence should be evaluated in psychoeducational intervention to see if this variable

has changed in caregivers. Caregiver competence is important for success in the caregiver role (Hepburn et al., 2003).

Caregivers who lack preparedness and self-confidence in their role as caregivers often experience heightened levels of stress (Pearlin et al., 1990). This higher stress could work to the detriment of the care receiver and the family providing care. Few psychoeducational intervention studies have examined caregiver competence, an area of future research that warrants further exploration and would add to the field of caregiving research.

Stress

Caring for a family member with dementia can be particularly stressful and may contribute to psychiatric and physical illness among caregivers (Ferrara et al., 2008; Kiecolt-Glaser et al., 2003). Caregiving can also increase caregiver morbidity and mortality (Kiecolt-Glaser et al., 2003). Psychoeducational interventions have been shown to have a positive impact on the health and wellbeing of caregivers (Belle et al., 2006; Sörensen et al., 2002). Caregiver stress is sometimes labeled as ‘burden’ in the literature. There is a shift away from the use of the term *caregiver burden*, because some caregivers may not perceive caregiving as a burden (Arevalo-Flechas, 2009). Therefore, in this dissertation, *stress* was used to refer to the negative consequences associated with providing care to a person with dementia.

The REACH II study was a multi-site and randomized controlled trial, which used psychoeducational interventions to enhance family caregiving for persons with dementia (Belle et al., 2006). The REACH II study was guided by the results from the REACH I study (Wisniewski et al., 2003) that investigated various theory-driven interventions

(Gallagher-Thompson, Gray, Dupart, Jimenez, & Thompson, 2008). In the REACH II study, the intervention was tailored to meet specific needs of the caregiver, based on the caregiving situations and the ethnic diversity of caregivers (Belle et al., 2006).

Caregivers who provided care to the care receiver for at least four hours per day were included in the study (Belle et al., 2006). The intervention included ten home visits by trained personnel, who provided information; didactic instruction, role playing, problem solving, skills training, stress management techniques, and telephone support groups (Belle et al., 2006). REACH II also included five follow-up phone calls from trained personnel through an innovative computer-telephone technology system over the course of six months. The follow-up provided information and emotional support to caregivers (Belle et al., 2006). When comparing outcomes between Caucasian, Hispanic, and African American caregivers, results showed that the intervention significantly reduced caregiver stress in all caregivers; pretest and posttest scores were not shown in the article (Belle et al., 2006). Caregiver stress alone improved 15.8% ($n = 212$) in Hispanic caregivers, 9.4% ($n = 219$) in Caucasian caregivers, and 31.3% ($n = 211$) in African American caregivers (Belle et al., 2006). The REACH II study demonstrated a reduction in caregiver stress, thereby indicating that caregiver stress can be reduced by psychoeducational intervention.

Ducharme and her colleagues' (2005) Taking Care of Myself intervention targeted daughter caregivers of persons with dementia residing in a long-term care facility. Thus, the caregivers were not cohabiting with their elderly relative. The intervention consisted of ten, 90-minute weekly sessions for groups of six to eight caregivers. The intervention utilized a participatory action and mixed method approach

to implement a psychoeducational intervention to reduce caregiver stress ($n = 137$). The intervention included strategies to help caregivers feel at ease when interacting with the care receiver and to help them express their concerns to health care staff. These strategies included coping (e.g., cognitive reframing and accepting the diagnosis of the care receiver), empowerment, and self-care strategies for the caregiver. Study outcomes showed no significant differences in stress levels at 10 weeks post-intervention, across all groups, the Taking Care of Myself intervention group ($n = 45$), a comparison group (standard Alzheimer's support group; $n = 51$), and a control group (no treatment; $n = 41$) using the *Stress Appraisal Measure* (Peacock & Wong, 1990).

However, further analysis of the data using prediction analysis, a method of specifying change scores according to quartiles, showed efficacy of treatment conditions (Ducharme et al., 2005). More caregivers in the experiment group than those in the control group had successful outcomes predicted across all outcomes measured (51.1% to 71.1%) in the study, including stress and coping; the study did not specify percentages specifically for stress and coping (Ducharme et al., 2005). For the caregivers in the control group, the inverse was observed, as fewer of these caregivers obtained non-predicted successful outcomes (29.3% to 41.5%) including stress and coping (Ducharme et al., 2005). These findings contradicted previous caregiver studies that had positive outcomes on reducing caregiver stress levels. Contradictory findings from this study may have been attributed to the fact that caregivers were caring for an institutionalized care receiver and were not full-time caregivers. This difference in the caregiver role could be the reason why caregiver stress levels were not significantly affected by the intervention.

The *Coping with Caregiving* intervention was an updated version of the *Coping with Frustration* intervention—part of the REACH II study (Gallagher-Thompson et al., 2003; Gallagher-Thompson, Solano, Coon, & Areán, 2003). The Coping with Caregiving intervention utilized an experimental design and taught a variety of cognitive and behavioral skills to reduce stress in Caucasian ($n = 95$) and Hispanic ($n = 89$) female caregivers of persons with dementia (Gallagher-Thompson et al., 2008). The intervention lasted approximately two hours per week over 10 weeks. The intervention had one post-treatment assessment completed at six months after baseline assessment (Gallagher-Thompson et al., 2008). The 10-item *Perceived Stress Scale* was utilized to measure stress in dementia caregivers (Cohen & Williamson, 1988). Posttest scores were significantly lower in the experimental group than in the comparison group, from 18.92 points to 15.97 points, $p = 0.000$, in Caucasian caregivers ($n = 50$). Hispanic caregivers ($n = 42$) in the intervention group also scored significantly lower on caregiver stress, from 18.02 points to 15.23 points, $p = 0.022$. These findings indicated that caregivers in the intervention group who received psychoeducation to reduce their stress, showed significantly greater improvement than those in the comparison group (Gallagher-Thompson et al., 2008).

Another randomized controlled trial, known as Savvy Caregiver, evaluated the effectiveness of an interdisciplinary psychoeducational family group intervention in decreasing caregiver stress (Ostwald et al., 1999). The 22-item revised *Caregiver Burden Scale* was used to measure caregiver stress (Zarit, Orr, & Zarit, 1987). The intervention consisted of two-hour multimedia training sessions over seven weeks (Ostwald et al., 1999). Education, family support, and skills training related to the role of caregiving

were delivered through the use of psychoeducation (Ostwald et al., 1999). Caregiver stress significantly decreased from pretest ($t = 40.40$) to posttest scores ($t = 38.13$; $p = 0.047$) in caregivers in the experimental group ($n = 63$; Ostwald et al., 1999). Findings suggested that the intervention was effective in improving caregiver stress as reported by caregivers following the Savvy Caregiver intervention (Ostwald et al., 1999). Caregiver competence was also evaluated in the study and will be discussed later.

Synthesis of the Review of the Literature

In summary, a number of studies have shown that psychoeducational interventions have a positive effect on caregivers' coping skills and stress. Table 1 provides a grid of the interventions tested and outcomes evaluated related to the concepts of coping, competence, knowledge, and stress.

Table 1*Psychoeducational Interventions and Measurements*

Intervention (Author)	Sample Size (<i>n</i>)	Concepts Measured	Scales
Education to Assist Spouses in Coping with Alzheimer's Disease (Chiverton & Caine, 1989)	Spousal caregivers of persons with AD (<i>n</i> = 29)	Coping and Knowledge	Health Specific Family Coping Index (Choi et al., 1983)
Psychoeducational Model for Hispanic Alzheimer's Disease Caregivers (Morano & Bravo, 2002)	Hispanic caregivers of persons with AD (<i>n</i> = 20)	Knowledge	Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988)
Coping with Caregiving (Gallagher-Thompson et al., 2003)	Female non-Hispanic white (<i>n</i> = 95) and Hispanic/Latina (<i>n</i> = 89) caregivers of persons with dementia	Coping	Positive Coping Subscale derived from the Revised Ways of Coping Checklist (Vitaliano et al., 1985)
		Stress	Perceived Stress Scale (Cohen & Williamson, 1988)
Savvy Caregiver (Hepburn et al., 2003)	Caregivers of persons with dementia (<i>n</i> = 140)	Competence	Caregiving Competence Scale (Pearlin et al., 1990)
		Stress	Caregiver Burden Scale (Zarit et al., 1985)

Table continues

Intervention (Author)	Sample Size (<i>n</i>)	Concepts Measured	Scales
Taking Care of Myself (Ducharme et al., 2005)	French-speaking daughter caregivers of institutionalized persons with AD (<i>n</i> = 137)	Coping Stress	Carers' Assessment of Managing Index (Nolan et al., 1996). Stress Appraisal Measure (Peacock & Wong, 1990)
REACH II (Belle et al., 2006)	Hispanic caregivers (<i>n</i> = 212), Caucasian caregivers (<i>n</i> = 219), and African American caregivers (<i>n</i> = 211) of persons with dementia	Stress	Brief Zarit Burden Interview (Bédard et al., 2001)

Past psychoeducational caregiving interventions also have been shown to increase caregiver knowledge about the disease and community resources (Sörensen et al., 2002; Thompson et al., 2007). A meta-analysis evaluated the effectiveness of 78 intervention studies with caregivers (Sörensen et al., 2002). Researchers found that psychoeducational interventions showed the most consistent and improved short-term impact on caregiver stress and knowledge (Sörensen et al., 2002).

Caregivers can also be trained to succeed in their new roles as caregivers with less detriment to themselves (Belle et al., 2006; Gallagher-Thompson & DeVries, 1994). Two National Institute for Nursing Research (NINR)-supported, randomized, controlled trials demonstrated that psychoeducational interventions were effective in reducing caregiver stress (Belle et al., 2006; Ostwald et al., 1999). Other psychoeducational interventions have demonstrated beneficial outcomes regarding coping, delay of institutionalization of the care receiver, and care receiver mortality (Chiverton & Caine, 1989; Gallagher-Thompson et al., 2000; Gallagher-Thompson et al., 2003). It is important for caregivers to benefit from successful, psychoeducational, research-based interventions.

Teaching specific skills for reducing caregiver stress is the focus of psychoeducational interventions. However, the content and delivery of these interventions vary widely (Sörensen et al., 2002). Psychoeducational interventions assist caregivers in the management of stress over a series of time-limited meetings (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003). Usually, groups of caregivers are kept at less than 10 persons per group (Gallagher-Thompson et al., 1997). The rationale for this small group size is to ensure adequate individual attention for each

participant (Gallagher-Thompson & DeVries, 1994). Typically, each session utilizes interactive learning to teach caregivers a series of psychological skills (Gallagher-Thompson et al., 1997). For example, relaxation skills can be taught using a brief relaxation exercise that includes deep breathing, guided imagery, and cognitive reframing (Gallagher-Thompson & DeVries, 1994; Knight, 2004).

Psychoeducational interventions provide problem-solving strategies that have shown effectiveness in reducing emotional distress (D'Zurilla, 1986). These interventions have targeted diverse populations, including caregivers of persons with dementia (Belle et al., 2006; D'Zurilla, 1986). Psychoeducational interventions are noted to be helpful in minimizing stress, addictive behaviors, and depression of dementia caregivers (D'Zurilla, 1986). Providing problem-solving skills can reduce caregiver stress (Gallagher-Thompson et al., 1997). Caregiver stress was significantly reduced when caregivers received information, advice, and support related to caregiving (Nolan et al., 1996). Time after time, these interventions have shown effectiveness in improving caregivers' stress and coping (Melillo & Houde, 2010).

Past studies have demonstrated the effectiveness of group interventions rather than individual instruction (Sörensen et al., 2002). Group settings promote the exchange of experiences and techniques of caregiving, and shared learning amongst caregivers (Sörensen et al., 2002). Findings from a randomized controlled trial found group instruction to be effective in behavior management and problem solving among dementia caregivers (Belle et al., 2006; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Taylor, David, Fields, Phillips, & Scherger, 2005). Families experienced decreased

stress, less depression, and enhanced physical health (Belle et al., 2006; Mittelman et al., 1996; Taylor et al., 2005).

Some psychoeducational intervention studies have demonstrated mixed findings (Belle et al., 2006; Ducharme et al., 2005; Ostwald et al., 1999; Sørensen et al., 2002). Some studies contradict the effectiveness of psychoeducational interventions on caregiver stress and coping. A meta-analysis refuted the rationale for psychoeducational intervention among caregivers (Sørensen et al., 2002). Instead of solely relying on psychoeducational interventions, the study found that multi-component interventions significantly decreased caregiver stress (Sørensen et al., 2002). Multicomponent interventions include psychoeducation, respite, counseling, or support groups (Sørensen et al., 2002).

Findings from most research studies, systemic reviews of the literature, and meta-analyses suggest that psychoeducational interventions are beneficial for caregivers. These studies indicate that psychoeducational interventions have a positive effect on caregiver's coping, knowledge/competence, and stress levels. These interventions equip caregivers with knowledge and skills needed to cope with stressors of caregiving. More research is needed to further examine the impact that psychoeducational interventions have on the prevention and reduction of caregiver stress. Such interventions have the potential to prevent caregiver burnout and to maintain, improve, and optimize their physical health.

Conceptual Framework

The Stress Process Model of Alzheimer's Caregiving served as the conceptual framework for this dissertation (Pearlin et al., 1990). The model explains the

consequences of caregiving and interrelationships of several factors related to caregiver stress. These factors include the background of the caregiver and contextual caregiving situation, the primary and secondary stressors to which caregivers are exposed, and the caregiver's appraisal of these stressors (Pearlin et al., 1990). The model points to *coping* and *social support* as variables that mediate the impact of stress from caregiving (Pearlin et al., 1990). Through the application of the Stress Process Model, this study evaluated the impact of a psychoeducational intervention, called the Family Series Workshop, on caregivers' coping, competence, and stress levels. Coping was hypothesized as the interventional mediator that changed stress and competence levels.

In the Stress Process Model, caregiving is comprised of the interrelationships of several factors including: (a) background and context of the caregiving situation, (b) primary stressors, (c) secondary role strains, (d) secondary intrapsychic strains, (e) outcomes, and (f) mediators (Pearlin et al., 1990). Figure 1 depicts the Stress Process Model with its concepts, constructs, and mediators.

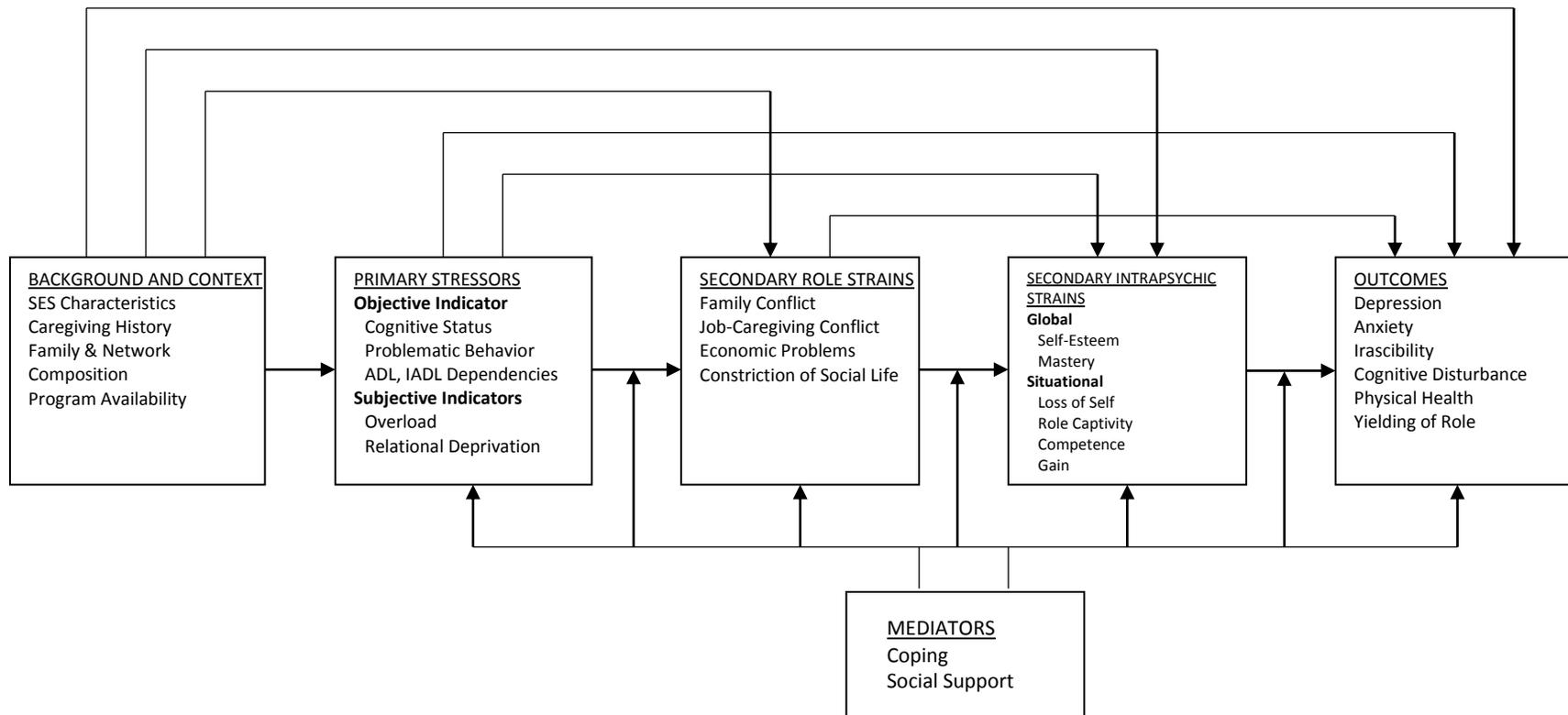


Figure 1. The Stress Process Model of Alzheimer's Caregiving. This figure illustrates the domains that make up the Stress Process Model of Alzheimer's caregiving. From—"Caregiving and the stress process: An overview of concepts and their measures," by L. I. Pearlin, J. T. Mullan, S. J. Semple, and M. M. Skaff, 1990, *The Gerontologist*, 30, 583-594. Copyright 1990 by The Gerontological Society of America. Used with permission (see Appendix N).

Background and Context

The first concept in this model includes the background of the caregiver and the contextual situation (Pearlin et al., 1990). Age, gender, ethnicity, along with educational, occupational, and socioeconomic status influence the caregiver and their caregiving experience (Pearlin et al., 1990). The intensity of the stressors to which caregivers are exposed depends on the personal and social resources available to caregivers (Pearlin et al., 1990). For example, the lack of financial resources reduces nursing home placement of care recipients (Aneshensel, Pearlin, & Schuler, 1993).

For this study the investigator collected the following demographic information: relationship between the caregiver and person with dementia, race, ethnicity, age, gender, caregiver employment status, length of caregiving, living situation of the person with dementia, caregiver education level, stage of dementia of the person with dementia, type of dementia, and whether the caregiver was experiencing financial strain.

Mediator

The second concept, coping, was regarded as a mediator. A mediator is a variable that implies a causal hypothesis: an independent variable (e.g., psychoeducation) causes a mediator (e.g., coping), which then affects a dependent variable (e.g., caregiver stress; MacKinnon, 2008). Mediator variables provide a clearer interpretation of the relationship between the two variables (Pearlin et al., 1990). In this model, coping represents behaviors and practices of caregivers. Coping has three possible functions: (a) management of a stressful situation, (b) management of the situation's meaning for stress

reduction, and (c) management of the stress symptoms that result from the caregiving situation (Pearlin et al., 1990).

Previous research has shown that people use coping skills or strategies in nearly every type of stressful encounter (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). For example, problem-focused forms of coping include rational and deliberate efforts to solve problems (Folkman et al., 1986). Coping skills can be enhanced through psychoeducation (Chiverton & Caine, 1989; Folkman et al., 1986; Pearlin et al., 1990). The effects of coping on the stress associated with caregiving can reduce the negative health outcomes of the stress process, including depression, anxiety, declining physical health, and improve or strengthen the role of the caregiver (Pearlin et al., 1990).

Stressors

Stress is a key concept of the Stress Process Model of Alzheimer's caregiving. Stress or stressors are the conditions, experiences, and activities that "threaten the [caregiver], thwart their efforts, fatigue them, and defeat their dreams" (Pearlin et al., 1990, p. 587). Stressors are categorized as *primary* and *secondary*.

Primary Stressors. Primary stressors stem from the needs of the care receiver, and the intensity of the care demanded by the needs of the care receiver (Pearlin et al., 1990). Instances of primary stressors include: cognitive status of the care receiver, daily task needs of the care receiver, and/or neuropsychiatric symptoms associated with the progression of dementia (Pearlin et al., 1990). For example, the more dependent and impaired the person with dementia, the greater the amount and difficulty of work a caregiver must perform for them. Memory loss, communication deficits, and failure to

recognize loved ones can cause primary stress for the caregiver (Pearlin et al., 1990). Primary stressors can lead to other problems and hardships otherwise known as secondary stressors (Pearlin et al., 1990).

Secondary Stressors. Secondary stressors include secondary role strains and secondary intrapsychic strains. Secondary role strains often include family conflict, job-caregiving conflict, economic problems and limitations placed upon the caregiver's social life (Pearlin et al., 1990). Role strains are found in roles and activities outside the caregiving situation (Pearlin et al., 1990). For example, economic strains due to the cost of buying disposable incontinence briefs and other special supplies can contribute to stress. Additionally, constant supervision of the person with dementia, especially in the middle stage of the disease, can lead to marked constriction of the caregiver's social life (Pearlin et al., 1990).

Secondary intrapsychic strains are another type of secondary stressor. Secondary intrapsychic strains involve dimensions of self-concept. Past research has indicated that under conditions of enduring hardships, a person's self-concepts may be negatively altered (Pearlin et al., 1980). When this occurs, caregivers are more likely to suffer symptoms of depression (Powers, Gallagher-Thompson, & Kraemer, 2002). Caring for a person with a chronic disease or ailment fits this scenario. The relentless and expanding demands of caregiving along with ensuing secondary role strains are capable of diminishing positive elements of self in caregivers (Skaff & Pearlin, 1992). Caregivers are at risk for low self-esteem and may feel that they have no control over certain areas of their life circumstances (i.e., mastery; Skaff & Pearlin, 1992), which in turn, can leave caregivers increasingly vulnerable to stress outcomes (Pearlin et al., 1990).

Outcomes

The outcomes presented in the Stress Process Model are the effects that are usually observed as a person takes on the role of caregiver (Pearlin et al., 1990). Outcomes involve the well being of people, their physical and mental health, and their ability to sustain themselves in their social roles. Numerous research studies have shown an association among stressors and two factors, caregiver health and depression (Coon et al., 2003; Schulz, 2000). Compared with non-caregivers, caregivers who provide care to a spouse with a stroke or dementia reported more infectious illnesses, poorer immune responses, slower wound healing, and more vascular diseases (Kiecolt-Glaser et al., 2003).

The Stress Process Model guided this research. Past studies have supported psychoeducational interventions as one method to provide caregivers with the necessary coping strategies to reduce stress associated with the caregiving role. The Family Series Workshop intervention consists of a curriculum and individualized strategies to prepare and support caregivers of persons with dementia. The Family Series Workshop intervention, as conceptualized in the Stress Process Model model's framework, aims to enhance coping, increase competence, and decrease stress levels. Information and cognitive strategies may help caregivers to develop more effective coping skills, increase their competence level, improve their awareness of home and community-based services, and decrease caregiver stress.

Summary of the Conceptual Framework

In summary, the Stress Process Model of Alzheimer's caregiving guided this dissertation. The framework of the Stress Process Model addressed the interrelationships

of coping, caregiving competence, and caregiver stress. The Stress Process Model supported an approach of using psychoeducational interventions, such as the Family Series Workshop, with caregivers of persons with dementia. Pearlin et al. (1990) expressed the importance of using the Stress Process Model as an evolving learning or discovery framework, based upon context, rather than a framework to be strictly followed. The Stress Process Model is a useful framework to evaluate the influence of psychoeducational interventions on the stress process in family caregivers of persons with dementia. By applying the key concepts of caregiver coping, caregiving competence, and stress as they relate to the Family Series Workshop intervention, a modified version of the Stress Process Model provides a starting point for examining the outcomes of the intervention (see Figure 2).

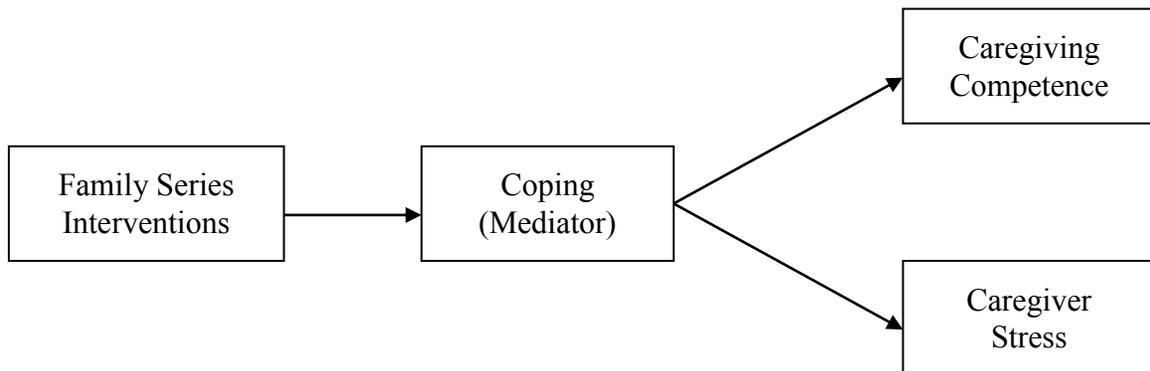


Figure 2. Model of the Family Series Workshop Intervention. This figure illustrates the key concepts of the Family Series Workshop intervention as it relates to the Stress Process Model.

CHAPTER 3

METHODOLOGY

The purpose of this study was to examine the impact of a psychoeducational intervention, the Family Series Workshop, on coping, caregiving competence, and stress levels of unpaid caregivers (e.g., family members) who were providing care to community-dwelling persons with dementia. This study was guided by the Stress Process Model of Alzheimer's caregiving (Pearlin et al., 1990). A non-controlled, pretest-posttest design was used to examine changes on participants' coping, caregiving competence, and stress levels (Shadish, Cook, & Campbell, 2002).

Intervention

The Family Series Workshop intervention was developed by Michelle Niedens, L.S.C.S.W., who is the Director of Education, Programs, and Public Policy for a non-profit Alzheimer's organization in Kansas City. The intervention for this study consisted of six weekly psychoeducational sessions for caregivers in a group setting. The intervention was designed to enhance the caregiving skills of caregivers who were currently providing care for persons with dementia. Additionally, the intervention was intended to help caregivers who were caring for a person in the later stages of dementia. The intervention's curriculum was guided by constructs of the Stress Process Model (Appendix A; Pearlin et al., 1990). Resources for in-home care and information regarding placement of the care receiver in long-term care were discussed. The group intervention included caregivers of persons with dementia whose condition varied in severity of cognitive decline. Caregivers chose their preferred workshop session from a variety of caregiving topics (Appendix B).

Six educational sessions were provided to caregivers. Caregivers met weekly for one hour and 30 minutes for each session. These sessions included information regarding resources available to help caregivers provide care. Resources pertaining to a particular session's topic were discussed. Skills provided at each session to caregivers of persons with dementia are presented in Appendix C. A question and answer session followed each session with the participants. Handouts and presentation materials were distributed to caregivers at every session. A health care professional with a minimum of a Bachelor's degree in the field of social work, nursing, or pharmacy or a background in gerontology with in-depth knowledge about caregiving and dementia, delivered the psychoeducational sessions to caregivers.

Design

This study used a non-controlled, pretest-posttest design (Shadish et al., 2002) to examine the impact of a psychoeducational intervention, the Family Series Workshop, to adult nonpaid caregivers of individuals with dementia. Outcome variables of interest to this study were coping, caregiving competence, and stress. Coping was hypothesized as the interventional mediator. The Family Series Workshop intervention aimed to enhance coping, increase the level of competency for caregiving, and reduce caregiver stress level. Data were collected at two time points: pre-intervention (Time 1) and post-intervention (Time 2).

Sample

Family caregivers of persons with dementia living in a Midwest metropolitan area participated in the study. Inclusion criteria for this study were: (a) non-paid caregiver, (b) family member, and (c) caring for a person requiring various levels of caregiving due to

dementia. The inclusion criteria for caregiver selection were: (a) 18 years of age or older; (b) self-identified as a non-paid/informal primary caregiver of a person with dementia providing unpaid care at home or in a non-institutional setting; (c) able to read and write in English, and (d) able to attend four of the six Family Series Workshop intervention sessions. The caregiver and care receiver did not need to live together, but the caregiver must be providing some assistance with the care receiver's activities of daily living or instrumental activities of daily living. Exclusion criteria were: caregivers who were not able to adequately read or write in English via self-report or those who had a health condition that would inhibit them from participating in the intervention.

Power Analysis

This non-controlled, pretest-posttest study examined a new intervention, the Family Series Workshop. An *a priori* power analysis was performed to determine the number of participants needed for statistical significance. Using a power of 0.80, with a moderate effect size of 0.50, and a one-sided, paired *t*-test, a minimum of 34 participants was needed in each pretest and posttest group (Time 1 = 34, Time 2 = 34; Munro, 2005). A power of 0.80 was deemed reasonable for social science researchers (Munro, 2005). An effect size of 0.30 to 0.50 was considered consistent with other psychoeducational interventions that have been previously tested and published in the literature (Belle et al., 2006; Brodaty, Green, & Koschera, 2003; Sørensen et al., 2002).

Measures

Demographic Characteristics

A demographic questionnaire developed by the Investigator for the current study was used to collect demographic data at Time 1. Information collected from the

caregiver included the caregiver's age, sex, race, ethnicity, gender, employment status, marital status, education level, caregiver-care receiver relationship, length of time caregiving, and living situation of the caregiver and care receiver (Appendix D). These demographic variables were selected according to the Stress Process Model (Pearlin et al., 1990). The effects of ascribed caregiver statuses encompassed various demographic characteristics and caregiver backgrounds such as age, gender, and ethnicity, along with educational level, occupational, and economic attainments (Pearlin et al., 1990). These variables were threaded throughout the entire Stress Process Model (Pearlin et al., 1990). The effects of such ascribed statuses included the types and intensities of stressors, the resources for the stressors, and how the stress was expressed in the Stress Process Model (Pearlin et al., 1990).

Coping

The *Brief COPE Scale* was used for the current study. This scale is a 28-item, Likert scale, from one (I haven't been doing this at all) to four (I've been doing this a lot) that measures coping strategies (Appendix G; Carver, 1997). The scale consists of three subscales measuring emotion-focused, problem-focused, and dysfunctional coping. Carver reported that internal consistency of all subscales was $\alpha > 0.50$. Caregivers in this research study were asked to score each item from one (not doing it at all) to four (doing it a lot). In addition, Cooper, Katona, Orrell, and Livingston (2006) tested the validity and reliability of the scale in caregivers of persons with dementia; their study demonstrated good internal consistency and adequate test-retest reliability of the scale. Cronbach's alpha scores for the subscales were: 0.72 for the emotion focused scale, 0.84 for problem-focused scale, and 0.75 for the dysfunctional coping scale. A study by

Cooper et al. (2006) tested *Brief COPE Scale* in caregivers of persons with dementia, which showed evidence for good internal consistency and construct validity. It is estimated that this scale takes approximately 15 to 30 minutes to complete (Michigan Dementia Coalition, 2009). Possible scores range from 28 points (lowest possible score) to 112 points (highest possible score).

Caregiving Competence

The *Caregiver Competence Scale* was used in this current study, a 4-item, 4-point Likert scale, ranging from 1 (*not at all*) to 4 (*very much*). Developed by Pearlin et al. (1990), the scale measures the construct of caregiving competence as conceptualized in the Stress Process Model (Appendix F). Participants were asked to rate their caregiving competence and confidence in their caregiver role. This instrument requires approximately three minutes to complete. Possible scores range from four to 16 points, with higher scores denoting greater caregiving competence. Pearlin et al. (1990) indicated that the scale demonstrated adequate internal consistency with a Cronbach's alpha of 0.74. A study revealed significant improvement in caregiving competence among older stroke caregivers following a telephone intervention that provided psychoeducation and emotional support to participants (Hartke & King, 2003).

Stress

The *Caregiver Burden Inventory* (CBI) used in the current study was a 24-item, Likert scale (0-4 points), instrument originally developed by Novak and Guest (1989) and revised by Caserta, Lund, and Wright (1996). The CBI was designed to assess the physical and emotional effects of caregiving. This scale provides a multidimensional view of caregiver burden and measures five dimensions of burden, which are time

dependence, developmental, physical, social and emotional burden (Caserta et al., 1996). *Time dependence burden* stems from time restrictions and demands, which caregivers perceive as problematic (Caserta et al., 1996). *Developmental burden* represents the disruption that caregiving presents to life (Caserta et al., 1996). *Physical burden* represents the strain demands placed upon the caregiver's health, strength and energy (Caserta et al., 1996). *Social burden* relates to caregivers' interrelational conflict (Caserta et al., 1996). *Emotional burden* describes caregivers' negative feelings towards the care receiver (Caserta et al., 1996). A copy of the CBI can be found in Appendix E.

In the study of Caserta et al. (1996) study, the Cronbach's alpha for each of the subscales ranged from 0.73 to 0.86, demonstrating an acceptable internal consistency or reliability: time alpha = 0.85, behavior alpha = 0.85, physical alpha = 0.86, social alpha = 0.73, and emotional alpha = 0.77. A commonly accepted rule is that a Cronbach's alpha of 0.60 to 0.70 indicates acceptable reliability, and 0.80 or higher indicates good reliability (Pett, Lackey, & Sullivan, 2003). This instrument has been used in past studies with caregivers of persons with dementia (Aguglia et al., 2004; Ferrara et al., 2008; Razani et al., 2007). This instrument takes 10 to 15 minutes to complete (Caserta et al., 1996). The scores on the CBI are summed and totaled; scores range from zero to 96 points. A score of 36 points or more indicates a risk of *burning out*. A score near or slightly above 24 indicates the need to seek some form of respite care (Caserta et al., 1996).

Data Collection Procedures

Recruitment

Participants for this study were recruited from a non-profit Midwestern Alzheimer's organization. Flyers, an educational calendar, and personal contact with caregivers through home/office visit care consultations were utilized as recruitment strategies (Appendix H and I). The potential participant pool was based on year 2009 data from the Alzheimer's organization which indicated that 7,753 caregivers and persons with dementia attended 275 community education workshops and seminars coordinated by the non-profit Alzheimer's organization (M. Niedens, Personal Communication, December 20, 2010). For the Family Series Workshop psychoeducational intervention, between four to 80 individuals were expected to attend a workshop session at any given time (M. Niedens, Personal Communication, December 20, 2010).

Retention

In an effort to reduce attrition and retain participants in the study, the investigator reminded study participants, after each session, to complete questionnaires and return them to the investigator at the next workshop session or stay after the end of a session to complete the questionnaires. Another strategy to increase retention was to utilize incentives to acknowledge participants' time (Polit & Beck, 2007). Each participant selected a book about caregiving, at no charge, from the non-profit Alzheimer's library, and received that book by mail after completing pre- and posttest questionnaires (see choice of books listed in Appendix J).

Setting

Study participants were recruited at three different Family Series Workshop implementation sites. The intervention implementation/recruitment sites were one hospital and two different churches. The Family Series Workshop intervention included educational sessions that were given at prearranged times during the day, afternoon, and evening for all three sites. All three recruitment sites were located in or just outside the greater Kansas City metropolitan area. Two sites were located in a suburban area and one site was located within a smaller nearby rural town. The racial makeup of the population living near all three recruitment sites was predominantly Caucasian (range 92% to 97%; U.S. Census Bureau, n.d.).

Intervention Implementation

A PowerPoint® presentation on each caregiving topic was used to deliver the intervention content and guide the intervention sessions. The curriculum is displayed in Table A1 in Appendix A. Participants were provided with handouts and supplemental brochures/handouts related to each topic presented. A script provided details on how to complete the data collection questionnaires and was provided to participants. Additionally, a sign-in sheet requesting the participant's name, phone number, and address was provided to record attendance; this record was maintained by a staff member from the Alzheimer's organization. The educational session began once the demographic data sheet (Appendix D) and the consent forms (Appendix K) were collected. After caregivers attended four of the six sessions, they were provided with the posttest questionnaires. Caregivers had the option of turning back the posttest to the investigator at the end of that fourth session or by mail.

Human Subjects and Informed Consent

The Institutional Review Board (IRB) of the University of Missouri-Kansas City provided an expedited approval of the study including the human subjects consent form (Appendix L). The non-profit Alzheimer's organization that partnered with this study wrote a letter of support for the investigator to conduct this study (Appendix M). The investigator informed the participants about the research study at the first, second and third sessions of the Family Series Workshop intervention and then allowed them a period of time to consider participation. Those who chose to participate signed the written consent form and responded to pretest questionnaires (Appendices D, E, F, G, and K). The investigator asked participants who did not complete the questionnaires to do so at the end of each session on their own time, return them completed before the next session, or submit them by mail.

The investigator assigned a confidential identification number to each participant. The Alzheimer's organization maintained an attendance record of participants. Participants must have attended at least four of the six Family Series Workshop sessions to participate in the study. The investigator distinguished the pre- and posttest questionnaires by noting *pretest* or *posttest* at the top, along with the study identification number. Each questionnaire packet included instructions on how to complete each questionnaire. Consent forms and questionnaires received separate, secured storage so that names could not be linked to identification numbers. All study data, in de-identified format, was saved on the principal investigator's password-protected computer and will be retained for up to three years per IRB regulations.

Data Analysis

Descriptive statistics were utilized to describe the study population. Paired *t*-tests with random effect were used to test the impact of the intervention on coping, caregiving competence, and stress levels. Random effect was used to account for any differences on outcome measures due to site (i.e. the three different recruitment sites). Paired *t*-test is a robust method for comparing differences between two dependent groups at different time points (Munro, 2005). The test requires that continuous dependent outcome data be utilized (Munro, 2005). This type of test is considered to be particularly appropriate for quasi-experimental research designs (Munro, 2005). Additionally, regression analysis was used to study the relationships between coping, caregiving competence, and stress.

Statistical Package for the Social Sciences (SPSS) 18.0 for Windows was used to perform data analysis along with Statistical Analysis System (SAS) 9.2. All questionnaires were examined for missing data prior to entering it into SPSS. Missing data were handled by mean substitution. The mean was calculated based on the cases that were not missing. The value of the mean replaced missing data. The advantage of mean substitution encompasses the provision of all cases with completed data (Munro, 2005). Significance for hypothesis testing was set at the 0.05 level of significance (Munro, 2005).

There were no reverse-coded items in the instruments that measured coping, caregiving competence, and stress. The *Caregiver Burden Inventory* that measures stress employs a 5-point Likert scale in which a high stress response to an item results in a high score and a low stress response results in a low score. For this study, the *Caregiver Burden Inventory* scores were systematically reversed so that a high score for an item

would reflect a low level of stress, and a low score would reflect a high level of stress. That is, if a participant's response were recorded as 0 on the Likert scale, it was converted to a score of 4, as follows:

0 was converted to a score of 4 points

1 was converted to a score of 3 points

2 remained 2 points

3 was converted to a score of 1 point

4 was converted to a score of 0

Chapter Summary

This chapter discussed the methodology used in the study. It included a description of the research design and variables used in the study. An overview of the Family Series Workshop intervention was provided. Clarity regarding the type of sampling technique to be used in the study was provided. A power analysis was performed to determine the number of participants required in this study to avoid making a Type I error or rejecting a null hypothesis that is true. Information concerning the measurement of outcome variables and their reliability and validity was also described. The protection of participants' rights and the treatment of incomplete data were also presented in this chapter. Finally, an overview of the management and analysis of data was described.

CHAPTER 4

RESULTS

This dissertation study was conducted to examine the impact of a psychoeducational intervention, the Family Series Workshop, on the coping, caregiving competence, and stress levels of caregivers of persons with dementia. The conceptual framework used to guide this study was the Stress Process Model of Alzheimer's caregiving (Pearlin et al., 1990). This chapter presents the findings of the study.

Methods

Adult caregivers ($N = 35$) of individuals with dementia participated in this study. Descriptive statistics were used to examine the demographic characteristics of the study participants. The primary outcome variables of interest in this study were coping, caregiving competence, and stress levels. Paired *t*-test with random effect was used to examine the changes on the primary outcome variables from Time 1 to Time 2. Separate regression models were used to study the relationships among coping, caregiving competence, and stress. Data were analyzed using SAS 9.2 with SPSS for Windows 18.0. The level of significance was set at 0.05.

Results

Description of Sample

There were 35 caregivers of persons with dementia who participated in this study from February to August, 2011. Participants were recruited from three sites in the same greater Midwestern metropolitan area: a suburban hospital, a rural church, and a suburban church. The majority of participants were female (66%) with a mean age of 63 years. Most participants had been caregivers for over two years ($n = 21$; 60%) and lived with the

person in their care ($n = 22$; 62.9%). All participants were Caucasian ($N = 35$), one of whom self-identified as Hispanic. Most of the participants were not experiencing financial strain, that is, difficulty paying for life's basic needs (68.6%, $n = 24$), while 22.9% of participants ($n = 8$) were experiencing financial strain at the time of the study. Three (8.6%) persons preferred not to divulge whether or not they were experiencing financial strain. Overall, the majority of participants had above a college education (college graduate, $n = 11$, 31.4%; graduate education, $n = 8$, 22.9%) or had taken some college classes ($n = 10$, 28.6%). Only six participants (17.1%) had a high school education or GED. There were no participants who had less than a high school education. AD was the predominant type of dementia (74.3%, $n = 26$) that caregivers reported for their care receivers; some caregivers (11.4%, $n = 4$) did not know the type of dementia of their care receiver. Most caregivers were caring for a person with dementia in the early (40%, $n = 14$) and middle (also 40%, $n = 14$) stages of the disease (refer to Table 2).

Table 2*Participants' Demographic Characteristics by Recruitment Site*

Variable	<i>f</i> (%)
Sample size	<i>N</i> = 35
Average age (SD)	62.7 (13.6)
Ethnicity	
Hispanic	1 (2.9)
Non-Hispanic	34 (97.1)
Race	
Caucasian	35 (100)
Gender	
Male	12 (34.3)
Female	23 (65.7)
Employment	
Full-time	11 (31.4)
Part-time	3 (8.6)
As Needed	3 (8.6)
Not Employed	18 (51.4)

Table continues

Variable	<i>f</i> (%)
Caregiver Relationship to Care Receiver	
Spouse	18 (51.4)
Parent	2 (5.7)
Child	9 (25.7)
In-Law	2 (5.7)
Other Relative	1 (2.9)
Friend	3 (8.6)
Length of Caregiving	
Less than 6 months	7 (20.0)
6 months to 1 year	4 (11.4)
1-2 years	3 (8.6)
Over 2 years	21 (60.0)
Residence of Person with Dementia	
Living with the caregiver	22 (62.9)
Living with other family member(s)	4 (11.4)
Living with other person(s)	4 (11.4)
Live alone	5 (14.3)
Education Level	
High school/GED	6 (17.1)
Some college	10 (28.6)
College graduate	11 (31.4)
Graduate education	8 (22.9)

Table continues

Variable	<i>f</i> (%)
Caregivers Experiencing Financial Strain	
Yes	8 (22.9)
No	24 (68.6)
Preferred not to answer the question	3 (8.6)
Dementia Type	
Alzheimer's	26 (74.3)
Mild Cognitive Impairment	1 (2.9)
Parkinson's disease dementia	1 (2.9)
Traumatic Brain Injury	2 (5.7)
Normal Pressure Hydrocephalus	1 (2.9)
Unknown	4 (11.4)
Stage of Dementia	
Early	14 (40.0)
Middle	14 (40.0)
Late	6 (17.1)
Unknown	1 (2.9)

Research Question 1

What is the impact of the Family Series Workshop intervention on the coping, caregiving competence, and stress levels of dementia caregivers from pre- to post-intervention?

Paired *t*-test with random effect for all recruitment sites, was used to examine changes on measures of coping, caregiving competence, and stress levels from Time 1 to

Time 2. The mean scores of all measures (i.e., coping, caregiving competence, and stress levels) changed in the clinically desired direction from Time 1 to Time 2 (see Table 3).

Table 3*Change in Outcome Measures from Time 1 to Time 2*

Variable	Time 1		Time 2	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Coping	58.6	11.0	72.6	14.8
Caregiving Competence	11.6	2.9	14.6	1.9
Stress	20.7	7.8	21.2	8.7

Table 3 presents a summary of results utilizing paired *t*-test with random effects for site differences. There was no significant difference observed from Time 1 ($M = 58.6$) to Time 2 ($M = 72.6$) on caregiver's coping level ($p = 0.0718$; $t = 3.53$). Results from the data analysis indicated that caregiving competence significantly improved ($p = 0.0358$; $t = 5.14$) from pre (Time 1) to 6-weeks post (Time 2) intervention. Caregiving competence scores increased from Time 1 ($M = 11.6$) to Time 2 ($M = 14.6$). The mean stress scores also improved from 20.7 (Time 1) to 21.2 (Time 2). Although there was a marginal difference observed from Time 1 to Time 2 on measures of stress, the difference was not significant ($p = 0.7081$; $t = 0.43$). A summary of the results of paired *t*-tests with random effect is presented on outcomes of coping, caregiving competence, and stress (see Table 4).

Table 4

Summary for Paired t-tests with Random Effect Analysis Results (N = 35)

	Estimate	SE	df	t	p
Coping	14.2691	4.0452	2	3.53	0.0718
Caregiving Competence	2.9429	0.5724	2	5.14	0.0358*
Stress	0.5294	1.2267	2	0.43	0.7081

* $p < 0.05$.

Figures 3 through 5 provide a visualization of the change in mean scores from Time 1 to Time 2 on measures of coping, caregiving competence, and stress.



Figure 3. Change in mean outcome score of coping levels.

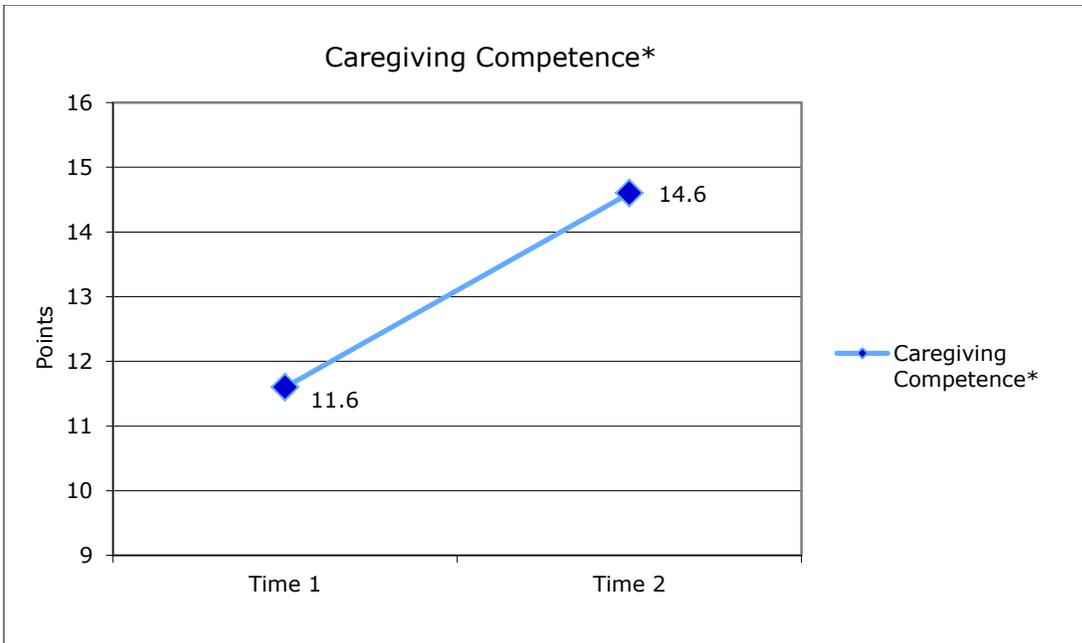


Figure 4. Change in mean outcome score of caregiving competence.

* $p < 0.05$.

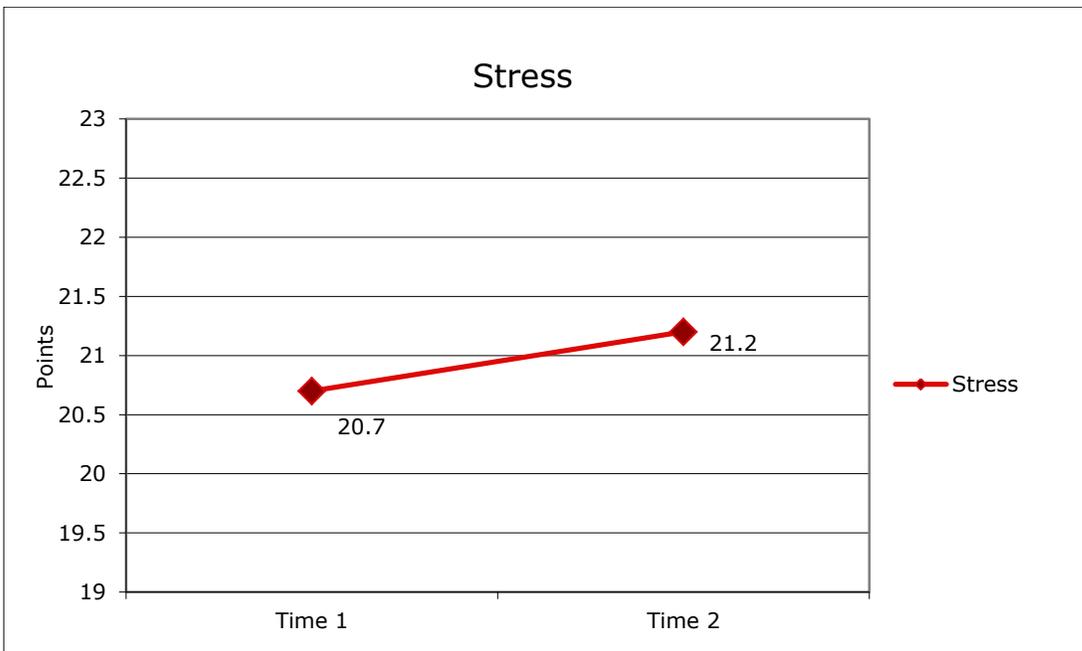


Figure 5. Change in mean outcome score of stress levels.

Research Question 2

What is the relationship among coping, caregiving competence, and stress?

Separate regression analyses were used to examine the relationship among coping, caregiving competence, and stress. Results indicated that coping was associated with caregiver competence ($p < 0.000$). That is, with every one unit increase in coping, caregiving competence increased by 0.1406 points. Coping, however, was not significantly correlated with stress ($p = 0.858$). Tables 5 and 6 provide a summary of regression results of the mediating effect of coping on caregiving competence (Table 5) and on stress (Table 6).

Table 5

Effect of Coping on Caregiving Competence

Effect	Estimate	SE	df	t	p
Intercept	0.9737	0.5413	2	1.80	0.2138
Coping	0.1406	0.02487	31	5.65	<0.0001*

* $p < 0.05$.

Table 6

Effect of Coping on Stress

Effect	Estimate	SE	df	t	p
Intercept	0.3414	1.6236	2	0.21	0.8529
Coping	0.01331	0.07376	30	0.18	0.8580

Figure 6 presents a visualization of the intervention model with regards to the outcome measures. The broken line from the Family Series Workshop intervention to coping represents the non-significant effect ($p = 0.072$) of the intervention on coping, which the investigator hypothesized as a mediator. The association of coping with caregiving competence was significant ($p < 0.000$) and is represented by a solid line. The association of coping with stress was not significant ($p = 0.86$), represented by a broken line.

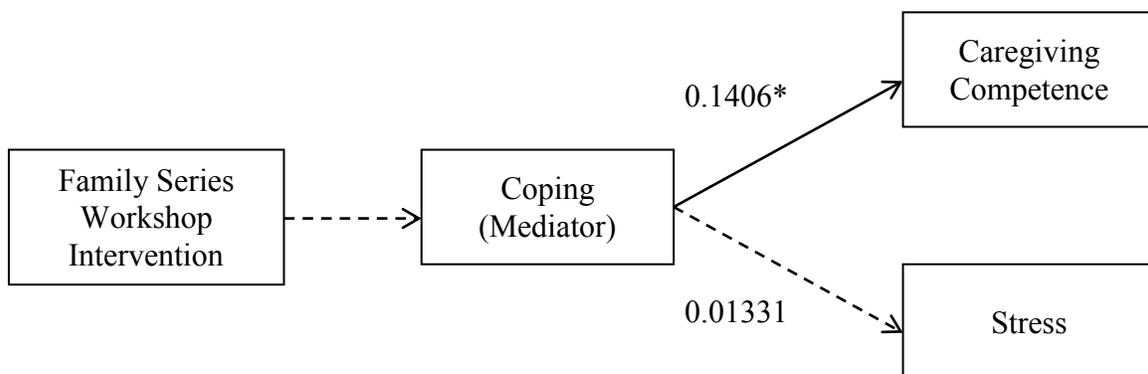


Figure 6. Intervention Model with Results from Family Series Workshop. Broken arrows represent non-significant associations between concepts and intervention. The solid arrow represents a significant relationship between concepts.

* $p < 0.05$.

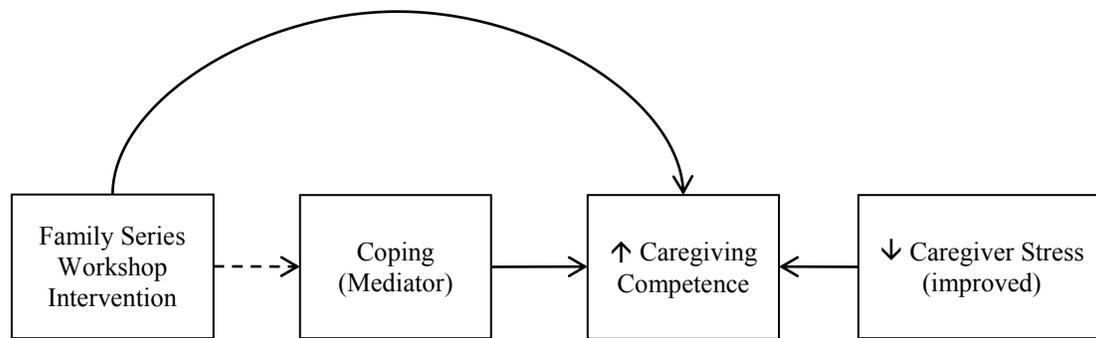
Further analysis of the data using multiple regression analysis suggests that caregiving competence was significantly associated with stress in caregivers of persons with dementia ($p = 0.0458$). This means that with every one unit increase in caregiver's stress level (or improvement of stress level), caregiving competence increased and improved by 0.7227 points. These findings are represented in Table 7.

Table 7
Effect of Stress on Caregiving Competence

Effect	Estimate	SE	df	t	p
Intercept	-1.6390	1.5652	2	-1.05	0.4049
Stress	0.7228	0.3469	30	2.08	0.0458*

* $p < 0.05$.

After analyzing the results of the data, the final model was developed. This model is indicative of the significant correlations and the mean score changes between outcome measures and the Family Series Workshop intervention. Figure 7 provides a visual representation of the final model.



Legend $--\rightarrow$ $p < 0.1$
 \rightarrow $p < 0.05$

Figure 7. Final Model by Sarah Llanque, M.S.N., M.Ed., R.N.

Missing Data

There were two participants with missing data at Time 2 on the measures of coping and stress. Specifically, for the first participant seven items measuring stress were missing from Time 2 on the *Caregiver Burden Inventory*. As for the second participant, one item had missing data at Time 2 on the *Brief COPE Scale*. In both cases, the mean was substituted for each missing data point. In addition, two participants declined to provide their age, so the mean age for all participants was substituted in place of missing data for age.

Chapter Summary

This chapter presented the findings from a non-controlled pretest-posttest study to examine the impact of a psychoeducational intervention, the Family Series Workshop, conducted with caregivers of person with dementia. Statistical analyses used in this study included descriptive statistics, paired *t*-tests, and regression analysis with random effect

to account for any differences that may have occurred due to recruitment site and regression analysis. Findings revealed a significant improvement on measures of caregiving competence, that is, caregiver's competence level improved from Time 1 to Time 2. Neither coping nor stress scores showed significant changes in mean scores from baseline to posttest. However, the changes in mean scores related to coping approached significance. Coping was shown to be significantly associated with caregiving competence, but not stress. Both coping and stress were significantly associated with caregiving competence. Moreover, caregiving competence was significantly related to stress.

CHAPTER 5

DISCUSSION

There are approximately 14.9 million caregivers of people with dementia in the U.S. (Family Caregiver Alliance, 2006b; Plassman et al., 2008). These caregivers are considered the ‘backbone’ of the long-term, home, and community-based care system (Rosalynn Carter Institute for Caregiving, 2009). Due to the chronic stress of caregiving, many caregivers are at risk for negative health outcomes from their duties (Schulz et al., 1995; Kiecolt-Glaser et al., 2003; Reinhard, Brooks-Danso, Kelly, & Mason, 2008). The Family Series Workshop, a psychoeducational intervention, was developed by Michelle Niedens, L.S.C.S.W., Director of Education, Programs, and Public Policy, Heart of America Chapter, Alzheimer’s Association, to help individuals who are caring for persons with dementia cope by addressing the common challenges of caregiving, as well as providing information related to improving the care of the person with dementia (M. Niedens, Personal Communication, December 20, 2010). Past research has indicated that psychoeducational interventions for caregivers of persons with dementia can improve caregivers’ wellbeing and decrease their risk of depression (Belle et al., 2006; Schulz et al., 2002; Sörensen et al., 2002).

This dissertation study evaluated the impact of the Family Series Workshop intervention. Measures of coping, caregiving competence, and stress were utilized to assess the impact of the intervention. This chapter discusses the results of the investigator’s research. It puts forth the implications, limitations, recommendations, and conclusions garnered from the results and findings.

Method

This study employed a non-controlled, pretest-posttest research design to examine the impact of the Family Series Workshop intervention. Main outcome measures were coping, caregiving competence, and stress in caregivers of individuals with dementia. A convenience sample of caregivers of community-dwelling individuals with dementia participated in this study. Participants completed pencil and paper questionnaires at baseline and at six-weeks post-intervention. Results were analyzed using paired *t*-test with random effect for study sites, descriptive statistics, and multiple regression analysis. A discussion of these results ensues.

Discussion

Coping

The results of this study demonstrated that the Family Series Workshop intervention had a marginal impact on coping levels of caregivers of persons with dementia. Although the variable of coping did not significantly improve in caregivers, coping levels approached significance ($p = 0.0718$; $t = 3.53$). Perhaps a larger sample size may have yielded significant increases on coping. Past findings from other caregiving interventions (Chiverton & Caine, 1989; Ducharme et al., 2005; Gallagher-Thompson et al., 2003) have shown mixed results with regard to whether coping significantly increased among caregivers of persons with dementia.

Caregiving Competence

The Family Series Workshop intervention had a significant positive effect on caregiving competence in a convenience sample of nonpaid caregivers of persons with dementia living in the community. Past studies that evaluated the effect of

psychoeducational interventions on caregiving competence have shown mixed results as to whether caregiving competence improved post-intervention (Hepburn et al., 2003; Morano & Bravo, 2002). The Family Series Workshop intervention differed from past studies in several ways. For example, the majority of participants were spousal caregivers who lived and cared for the person with dementia for over two years. In contrast with past interventions, the Family Series Workshop intervention addressed a variety of caregiving topics (e.g., disease process, caregiver guilt, and personal care of the person with dementia). In addition, caregivers who participated in the Family Series Workshop intervention were taking care of persons whose dementia reflected different stages of the disease process. Overall, participants appeared to benefit from the Family Series Workshop, as evidenced by the significant increase on the measure of caregiver competence from pre- to post-intervention.

Stress

In the present study, the variable of stress did not show significant improvement in caregivers of persons with dementia. In hindsight this result is not surprising, given that caring for a person with a chronic and incurable illness, such as dementia can increase a caregiver's stress over time. Studies have shown that progression of the disease process over time usually results in continued decline in the care receiver's ADLs/IADLs (Pearlin et al., 1990). The progression of disease symptoms can wear on the caregiver's ability to provide care for the care receiver (Pearlin & Skaff, 1995). There is a strong correlation with the stage of dementia and the level of stress a caregiver experiences (Pearlin et al., 1990). As the disease progresses, persons with dementia in

the late stages of the disease usually require more assistance with ADLs and show a decrease in the incidence of neuropsychiatric symptoms (Pearlin et al., 1990).

Association with Coping and Stress

The relationship between coping and stress was examined in this study. Results indicated that coping was not significantly associated with stress among the participants in this study sample. This finding could be due to the fact that many of the caregivers were providing care to persons with AD ($n = 26$; 74%) who were in the middle ($n = 14$; 40%) and late ($n = 6$; 17%) stages of the disease process.

Approximately 60% to 98% of persons with dementia experience some type of neuropsychiatric symptom (Sink, Holden, & Yaffee, 2005). Neuropsychiatric symptoms have been found to be more common among persons with dementia in the middle stages of the disease process (Pearlin et al., 1990). Because the majority of caregivers were taking care of persons with AD in the middle stage of the disease process, it is not surprising to the investigator that coping did not significantly mediate stress in this sample of caregivers.

The study evaluated coping, caregiving competence, and stress levels from Time 1 (baseline) to Time 2 (six-weeks post-intervention). A longer follow-up period could have provided more insight as to whether stress and coping would have significantly improved or not improved among caregivers. In addition, a longer follow-up period of time might have revealed that coping had a significant effect on stress. Past studies have evaluated psychoeducational interventions from two to six months post-intervention (Belle et al., 2006).

A *post hoc* power analysis was not carried out after the intervention, because the investigator was able to obtain an adequate sample size compared with the minimum sample size needed from the *a priori* power analysis.

Limitations

Despite the encouraging results of this study, there were limitations. The study used a one-group, non-controlled, pretest-posttest study design and lacked a control group. Utilizing a convenience sampling technique and the small sample size limited this study. In addition, there was no long-term follow-up of study participants. Data collection occurred at only two time points: pre-intervention (baseline) and post-intervention. The study sample mainly consisted of Caucasian, non-Hispanic caregivers. Future studies should include a larger sample size that is diverse and inclusive of individuals from minority populations. Diversity is important because according to the Administration on Aging (2011), the demographics of aging show a trend towards significant growth in the number of minority elders. In addition, the lack of biomarkers used to evaluate caregiver stress was a limitation in this study. Evaluating biomarkers for stress (e.g., cortisol levels) could have provided a more precise indicator of changes in the stress level of caregivers.

Future Implications

Findings from this study are encouraging and suggest that interventions, such as the Family Series Workshop, have the potential to improve health outcomes for caregivers of persons with dementia. A statistically significant change on the variable of caregiving competence was found. Although the variables of stress and coping did not significantly improve from Time 1 to Time 2, these variables did change in the clinically

desired direction. Therefore, it is plausible that the intervention may have shown effectiveness if participants had been followed for a longer time period. For example, past research studies have evaluated psychoeducational interventions for six months after the completion of the intervention (Gallagher-Thompson et al., 2008; Belle et al., 2006) rather than immediately post-intervention. Future research with the Family Series Workshop intervention could assess caregivers for a longer period of time to obtain additional information about the long-term effectiveness of the intervention.

This study was conducted in a Midwestern suburban setting with predominantly non-Hispanic Caucasian participants. Just one participant self-identified as Hispanic. Evaluating the impact of this intervention with caregivers from different ethnic backgrounds who live in different settings is needed. By the year 2050, the number of older adults aged 65 and older is expected to double and the number of people aged 85 and older is expected to triple (Administration on Aging, 2011). This increase will be observed, particularly, in minority older adults. African Americans, Native Americans, Native Alaskans, Asians, Hawaiians, Pacific Islanders, and Hispanic older adult populations are expected to increase three- to six-fold (Administration on Aging, 2011). This predicted demographic change has implications for how health care is delivered and implemented. Culturally appropriate and culturally sensitive interventions that respect and honor the cultural traditions of diverse populations within the caregiving context are warranted.

One ethnic group in which dementia is on a sharp rise is Hispanic elders, particularly due to their increased risk for factors associated with AD and vascular dementia such as hypertension, hyperlipidemia, and diabetes (Novak & Riggs, 2004).

Implementing interventions tailored to specific, ethnic, or regional groups, such as Hispanics, will allow researchers to observe outcomes among specific caregiving populations. Moreover, comparisons could be made between African American caregivers living in large cities and those living in rural southern communities. According to the National Institute on Aging (2010), "...sensitivity to the influence of race, culture and ethnicity on health behavior and aging is of growing importance" (Recommendation 2 section, para. 4).

Utilizing a participatory action research approach may also be a strategy that could help future researchers tailor interventions, such as the Family Series Workshop, for diverse populations of caregivers. This methodology allows both the researcher and study participants to work together as collaborators to "...define a problem, take action, and evaluate their work" (Kelly, 2005). Research that focuses on improving the wellbeing and health of the minority caregiving populations is noteworthy and needed.

Due to the various topics and multifaceted design of the Family Series Workshop intervention, the developer of the intervention, Michelle Niedens, L.S.C.S.W., suggests that this intervention should be regarded as something to be built upon, rather than followed precisely (M. Niedens, Personal Communication, December 20, 2010). Implementing a modified version of the intervention with the input of other caregiving populations (e.g., caregivers of persons with stroke or intellectual disabilities) could be beneficial. Evaluation of the Family Series Workshop intervention in other populations could provide more data on the effectiveness of the intervention. Input from caregivers, care receivers, healthcare providers, and other family members could be utilized to tailor the intervention and enhance its effectiveness.

The use of physiological measures, in addition to psychosocial measures, when assessing the impact of the Family Series Workshop intervention in the future could strengthen evaluation (Vitaliano, Zhang, & Scanlan, 2003). Correlating physiological measures with psychosocial (attitudinal) measures could provide rich information about the effect of the Family Series Workshop intervention. For example, Kiecolt-Glaser et al. (2003) found a four-fold increase in the level of IL-6 immunoglobulin--a key proinflammatory cytokine that appears to enhance morbidity and mortality in caregivers of persons with dementia as compared with noncaregivers. Vitaliano and colleagues (2003) examined the results of past caregiving studies relating physical health indicators in caregivers with demographically matched non-caregivers. Examples of physiological measures include functional immune measures (e.g., T cell counts), stress hormones (e.g., cortisol), cardiovascular indicators (e.g., heart rate and blood pressure), metabolic profiles (e.g., cholesterol, insulin, and glucose), and stress antibodies (e.g., immunoglobulin G). Strong relationships have been found among caregivers' stress and hormones, antibodies, and global reported health (Vitaliano et al., 2002). Extending the post-intervention evaluation time (e.g., six months) and including the biomarkers of stress as a biological confirmation of caregivers enhanced adaptability to the stressors could enhance future studies involving the Family Series Workshop intervention. Few studies have utilized biomarkers in evaluating interventions involving caregivers (Harmell, Chattillion, Roepke, & Mausbach, 2011).

Furthermore, utilizing physiologic measures to assess the impact of the Family Series Workshop intervention may provide a greater appreciation of the positive aspects or gains of being a caregiver. More often than not, research has focused on negative

aspects of caregiving such as stress, depression, and strain in caregivers of persons with dementia (Tarlow et al., 2004). Measuring the positive aspects of caregiving has the potential to add rich information about the impact of the Family Series Workshop intervention. Pearlin et al. (1990) and Tarlow et al. (2004) developed both valid and reliable instruments that assess caregiving gain and the positive aspects of caregiving, respectively. Research assessing positive aspects of caregiving in psychoeducational interventions has found that caregivers of patients dying of cancer had a more positive caregiver experience after participating in a psychoeducational intervention (Hudson, Aranda, & Hayman-White, 2005). It may be that psychoeducational interventions could increase caregiver rewards in spite of the fact that caregivers are immersed in challenging circumstances that often yield considerable negative biopsychosocial sequelae.

Adding a qualitative methodological component could also provide a better understanding of the impact of the Family Series Workshop intervention and a more in-depth perspective of both the caregiver and the person with dementia (if he/she were able to do so). For example, future research studies could ask questions such as: Which session of the intervention was most helpful? What are some ways the intervention could be improved? The findings from qualitative research questions could be used to tailor the intervention and strengthen theoretically based components of the intervention as they relate to the Stress Process Model of Alzheimer's caregiving (Pearlin et al., 1990). Varying the health dimensions as they occur within the caregiver-care receiver dyad could also provide information about how to improve the intervention.

Conclusion

Caregiving is a universal experience that has been present in our society since time immemorial. Caregiving cuts across all ethnicities, lifestyles, and socioeconomic status levels. Some persons may see caregiving as a task, yet others see caregiving as an act of love. As the population ages, the number of caregivers will certainly grow.

The predicted increase in the number of caregivers requires that our society provide the needed resources to persons in a caregiver role so that they may gain the knowledge and skills to provide effective and humane care to the care receiver.

Caregivers must have opportunities to learn new skills, as they become necessary, access new resources, and learn about options for care as their situations change. Information and caregiver training can change throughout the course of the care receiver's illness.

Caregivers must have appropriate, timely, and ongoing education and training in order to successfully meet their caregiving responsibilities and to be advocates for the care receiver across all health care settings.

Health care professionals working with caregivers of persons with dementia are in a unique position to implement effective caregiving interventions that reflect sensitivity to the caregiver's needs. Policy makers should support programs that bring family caregivers and professionals together for further collaboration. A current priority of the National Institutes of Health is to develop research that is translational to the 'real world' (Westfall, Mold, & Fagan, 2007). The Family Series Workshop intervention was developed to meet the practical needs of caregivers caring for persons with dementia at different stages of dementia, thus meeting the needs of the caregiver-care receiver dyad. A participatory approach to revise the Family Series Workshop intervention in

partnerships with researchers, health care professionals, and caregivers may lead to a collaborative model to enhance the effectiveness and receptivity of future caregiving interventions.

Caregiving is a complex undertaking that involves decision-making, emotional support, household management, medical care, and navigation of various agencies. Caring for a person with dementia can be both rewarding and challenging. The disease process of dementia not only affects the person diagnosed with dementia, but also their family, friends, and community.

Support for caregivers who are taking care of persons with dementia living at home is critical. Psychoeducational interventions, such as the Family Series Workshop, have the potential to positively impact the caregiver. Although no definitive conclusions can be drawn from this dissertation study due to its small sample size, the results are encouraging and suggest that the Family Series Workshop intervention had a positive impact on caregivers' competence and suggestions of positive impacts on their coping and stress. Health care professions are in a unique position to enhance the quality of life of caregivers and persons with dementia. Future research is warranted to tailor the Family Series Workshop intervention and to examine its efficacy in a prospective controlled study with a larger sample size.

APPENDIX A

INTEGRATION OF THE STRESS PROCESS MODEL WITH THE FAMILY SERIES WORKSHOP INTERVENTION

Table A1

Integration of the Stress Process Model with the Family Series Workshop Intervention

Session	Coping	Competence	Caregiver Stress
I	Cognitive reframing will help caregiver in their understanding of behavior and memory changes that occur as the disease progresses. This will help caregivers cope with impairments caused by dementia.	Provides information regarding pathophysiology of dementia, diagnosis, stages of dementia, prognosis, genetics, risk factors of getting dementia, Alzheimer's Association's services, and online resources to help caregivers.	

Table Continues

Session	Coping	Competence	Caregiver Stress
II	<p>Caregivers are able to utilize problem-solving skills with assisting the person with the disease with activities of daily living.</p> <p>Caregivers are able to understand cognitive processes in affecting communication skills of the person with the disease.</p>	<p>Caregiving skills discussed regarding techniques in assisting with personal care, bathing, perineal care, pain, psychosis, boredom, paranoia, depression, visual-spatial problems, and communication.</p> <p>Home and community-based resources are discussed.</p>	<p>Caregivers are able to maintain their physical health and stress level (i.e., feelings of tiredness, sleep deprivation, feeling sick, perceived health).</p>
III	<p>Engaging in failure-free activities and structuring each day with a routine helps caregivers cope with the disease progression.</p>	<p>Information regarding activity/structure for the person with dementia that caregivers can do during various stages of dementia.</p> <p>Resources such as Adult Day Programs and In-Home Respite will be addressed.</p>	<p>Persons with dementia experience slower progression of certain types of dementia and are able to share in memories with the person with dementia, while the person with dementia and the caregiver engage in activities. Resources can decrease caregiver stress via respite care, so that the caregiver gets reprieve.</p>

Table Continues

Session	Coping	Competence	Caregiver Stress
IV		Caregivers obtain understanding of certain medications typically prescribed to persons with dementia, as well as psychotropic medications that may help with behavioral problems as dementia progresses.	
V	Discussion on whether long-term care placement is right for the person with dementia and the caregiver. Addresses the management of the caregiving situation, giving rise to nursing home placement.	Information regarding the placement of the care receiver in a long-term care facility is discussed. Options for aging in place are covered.	
VI	Caregivers are able to manage the meaning of their caregiving situation such that feelings of guilt are reduced.	A facilitated group discussion about caregiver guilt will take place. Information about how support groups, counseling, or talking with a trusted person about caregiver guilt will be discussed.	Topics related to how caregivers can reduce caregiver stress and using cognitive reframing in relation to the contextual caregiving situation and cognitive status of the care receiver.

APPENDIX B

FAMILY SERIES WORKSHOP CURRICULUM

Table A2

Family Series Workshop Curriculum

Session	Topic/Content
I	An overview of dementia including diagnosis, stages and family experiences will be discussed.
II	A discussion of managing activities of daily living including task breakdown, provision of care and other issues associated with bathing, toileting, dressing, taking medication and feeding.
III	Explores the role of activities and structure for the person with Alzheimer's disease including suggestions on activities and options to maximize strengths.
IV	Discusses the concerns and appropriate benefits of commonly prescribed medications in the care of the person with dementia.
V	Discusses the dilemma and issues around the placement decision. Covers options, resources and the decision making process.
VI	Covers the guilt that typically goes along with the role of caregiver as well as the impact guilt has on caretaking.

Note: This table shows the curriculum of Family Series Workshop intervention as it applies to the key concepts: coping, caregiving competence, and stress. Topics and content covered under each session was written and described by Michelle Niedens, L.S.C.S.W., Director of Education, Programs, and Public Policy, at the Alzheimer's Association, Heart of America Chapter. Adapted with permission.

APPENDIX C

SKILLS PROVIDED BY THE FAMILY SERIES WORKSHOP INTERVENTION

Table A3

Skills Provided by the Family Series Workshop Intervention

Session	Knowledge/Skills Provided
I	<ul style="list-style-type: none">• Contributors to memory loss in aging• Four most common types of dementia• Signs and symptoms to expect as the disease progresses• The importance of early detection of dementia• The components of a dementia evaluation
II	<ul style="list-style-type: none">• Skills to promote independence in ADL and IADL completion.• Ability to recognize potential contributors to neuropsychiatric symptoms of the disease• Recognition of signs and symptoms of delirium• Expand inventory of responses to neuropsychiatric challenges• Empowerment in communicating with physicians/health care providers• Recognition of symptoms of depression throughout the disease process.
III	<ul style="list-style-type: none">• Benefits of activities with the person with dementia• Activity related issues with the disease process associated with different stages of dementia• Implementing successful activities• Activities for each stage of the disease process (i.e., using bifocal kits, reminiscing, music therapy, gardening, empowerment groups, etc.)• Creating a daily plan for activities

Table Continues

Session	Knowledge/Skills Provided
IV	<ul style="list-style-type: none"> • Recognition of the signs and symptoms of delirium, depression, and psychosis • Information regarding SSRI and Tricyclic antidepressants, cholinesterase inhibitors, NMDA receptor agonists, mood stabilizers, neuroleptics, and anxiolytics
V	<ul style="list-style-type: none"> • Understanding of variables that can complicate care • Understanding of caregiver emotional/behavior connections that impact accepting and determining care needs • Understanding grief issues • Identification of levels of care • Information about care plans • Ability to access helpful resources
VI	<ul style="list-style-type: none"> • Mechanisms of coping with feelings of grief and guilt associated with caregiving • Recognition of value of being in the company of others who have experience similar losses and challenges.

APPENDIX D

CAREGIVER DEMOGRAPHIC QUESTIONNAIRE

What is your relationship with the person with dementia? Are you their:

- Spouse Parent Child Grandchild
 in-law Friend Other relative Other

What is your Race?

- White Black Native American
 Asian/Pacific Islander Other
 Prefer not to answer

Ethnicity Hispanic Not Hispanic

Age _____ Prefer not to answer

Gender Male Female

Are you (caregiver) employed?

- Full-time Part-Time As Needed
 Not employed

How long have you been providing care?

- Less than 6 months
 6 months to 1 year
 1 - 2 years
 Over 2 years

Does the person with dementia:

- Live with the caregiver(s)
 Live with other family member(s)
 Live with other person(s)
 Live Alone

What is your Education Level?

- Less than High School
 High School/GED
 Some College
 College Graduate
 Graduate Education

Are you experiencing financial strain or difficulty paying for life's basic needs?

- Yes No Prefer not to answer

APPENDIX E

CAREGIVER BURDEN INVENTORY

Caregiver Burden Inventory (Novak & Guest, 1989) [With modifications suggested by Caserta et al, 1996]

For each statement below and tell us how often it describes your experience in caring for your loved one. Circle a number from 0-4 indicating

- 0** = never
- 1** = rarely
- 2** = sometimes
- 3** = quite frequently
- 4** = nearly always

	Never	Rarely	Some- times	Quite Frequently	Nearly Always
1. He/she needs my help to perform many daily tasks	0	1	2	3	4
2. He/she is dependent on me	0	1	2	3	4
3. I have to watch him/her constantly	0	1	2	3	4
4. I have to help him/her with many basic functions	0	1	2	3	4
5. I don't have a minute's break from his/her chores	0	1	2	3	4
6. I feel that I am missing out on life	0	1	2	3	4
7. I wish I could escape from this situation	0	1	2	3	4
8. My social life has suffered	0	1	2	3	4
9. I feel emotionally drained due to caring for him/her	0	1	2	3	4
10. I expected that things would be different at this point in my life	0	1	2	3	4
11. I'm not getting enough sleep	0	1	2	3	4
12. My health has suffered	0	1	2	3	4
13. Caregiving has made me physically sick	0	1	2	3	4
14. I'm physically tired	0	1	2	3	4
15. I don't get along with other family members as well as I used to	0	1	2	3	4
16. My caregiving efforts aren't appreciated by others in my family	0	1	2	3	4

17. I've had problems with my marriage(or other significant relationship)	0	1	2	3	4
18. I don't get along as well as I used to with others	0	1	2	3	4
19. I feel resentful of other relatives who could but do not help	0	1	2	3	4
20. I feel embarrassed over his/her behavior	0	1	2	3	4
21. I feel ashamed of him/her	0	1	2	3	4
22. I resent him/her	0	1	2	3	4
23. I feel uncomfortable when I have friends over	0	1	2	3	4
24. I feel angry about my interactions with him/her	0	1	2	3	4

APPENDIX F

CAREGIVING COMPETENCE SCALE

Caregiving Competence Scale

Scale Created by Marilyn F. Skaff

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement [questions 1 and 2] describe your thoughts about your caregiving? Circle or choose the best answer.

1. How much do you believe that you've learned how to deal with a very difficult situation?

Very much (4) Somewhat (3) Just a little (2) Not at all (1)

2. How much do you feel that all in all, you are a good caregiver?

Very much (4) Somewhat (3) Just a little (2) Not at all (1)

Think now of all the things we've been talking about: the daily ups and downs that you face as a caregiver; the job you are doing; and the ways you deal with the difficulties. Answer the following questions [3-4]. Circle or choose the best answer.

3. Putting all these things together, how **competent** do you feel?

Very (4) Fairly (3) Just a little (2) Not at all (1)

4. Putting all these things together, how **self-confident** do you feel?

Very (4) Fairly (3) Just a little(2) Not at all (1)

(Pearlin et al., 1990)

APPENDIX G

BRIEF COPE SCALE

Brief COPE Scale

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Choose a number from 0-4 indicating

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

(Carver, 1997)

APPENDIX H

FAMILY SERIES WORKSHOP FLYER

The Family Series

*A free, six-part series
about Alzheimer's disease and other related dementia
and some of the quandaries that caregivers face*

Hosted by the Alzheimer's Association Heart of America Chapter

To register, please call (913) 831-3888

Part One: "What Can I Expect"

An overview of Alzheimer's disease

Part Two: "I Don't Need Any Help"

A discussion of managing activities of daily living

Part Three: "He Just Sits Around All Day"

Explores the role of activities and structure for persons with Alzheimer's

Part Four: "Is She On Too Many Medications?"

Concerns and appropriate benefits of commonly prescribed medications

Part Five: "I Can't Do This Anymore"

*The dilemma around the placement decision –
covers options, resources and the decision making process.*

Part Six: "I Should, I Ought, I Have to"

A discussion of the guilt that typically goes along with the role of a caregiver

APPENDIX I

EDUCATION CALENDAR

Train the Trainer
This program is geared toward individuals in facilities/agencies that are charged with educating others about the illness and includes discussion of designing and implementing dementia training programs. **Cost: \$50.00**

October 20 (2010)
9:00 a.m. – 4:00 p.m.
Main Chapter Office

April 20 (2011)
9:00 a.m. – 3:00 p.m.
Topeka, KS

Younger Onset Alzheimer's
Coping with the unique issues associated with having a family member diagnosed under the age of 65.

August 20 (2010)
5:30 – 7:00 p.m.
Main Chapter Office

Additional plans are underway for a clergy forum and an activities workshop. Contact the Main Chapter office if you would like to receive information on these events.

education
calendar

Education Calendar Cross Reference
The descriptions of the monthly offerings can be found in the main part of this calendar.

2010

July
Family Series
Ten Warning Signs of Alzheimer's Disease

August
Building Effective Skills Training (BEST)
Family Series
Let's Talk About Dementia: A Community Discussion
Ten Warning Signs of Alzheimer's Disease
Younger Onset Alzheimer's

September
ABC's – Alzheimer's Basic Care
Family Series
Legal Issues
So You Have Been Newly Diagnosed with Alzheimer's
Ten Warning Signs of Alzheimer's Disease

October
Family Series
Ten Warning Signs of Alzheimer's Disease
Train the Trainer

November
A Family Affair
Alzheimer's Research Forum
Caregiver Conferences
Family Series
10th Annual Defining Hope Conference

December
Family Series
Legal Issues

2011

January
Growing Through Grief

March
ABC's – Alzheimer's Basic Care
Family Series
Legal Issues
Let's Talk About Dementia: A Community Discussion

April
Alzheimer's and Intellectual Disabilities
Family Series
Legal Issues
Train the Trainer

May
ABC's – Alzheimer's Basic Care
Family Series

June
Let's Talk About Dementia: A Community Discussion



Alzheimer's Association – Heart of America Chapter
July 1, 2010 – June 30, 2011

alzheimer's association
the compassion to care, the leadership to conquer

All educational opportunities are free of charge unless otherwise noted. If you have any questions or would like to register for any of the offerings listed on this education calendar, please call the Heart of America Chapter Office nearest you:

Main Office	Midwest	Northeast Kansas	Northeast Missouri	Southeast Kansas
3845 W. 76th St. Prairie Village, KS 66208 913.831.3888 913.831.1916 fax	Midland Office 6400 Prospect West Building Kansas City, MO 64132 816.561.6664 816.561.6622 fax	Northeast Kansas Regional Office 4125 SW Gage Center Dr. Topeka, KS 66604 783.271.0444 783.271.1864 fax	Regional Office 100 and Farnson St. Joseph, MO 64501 816.564.4467 816.564.2553 fax	Regional Office 2601 Galsted Ponca, KS 67337 620.421.6550 ext. 1794 620.421.0671 fax

www.alz.org/kansascity 24-hour Information and Support Line: 800.272.3900

This education brochure, as well as support for specific education events, is made possible because of grants, donations and sponsorship by committed partners in our service area. To those partners, we express sincere appreciation for their acknowledgement of the importance of disease education.

Education calendar listings below are in alphabetical order. To check the listings by month, please refer to the back of this brochure.

LEGEND:

- ▶ For family members of individuals with a dementia
- ★ For individuals with early stage Alzheimer's disease
- For professionals

ABC's – Alzheimer's Basic Care
An overview of the disease process — how family caregivers can work with the individual experiencing the disease. Additional topics covered include communication, behaviors and feelings.

Station 1
Disease overview and community resources

Station 2
Planning and legal issues

September 13 and September 20 (2010)
5:30 – 8:00 p.m.
Topeka and Shawnee County Public Library
1515 SW 10th Avenue, Topeka, KS

March 21 and March 28 (2011)
5:30 – 8:00 p.m.
Anita Heartstone West
3415 SW 6th Avenue, Topeka, KS

May 12 and May 19 (2011)
10:00 a.m. – 12:00 p.m.
Southeast Library, Room A
6242 Snopce Parkway, Kansas City, MO

A Family Affair
A discussion with parents and grandparents about helping children who are part of the lives of individuals with Alzheimer's disease.

November 13 (2010)
10:00 – 11:30 a.m.
Main Chapter Office

Alzheimer's and Intellectual Disabilities:
A program for professional caregivers of persons with the dual diagnosis of Alzheimer's and an Intellectual Disability, such as Down Syndrome.

April 14 (2011)
10:00 – 11:00 a.m.
Topeka, KS
Call for location
\$20 per person

Alzheimer's and Intellectual Disabilities: A Family Discussion
A program for family members of persons with the dual diagnosis of Alzheimer's disease and an Intellectual Disability, such as Down Syndrome that focuses on special care decisions and maintaining positive connections throughout the disease process.

April 14 (2011)
10:00 a.m. – 12:00 p.m.
Topeka, KS
Call for location

Alzheimer's Research Forum
An update on current research and meaningful translation.

November 2 (2010)
8:30 a.m. – 4:00 p.m.
Johnson County Community College
Regener Building

Building Effective Skills Training (B.E.S.T.)
A 6-hour course designed specifically for nursing assistants in long term care and community settings. Participants will receive a certificate of attendance. **Cost: \$25.00.**

August 19 (2010)
8:30 a.m. – 3:30 p.m.
Research Medical Center
2316 E. Meyer Boulevard, Classroom C

Caregiver Conferences

▶ **November 10 (2010)**
10:00 a.m. – 12:00 p.m.
Menor County Library
601 Grant, Princeton, MO

▶ **May 3 (2011)**
10:00 a.m. – 12:00 p.m.
First Christian Church
10th and Farnson Street, St. Joseph, MO

Family Series
A 6-session course focusing on some of the most common topics around caring for someone with Alzheimer's disease or other dementia. Individuals are welcome to come for whichever topics are of concern.

Session I – What can I expect?
An overview of Alzheimer's disease including diagnosis, stages and family experience.

Session II – I don't need any help
A discussion of managing activities of daily living including task breakdown, provision of care and other issues associated with bathing, toileting, dressing, taking medication and feeding.

Session III – He just sits around all day
Explores the role of activities and structure for the person with Alzheimer's disease including suggestions on activities and options to maximize strengths.

Session IV – He/she is on too many medications
Discusses the concerns and appropriate benefits of commonly prescribed medications in the care of the person with Alzheimer's disease.

Session V – I can't do this anymore
Discusses the dilemmas and issues around the placement decision. Covers options, resources and the decision making process.

Session VI – I should, I ought, I have to...
Covers the guilt that typically goes along with the role of caregiver as well as the impact guilt has on caretaking.

Every Monday from July 26 through August 30 (2010)
6:30 – 8:00 p.m.
Church of the Ascension
13720 Roe, Leawood, KS
Room 2209 West Building

August 17 – Part 1; September 21 – Part 2; October 19 – Part 3; (No part 4) November 16 – Part 5; December 21 – Part 6 (2010)
12:00 – 1:30 p.m.
Nashua Memorial Regional Medical Center
629 S. Plummer, Chanute, KS

August 2 – Part 1; August 9 – Part 2; August 16 – Part 3; August 23 – Part 4; September 7 – Part 5; September 14 – Part 6 (2010)
10:00 – 11:30 a.m.
Bates County Memorial Hospital
615 West Nursery Street, Butler, MO

Every Thursday from October 7 through November 11 (2010)
1:50 – 2:30 p.m.
North Kansas City Hospital, Health Services Pavilion
Entrance 7, First Floor, Barry Room
2790 Clay Edwards Drive, North Kansas City, MO

Every Monday from April 4 through May 9 (2011)
11:00 a.m. – 12:30 p.m.
Centerpoint
1960 East 39th Street, Independence, MO

Every Wednesday from March 23 through April 27 (2011)
11:30 a.m. – 1:00 p.m.
Garnett, KS, call for location, bring a sack lunch

Growing Through Grief
A three part series discussing the unique experiences of grief in caring for individuals with Alzheimer's disease.

January 6, 13 and 30 (2011)
1:00 – 2:30 p.m.
Main Chapter Office

Individualized In-House Training
The Alzheimer's Association also offers individualized in-house training for facilities and community agencies. Choose from more than 10 topics including disease overview, behavior issues, communications, promoting independence, and end of life issues. Contact Michelle Nelson at 913.811.3888 to schedule training. **Cost: \$100.00 for up to 4 hours; \$200.00 for 4 to 8 hours.**

Training is available only for the 24-hour center, a 24-hour assisted living unit or a skilled nursing facility. Training is available for up to 10 participants. Training will be billed in the facility if training is cancelled or postponed after the trainer's arrival at the facility. \$100.00 will be charged based on the above for schedule, delivery and material charges on available in facilities and agencies that do not have education training budget sufficient to accommodate this fee policy.

Legal Issues
This session explores the various legal concerns and needs that arise throughout the course of the disease. Issues include durable power of attorney, guardianship, conservatorship, patient rights, division of assets and living wills.

September 20 (2010)
5:30 – 8:00 p.m.
Topeka and Shawnee County Public Library
1515 SW 10th Avenue, Topeka, KS

December 3 (2010)
9:00 – 10:30 a.m.
Main Chapter Office

March 28, (2011)
5:30 – 8:00 p.m.
Anita Heartstone West
3415 SW 6th Avenue, Topeka, KS

April 14 (2011)
4:00 – 5:30 p.m.
Research Medical Center
2316 E. Meyer Blvd, Meeting Room 1

Let's Talk About Dementia: A Community Discussion
August 26 (2010)
10:30 – 11:30 a.m.
Sullivan County Library
109 E. 2nd Street, Milan, MO

March 31 (2011)
4:00 – 5:30 p.m.
Carrizo County Health Department
5 North Hwy, Carrollton, MO

June 14 (2011)
11:30 a.m. – 12:30 p.m.
Putnam County Library
115 S. 16th Street, Unionville, MO

National Alzheimer's Month Conference

10th Annual Defining Hope Conference: The Second 12 Hours
A conference focusing on the implications of Alzheimer's disease during evening and night.

November 5 (2010)
9:00 a.m. – 4:30 p.m.
St. Francis Hospital Auditorium
1700 SW 7, Topeka, KS

Kansas Health Care Association coordinating CEU's
Susan McCurry, Ph.D., University of Washington
Debra Messina, Hebrew Home, Riverdale New York, The Night Program

Cost: \$65.00 per person — Discounted to \$50.00 per person if 3 or more participants are from the same facility/agency

So You Have Been Newly Diagnosed With Alzheimer's
An opportunity to discuss what early stage Alzheimer's disease means and management strategies.

September 2 (2010)
4:00 a.m. – 5:30 p.m.
Main Chapter Office

The Ten Warning Signs of Alzheimer's Disease
July 9 (2010)
12:00 – 1:00 p.m.
Via Christi Hospital
1102 E. Centralia, Pittsburg, KS

August 26 (2010)
12:00 – 1:00 p.m.
MedicalCollege of Columbus
101 N. Lee, Columbus, KS

September 7 (2010)
12:00 – 1:00 p.m.
Senior Citizens Village
1945 Grant, Baxter Springs, KS

October 5 (2010)
1:00 – 2:00 p.m.
Franklin Community Center
701 S. Broadway, Franklin, KS

Continued on back

APPENDIX J

CAREGIVING LITERATURE MATERIAL

PUBLICATIONS FOR STUDY PARTICIPANTS

- A to Z: About Me***, edited by Laura and Brian Smith (2006)
This is a general health and wellness organizer that is not specific to Alzheimer's disease. Cost \$5.50; ISBN 978-1425103668

- Alzheimer's Action Plan: The Experts' Guide to the Best Diagnosis and Treatment for Memory Problems*** by P. Murali Doraiswamy M.D., Lisa P. Gwyther M.S.W., and Tina Adler (2008)
This book provides a guide for step by step care planning to ensure the highest quality of life for individuals with Alzheimer's at all stages of disease. Cost \$14.00; ISBN 978-0312355395

- Alzheimer's Association Caregiver's Notebook***, by the Alzheimer's Association (2009)
Developed with input from caregivers, the Alzheimer's Association Caregiver Notebook is designed to be a tool throughout your journey. Using an easy-to-follow format, it covers the basics of Alzheimer's and contains tips for care and planning for the future, as well as a list of resources to use when you require additional information. Cost \$14.00; ISBN 978-0696244032

- The Big Brain Puzzle Book*** by Terry Stickel (2009)
This book has three different difficulty levels of puzzles that exercise your brain. Cost \$12.00; ISBN 978-1603208208

- Creating Moments of Joy*** by Jolene Brackey (2008)
A book that teaches about a way of viewing and approaching loved ones with Alzheimer's disease that supports moments of connection and enjoyment. Cost \$16.00; ISBN 978-1557534620

- Keeping Busy: A Handbook of Activities for Persons with Dementia*** by James R. Dowling (1995)
This book describes a variety of activities that are designed too bring meaning and enjoyment to the lives of people living with dementia. Cost \$13.00; ISBN 978-0801850592

- Love in the Land of Dementia*** by Deborah Shouse (2006)
 This is a collection of stories sharing the experience of a daughter walking through the Alzheimer's journey with her mother. An uplifting and honest picture of changes, new learning, new perspectives and enduring love. Cost \$15.00; ISBN 978-0977759040
- 36 hour day*** by Nancy Mace, M.A. and Peter Rabins, M.D., M.P.H. (2006)
 A reference of information for caregivers including disease information, typical challenges and management information. Cost \$10.00; ISBN 978-0446618762
- A Caregiver's Guide to Alzheimer's Disease: 300 Tips for Making Life Easier*** by Patricia Callone, M.A., MRE, Connie Kudlacek, B.S., Barbara Vasiloft, M.A., Janann Manternack, M.Div., and Roger Brumback, M.D. (2005)
 This book is a quick, easy guide for caregivers on behavior, care, communication and other important pieces that contribute to value in relationships through the disease process. Cost \$12.00; ISBN 978-1932603163
- What's Happening to Grandpa?*** by Maria Shriver and Sandra Speidel (2004)
 This is a children's book that tells the story of school aged, Kate and her Grandfather, who has Alzheimer's Disease. Cost \$7.00; ISBN 978-0316001014
- Wilford Gordon McDonald Partridge*** by Mem Fox (1989)
 A children's book about a boy and a friend with Alzheimer's disease who lives next door in a long term care facility. Great for younger kids with wonderful pictures and lots of room for conversation. Cost \$8.50; ISBN 978-0916291266
- Neuropsychiatric Symptoms of Dementia: A Visual Guide to Response Considerations*** by Michelle Niedens, LCSW (2011)
 This guide was developed by the Alzheimer's Association's Heart of America Chapter Director of Education and Public Policy and has been reviewed by dementia experts from around the country. It provides evidence-based intervention suggestions for a wide range of neuropsychiatric challenges, such as wandering, depression, and resistance to daily care. Cost \$20.00; ISBN N/A; This book may be purchased at the Alzheimer's Association Heart of America Chapter while supplies last. Call 913-831-3888 or E-mail michelle.niedens@alz.org.

APPENDIX K

CONSENT FORM FOR DISSERTATION STUDY

Consent for Participation in a Research Study *Effects of a Psychoeducational Intervention on Dementia Caregivers*

Sarah Llanque, PhD(c), RN, Principal Investigator
Maithe Enriquez, PhD, RN, ANP-BC, Faculty Supervisor

Invitation to Participate

You are invited to participate in a research study.

Investigator

This study will be conducted by Sarah Llanque, PhD(c), RN a doctoral candidate in the School of Nursing at the University of Missouri-Kansas City.

Who will Participate

Caregivers of persons with dementia attending the Family Series Workshop, held by the Alzheimer's Association Heart of America Chapter.

Participants eligible to participate must be (a) a caregiver of a person with dementia who is not residing in a nursing home or institutional setting, (b) providing care with activities of daily living (e.g., bath, dressing, toileting, etc.) or independent activities of daily living (e.g., transportation, shopping, paying bills, using the phone, housekeeping, etc.), and (c) capable of providing consent.

Purpose

The purpose of this study is to evaluate the Family Series Workshop, conducted by the Alzheimer's Association Heart of America Chapter, that you are currently attending.

Description of Procedures

You are being asked to fill out four questionnaires, before and after attending the Family Series Workshop. Completing the questionnaires will take approximately one (1) hour of your time. The findings will assess if the Family Series Workshop has an effect on the perceived stress, self-reported competence level, and perceived coping levels of caregivers of persons with dementia. The findings may be used in professional presentations or be published in professional journals; however, your identity will be protected.

Voluntary Participation

Participation in this study is voluntary at all times. You may choose to not participate or to withdraw your participation at any time or refuse to answer certain questions. Deciding not to participate or choosing to leave the study will not result in you being denied any current or future services provided by the Alzheimer's Association Heart of America Chapter to which you are entitled.

If you decide to leave the study, the information you have already provided will be discarded.

Fees and Expenses

You are not responsible for any costs or expenses associated with this study that would be in addition to your attendance at the free Family Series Workshop sponsored by the Alzheimer's Association Heart of America Chapter.

Compensation

You will receive one (1) free book from the Alzheimer's Association library to compensate you for your time to participate in this study. Sample books will be available at the Family Series Workshop sessions for you to review books available. After completing the study, you will be provided with a voucher with a list of publications available for purchase. You will have the choice of turning in your voucher to the PI or turning it in via snail mail (self-address postage paid envelope will be provided to you). You will receive your book via postal mail in two weeks from the date you mailed the voucher.

Risks and Inconveniences

Although there are no known risks for participating in this study, it is possible that you could become upset while completing the questionnaires. You may refuse to complete the questionnaires or skip questions, or discontinue your participation at any time. Should you experience any emotional upset triggered by the questions you may contact the PI, Sarah Llanque, at (###) ###-#### or E-mail her at smlc55@mail.umkc.edu.

Benefits

There are no direct benefits to you.

Alternatives to Study Participation

You can choose not to participate in this study. Your decision to not participate will not affect the services that you receive at the Alzheimer's Association Heart of America Chapter, now or in the future.

Confidentiality

All of the information you complete and share in this study will be kept confidential. Your identity will not be provided on the questionnaires. Instead, an identification number will be provided to you so the information collected will not be directly linked to you. Also, all of the questionnaires you complete will be kept in a locked drawer. The information collected will be entered into an electronic database and be stored on a password protected computer. The information obtained in this study may be presented at professional conferences or published in journals; however you will not be identified in any way.

While every effort will be made to keep confidential all of the information you complete and share, it cannot be absolutely guaranteed. Individuals from the University of Missouri-Kansas City Institutional Review Board (a committee that reviews and approves research studies), Research Protections Program, and Federal regulatory agencies may look at records related to this study for quality improvement and regulatory functions.

In Case of Injury

The University of Missouri-Kansas City appreciates the participation of people who help it carry out its function of developing knowledge through research. If you have any questions about the study that you are participating in you are encouraged to call **Sarah Llanque**, the investigator, at ###-###-####.

Although it is not the University’s policy to compensate or provide medical treatment for persons who participate in studies, if you think you have been injured as a result of participating in this study, please call the IRB Administrator of UMKC’s Social Sciences Institutional Review Board at ###-###-####.

Questions

If you have any questions about this study at any time, you may contact Sarah Llanque or Dr. Maithe Enriquez at the University of Missouri-Kansas City, School of Nursing 2464 Charlotte, Kansas City, Missouri, 64108. You may call Dr. Enriquez at ###-###-####, or e-mail her at enriquezm@umkc.edu. You may call Sarah Llanque at ###-###-#### or email her at smlc55@mail.umkc.edu. We will be happy to answer any of your questions.

Authorization

Printed Name of the Participant _____

Signature of the Participant _____

Date _____

Printed Name of the Investigator _____ Sarah Llanque, PhD(c), RN _____

Signature of the Investigator _____

Form Revision Date: 9/1/04

APPENDIX L

IRB STUDY APPROVAL LETTER

From: andermansh@umkc.edu
Subject: **Study SS11-18e: Effects of a Psychoeducational Intervention on Dementia Caregiving**
Date: March 25, 2011 10:33:21 AM CDT
To: Sarah Llanque <smlc55@umkc.edu>
Cc: andermansh@umkc.edu, andermansh@umkc.edu

March 25, 2011

Sarah Llanque, RN
UMKC - School of Nursing
2464 Charlotte
Kansas City, MO 64108

Dear Ms. Llanque:

Your research protocol IRB # SS11-18e, entitled: "Effects of a Psychoeducational intervention on dementia caregivers" was given an expedited review by a member of the UMKC Social Sciences Institutional Review Board.

The IRB approves research protocol IRB # SS11-18e as submitted. You are granted permission to conduct your study as described in your application effective immediately. The study is subject to continuing review on or before 2/09/2012, unless closed before that date. It is your responsibility to provide a Progress Report prior to that date to avoid disruption of your research.

The approval includes the following documents:

- Research protocol IRB #SS11-18e
- Consent Form Version date 2/8/11
- Education Calendar
- Appendix J (The Family Series)
- Appendix K (Publications Available)

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Rebekah Barreth (phone: 816-235-6150; email: barrethr@umkc.edu) if you have any questions or require further information.

Sincerely,

Sheila Anderman, CIP, CIM
Research Protections Program Manager
UMKC Social Sciences
Institutional Review Board

This e-mail is an official notification intended only for the use of the recipient(s). This letter indicates the status of the UMKC Social Sciences IRB review of the referenced research project. When appropriate, a member of the UMKC Social Sciences IRB staff will be contacting the recipient(s) informing them of other IRB documents related to this project that are available to either 1) be picked up at the IRB office - 5319 Rockhill Road or 2) be mailed via campus mail or postal service - i.e.; revisions to consent form, advertisements, etc. If a signed copy of this letter is needed, please contact a member of the IRB staff. If you have received this communication in error, please return it to the sender immediately and delete any copy of it from your computer system.

APPENDIX M

LETTER OF SUPPORT FROM RESEARCH STUDY SITE

September 8, 2010

Dear Sir or Madam:

As the Director of Education, Programs and Public Policy, at the Alzheimer's Association Heart of America Chapter, I am in full support and give permission for Sarah Llanque's Dissertation Project to progress forward in assessing the outcomes of the Family Series Caregiver Intervention Workshop for caregivers of persons with dementia (e.g., Alzheimer's disease). Participants will be recruited from our Family Series Workshop, which is on-going throughout the year. Participants will have the choice of joining the study by completing an informed consent form, and completing pretest and posttest instruments evaluating this intervention. I am comfortable in proceeding with the study since there is potential for discovery and understanding within this particular area of gerontology while bearing no risks to respondents. If you have any questions, please contact me.

Sincerely,

Michelle Niedens, L.S.C.S.W., M.S.W.
Director of Education, Programs and Public Policy

APPENDIX N
LETTERS OF PERMISSION

PERMISSION TO USE THE CAREGIVING COMPETENCE SCALE

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You are welcome to use all scales of the Brief COPE, or to choose selected scales for use. Feel free as well to adapt the language for whatever time scale you are interested in.

Excerpt from the website: <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>
Accessed: 12/2/2010

PERMISSION TO USE CAREGIVING COMPETENCE SCALE
BY AUTHOR

Re: Caregiver Competence Scale
From: Leonard Pearlman [lpearlin@socy.umd.edu]
Sent: Tuesday, November 02, 2010 9:05 AM
To: Llanque, Sarah M. (UMKC-Student)

Dear Ms. Llanque,

Please feel free to use whatever of my materials are appropriate to your work. Good luck.
Len Pearlman

>>> "Llanque, Sarah M. (UMKC-Student)" <smlc55@mail.umkc.edu> 11/01/10 3:08 AM >>>

Dear Dr. Pearlman,

My name is Sarah and I am currently a doctoral nursing student at the University of Missouri-Kansas City. I would like to request permission to use your Caregiver Competence Scale, published in your article "Caregiving and the Stress Process: An Overview of the Concepts and Their Measures" published in 1990. I will evaluate an educational program/intervention for caregivers of persons with dementia that the Alzheimer's Association conducts. I have enjoyed reading your article and the information you and your colleagues produce. Thanks for your help!

Sincerely,

Sarah Llanque

PERMISSION TO USE CAREGIVER BURDEN INVENTORY

RE: Caregiver Burden Inventory
From: Mike Caserta [Michael.Caserta@nurs.utah.edu]
Sent: Monday, November 01, 2010 7:44 AM
To: Llanque, Sarah M. (UMKC-Student)

Hi Sarah

Feel free to use the scale in your research. The only thing we ask is that you cite the sources you use regarding the scale as appropriate.

Best wishes for success in your doctoral work.

Mike

Michael Caserta, Ph.D.
Robert L. & Joyce T. Rice Presidential Endowed Chair in Healthy Aging
Professor - Gerontology Interdisciplinary Program
College of Nursing
University of Utah
10 South 2000 East
Salt Lake City, UT 84112
Phone (801) 581-3572
Fax (801) 581-4642
michael.caserta@nurs.utah.edu
nursing.utah.edu/gerontology

From: Llanque, Sarah M. (UMKC-Student) [smlc55@mail.umkc.edu]
Sent: Monday, November 01, 2010 2:27 AM
To: Mike Caserta
Subject: Caregiver Burden Inventory

Dear Dr. Caserta,

My name is Sarah. I am a doctoral nursing student at the University of Missouri in Kansas City. I have been reading your article "Exploring the caregiver burden inventory (CBI): Further evidence for a multidimensional view of burden." I would like to request your permission to use the CBI to evaluate an educational workshop intervention for Dementia Caregivers. It is part of my dissertation. I think it would be a great instrument to use because, as you state, it is "multidimensional." Thanks for your contribution to gerontology. I look forward to your response.

Sincerely,

Sarah Llanque, MSN, RN

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VITA

Sarah Mariano Llanque was born to Angelita R. Mariano and Justino Llanque-Chana, in Gainesville, Florida. She was educated in local public schools and graduated as dual enrollment student from both Gainesville High School and Santa Fe College with honors in 1999. She received the Florida Merit Scholarship to attend Jacksonville University, from which she graduated, with a Bachelor of Science in Nursing, in 2003.

Ms. Llanque was a registered nurse and case manager at an Alzheimer's day program for three and one-half years. Simultaneously, Ms. Llanque completed a Master's in Education and a Master's of Science in Nursing Leadership and Management degree in 2005 and 2006, respectively. She began the Ph.D. in Nursing program and Graduate Certificate in Gerontology at the University of Missouri-Kansas City in 2007.

In December 2009, Ms. Llanque assumed a position as the Project L.E.A.R.N. Coordinator at the Alzheimer's Association Heart of America Chapter, where she worked with people newly diagnosed with dementia and their families. In this role she provided education, counseling, and referral to home and community-based resources for clients. Ms. Llanque also provided health assessments for seniors in the community with the Wyandotte/Levenworth Area Agency on Aging as part of their SeniorFit program. Upon completion of her degree requirements, Ms. Llanque plans to continue with her research and work with older adults and their families in the community setting.

Ms. Llanque is a member of the National Gerontological Nurses Association, the Gerontological Society of America, American Society on Aging, the UMKC chapter of Sigma Phi Omega (i.e., the national academic honor and professional society in gerontology), Sigma Theta Tau International Nursing Honor Society, and the chapter

President of the National Association of Hispanic Nurses (NAHN), El Corazón de la Tierra (Heart of the Earth) Chapter. During her free time Ms. Llanque enjoys hiking mountains, spending time with her family, learning Aymara (Native American language) from her father, learning the native traditions of her grandmother, and playing guitar.