THE PHYSICAL AND MENTAL HEALTH OF SPOUSE CAREGIVERS IN DEMENTIA: FINDING MEANING AS A MEDIATOR OF BURDEN

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PHD IN NURSING

ABSTRACT

The purpose of this study was to examine the effect of caregiver burden on the physical and mental health of caregivers of spouses with dementia and to determine if finding meaning through caregiving mediated the relationship between burden and health. This was a cross-sectional, correlational study in a convenience sample of 84 community-residing spouse caregivers of adults with dementia recruited from North-Central Florida. Measures included the Zarit Burden Interview, the Finding Meaning through Caregiving Scale, and the Medical Outcomes Short Form-36, version 2. Data analyses consisted of descriptive, correlational, and standard multiple regression statistical methods. The sample consisted of 50 women and 34 men, between 49 and 96 years of age who were 64% Caucasian, 14% African American, 5% Hispanic/Latino, and 1% other. Results of the correlation analyses indicated associations between income, duration of caregiving, and caregiver physical health; and between burden, finding meaning, and caregiver mental health. Results of the mediation testing indicated that finding meaning partially mediated the effect of burden on mental health. These results suggest that caregivers of spouses with dementia may be at risk for declines in mental health due to caregiving burden. Because of the increased risk for mortality, the effect of burden on caregiver physical health needs further research.
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CHAPTER 1
INTRODUCTION

The prevalence of dementia in the United States in the year 2000 was estimated at approximately 4.5 million people, with an expected increase to 13 million affected persons by the year 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Since dementia risk rises with age, the expected increase has been attributed to the rapid growth of older age groups. Of the 13 million people anticipated to have dementia in the year 2050, 8 million of those will be people age 85 or older and 4.8 million will be people ages 75 - 84 (Hebert, et al., 2003). Most people with dementia reside at home and are cared for by informal caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Informal caregivers are people who provide unpaid care for family members, friends, and neighbors who are unable to care for themselves independently (Family Caregiver Alliance, 2003; Pearlin, Mullan, Semple, & Skaff, 1990). As a result of the anticipated increase in elders affected by dementia, there will be a concomitant increase in informal caregivers.

Informal caregivers make an important economic impact as healthcare resources. The cost of caring for persons with Alzheimer’s disease has been estimated at more than $18 billion nationally, with average annual costs as high as $25,000 per individual (Langa, et al., 2001; Zhu, et al., 2006). The economic value of the informal caregiver system as a health care resource deserves recognition because of its fragility secondary to caregiver vulnerability to stress and stress-related effects (Arno, Levine, & Memmott,
1999; Langa, et al., 2001). Because of their significant social and economic contributions to the quality of life of American elders, the protection of caregiver physical and mental health should be considered of utmost importance.

Most elders prefer to live at home and avoid institutionalization as long as possible (Mittelman, 2003; Spruytte, Van Audenhove, & Lammertyn, 2001). The responsibilities of caregiving primarily reside with one person, most often the spouse (Schulz & Martire, 2004). However, caring for a spouse with a chronic, progressive disease such as dementia is time-consuming, and physically and emotionally demanding (Mittelman, 2003). The stressful nature of dementia caregiving has been well documented in the research literature (Ory, et al., 1999; Schulz & Martire, 2004; Vitaliano, Zhang, & Scanlan, 2003).

In a recent quantitative meta-analysis of 23 studies that included both caregiver and noncaregiver comparison groups with a combined total of 1,594 caregivers, authors reported that dementia caregivers demonstrated a 9% greater risk for health problems than noncaregivers (Vitaliano, et al., 2003). Although a 9% greater risk may seem like a modest increase in risk for ill health, when considering the anticipated 13-million dementia caregivers in the year 2050, the overall effect translates to more than 1 million affected caregivers. In addition, Schulz and Beach (1999) reported a 64% greater risk for mortality in caregivers who reported strain due to caring for a spouse with difficulty in at least one activity of daily living.

Determinants of the health of informal caregivers in dementia have been successfully and predominantly studied within a stress-process framework (Oyebode, 2003; Schulz & Martire, 2004; Zarit & Edwards, 1996). A model developed specifically
to describe the stress-process in dementia caregivers is the Alzheimer’s Caregiver Stress model (Pearlin, et al., 1990). In this model, stress has been described as a process that changes over time and is influenced by contextual factors of the caregiver-care recipient situation that affect primary and secondary stressors, mediators, and outcomes.

Demographic and contextual factors such as type of relationship (eg. spouse, child), sex, income, educational level, and duration of caregiving have been found to influence caregiver stress in dementia. It is generally accepted that spouse caregivers in dementia are at greater risk for a variety of negative outcomes including stress-related mental and physical health problems than other caregivers or noncaregivers (Covinsky, et al., 2003; Kolanowski, Fick, Waller, & Shea, 2004; Messinger-Rappaport, McCallum, & Hujer, 2006; Pinquart & Sorensen, 2003; Vitaliano, et al., 2005). This is thought to be due to a variety of factors such as greater age (Patterson, et al., 1998; Pinquart & Sorensen, 2003; Rinaldi, et al., 2005; Yaffe, et al., 2002), poorer health (Vitaliano, et al., 2005), reduced social support (Cannuscio, et al., 2004; Keller, Magnuson, Cernin, Stoner, & Potter, 2003; Messinger-Rappaport, et al., 2006), and greater health care utilization (Kolanowski, et al., 2004). In addition, being a female caregiver has been reported to contribute to dementia caregiver stress and poorer health (Chumbler, Grimm, Cody, & Beck, 2003; Harwood, et al., 2000; Mahoney, Regan, Katona, & Livingston, 2005; Rinaldi, et al., 2005; Thomas, et al., 2006; Thommessen, et al., 2002; Vitaliano, et al., 2003).

The research regarding the influence of income, educational level, and duration of caregiving on caregiver stress is mixed. Some authors have reported that lower income and educational levels have been associated with greater caregiver stress (Burton,
Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Covinsky, et al., 2003) while others report no differences (Annerstedt, Elmstahl, Ingwad, & Samuelsson, 2000; Farran, Miller, Kaufman, & Davis, 1997). Also, the role of duration of caregiving is unclear. For example, both greater caregiver stress (Burton, et al., 2003) and lower caregiver stress have been associated with greater duration of care (Gaugler, Kane, Kane, Clay, & Newcomber, 2005; McConaghy & Caltabiano, 2005).

Caregivers have perceived the stress of caregiving differently depending upon their appraisal of the situation (Pearlin, et al., 1990). One way that the stress of caregiving has been conceptualized is as caregiver burden, defined as the caregiver’s appraisal of their situation or experience (Oyebode, 2003; Zarit, Reever, & Bach-Peterson, 1980). The concept of caregiver burden has been assessed by questions related to the amount of time spent caregiving, the amount of control over one’s life, the time available for social experiences or for self, and feelings of anger, guilt, and uncertainty about caregiving (Zarit, et al., 1980).

Although informal caregivers in dementia have a risk for negative health effects due to caregiving, few researchers have focused on identifying the process of how informal caregivers cope with the demands of caregiving dementia and whether specific coping strategies may protect their health (Schulz & Martire, 2004). Coping represents personal management of a stressful situation such that the meaning of the situation is changed and the threat reduced (Pearlin, et al., 1990). Caregivers who have successfully coped with the stress associated with caregiving described less burden and better health outcomes (Pearlin, et al., 1990; Rapp & Chao, 2000; Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005).
Finding meaning in caregiving has been conceptualized as a coping strategy with an existential perspective (Farran, 1997; Pearlin, et al., 1990). Specifically, finding meaning has been described as a process resulting from suffering, and seeking to understand an unpleasant situation that induces personal growth and change (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Farran, et al., 1997; Frankl, 1978). Caregivers who have found caregiving to be meaningful have been enabled to continue providing care for their relative (Oyebode, 2003). In previous research, finding meaning has shown promise as a mediator of the effect of burden on health-related outcomes (Farran, et al., 1991; Farran, et al., 1997).

The overall construct of health has been conceptualized as a composite of both physical and mental health (Ware, Kosinski, & Dewey, 2000). Physical health has been defined as comprising four aspects: the performance of physical activities and role, the extent of physical limitations due to pain, and self-assessed general health (Ware, et al., 2000). Mental health has been thought to include perceptions about vitality (amount of energy), and the extent that emotional problems interfere with ability to participate in social activities and roles, as well as overall feelings (Ware, et al., 2000).

Currently, intervention studies with caregivers of older adults with chronic illness and dementia caregivers have only been met with mild to moderate success (Brodaty, Green, & Koschera, 2003; Sorenson, Pinquart, & Duberstein, 2002). However, a better understanding of coping strategies such as finding meaning could provide additional insight into the caregiving process to incorporate into intervention designs. In addition, because dementia caregivers have been found to be at greater risk for adverse health outcomes, including death, than non-caregivers, it is crucial to identify coping strategies
that may assist dementia caregivers to better manage the burden of caregiving (Gallant & Connell, 1997; Patterson & Grant, 2003; Schulz & Beach, 1999; Vitaliano, et al., 2003). Protecting the health of caregivers may enable them to continue providing care for their loved one and potentially decrease the risk for care recipient institutionalization (Aneshensel, Pearlin, Levy-Storms, & Schuler, 2000; Schulz & Martire, 2004).

This study addressed two gaps in the literature. First, it expanded our understanding of the role of caregiver burden on health of people who were caring for their spouse with dementia. Second, it examined the role of finding meaning in caregiving as a mediator of the effect of caregiver burden on health.

Purposes

The purposes of this study were to examine (1) the influence of caregiver burden on physical and mental health and (2) the role of finding meaning in caregiving as a mediator of the relationship between caregiver burden and physical and mental health outcomes, controlling for the background and contextual factors of income, education, and duration of caregiving. The Alzheimer’s Caregiver Stress Model provided an explanatory framework (Pearlin, et al., 1990).

Research Questions

In spouse caregivers in dementia:

1. What is the relationship between caregiver burden and physical health, after controlling for income, education, and duration of caregiving? Hypothesis: Greater caregiver burden will be associated with poorer physical health.
2. What is the relationship between caregiver burden and mental health, controlling for income, education, and duration of caregiving? Hypothesis: Greater caregiver burden will be associated with poorer mental health.

3. What is the relationship between burden and finding meaning, controlling for income, education, and duration of caregiving? Hypothesis: Greater burden will be associated with less finding meaning.

4. Does finding meaning mediate the relationship between caregiver burden and physical health, controlling for income, education, and duration of caregiving? Hypothesis: Finding meaning will mediate the relationship between caregiver burden and physical health.

5. Does finding meaning mediate the relationship between caregiver burden and mental health, controlling for income, education, and duration of caregiving? Hypothesis: Finding meaning will mediate the relationship between caregiver burden and mental health.

Assumptions

1. Dementia caregiving is stressful.

2. Women report greater caregiver burden than male caregivers.

3. Dementia caregiving is unique and chronic.

Theoretical Framework

Building upon the earlier work of Lawton and colleagues (1969; 1989) Pearlin and colleagues (1990) developed a model for use in dementia caregiver research (Figure
1). This model was based on the theory that the relationships among stressors, mediators, and outcomes change over time and that stress is a process. It consists of background and contextual factors, primary and secondary stressors, mediators, and outcomes. Background factors form the underlying social characteristics of the group. Secondary stressors, role strain and intrapsychic, were thought to be derived from primary stressors. Mediator variables such as social support and coping were conceived to affect the outcomes: depression, anxiety, cognitive disturbance, health, and change in role.

Figure 1

*Alzheimer’s Caregiver Stress Model*
*(Pearlin, Mullan, Semple, & Skaff, 1990)*
Background and Contextual Factors

The background and contextual factors as conceptualized by Pearlin and colleagues (1990) form the underlying social milieu that influences the stress process. Included were broad categories that described the characteristics of the group under study such as age, gender, ethnicity, education, occupation, and income. These characteristics were thought to reflect where people were stratified in the social environment in terms of distribution of rewards and opportunities, types of stressors, and available resources (Pearlin, et al., 1990). In addition, access to services, type of relationship (eg. spouse, adult child), and duration of caregiving (length of time the care recipient has required care) were also included.
Primary and Secondary Stressors

Primary stressors were proposed to be conditions and experiences that threaten or cause problems for people. They included specific objective stressors such as cognitive status of the care recipient, problem behaviors, and activities of daily living (ADL’s) (bathing, dressing, eating, toileting), and assistance with independent activities of daily living (IADL’s) (dialing the telephone, cooking, and shopping) (Hunt, 2003; Pearlin, et al., 1990). Within the stress-process framework, primary stressors were thought to drive the progression of the stresses that follow (Pearlin, et al., 1990). In other words, serious stressors often triggered the development of other stressors. Primary and secondary stressors did not necessarily follow each other in a time progression, but may co-exist, feedback, and inter-relate (Pearlin, et al., 1990).

Mediators

Mediating conditions explained the variability in outcomes. The concepts of coping and social support were the mediators proposed in the original Pearlin model. Researchers attempted to learn if differences in coping styles or the use of social support accounted for why some people managed better than others in equal circumstances. Then determinations about whether the strength of the relationship between the stressor and the outcome was reinforced or attenuated could be made.

In this model, coping represented behaviors by caregivers to reduce threat, deal with stress, and manage the meaning of the situation (Pearlin, et al., 1990). Farran (1997) proposed to extend or broaden this conceptualization of coping to incorporate the existential paradigm of finding meaning (Frankl, 1978). It was thought that an existential
paradigm better described the dementia caregiving situation because, defined existentially, finding meaning included the idea that humans can “create meaning through transcendence and transformation of difficult life experiences” (Farran, et al., 1991, p. 255). Farran (1997) proposed that by incorporating finding meaning into stress-process models, it would enable researchers to view the caregiving situation in a broader context that included a spiritual dimension of growth, the search for meaning, and change.

Therefore, in this study, an extension of the Pearlin model is proposed, that of expanding the original conceptualization of coping and the management of meaning to include finding meaning from an existential perspective, and to test finding meaning as a mediator of burden and the physical and mental health of spouse caregivers in dementia (Figure 2).

Outcomes

The effects of the stress process on people’s lives usually involve their health, well-being, and social role fulfillment. According to the Pearlin model, specific outcomes could include depression, anxiety, irascibility, cognitive disturbance, physical health, and yielding of role. The authors hypothesized that declines in caregiver physical and emotional health would likely result in a reduction or yielding of the caregiver role.
CHAPTER 2
REVIEW OF THE LITERATURE

Background

Due to advances in health care technology and reductions in reimbursement, it is anticipated that the complexity and duration of dementia caregiving will increase (Schulz & Martire, 2004). In the future, it is likely that dementia caregivers will be providing care at home for an extended period of time, shouldering an increasing burden of physical care that is both emotionally demanding and time consuming, using complex technologies, balancing their personal and social life with caregiving responsibilities, while financial resources diminish due to increasing medical expenses (Alzheimer’s Association, 2004). As a result, there is a significant risk for negative health outcomes due to the chronic daily stress associated with caregiving (Patterson & Grant, 2003; Pinquart & Sorensen, 2004; Schulz & Beach, 1999; Vitaliano, et al., 2003).

As caregivers’ health declines, their ability to provide care may be reduced, which increases the risk for institutionalization of the family member (Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Kesselring, et al., 2001; Vitaliano, et al., 2003). In fact, in a study of 608 community residing caregivers who were randomly selected, as many as 57% of family caregivers have reported that health limitations had reduced their ability to provide care for their relative, and 25% stated that caregiving duties had negatively affected their health (Toseland, McCallion, Gerber, & Banks, 2002). However, institutionalization has not consistently been found to decrease levels of caregiver burden
or to improve their health. In fact, caregiver health may worsen after institutionalization (Aneshensel, et al., 2000; Schulz, et al., 2004). Some reasons given for this phenomenon have included continued caregiver anxiety, depression, and feelings of loss after placement (Lieberman & Fisher, 2001; Moyle, Edwards, Clinton, 2002; Schulz, et al., 2004). Therefore, identifying factors that protect or preserve caregiver health remains an important goal for health professionals. Demographic factors such as type of relationship, age, and gender have been reported as aspects that may influence research findings.

Demographics

Spouses. Caregiving in dementia has been described as a source of chronic stress for spouses who experience regular and frequent stressors such as assisting with daily hygiene (bathing, toileting, dressing), feeding, mood changes (depression, irritability, agitation), wandering, and communication difficulties when managing their spouse with dementia (Vitaliano, et al., 2005). Recent quantitative meta-analyses indicated that dementia caregivers were at risk for greater burden and physical and mental health declines when compared with non-caregivers (Pinquart & Sorensen, 2003; Vitaliano, et al., 2005). The findings were similar when comparing spouse caregivers in dementia to adult children (Pinquart & Sorensen, 2003). This may be due to higher levels of burden and less available coping resources for spouses than adult children (Pinquart & Sorensen, 2003). As the current population ages, the majority of dementia caregivers in the future will likely be spouses. Because it has been consistently reported in the literature that there is an increased risk for health declines in spouses who are caregivers, they were the focus of this study.
Age. Being an older dementia caregiver increases the risk for greater stress and negative health outcomes such as depression and declines in physical health due to caregiving (Schulz & Martire, 2004). Patterson and colleagues (1998) described the results of a study of caregiver burden and health in 74 spouse dementia caregivers. The mean age of the sample was 70.4 (S.D. = 5.6). Caregiver burden was measured as role overload and defined by Pearlin and colleagues (1990) as the subjective report of caregiver hardships from the daily stress of caregiving. In that sample, statistical analysis via path modeling based on the Alzheimer’s caregiver model (Pearlin, et al., 1990) indicated that greater caregiver age predicted increased role overload, depression and more physical symptoms.

Time to nursing home placement was examined in a prospective, multi-site study of 5,788 community-dwellers with dementia and their caregivers. It was determined that greater caregiver age and high burden scores were determinants of placement of the care recipient (Yaffe, et al., 2002). Similarly, Rinaldi and colleagues (2005) determined that dementia caregivers over the age of 70 were three times more likely to report burden, distress, depression, and anxiety in a sample of 419 outpatients from 15 Italian geriatric clinics.

Pinquart and Sorensen (2003) utilized a large meta-analysis of the developmental and gerontological literature between the years of 1987 to 2002 to determine differences among caregivers (63% were dementia caregivers, 59% were spouses) and non-caregivers in stress, depression, physical health, and other outcomes. They reported that greater caregiver age predicted more depression when compared with non-caregivers. The mean age of the caregivers was 62 and they had been providing care for an average
of 55 months, spending approximately 43 hours per week in caregiving tasks. Therefore, current findings indicate that greater dementia caregiver age is a significant factor in predicting greater burden and negative health effects due to caregiving.

**Females.** Female dementia caregivers are at greater risk for adverse health effects and burden from caregiving responsibilities (Schulz & Martire, 2004). This may be partly due to the fact that there are more female (60%-75%) than male caregivers (Arno, 1999; Family Caregiver Alliance, 2003; Navaie-Waliser, et al., 2002; Vitaliano, et al., 2003). However, even when controlling for this effect, in the meta-analysis by Vitaliano and colleagues (2003), women still reported more health problems. In addition, there is an abundance of literature where authors similarly reported either greater burden and/or health declines for women dementia caregivers (Chumbler, et al., 2003; Harwood, et al., 2000; Mahoney, et al., 2005; Pinquart & Sorensen, 2003; Rinaldi, et al., 2005; Thomas, et al., 2006; Thommessen, et al., 2002).

In the meta-analysis previously described (Pinquart & Sorensen, 2003), authors analyzed 84 research studies and determined that female caregivers (63% of the studies were of dementia caregivers) were significantly more likely to experience depression and poor physical health than non-caregivers. Authors reported this effect was likely due to greater participation in personal and instrumental care than men, greater willingness to report negative feelings, and less effective coping styles (Pinquart & Sorensen, 2003).

Similarly, Chumbler and associates (2003) examined gender and kinships effects in community-dwelling dementia caregivers. In the sample of 305 family caregivers, data were analyzed from a larger project, the Arkansas Older Adult with Cognitive
Impairment and Family Caregiver Project, which consisted of random sampling, telephone screening for cognitive impairment in persons over the age of 70 and their identified caregiver. Caregiver burden was measured using Pearlin and colleagues (1990) role overload scale, defined as self-assessment of their caregiving situation and their feelings about their experience. There were no gender differences in burden reports. However, a greater percentage of women reported health problems such as high blood pressure and nervousness than the male participants that may predispose them to greater difficulties with providing care (Chumbler, et al., 2003, Yee & Schulz, 2000).

A convenience sample of 40 Cuban-American dementia caregivers were recruited from a memory disorder clinic associated with the University of Miami and participated in a cross-sectional study of predictors of caregiver satisfaction and burden (Harwood, et al., 2000). Caregiver burden was conceptualized according to a stress-process framework (Lawton, Kleban, Moss, Rovine, & Glickman, 1989). Authors reported that being female significantly predicted greater caregiver burden, consistent with non-Hispanic samples and recommended further investigation of the interaction between social support, care recipient problems and gender, particularly in diverse ethnic groups.

Nationally and internationally women report greater negative effects from caregiving (Harwood, et al., 2000; Mahoney, et al., 2005; Rinaldi, et al., 2005; Thommessen, et al., 2002). Italians researchers stratified 419 dementia caregivers into two groups: low-level burden, distress, depression and anxiety and high-level burden, distress, depression and anxiety using cluster analysis. Women caregivers were significantly more likely to be represented in the high-level group than in the low-level group. In addition, greater care recipient disability with activities of daily living and
behavioral disturbances were associated with caregivers in the high-level group (Rinaldi, et al., 2005). It has been speculated that female caregivers were more likely to experience greater burden and negative health effects from caregiving due to greater participation in direct and personal care of the care recipient than male caregivers (Yee & Schulz, 2000).

Thomassen and colleagues (2002) studied 186 patient-spouse dyads in Parkinson’s disease, stroke, and dementia and identified characteristics associated with psychosocial burden in the spouse. Data analysis through structural equation modeling identified covariates of caregiver stress. When divided into groups by disease, in the dementia caregiver group the female spouses reported significantly greater stress.

Outcomes of anxiety and depression were measured in interviews with 153 English dementia caregivers (Mahoney, et al., 2005). Authors reported greater anxiety in female caregivers, particularly in those who lived with the care recipient. Participants were recruited using purposive sampling from the London community to represent people with mild, moderate, and severe dementia and their informal caregivers. In the sample, 70% were female with a mean caregiver age of 64 years. According to the authors, although depression had been included in many dementia caregiver studies, anxiety had been less studied. The authors reported that being female was a significant predictor of anxiety. Discussion included the overall finding of greater anxiety in older dementia caregivers compared to the general population and the need for further investigation into measurement of depression which may have obscured differences between anxiety and depression (Mahoney, et al., 2005). In addition, risk factors for anxiety and depression such as caregiver poor health, relationship quality, and care recipient irritability were discussed as possible alterable factors for clinician intervention.
Together, the above studies indicate a greater risk for female caregivers to have negative outcomes in terms of both burden and health while providing care for their relative with dementia. As well, contextual factors may also be an important consideration among dementia caregivers as potentially influencing factors of caregiver stress.

**Contextual Factors**

There are mixed findings in the literature reports regarding the role of contextual factors that comprise the caregiver-care recipient milieu. However, there is a body of literature that provides some evidence that income, educational level, and the duration of caregiving may play a role in caregiver stress and health.

**Income and education.** The importance of socioeconomic status (SES) as an influencing factor on health outcomes has been documented in the research literature (Braveman, et al., 2005; Oakes & Rossi, 2003). However, the findings have been complicated and compromised by ambiguity surrounding the term socioeconomic status. As a multidimensional construct, socioeconomic status has been described as comprised of factors such as occupation, income, wealth, education, neighborhood characteristics, and past experiences (Braveman, et al., 2005).

Regarding the selection of SES variables for study in dementia caregiving, the two most commonly used factors to assess SES have been education and income. In the caregiving literature, there have been some indications that lower income is associated with greater stress among caregivers (Burton, et al., 2003; Covinsky, et al., 2003). This
may partly be explained by the increase in cost of medical care as dementia severity worsens (Meiland, Kat, vanTilburg, Jonker, & Droes, 2005; Zhu, et al., 2006). However, others have reported that income levels did not influence caregiver stress (Annerstedt, et al., 2000; Farran, et al., 1997). Moreover, the role of caregiver educational level remains ambiguous. Some researchers have reported an association between lower educational levels and greater caregiving stress in dementia (Patterson, et al., 1998), while others have reported either an opposite relationship (lower caregiver educational level with less stress) (DiBartolo & Soeken, 2003) or no difference (Annerstedt, et al., 2000).

**Duration of caregiving.** When evaluating contributors to caregiver stress, the function of the duration of caregiving is also an important factor to consider. Pearlin and colleagues (1990) described the duration of caregiving as an indicator of chronic stress. Conflicting reports can be found in the literature. Researchers have reported that the longer periods of time in the caregiving role may be associated with decreased stress due to adaptation (Gaugler, et al., 2005; McConaghy & Caltabiano, 2005) or increased stress due to greater assistance with activities of daily living required by the care recipient (Burton, et al., 2003).

**Caregiver Burden**

Caregivers have perceived the stress of caregiving differently depending upon their appraisal of the situation (Pearlin, et al., 1990). Caregiver burden is a term that has been used to describe the overall toll of providing care for a person with dementia (Parks & Novielli, 2000). Specifically, caregiver burden has been described as the stress
associated with caregiving and defined as the caregiver’s appraisal of their situation or experience (Oyebode, 2003; Zarit, et al, 1980). There is ample evidence that dementia caregivers experience greater burden than noncaregivers and non-dementia caregivers (Ory, et al., 1999; Patterson, et al., 1998; Pinquart & Sorensen, 2003; Thommessen, et al., 2002).

*Caregiver Burden and Health*

The greater burden of dementia caregivers has been attributed to greater amounts of care required due functional limitations when compared with another type of chronic illness (Clipp & George, 1993). For example, people with dementia are more likely to be older, require assistance with medications, transportation, and require intervention and support to manage problem behaviors (Alzheimer’s Association, 2004; Messinger-Rappaport, et al., 2006). The toll of caregiving on caregiver’s health has been attributed to living with the daily burden of caregiving (Schulz & Martire, 1999). Specifically, physical health declines have been reported as poorer self-rated health, reduced participation in healthy behaviors, disabling physical conditions, and increased physical symptom reports (Bruce, et al., 2005; Pinquart & Sorensen, 2003; Roth, Haley, Owen, Clay, & Goode, 2001; Vitaliano, et al., 2003).

In addition, caregiver burden has been attributed to declines in the mental health of caregivers. Dementia caregivers have reported a greater incidence of psychological effects, primarily anxiety and depression, due to caregiving (Crespo, Lopez, & Zarit, 2005; Edwards, Zarit, Stephens, & Townsend, 2002; Mahoney, et al., 2005; Pinquart & Sorensen, 2003). However, in spite of the burden of caregiving, some caregivers cope
with the stress of caregiving quite well in spite of difficult circumstances. A growing body of literature has documented that caregiver spirituality and/or religiosity may be a protective factor.

*Spirituality-Religiosity*

In general, the concepts of spirituality and religiosity have been interpreted in the empirical literature in a variety of ways (LeBlanc, Driscoll, & Pearlin, 2004). Spirituality has been considered to encompass religiosity in the sense that it is defined as being connected to something greater than the self (Acton & Miller, 2003; Reed, 1987). Moberg (2005) recommended that the terms should be considered overlapping constructs that need to be considered together. Various aspects of spirituality and religiosity have been reported to have health benefits (Koenig, Larson, & McCullough, 2000; Moberg, 2005). Reed (1987) argued that spirituality may be a coping mechanism for feelings of distress, a finding that has been corroborated in other studies (Acton & Miller, 2003; Morano & King, 2005).

The positive associations between spirituality/religiosity and health have been theoretically proposed to occur through various behavioral pathways that may mediate or moderate the negative effects of caregiver stress on well-being (LeBlanc, et al., 2004). However, LeBlanc and colleagues (2004) reported that while care-related stressors in dementia led to depression, only limited mediation effects (applicable only to a small subgroup) and no moderation effects from religiosity were found. The measure of religiosity was limited to traditional Judeo-Christian practices such as attendance at church and prayer. Among minorities such as Latinos and African Americans there is
some evidence for the mediation effect of religiosity on caregiver stress and caregiver strain (Morano & King, 2005; Roff, et al., 2004).

Others have found that a more global conceptualization of spirituality may be more descriptive of the actual processes that occur during times of caregiving stress (Acton & Miller, 2003). Qualitative transcripts from dementia caregivers revealed more global expressions of spirituality attained through caregiving and included ideas about the process of connecting with others, with self, and with a higher power, gaining comfort, strength, and inner peace, attaining acceptance and finding a purpose in life (Acton & Miller, 2003). As a result of their study, authors suggested that some caregivers find spiritual meaning that “empowers them to transcend their caregiving difficulties” (Acton & Miller, p. 117). A similar construct, finding meaning in caregiving, has been explored in the work of Farran and colleagues (1997).

Finding Meaning

Finding meaning has its roots in existentialism, a theoretical and philosophical perspective founded on the idea that human suffering is necessary before finding meaning can occur (Frankl, 1978; Levine, et al., 1984). The concept of finding meaning has been described as the way that caregivers have sought to find a larger perspective from which to understand their relatives’ illness, have suffered as a result of their difficulties, and having done so, have changed their thinking and feelings about the situation and grown, become stronger and transformed as a result of it and have been better able to cope with their situation (Farran, et al., 1997; Farran, et al., 1991; Noonan & Tennstedt, 1997; Salmon, et al., 2005).
Caregivers have reported that finding meaning in caregiving has helped them to deal with the burden of providing long term care for their relative with dementia (Farran, et al., 1991; Kramer, 1997). There is some evidence that ways of caregiving coping may influence health-related outcomes in informal caregivers (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Salmon, et al., 2005). In addition, types of caregiver coping strategies were linked with a greater risk for care-recipient mortality in dementia (McClendon, Smyth, & Neundorfer, 2004).

Coping represents personal management of a stressful situation that changes its’ meaning and reduces threat (Pearlin, et al., 1990). Caregivers who have successfully coped with the stress associated with caregiving described less burden and better health outcomes (Pearlin, et al., 1990; Rapp & Chao, 2000; Salmon, et al., 2005). Specifically, caregiver coping strategies were reported to partially or completely ameliorate the effects of perceived stressors on negative caregiving outcomes such as physical and mental health (Gottlieb & Rooney, 2004; Kneebone & Martin, 2003).

Although informal caregivers in dementia have a greater risk for negative health effects due to caregiving, relatively few researchers have focused on identifying the process of how informal caregivers cope with the demands of dementia caregiving and whether specific coping strategies may protect their health (Schulz & Martire, 2004). One such coping strategy is finding meaning in caregiving. Specifically, finding meaning has been described as a way of feeling positive about the caregiving situation (Farran, et al., 1997). Researchers have identified that caregivers have reported, anecdotally and through qualitative work, that caregiving has provided them with an opportunity for growth and
change (Farran, et al., 1991). This process has been called finding meaning in caregiving (Farran, et al., 1991).

According to Farran and colleagues (1999), attempts to operationalize the positive aspects as a way to explain why and how some people do so well under negative circumstances, led to studying such constructs as finding meaning in caregiving. Initially, Farran and colleagues (1991) identified the construct of finding meaning in caregiving through qualitative work. They cited theoretical support from early work by Frankl (1978) that was based on an existential perspective that evolved from personal experiences in Nazi concentration camps. The ability of caregivers to find meaning may enable them to continue providing care in challenging and difficult circumstances.

The construct of finding meaning in caregiving has been defined in terms of the combined effect of three separate but related concepts: loss and powerlessness, referring to the difficulties with caregiving, provisional meaning, which describes the finding of day-to-day meaning, and ultimate meaning, a term that explains the philosophical, religious, or spiritual aspects of the caregiving experience (Farran, et al., 1999). In previous research, the hypothesis that finding meaning may operate as a mediator of the effect of burden on health-related outcomes was proposed (Farran, et al., 1991).

When including the concept of meaning, described as a positive aspect of caregiving, into an adaptation of a stress framework, researchers reported that finding meaning and perceived burden were associated with less negative mental health outcomes in caregivers of dementia patients when compared to caregivers of people without dementia (Cohen, Colantonio, & Vernich, 2002; Noonan & Tennstedt, 1997). However, there has been little research that examines the influence of finding meaning,
operationalized with an existential paradigm similar to Frankl (1978) and Farran and colleagues (1999). Finding meaning operationalized in this way has been proposed to act as an internal coping resource (Farran, et al., 1997). Therefore in this study, an examination of finding meaning as a coping strategy and a mediator of burden on the physical and mental health of caregivers in dementia was undertaken.
CHAPTER 3

METHODOLOGY

In this study, the relationships between demographic and background data, caregiver burden, finding meaning through caregiving (FMTCG), and physical and mental health among caregivers of people with dementia residing in the community were examined. This chapter is organized as follows: Design, Sample Size and Power, Recruitment and Setting, Data Collection Procedures, Instruments, Protection of Human Subjects, Data Management, and Analyses.

Design

This was a cross-sectional, correlational design based on the Alzheimer’s Caregiver Stress Model (Pearlin, et al., 1990). This type of design was chosen because the stage of the literature about finding meaning as a way of coping with stressors in informal caregiving is still relatively young and because cross-sectional designs are practical and comparatively inexpensive (Polit & Beck, 2004). In addition, it contributed to the development of the Pearlin model by testing the role of finding meaning as a type of coping and mediator variable. It is anticipated that the results may provide the foundation for the development of an intervention to enhance the caregiving experience of spouses with dementia.

In this study, the associations between caregiver burden, finding meaning through caregiving, and the physical and mental health of spouses of people with dementia in a
community-residing sample, while controlling for the effects of the background variables of duration of caregiving and income, were examined. As well, finding meaning through caregiving as a way of coping and mediator of burden on health was tested. Data were collected using a set of self-report questionnaires by interviews with the spouse caregiver.

Sample Size and Power

Results from recent studies and effect sizes reported in the literature (Polit & Beck, 2004; Portney & Watkins, 2000) and recommendations by Cohen (1984) were used to calculate sample size and power. The recommendations from Tabachnik and Fidell (2000) provided additional evidence of the adequacy of the calculations.

Prior research on caregiver stressors and coping accounted for 10-39% of the variance in health-related outcomes in caregivers (Farran, et al., 1997; Haley, et al., 2003; Noonan & Tennstedt, 1997; Pot, Deeg, vanDyck, & Jonka, 1998; Pruchno & Resch, 1989; Salmon, et al., 2005). In the most similar study, an effect size of .24 was obtained when analyzing the effect of provisional meaning on caregiver distress (Farran, et al., 1997).

According to Cohen (1984), small effect sizes can be estimated using $R^2 = .02$, medium effect sizes at $R^2 = .13$, and a large effect size of $R^2 = .30$. A small effect size is ideal because of the increases obtained in statistical power for reducing the risk of Type II errors (Polit & Beck, 2004). However, a balance must be obtained between power and study feasibility. Therefore, a medium effect size was selected based on the literature and Cohen’s (1984) recommendations.
Based on convention, an alpha of .05 and a power of .80 were selected. For this study, the independent variables included in the analysis were: background variables (income and duration of caregiving), caregiver burden, and finding meaning through caregiving. The formula used for calculating effect size was drawn from Polit and Beck (2004), based on Cohen’s effect sizes (1984), where $N$ represents the estimated sample size, $\lambda$ represents the estimated effect size, $L$ represents the tabled value for the desired alpha and power, and $k$ represents the number of independent or predictor variables.

Formula: 
\[
\lambda = \frac{R^2}{1 - R^2} \quad N = \frac{L}{1 + k + 1}
\]

Medium effect size (.13) 
\[
\lambda = \frac{.13}{1 - .13} = .149 \quad N = \frac{10.90}{.149} + 3 + 1 = 77
\]

Therefore for this study, a sample size of 77 based on a medium effect size of .13, power of .80, and alpha of .05 for three independent variables (background variables, burden, and FMTCG) was calculated. Further evidence of the adequacy of the sample size was obtained from the recommendations of Tabachnik and Fidell (2000). Following their guidelines, a minimum of a 20 to 1 ratio of number of participants per each independent variable for multiple regression analyses are needed (20 x 3 independent variables = N of 60). To allow some flexibility for lost or non-usable data, the sample size of 77 was used.

Recruitment and Setting

A convenience sample of 84 community-residing spouse caregivers who were caring for their spouse with dementia and who represented the ethnicity of the larger
community of caregivers in the north-central Florida were recruited for the study. Inclusion criteria were caregivers who: 1) considered themselves to be the primary caregiver, 2) had been providing care for at least 6 months (Haley, et al., 2003), 3) were able to speak and read English, and 4) reported that their spouse had dementia or memory loss. No participants were excluded because they were taking memory enhancing medications or scored less than 3 on the Six-Item Screener (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002).

Participants were recruited from independent-living facilities (49%), support groups (29%), adult day care centers (14%), subsidized housing (6%) and physicians’ offices (4%) throughout North-Central Florida. The primary recruitment strategy was to target key contact people at independent living facilities and local agencies who identified potential participants and obtained permission for the principal investigator to contact them. At support groups and at one regional caregiver conference, after receiving an invitation from facilitators, a short presentation was given about the study with contact information provided via flyers and business cards. Facilitators and/or designated contact people were also queried about referrals to additional facilities, agencies, or other contacts that could be recommended as potential recruitment sources. These techniques facilitated the enrollment of an adequate number of willing participants from a sometimes difficult to recruit population.

Data Collection Procedures

This study and procedures were approved by the Institutional Review Board (IRB) of the University of Alabama at Birmingham, protocol # X061116002. Flyers with
study information, inclusion and exclusion criteria, and principal investigator (PI) contact information were provided to potential sites through key contact personnel. The majority of the participants were recruited in one of three ways. The agency contact person either: 1) contacted the researcher with a list of willing participants and telephone numbers or email addresses, 2) provided study information to the participant who directly contacted the PI by telephone or email, or 3) the PI was invited to attend a support group meeting or conference to speak about the study. In addition, a few participants contacted the PI directly from study information posted on an Alzheimer’s Association caregiver internet site.

Potential participants either self-screened or were preliminarily screened by the agency contact person for study eligibility. When contact occurred between the potential participant and the PI, the PI rescreened for study eligibility. Appointments were scheduled for a one-time meeting at the date, time, and location of choice of the participant. At the meeting, introductions and the overall purpose and description of the study were described. The informed consent was reviewed in detail, including risks and benefits and approximate length of time to complete the questionnaires. The consent was signed by the participant and the PI and one copy was given to the participant while one copy was kept by the PI. Informed consents were stored in a separate location from the data files. No data were collected prior to obtaining informed consent. Once informed consent was obtained, the two screening instruments, the Six-Item Screener (Callahan, et al., 2002), administered to screen for memory loss in the caregiver as a method to assist with data accuracy, and the Cognitive Status Scale (Pearlin, et al., 1990), administered as a proxy screen for memory loss in the care recipient, were completed.
The settings of the interviews varied but the majority of interviews took place in the participants’ homes. Other locations for meetings included public libraries, churches, offices and clinics in independent living facilities, and day care centers. Care was taken to ensure that the caregiver could provide verbal responses out of range of hearing of the care recipient so as not to influence their responses. In some cases, the participants elected to complete the questionnaires via pen and paper responses rather than by interview for this reason. Care was taken to ensure privacy, adequate lighting, and the general comfort of the participants. All participants completed the questionnaires in the presence of the PI at the time of the meeting. The questionnaires were placed in the same order in a folder as follows: eligibility screeners, Finding Meaning through Caregiving Scale, Zarit Burden Interview, the SF-36 v2, and demographic data collection tool (Appendices A – F). The length of time required to complete the questionnaires was approximately 30 to 45 minutes, although in most cases the actual meetings lasted between one to three hours. Many of the participants shared additional personal stories, information, and anecdotes during this time. Study findings will be provided to the participants and agencies who requested that information.

_**Instruments**_

The lack of use of common measures and models across studies is an area commonly criticized by authors of meta-analytic papers and literature reviews in the dementia caregiving literature (Kneebone & Martin, 2003; Kramer, 1997; Pinquart & Sorensen, 2004; Schulz & Martire, 2004). Therefore, in order to compare across studies and make generalizations about scientific findings to the intended population, using
measurement tools that have been commonly used in the dementia caregiving literature will allow for comparisons across studies. This section will focus on substantiating the choice of measures with supporting literature and confirm that the definitions and conceptualizations used in the measure are consistent with the model used in this study.

The measurement tools in this study were selected after a careful review of the literature and conceptual model to strengthen internal and external consistency. Cronbach’s alpha internal consistency scores were reported and interpreted based on recommendations in Polit and Beck (2004) where adequate reliability is indicated by scores greater than .70, with a desired score of .80 or better. A reliability coefficient of .80 indicates that 80% of the variability (degree of score dispersion) in the obtained scores indicates true differences and 20% represents random error. Documentation of measure validity is important because it represents the degree that the tool assesses what it purports to measure. The validity of each proposed measure has been provided. Validity coefficients between .30 and .60 are generally considered acceptable (Nunnally & Bernstein, 1994).

The following tools were used in this study of dementia caregivers: caregiver burden was measured using the Zarit Burden Interview (Zarit, et al., 1980), finding meaning was measured with the Finding Meaning Through Caregiving Scale (FMTCG) scale (Farran, et al., 1999), physical and mental health was measured with the Short Form Health Survey (SF-36 Version 2), (Ware, et al., 2000) and a demographic survey was used to collect background and contextual factors. The Cognitive Status Scale was administered to the caregiver to confirm the presence of memory loss in the spouse
(Pearlin, et al., 1990). The Six-Item Screener was used as a screener for cognitive impairment in the caregiver and to confirm study eligibility (Callahan, et al., 2002).

Caregiver burden. The Zarit Burden Interview (BI) (Zarit, et al., 1980) (Appendix B) is a 22-item self-report tool that was used to operationalize subjective caregiver burden, defined as the caregiver’s appraisal of their situation or experience (Oyebode, 2003; Zarit, et al., 1980). The BI was administered to the participants who were given directions to circle the response choice that best describes their feelings. Response choices consisted of a 5-point Likert scale that ranged from 0 = never to 4 = nearly always. A total score was obtained by summing the items. Possible scores range from 0 to 88, where higher scores indicated greater burden. Specifically, scores of 21 to 40 indicate little or no burden, between 41 and 60 indicate moderate to severe burden, and 61 to 88 indicate severe burden. The scores were coded as a continuous variable. Sample items include “do you feel that your relative asks for more help than he/she need?” and “are you afraid what the future holds for your relative?”

The BI has been one of the most commonly used measures in the caregiving literature for global (one scale, one total score) caregiver burden (Knight, Fox, & Chow, 2000; Rymer, et al., 2002). Consistent with the stress-coping theoretical framework of Lazarus & Folkman (1984), the BI was developed to assess the stressors of caregiving (Sherrell, Buckwalter, & Morhardt, 2001). Burden was defined by Zarit and colleagues (1980) as the most common problems associated with caregiving such as caregiver health, well-being, financial concerns, social life, and the relationship. The Cronbach’s alpha scores (.91 to .93) have been consistently high when used with dementia caregivers (McConaghy & Caltabiano, 2005; Rymer, et al., 2002; Seltzer & Li, 1996). Split-half
reliability has been reported at .92 and test-retest reliability at .71 (Kinsella, Cooper, Picton, & Murtagh, 1998; Rush, 2000). Concurrent validity was assessed by comparisons with Activities of Daily Living, Social Life Restrictions, and the Brief Symptom Inventory and calculated with Spearman’s rho correlations at .32, .32, and .41 (Chou, Chu, Tseng, & Lu, 2003; Hebert, Bravo, & Preville, 2000; Vitaliano, Young, & Russo, 1991).

*Finding meaning.* The Finding Meaning Through Caregiving Scale (Appendix C) consists of 43 items in three subscales: Loss/Powerlessness (LP) = 19-items, Provisional Meaning (PM) = 19-items, and Ultimate Meaning (UM) = 5-items on a five-step summated rating scale with response choices ranging from anchors of 1 = strongly agree (SA) to 5 = strongly disagree (SD). The 19-item Loss/Powerlessness subscale was designed to measure the difficult aspects of caregiving such as sense of loss of the relationship with their relative and the feelings of powerlessness associated with caregiving. The scores on this subscale can range from 19-95. The 19-item Provisional Meaning subscale assesses, for example, the caregivers’ abilities to enjoy their relationship with their relative, to appreciate the blessings they receive, and to feel a sense of purpose or a sense of having grown because of their experience. The scores on this subscale can range from 19-95. The 5-item Ultimate Meaning subscale assesses the participants’ spiritual or religious belief system with scores that can range from 5-25.

A total “finding meaning” score may be obtained by reverse scoring the Loss/Powerlessness subscale and then summing the three subscales. Higher scores indicate greater levels of finding meaning. Subscales can be scored independently of each other by summing them individually. Higher scores indicate greater loss and
powerlessness, or greater provisional and ultimate meaning. This scale was designed to assess the participant’s opinions or feelings about themselves, their relative, and their caregiving experience by selecting the response to indicate the extent of agreement or disagreement with each statement.

The questionnaire contained introductory statements to orient the participant to the purpose of the measurement tool, and gave instructions for reading the statements and then to choose the extent of agreement or disagreement with each statement by circling the category. The authors indicated that the test would take approximately 10-15 minutes to self-complete. The scale also could be orally administered, however time to completion increases to 20-25 minutes (Farran, et al., 1999). It was intended for use in caregivers of people with dementia.

The underlying frameworks that guided the development of the measure were a combination of stress-adaptation models (Lazarus & Folkman, 1984; McCubbin & Thompson, 1978) with an existential philosophical perspective (Frankl, 1978; Yalom, 1980). Historically, stress adaptation models have successfully guided caregiver research. This relatively new scale has been devised based on an existential perspective which is slightly different from the conceptualization of management of meaning as described and measured by Pearlin and colleagues (1990). The tool proposed for use by Pearlin, et al. (1990) did not achieve high reliability scores and recommendations were for the measures to be used with caution (Pearlin, et al., 1990).

In order to establish reliability for the shortened version of the measure (135-item reduced to 43-items), the test was administered to two groups of dementia caregivers in two different studies (Farran, et al., 1999; Miller, Campbell, Farran, Kaufman, & Davis,
In the first study, test-retest scores were obtained and reported as Spearman correlations at .85 for Loss/Powerlessness, .85 for Provisional Meaning, .89 for Ultimate Meaning, and .80 for the total meaning score. This provided evidence for use of the shortened version, since all scores were greater than or equal to .80.

In study 2, a larger sample was used as part of another cross-sectional study to examine race and gender differences in spouse caregivers in dementia. This sample of 215 spouse caregivers of people with dementia was primarily white (64%), women (63%), with a mean age of 72, and fairly well educated with an average educational level of 13 years. This sample differed from study 1 in that it was a larger sample (215 compared to 46) comprised of a greater number of African American participants (36% in study 2 and 4% in study 1), consisted only of spouses, with a slightly older mean age (73 compared to 65 in study 1). Internal consistency reliability coefficients reported for study 2 were .89 for Loss/Powerlessness, .88 for Provisional Meaning, .91 for Ultimate Meaning, and .91 for the total meaning score.

Physical and mental health. The Short Form Health Survey, SF-36 Version 2 (Ware, et al., 2000) (Appendix D) measured caregiver physical and mental health. The measure consists of 36 items with two summary measures, physical & mental health, based on a total of eight health domains, four for physical health and four for mental health. For physical health, the four domains include physical function, physical role, bodily pain, and general health. For mental health, the four domains consist of vitality, social functioning, emotional role, and mental health. A variety of three, five, and six point scales comprise each of the 8 domains with multiple choices for each. In
caregivers, the physical health summary score yielded a Cronbach’s alpha of .85, and the mental health summary score demonstrated an alpha of .95 in similar groups (Ware, et al., 2000). It has good construct validity based on factor analysis and good criterion validity when compared to other health rating scales (Ware, et al., 2000).

This measure was selected because it is one of the most often used measures to assess health status in the research literature, having been documented in approximately 4,000 publications and has demonstrated high validity and reliability in a wide variety of groups, including the intended sample (Ware, et al., 2000). It is a generic measure, not targeted to a specific group, and has proved to be useful for a variety purposes (Ware, et al., 2000). It has been translated into several different languages successfully. In this study, the dependent variable, physical health was represented by the sum of the four physical health domains and calculated as a physical health summary score. The second dependent variable was mental health, calculated by the summary score of each of the four mental health domains.

**Demographic survey.** A demographic survey (Appendix A) was designed to collect pertinent data about the sample and was used to describe the characteristics of the group of participants. Data about the characteristics of the sample such as age, sex, ethnicity, income, and educational level for the caregiver and care recipient were collected. Duration of caregiving was obtained by asking the question “How long have you been the primary caregiver (person who performs the majority of the daily care) for your spouse?” The answer was recorded in number of months.
In health research, socioeconomic status has generally been used as a correlate of health or as a control variable (Oakes & Rossi, 2003). It has been commonly accepted that a lower socioeconomic status correlates with poorer health (Oakes & Rossi, 2003; Schulz & Martire, 2004; Williams & Collins, 1995). Education and/or income levels have been the most commonly measured aspects of SES in aging studies (Baltrus, Lynch, Everson-Rose, Raghunathan, & Kaplan, 2005; Kubzansky, Kawachi, & Sparrow, 1999; Braveman, et al., 2005; Lynch, et al., 1998; Robinson & Austin, 1998; Williams, 2005).

Critics have pointed out that education and income, although somewhat correlated, have not been found to be equivalent and interchangeable, primarily due to racial differences (Braveman, et al., 2005). Moreover, questions about collinearity have been met with ambiguous recommendations. Some authors recommend against using income and education as individual variables in the same study due to concerns about collinearity (Braveman, et al., 2005), while others recommend the opposite, to measure both income and education as separate variables when controlling for them in regression models (Oakes & Rossi, 2003). One solution has been to calculate a SES score based on a number of different factors. Recommendations for the selection of which measure and which factors are important to include are not clear cut due to the lack of consensus on the definition of SES and lack of adequate measures based on sound psychometric principles of development and testing (Braveman, et al., 2005; Oakes & Rossi, 2003).

Therefore, based on a review of the literature regarding measurement of socioeconomic status, as well as an examination of the dementia and caregiver literature, and to avoid issues related to use of measurement tools without adequate psychometric
testing, the information about the income and educational level of the study participants was collected and reported as separate variables.

*Cognitive status of the care recipient.* Although the inclusion criteria included verification by the caregiver that they had been told by a health care professional that their spouse had dementia or memory loss, another screener, the Cognitive Status Scale, was added to strengthen the study design (Appendix E). The Cognitive Status Scale (Pearlin, et al., 1990) was developed as a questionnaire for caregivers as a method of reporting the level of cognitive impairment in their relative. The questions contained in the scale were based on the Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) and tested on the 555 participants from the San Francisco Bay Area and Los Angeles (Pearlin, et al., 1990). This eight-item scale contained items to assess recent memory, time and place orientation, recognition, and language skills. Caregivers were instructed to rate the level of difficulty that their relative had with each of the scale items (eg. remembering recent events and words). Choices range from 5 = “can’t do it at all” to 1 = “not at all difficult”.

Good criterion validity was demonstrated by correlations that compared caregiver ratings and MMSE scores obtained by trained clinicians (r = .65) (Pearlin, et al., 1990). Internal consistency reliability obtained by Pearlin and colleagues was reported as a Cronbach’s alpha of .86 and has been demonstrated in subsequent dementia caregiver studies at .84 (Burns, Nichols, Graney, Martindale-Adams, & Lummus, 2006; Fortinsky, Kercher, & Burant, 2002; Savundranayagam, Hummert, & Montgomery, 2005).
**Cognitive status of the caregiver.** Since this study relied on proxy data obtained from spouse caregivers about the care recipient and the caregiving experiences, both past and present, it was considered important to screen out caregivers with memory loss who might have been unable to provide accurate information about themselves and their. The Six-Item Screener, developed by Callahan and colleagues (2002) (Appendix F) was developed as a brief cognitive screener to identify cognitive impairment in older adults who prior to participation in research. Each of the six items were drawn from the Mini-Mental State Examination (MMSE) (Folstein, et al., 1975) but was brief enough to be part of an initial screen either in person or by telephone (Callahan, et al., 2002). In testing the tool in two studies, a community-based survey and specialty clinic, an estimated administration time of 1 – 2 minutes was reported.

Content validity of the screener was discussed by the developers in terms of its relation to the MMSE (Folstein, et al., 1975), with test items selected that were the most sensitive to short-term memory. Criterion validity was demonstrated by comparison of the screener against the gold standard of a clinical assessment by a geriatric psychiatrist or neurologist. Using a cut-off of three or more errors, the sensitivity of the screener for a dementia diagnosis by clinical assessment was 88.7 and specific for dementia at 88.0. For comparison, in the same samples, the MMSE was sensitive at 95.2 and specific at 86.7 for a dementia diagnosis by clinical assessment. Convergent validity was demonstrated through significant correlations with other dementia measures: MMSE = .75 (Folstein, et al., 1975), Word List Recall = .64 and the Blessed Dementia Rating Scale = .45 (Blessed, Tomlinson, & Roth, 1968).
The number of errors on the Six-Item Screener can be compared with other standard screening tests to choose the desired cut-off and for comparison of the meaning of scores. For example, a cut-off of 2 errors (score of 4) is correlated with a score of 24.8 on the MMSE in the community sample, and a cut off of 3 errors (score of 3) is correlated with a score of 22.4 on the MMSE in the community sample. An MMSE of 19-23 is generally considered as mild impairment, therefore for study eligibility screening, a cut-off of 3 score of 3 or more errors on the Six-Item Screener would be acceptable as it would be comparable to an MMSE of approximately 22.4, almost the cut-off on the MMSE for normal (24).

Protection of Human Subjects

Measures taken to ensure human subject protection included IRB approval, informed consent, confidentiality, and privacy. Institutional Review Board approval was sought and obtained through the University of Alabama at Birmingham. The informed consent was also approved by the IRB and care taken to thoroughly explain each section, offer time for questions and answers, and a copy provided to the participant and a copy stored in a separate location from the data. The informed consent covered aspects such as purpose, voluntary participation, risks, benefits, alternatives, right to withdraw, cost, payment, legal rights, and contact information for the investigator and the IRB.

Confidentiality of the data was maintained by lack of personal identifiers on the study materials and in the data files. Study data were identified by numbers on the questionnaires and coded into the computer data file by numbers without identifying information. Privacy was maintained during data collection by ensuring that interviews
took place in a private location so that personal information was not revealed to bystanders and study materials were not shared with others. However, study results will be distributed to interested participants as requested.

Data Management

Within one week after meeting with the participants and completion of the questionnaires, the instruments were scored and entered into the data file using the Statistical Package for the Social Sciences (SPSS) Graduate Pack version 11.5 for Windows (Chicago, IL). A code book was created for use with scoring and to facilitate accuracy with data entry. For accuracy, each entry was double-checked and documented. Scoring was accomplished using the recommended instructions from the authors of each of the instruments. When scoring the SF-36 v2, the instructions provided in the guidebook from the Medical Outcomes Trust and QualityMetric Inc. (2002) were used. All completed questionnaires were filed numerically in a separate folder with a cover page containing the date of collection, date of double check, date of entry, eligibility screened, and informed consent completed and on file, and stored in a covered box.

Statistical Analyses

The SPSS Graduate Pack 11.5 for Windows was used for all statistical analyses. Analyses used two-tailed tests with a statistical significance of $p < 0.05$. Descriptive statistics were calculated to summarize the demographic and background characteristics of the sample. Frequencies and percentages were employed to describe the categories of caregiver and care recipient age, gender, ethnicity, education, income, and duration of
caregiving. In addition, ranges, means, and standard deviations were calculated for the continuous variables of caregiver and care recipient age, and duration of caregiving as well as the main study variables of caregiver burden, finding meaning through caregiving, and physical and mental health. For each of the instruments, Cronbach’s alpha coefficients were computed and reported (see Chapter 4). Bivariate Pearson correlations were calculated to examine the associations between study variables.

The physical and mental health summary scores for the SF-36 v2 were calculated following the guidelines provided in the scoring manual. Steps in the scoring process were to 1) reverse score and/or recalibrate scores for 10 of the items, 2) recode missing items with mean substitution where indicated, 3) check for out-of-range values, 4) compute raw scale scores by summing, 5) transform raw scores to a 0 – 100 scale, 6) transform 0 – 100 scale to norm-based scores, and 7) re-check scoring. The transformation of raw scores to 0 to 100 scores was accomplished by computing a z-score by subtracting the 1998 U.S. population mean for each of the eight scales and dividing by the SD. Transforming the z-scores to norm-based scoring was achieved by multiplying the z-score for each scale by 10 and adding 50.

Missing data (n = 2) was addressed by estimating the average score across the items completed in the same scale (Ware, Davies-Avery, & Brook, 1980). According to the authors, there are several advantages to norm-based scoring. Scores are more easily interpreted across studies, score differences can interpreted similarly, and results are more likely to have reliability and validity similar to the SF-36 v2. After norming the data, results can be interpreted directly relative to the general population of the United States in 1998. Thus, all scores above or below 50 can be interpreted as being above or
below the average in the 1998 U.S. population. Each one point difference in score equates to 1/10 of a standard deviation or an effect size of .10.

Figure 3

*Mediation Model for Finding Meaning Through Caregiving in the Relationship between Caregiver Burden and Caregiver Physical and Mental Health*

For the following tests, standard multiple regression statistical analyses were completed with the variables to be controlled entered first as the independent variables, followed by the variable to be tested, with the outcome variable entered as the dependent variable. See Figure 3. To determine the mediating effect of finding meaning through caregiving the criteria outlined in Baron and Kenny (1986) were followed:

1. the independent variable must affect the dependent variable (physical and mental health);
2. the independent variable (burden) must affect the mediator (finding meaning) and;
3. the mediator (finding meaning) must affect the dependent variables (physical health, mental health) while reducing the effect of the independent variable (burden) on the dependent variables.

If the conditions were met (in the predicted direction), then the effect of the independent variable (burden) on the dependent variables (physical health, mental health) must be less than the effect of finding meaning on health. Perfect mediation was considered to have occurred if the independent variable (burden) had no effect when controlling for the mediator (finding meaning). If any of the steps did not meet the expected conditions, no further testing was warranted and testing was not completed. The following steps were undertaken to test for mediation (Baron & Kenny, 1986). For the first set of regression equations:

1. Physical health was regressed on burden, controlling for duration of caregiving and income.

2. The second step, the regression of finding meaning on burden controlling for duration of caregiving was not reported because it was not applicable, and step three was not performed due to no significant findings in step one.

For the second set of regression equations:

1. mental health was regressed on burden,

2. finding meaning was regressed on burden, controlling for duration of caregiving,

3. and mental health was regressed on burden and finding meaning, controlling for duration of caregiving.

As stated, standard multiple regression statistical procedures were used to identify the relationships between the independent and dependent variables. Previous research had
demonstrated a relationship between education, income, and duration of caregiving with
caregiver health, thus were considered variables to control for in the regression models.
Bivariate Pearson correlation analyses were examined for significant ($p < .05$)
relationships between the control variables and caregiver physical and mental health, and
for finding meaning. Only the variables that were significantly correlated with the
outcome variables were entered in the models. Income and duration of caregiving were
significantly associated with caregiver physical health, and duration of caregiving was
significantly associated with finding meaning.
CHAPTER 4
RESULTS

Introduction

The results will be presented in this chapter and are organized as follows. First, the findings of the descriptive statistics of the demographics (age, gender, ethnicity) and background variables (income, education, duration of caregiving) will be presented, followed by the caregiver reports of the screen for cognitive status. Then, the summary of the descriptive statistics (mean, range, standard deviation) for the main study variables of caregiver burden, finding meaning through caregiving, and physical and mental health follow. The next sections contain the reliability statistics for each of the study measures and the results of bivariate correlations, respectively. Finally, the results of the multivariate regression statistical analyses for each of the research questions (i.e. steps in mediation testing) will be displayed.

Description of the Sample

This convenience sample consisted of 84 spouse caregivers who were recruited through contacts with a designated person at various independent living facilities and community agencies throughout North-Central Florida between March and August 2007. The participants were screened for initial eligibility by the contact person at each facility or agency and asked if they were interested in being contacted about the study. Interested individuals were then contacted by the principal investigator and rescreened by telephone.
or in-person for eligibility based on the inclusion and exclusion criteria. Of the 88 people who were contacted for study participation, two refused and two were ineligible. The two who refused to participate cited family problems as their reason for refusal. Of the two who were ineligible, one did not consider himself to be a caregiver and the other had placed his wife in assisted living and was not a current caregiver. After signing the informed consent, the remaining 84 caregivers were screened for cognitive impairment with the Six-Item Screener (Callahan, et al., 2002). To complete the screening process, memory loss in the care recipient was confirmed by proxy report from the caregivers using the Cognitive Status Scale (Pearlin, et al., 1990).

Six-Item Screener scores for the caregivers were greater than 3 out of 6 for all of the caregivers, thus all were eligible to participate. Of the 84 caregivers, 68 scored 6 of 6, 15 scored 5 of 6 and 1 person scored 4 of 6. Scores on the Cognitive Status Scale for the care recipients, completed by the spouse caregiver, ranged from 9 to 38 ($M = 23.56, SD = 6.9$) out of a possible range of 40. Thus all care recipients were confirmed to have dementia or memory loss by the screener as well as by caregiver reports.

The demographic and background data collected from the participants were caregiver and care recipient age, gender, ethnicity, educational level, income, and duration of caregiving. These data are summarized in Table 1. The final sample of 84 spouse caregivers ranged in age from 49 to 96 ($M = 76.8, SD = 10.48$). Most of the participants (62%) were 75 years of age or older. Of those, 26% were age 85 and older. The 84 caregivers were comprised of 50 women aged 52 to 95 years ($M = 73.3, SD = 9.69$) who cared for their partners aged 42 to 92 ($M = 80.4, SD = 9.97$). Two of the female caregivers cared for their female partner and were considered spouse caregivers.
because they identified themselves as having shared a committed relationship with joint financial arrangements for many years. In addition, there were 34 husbands between the ages of 49 and 96 years ($M = 82, SD = 9.5$) who were the primary caregivers for their wives whose ages ranged from 62 to 95 years ($M = 78.5, SD = 8.12$).

Most of the caregivers identified themselves as Caucasian (76%), with the remaining participants identifying themselves as African-American (17%), Hispanic/Latino (6%), and other (1%). The ethnicity of the care recipients was the same as for the caregivers. The majority of the caregivers had completed 3 to 4 years of college or more (52.4%) while 38.1% of the care recipients had completed 3 to 4 years of college or more. Most of the caregivers (52%) reported that their joint annual income was less than $55,000 for the previous year. The income category most frequently reported (mode) was $26,000 to $40,000 by 23 (27.4%) of the participants. The caregivers had been caring for their spouse for an average of 55 months ($R = 12 – 144, SD = 32.6$) with more than half (56.8%) indicating a caregiving duration of more than three years.

Table 1

*Descriptive Statistics of Sample Demographics ($N = 84$)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Range</th>
<th>Mean</th>
<th>$SD$</th>
<th>$n$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54 years</td>
<td>49-96</td>
<td>73.3</td>
<td>10.48</td>
<td>2 (2.4)</td>
</tr>
<tr>
<td>55-64 years</td>
<td></td>
<td></td>
<td></td>
<td>10 (11.9)</td>
</tr>
<tr>
<td>65-74 years</td>
<td></td>
<td></td>
<td></td>
<td>20 (23.8)</td>
</tr>
<tr>
<td>75-84 years</td>
<td></td>
<td></td>
<td></td>
<td>30 (35.7)</td>
</tr>
<tr>
<td>≥ 85 years</td>
<td></td>
<td></td>
<td></td>
<td>22 (26.2)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
<td></td>
<td>50 (59.5)</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
<td>34 (40.5)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Count</td>
<td>Percentage</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------</td>
<td>------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>64</td>
<td>(76.2)</td>
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<td></td>
</tr>
<tr>
<td>African-American</td>
<td>14</td>
<td>(16.7)</td>
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<td>Hispanic/Latino</td>
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<td>(6.0)</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>(1.2)</td>
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<td></td>
</tr>
<tr>
<td><strong>Language</strong></td>
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</tr>
<tr>
<td>English</td>
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<td></td>
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</tr>
<tr>
<td><strong>Income</strong></td>
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</tr>
<tr>
<td>&lt;$10,000</td>
<td>2</td>
<td>(2.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$10,000 - $25,000</td>
<td>9</td>
<td>(10.7)</td>
<td></td>
<td></td>
</tr>
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<tr>
<td>$41,000 - $55,000</td>
<td>18</td>
<td>(21.4)</td>
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<td>$56,000 - $70,000</td>
<td>10</td>
<td>(11.9)</td>
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<td></td>
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<tr>
<td>&gt; $71,000</td>
<td>9</td>
<td>(10.7)</td>
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<td><strong>Missing</strong></td>
<td>13</td>
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</tr>
<tr>
<td><strong>Duration of Caregiving</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>6 to 36 months</td>
<td>35</td>
<td>(41.7)</td>
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<td></td>
</tr>
<tr>
<td>37 to 84 months</td>
<td>37</td>
<td>(44.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 to 132 months</td>
<td>10</td>
<td>(11.9)</td>
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<tr>
<td>133 to 144 months</td>
<td>2</td>
<td>(2.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Care Recipients</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>42 - 95</td>
<td>79.3</td>
<td>8.9</td>
<td>1 (1.2)</td>
</tr>
<tr>
<td>45-54 years</td>
<td>2</td>
<td>(2.45)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64 years</td>
<td>22</td>
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<td>75-84 years</td>
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<td>&gt; 85 years</td>
<td>1</td>
<td>(1.2)</td>
<td></td>
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</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
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</tr>
<tr>
<td>Female</td>
<td>52</td>
<td>(61.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>(38.1)</td>
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<tr>
<td><strong>Educational Level</strong></td>
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</tr>
<tr>
<td>≤ 8th grade</td>
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<td>(7.1)</td>
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<tr>
<td>Some high school</td>
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<td>(6.0)</td>
<td></td>
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</tr>
<tr>
<td>High school graduate</td>
<td>25</td>
<td>(29.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 years college</td>
<td>16</td>
<td>(19.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-4 years college</td>
<td>13</td>
<td>(15.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>6</td>
<td>(22.6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Descriptive Statistics of the Main Variables

Descriptive data (range, mean, and standard deviation) of the main variables of caregiver burden, finding meaning (sum score for subscales of loss/powerlessness, provisional meaning, and ultimate meaning), and the two summary scales of physical health (sum of subscales of physical functioning, role-physical, bodily pain, and general health), and mental health (sum of subscales of vitality, role-emotional, mental health, and social functioning) are presented in Table 2. Caregiver burden, the caregivers’ appraisal of their caregiving experience, was measured as a sum score from the 22-item Zarit Burden Scale, with possible scores ranging from 0 to 88 and higher scores indicating greater burden. The mean burden score was 30.73 ($SD = 14.9$) with an actual range of 6 to 68.

The Finding Meaning Through Caregiving scale (FMTCG) was used to determine how much meaning the caregivers derived from their caregiving experience. It consisted of three subscales, Loss/Powerlessness, Provisional Meaning, and Ultimate Meaning, which were summed to create a total score for finding meaning in caregiving. Out of a possible score of 215 for FMTCG, the mean in this sample was 151.05 ($SD = 19.7, R = 93 - 193$). Higher scores indicated greater finding meaning in caregiving.

The SF-36 v2 measured the health of the caregivers and was comprised of two summary scales for physical and mental health. Higher summary scores for each scale were indicative of better health. For physical health the mean was 45.22 ($SD = 10.5, R = 24.1 - 63.5$) with a possible range of 19.34 to 65.35, and for mental health the mean score was 47.36 ($SD = 11.5, R = 16.5 – 64.3$) with a possible range of 16.38 to 70.66.
Table 2

*Descriptive Statistics of the Main Study Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>(SD)</th>
<th>Actual Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Burden</td>
<td>30.72</td>
<td>(14.9)</td>
<td>6-68</td>
</tr>
<tr>
<td>Finding Meaning Through Caregiving (sum of Loss/Powerlessness, Provisional Meaning, Ultimate Meaning)</td>
<td>151.05</td>
<td>(19.7)</td>
<td>93-193</td>
</tr>
<tr>
<td>Physical Health (sum of Physical Functioning, Role-Physical, Bodily Pain, General Health)</td>
<td>45.22</td>
<td>(10.5)</td>
<td>24.1-63.5</td>
</tr>
<tr>
<td>Mental Health (sum of Vitality, Role-Emotional, Mental Health, Social Functioning)</td>
<td>47.36</td>
<td>(11.5)</td>
<td>16.5-64.3</td>
</tr>
</tbody>
</table>

*Reliability of the Instruments*

Each of the selected instruments in this study had demonstrated acceptable reliability and validity in previous similar samples. In this study, the internal consistency reliabilities or Cronbach’s alpha coefficient for the instruments, the Zarit Burden Scale, Finding Meaning Through Caregiving Scale, and the SF-36 v2, were excellent as shown in Table 3.

Table 3

*Reliabilities of the Instruments*

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Number of items</th>
<th>Cronbach’s α coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zarit Burden Scale</td>
<td>22</td>
<td>.91</td>
</tr>
<tr>
<td>Finding Meaning Through Caregiving Scale</td>
<td>43</td>
<td>.88</td>
</tr>
<tr>
<td>SF-36 v2: Physical Health</td>
<td>19</td>
<td>.92</td>
</tr>
<tr>
<td>Mental Health</td>
<td>14</td>
<td>.90</td>
</tr>
</tbody>
</table>
**Bivariate Correlations among Study Variables**

Results of the bivariate correlations between study variables are presented in Table 4 and include the background factors of income, education, duration of caregiving, caregiver burden, finding meaning and physical and mental health. Caregiver physical health was positively correlated with income \((r = .259, p < .05)\) and negatively correlated with duration of caregiving \((r = -.226, p < .05)\). There was a positive correlation between income and education \((r = .430, p < .001)\). However, there were no significant correlations between caregiver mental health and income, education, and duration of caregiving.

Caregiver burden was positively correlated with duration of caregiving such that greater burden was associated with longer durations of providing care \((r = .371, p < .001)\). As well, greater burden was correlated with lower caregiver mental health \((r = -.760, p < .001)\). There were no statistically significant relationships between burden and caregiver physical health, income, or educational level.

The proposed mediator variable, finding meaning through caregiving, was negatively correlated with duration of caregiving \((r = -.226, p < .05)\) and with caregiver burden \((r = -.757, p < .001)\). Longer duration of caregiving and greater burden were negatively associated with finding meaning through caregiving. Finding meaning was positively associated with better mental health in this sample of spouse caregivers \((r = .720, p < .001)\). However, there were no significant correlations with physical health, income, or education.
Table 4

*Bivariate Correlations between the Main Variables*

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>.430***</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>-.068</td>
<td>-.156</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>-.082</td>
<td>-.072</td>
<td>.371***</td>
<td>1.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>.008</td>
<td>.079</td>
<td>-.226*</td>
<td>-.757***</td>
<td>1.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>.194</td>
<td>.259*</td>
<td>-.226***</td>
<td>-.038</td>
<td>.002</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>.098</td>
<td>.025</td>
<td>-.175</td>
<td>-.760***</td>
<td>.720***</td>
<td>-.102</td>
<td>1.0</td>
</tr>
</tbody>
</table>

*p<.05. ***p<.001.

*Testing of Assumptions*

Prior to performing the statistical analyses, the data were examined for the four assumptions of normality, linearity, homoscedasticity, and independence which undergird the statistical technique of multiple regression. For the assumption that the data were normally distributed, histograms, boxplots, and scatter plots were constructed. Because of potential outliers identified from histograms and box plots, calculations of the Mahalanobis distance were performed (Mertler & Vannatta, 2004). Univariate analysis for outliers in the dependent variables indicated no outliers for the standard scores (z-scores) for physical health that exceeded the ±3.0 criterion for sample sizes larger than 80. However, for caregiver mental health, one score (case #61) was identified as an outlier with a standard score of -3.2667. The case was examined for errors in data entry,
coding, missing values, and miscalculations with no errors found. With the outlier removed, the assumption of normality for the dependent variable mental health was met.

Further examination for normality was undertaken for the multivariate regression models (income, duration of caregiving, burden, finding meaning), by calculating the Mahalanobis distance to identify any cases that exceeded the critical value of 18.47 for the regression equation with the dependent variable of physical health (chi square for $p < .001$ at $df = 4$) and 16.27 for the equation with the dependent variable of mental health (chi square for $p < .001$, $df = 3$). The highest value for the Mahalanobis distance for predicting physical health was 11.525, and for predicting mental health was 10.407, therefore there were no significant outliers were identified among the variables used in the regression models. In addition, bivariate scatter plots of the predicted residuals and standardized residuals for the two regression equations for physical and mental health indicated normality as evidenced by an even distribution of points above and below the reference line (Mertler & Vannatta, 2004).

Testing for linearity was accomplished by examination of the data via bivariate scatterplots (Mertler & Vannatta, 2004). Linearity was determined by the pattern of predicted and standardized residuals with a plot appearance as a relatively rectangular pattern along the reference line. In addition, the predicted and standardized residuals bivariate scatter plot did not show any evidence of homoscedasticity for the multiple regression models with physical and mental health as dependent variables as the points were fairly evenly dispersed around the reference line, showing constant variance (Mertler & Vannatta, 2004).
To test for independence of the variables, bivariate correlations of each of the study variables were examined for evidence of multicollinearity. None of the intercorrelations demonstrated values greater than .90 (Tabachnik & Fidell, 1996) indicating the variables were not conceptually overlapping. However, two additional statistical methods to assess multicollinearity were also examined as recommended by Mertler and Vannatta (2004). The strength of the linear association between the predictor and other variables was assessed by calculating the variance inflation factor (Stephens, 1992). In this data set, the variance inflation factors for the predictor variables were all less than 10, indicating a strong linear relationship (Stephens, 1992). Tolerance levels, or measures of collinearity, were also calculated. For possible values between 0 and 1, a cutoff of 0.1 or less is an indication of multicollinearity (Norusis, 2002). The tolerance levels for the regression equations were greater than 0.1 indicating no evidence of multicollinearity.

**Research Questions and Testing of Hypotheses**

Following the four-step process outlined by Baron and Kenny (1986), two series of multiple regression analyses were used to test whether finding meaning mediated the relationship between caregiver burden and physical and mental health in spouse caregivers of people with dementia. To summarize, complete mediation occurs when the relationship between the independent and dependent variables becomes non-significant when the mediator variable is entered into the regression model. However, according to Dudley and colleagues (2004), in the social sciences a complete mediation effect is rare while partial mediation is more commonly found.
For the first hypothesis, that greater caregiver burden would predict poorer caregiver physical health, standard multiple regression analyses was conducted with physical health as the dependent variable and income, duration of caregiving, and burden as the independent variables. Results of the testing are presented in Table 5. For step one of the first series of regression analyses, the relationships of the variables entered into the model were not significantly predictive \((B = .020, \beta = .028, p = .811)\) and explained 6% of the variance in physical health, \(F(3, 82) = 2.656, p = .054\). The first condition for mediation testing was not met, and no further testing was performed.

For the second hypothesis, that greater caregiver burden would predict poorer caregiver mental health, standard multiple regression analysis was performed with mental health as the dependent variable and duration of caregiving and burden as the independent variables. Results of the main and mediation effects are presented in Table 5. Findings indicated that the model explained 61% of the variance \(F(2,82) = 66.338, p < .001\), and significantly predicted caregiver mental health \((B = -.635, \beta = -.819, p = <.001)\). Hypothesis two was supported thus meeting the first condition for mediation testing.

For step two of mediation testing, the hypothesis that greater caregiver burden would predict less finding meaning, results of the testing for the effect of duration of caregiving and burden (respectively) on the dependent variable of finding meaning were significant \((B = -.990, \beta = -.762, p < .001)\), explaining 55% of the variance, \(F(2,82) = 50.542, p < .001\). The second condition for testing mediation was met.

In step three, testing the hypothesis that finding meaning mediated the effect of caregiver burden on mental health; duration of caregiving, burden, and finding meaning
were entered into the regression analyses as the independent variables with mental health as the dependent variable. The statistical analysis of the final model indicated that the predictor variables accounted for 64% of the variance $F(3,82) = 49.069, p < .001$, in caregiver mental health. Finding meaning in caregiving did not totally reduce the effect of burden to zero ($B = -.489$, $\beta = -.631), p < .001$). In other words, burden still had a direct effect on caregiver mental health when finding meaning was entered into the model. However, the amount of the effect was reduced, indicating a partial mediation effect, as demonstrated by a smaller beta coefficient for burden in the final model. Because the beta coefficient for burden in the final model was reduced, the hypothesis was partially supported.

To calculate the amount of partial mediation of finding meaning between caregiver burden and mental health, the recommendations of Sobel (1990) and MacKinnon and Dwyer (1993) were followed using the formula $a \times b / (a \times b) + c'$ where $a$ is the unstandardized coefficient for the path between the independent and the mediator variable, $b$ is the unstandardized coefficient for the path between the mediator variable and the dependent variable (from the full model), and $c'$ is the unstandardized coefficient for the path between the independent and dependent variable (full model). In this data set, $a = (-.990), b = (.147), c' = (-.489)$. Findings indicated that 64% of the variance in mental health was explained by caregiver burden. When finding meaning was entered into the model, there was a 23% reduction in the amount of variance explained by burden (23% of 64%). Finding meaning reduced the effect of burden on mental health by 15%.
### Table 5

*Mediation of FMTCG between Burden and Health*

<table>
<thead>
<tr>
<th>Step</th>
<th>Overall Model</th>
<th>AdjR²</th>
<th>B</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1:</strong> Physical Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D, I, B → PH</td>
<td>F(3,82)= 2.656,</td>
<td>.057</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>p = .054</td>
<td>-.063</td>
<td>-.196</td>
<td>-1.682</td>
<td>.097</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>1.861</td>
<td>.212</td>
<td>1.958</td>
<td>.054</td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td></td>
<td>.020</td>
<td>.028</td>
<td>.240</td>
<td>.811</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2:</strong> D, I, B → FM</td>
<td>Not applicable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 3:</strong> D, I, B, FM → PH</td>
<td>Not performed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 1:</strong> Mental Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D, B → MH</td>
<td>F(2,82)=66.338,</td>
<td>.61</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>p &lt; .001***</td>
<td>.032</td>
<td>.091</td>
<td>1.234</td>
<td>.221</td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td></td>
<td>-.635</td>
<td>-.819</td>
<td>-11.093</td>
<td>&lt;.001***</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2:</strong> D, B → FM</td>
<td>F(2,82)=50.542,</td>
<td>.55</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>p &lt; .001***</td>
<td>.025</td>
<td>.042</td>
<td>.528</td>
<td>.599</td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td></td>
<td>-.990</td>
<td>-.762</td>
<td>-9.520</td>
<td>&lt;.001***</td>
<td></td>
</tr>
<tr>
<td><strong>Step 3:</strong> D, B, FM → MH</td>
<td>F(3,82)=49.069,</td>
<td>.64</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>p &lt; .001***</td>
<td>.028</td>
<td>.081</td>
<td>1.125</td>
<td>.264</td>
<td></td>
</tr>
<tr>
<td>Burden</td>
<td></td>
<td>-.489</td>
<td>-.631</td>
<td>-.631</td>
<td>.000</td>
<td></td>
</tr>
<tr>
<td>FM</td>
<td></td>
<td>.147</td>
<td>.247</td>
<td>2.468</td>
<td>.016*</td>
<td></td>
</tr>
</tbody>
</table>

*p<.05. ***p<.001.

D = Duration of caregiving, B = Caregiver burden, I = Income, FM = Finding meaning through caregiving, PH = Physical health, MH = Mental health

**Summary**

Bivariate correlation analyses determined significant relationships between income, duration of caregiving and physical health; between finding meaning, burden and mental health; and duration of caregiving and burden. There was a partial mediating effect of finding meaning in the relationship between caregiver burden and caregiver mental health, thus hypothesis 5 was partially supported. Hypothesis 4 was not tested.
because there were no significant relationships between background factors, burden and caregiver physical health although the results approached statistical significance. Further discussion and implications of these findings will follow in Chapter 5.
CHAPTER 5
DISCUSSION

In this study the relationships between caregiver burden, finding meaning through caregiving (FMTCG), and caregiver physical and mental health were examined in a convenience sample of 84 community-residing spouse caregivers in north-central Florida. The main findings from this cross-sectional, descriptive study indicated that greater caregiver burden predicted poorer caregiver mental health, but not physical health, when controlling for background variables. In addition, FMTCG partially mediated the relationship between caregiver burden and mental health, while controlling for duration of caregiving.

In this chapter, the following sections are included: discussion of findings, implications, limitations, recommendations for future research, and conclusions. The findings are subdivided into the following sections: 1) Duration, Income, Caregiver Burden and Physical Health, 2) Duration, Caregiver Burden and Mental Health, and 3) the Mediating Effect of Finding Meaning through Caregiving.

Findings

Duration, income, caregiver burden and physical health. In this sample, the hypothesis that greater burden in spouse caregivers would predict poorer caregiver physical health, after controlling for duration of caregiving and income was not supported. The results from the statistical analysis of the regression model were not
significant $F(3, 82) = 2.656$, $p = .054$. These results are in contrast with the current literature indicating poorer physical health in caregivers and in dementia caregivers (Bruce, et al., 2005; deFrias, Tuokko, & Rosenberg, 2005; McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003; Vitaliano, et al., 2003). There are several possible explanations for these findings.

First, the participants in the sample reported better physical health than national norms for similar age groups. The normed physical health summary scores in the present sample of caregivers (age range = 49 - 96) ranged from 24.1 to 63.5 with a mean score of 45.22 ($SD = 10.5$), slightly lower than the 1998 national (age range = 18 – 96) normed mean score of 50 ($SD = 10.0$). When comparing this sample to the 1998 population norms for people 49 and over, the mean scores for physical health in this sample were higher for all groups. See Table 6. This finding may be a reflection of the better health of older adults today compared to the 1998 norms (Centers for Disease Control [CDC], 2007). Another possible explanation for this finding is that the sample size for norming the SF-36 v2 was comprised of 6,742 people, compared to the present sample of 84, which likely provided greater power.

Table 6

*Comparison by Age for Physical Health*

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Physical Health: Sample Means</th>
<th>Physical Health: 1998 United States Population Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>45 – 54 (n = 2)</td>
<td>61.69</td>
<td>49.62</td>
</tr>
<tr>
<td>55 – 64 (n = 10)</td>
<td>50.27</td>
<td>47.44</td>
</tr>
<tr>
<td>65 – 74 (n = 20)</td>
<td>48.05</td>
<td>44.70</td>
</tr>
<tr>
<td>75 and older (n = 52)</td>
<td>43.04</td>
<td>40.00</td>
</tr>
</tbody>
</table>
As well, it may be a reflection of the relatively high annual income level of the sample compared to national income levels for older adults. The median income of the study sample was between $41,000 and $55,000. In comparison, the median annual household income in 2005 for people over age 65 in the United States was $15,696 (CDC, 2007). The finding of a positive correlation between income and physical health in this study was similar to that demonstrated in the literature.

One explanation that has been hypothesized is that higher income offers greater access to respite care (Covinsky, et al., 2003). In addition, socioeconomic indicators such as income have been reported to affect health via pathways that include access to healthcare, healthcare utilization, neighborhood characteristics, occupation, access to daycare or other respite services, and other individual resources (Braveman, et al., 2005; Covinsky, et al., 2003). In the present study, 46% of the sample was recruited from independent living retirement settings with access to health care in the form of clinics and on-site physicians. Moreover, in a recent meta-analysis of 176 studies of correlates of caregiver physical health, caregivers with higher incomes were associated with better physical health (Pinquart & Sorensen, 2007). Although that meta-analysis included studies from caregivers in general, the majority were from dementia caregivers.

Second, the inability to find that greater caregiver burden predicted poorer physical health, may have been due to differences in measurement of physical health in this study compared to other studies. In the caregiving literature, physical health has been measured and reported as poorer self-rated health, reduced participation in healthy behaviors, medication use, number of chronic conditions, physiological markers, and physical symptom checklist (Pinquart & Sorensen, 2003; Roth, et al., 2001; Vitaliano, et
al., 2003). In contrast, the conceptualization of physical health with the SF-36 v2 focuses on caregivers’ abilities to function by measuring items such as lifting heavy objects, carrying groceries, and walking more than a mile. Physical role items included the amount of time spent in work or related activities, limitations in kinds of activities, and level of difficulty with performing activities. The bodily pain item asked the amount of pain in the last 4 weeks and the amount of interference in activities due to pain. The general health question referred to an overall self-perceived health rating and a rating of their health in comparison to others (eg. “getting sick easier than others”, “as healthy as anybody I know”).

However, other factors such as amount of sleep, medical conditions, medication use, health care utilization, health behaviors (substance use, nutrition, exercise, preventive health) that have been referenced in the caregiver literature were not included in the conceptualization of physical health in the SF-36 v2 (deFrias, et al., 2005; Bruce, et al. 2005; Pinquart & Sorensen, 2003; Vitaliano, et al., 2003). Qualitative data may elicit additional information to further describe and define caregiver physical health (Vitaliano, et al., 2003).

Third, there have been different conceptualizations of predictors of caregiver physical health. For example, caregiver stress and burden have been measured and reported differently in the literature (deFrias, et al., 2005; Bruce, et al., 2005; McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003). In two studies, caregiver health deterioration and caregiver stress predicted poorer physical health (measured with the SF-36) and accounted for 16% and 25% of the variance respectively (Bruce, et al., 2005; deFrias, et al., 2005). The relatively low amount of predicted variance in the two studies
suggests that there were other factors that influenced caregiver physical health that were not included.

DeFrias and colleagues (2005) measured deterioration in caregiver health associated with caregiving, a 4-item subscale of the Caregiver Reaction Assessment (Given, et al., 1992). The possibility of measurement error related to multicollinearity, which was not reported, between the variables of physical health and health declines in the deFrias study could be questioned. Bruce and colleagues (2005) measured caregiver stress with a single-item question that asked whether or not the caregiver was feeling stressed. All “yes” answers and “don’t know” answers were combined and coded as a dichotomous yes/no variable. Researchers have reported limitations to the use of a single-item measure (Fielding & Li, 1997; Frazier, Tix, & Barron, 2004; Polit & Beck, 2004). Reliability and validity information for the single-item stress question was not provided.

In this study, 75% of the caregivers reported mild to severe burden. The mean burden score was 30.72 (SD = 14.9) indicating that, as a group, they were mildly burdened by caregiving. This is similar to findings reported in the literature (McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003). In their study, McConaghy and Caltabiano reported that caregiver burden did not predict caregiver physical health (SF-12 v2). However, the small sample size (n = 42) may have had inadequate power to fully estimate the relationships between the variables and may have led to random sampling error. The shortened version of the SF-36 v2, the SF-12 v2, had demonstrated good reliability and validity, however according to the researchers it was designed for use in large samples of over 500 (Ware, Kosinski, & Keller, 1996) which may have reduced their ability to detect differences in the small samples.
Finally, there are inconsistencies in the caregiving literature regarding the influence of duration of caregiving on negative outcomes. The correlations found in the present study between duration and physical health (negative) and between duration and burden (positive) have been reported by other researchers (Pinquart & Sorensen, 2007; Thomas, et al., 2006). In contrast, McConaghy and Caltabiano (2005) reported no relationship between duration of caregiving and burden or physical health. This may have been due to inadequate sample size (n= 42) or because the group of participants were receiving homecare and respite services. However, in another study, Hooker and colleagues (2002) reported no relationship between duration of caregiving, caregiver stress and health outcomes once the effect of care recipient problem behaviors were considered in the analyses.

Gaugler and colleagues (2005) suggested that duration of care in dementia caregiving may be more complex than when it was previously conceptualized as a phenomenon of “wear and tear” (Walker, Acock, Bowman, & Li, 1996). In the present study, the mean duration of caregiving was 54.8 months, similar to the length of time reported in other dementia caregiver studies (DiBartolo & Soeken, 2003; Hooker, et al., 2002). However, other factors may influence duration of care such as caregiver adaptation over time, care recipient behavior problems, amount of care provided, and the use of respite services (Gaugler, et al., 2005; Gaugler, et al., 2000; Hooker, et al., 2002; McConaghy & Caltabiano, 2005). In addition, there is the potential for error when measuring duration of care because of difficulties in estimating the onset of caregiving (Gaugler, et al., 2005). It can be hypothesized that the onset of caregiving may have been particularly difficult to determine in a dyadic relationship such as spouse caregivers,
compared with adult children or other caregivers, due to the subtle nature of the onset of disease.

Several conclusions regarding the interpretation of the results in the present study can be made. First, as previously substantiated, it is possible that the construct of physical health as measured in the SF-36 v2 may not be a comprehensive conceptualization of the state of health of caregivers who are caring for a spouse with dementia because it lacks information about other factors that often influence physical health such as current or prior medical conditions, medication use, health behaviors, and health care utilization. Second, it is also possible that the caregivers in this sample were physically healthier compared to other older adults in the U.S. population. There is evidence to suggest that one of the main reasons that caregivers withdraw from caregiving and institutionalize their relative is because their own health declines (Buhr, Kuchibhatla, & Clipp, 2006; Gaugler, Kane, et al., 2003; Grasel, 2002; Liken, 2001). Thus, it is possible that one reason that the caregivers in this sample were able to participate in that role was because of their own good health.

Third, some selection bias may have been present due to characteristics of the caregivers who volunteered to participate compared with those who did not, resulting in an over-selection of caregivers with less burden and better health (Bruce, et al., 2005; McConaghy & Catalbiano, 2005). Fourth, stress-coping theorists posit that caregiving stressors lead to a group of physical and mental health outcomes described as any or all of the following: depression, anxiety, physical health effects, irritability, cognitive and role changes (Pearlin, et al., 1990). However, a recent meta-analysis revealed that a preponderance of the findings reported in the literature have indicated that caregiver
mental health, specifically depression, may lead to subsequent decline in physical health rather than simultaneous mental and physical health decline (Pinquart & Sorensen, 2007).

Last, the present study used a self-report measure of physical health rather than objective assessment which may have resulted in overestimation of the caregivers’ physical health due to the tendency to want to better represent themselves to the researcher (deFrias, et al., 2005; Pinquart & Sorensen, 2003; Polit & Beck, 2004). As well, there is a tendency for older male caregivers to underreport their health problems when participating in surveys and interviews (Fuller-Jonap & Haley, 1995). Since the present study was comprised of 41% men, this may have also influenced the results.

In summary, the lack of significance in predicting caregiver physical health may have been related to differences in conceptualization and measurement of physical health and predictors of physical health, selection bias, self-report error, sampling error, and theoretical limitations. Future research should consider a comprehensive conceptualization and measure of physical health that could be used across studies, greater emphasis on methodological techniques to reduce error such as larger sample sizes, more representative samples, and consistency in the selection of measures of caregiver burden and stress.

In addition, further testing and modification of theoretical models to reflect the recent findings that mental health declines may occur prior to physical health declines and the further development of factors that may mediate the effect of primary and secondary stressors on outcomes. For example, in the Alzheimer’s Caregiver Model (Pearlin, et al, 1990), coping and social support were included as mediators of caregiver stressors on outcomes, however specific types of coping have been found to be
influential. Caregiver wishfulness - intrapsychic coping was found to be related to shorter survival in care recipients (McClendon, et al., 2004). This was hypothesized to be due to the caregiver being less psychologically available to the recipient. In their literature review, Kneebone and Martin (2003) reported that problem-focused and acceptance-coping styles were associated with positive outcomes in the care recipients.

Individual differences should be considered as aspects of the background and contextual factors that influence the perception of caregiver stressors. For example, Gottlieb and Rooney (2004) reported that caregivers who were optimistic were more likely to cope effectively. In addition, spirituality and existential aspects of caregiving have been linked with coping with caregiver stress (Acton & Miller, 2003; Farran, 1997; Koenig, et al., 2000; Reed, 1987; Salmon, et al., 2005).

Duration, caregiver burden and mental health. In this section, the discussion will include findings from the present study regarding hypothesis two, that greater burden predicted caregiver mental health. The presentation of the findings will include a review of the significance of the results in relation to the body of the caregiving literature, contribution to the literature, missing information and measurement issues.

In this sample, after controlling for duration of caregiving, spouses with greater burden reported poorer mental health thus supporting the second hypothesis. These results are similar to the findings found in the literature (Crespo, et al., 2005; Mahoney, et al., 2005; McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003). The mental health scores from the SF-36 v2 ranged from 16.5 to 64.3, with a mean of 47.36 ($SD = 11.5$). Similarly, in a sample of 91 dementia caregivers, Bruce and colleagues (2005)
reported mean mental health scores on the Short Form Survey of 47.0 ($R = 43.3 – 51.5$, $SD$ not reported). The mental health scores in the present study were lower than the U.S. population norms in 1998 for the same age groups. See Table 7. This finding is consistent with previous studies that indicate more mental health problems among caregivers, particularly in caregivers who have sought assistance (Bruce, et al., 2005; McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003).

In the present study, 60% of the sample was recruited through contacts at support groups and day care settings suggesting that a substantial proportion of the sample were seeking support or assistance with caregiving. However, because a large percentage of the sample was from people who had sought assistance, it may not have represented the overall community of dementia caregivers.

Table 7

*Comparison by Age for Mental Health*

<table>
<thead>
<tr>
<th>Age Category</th>
<th>Mental Health: Sample Means</th>
<th>Mental Health: 1998 United States Population Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>45 – 54 (n = 2)</td>
<td>42.76</td>
<td>50.54</td>
</tr>
<tr>
<td>55 – 64 (n = 10)</td>
<td>47.65</td>
<td>51.71</td>
</tr>
<tr>
<td>65 – 74 (n = 20)</td>
<td>36.64</td>
<td>53.17</td>
</tr>
<tr>
<td>75 and older (n = 52)</td>
<td>50.82</td>
<td>50.37</td>
</tr>
</tbody>
</table>

Approximately 50% of the sample demonstrated mental health scores lower than the national norms for similar age groups. This is consistent with the literature that supports the finding of poorer mental health in dementia caregivers when compared with the general community (Bruce, et al., 2005; Mahoney, et al., 2005). Although not the
focus of the present study, it is worth noting that the mental health scores for the present sample were, in general, lower for younger caregivers. This has been reported in other studies (Bruce, et al., 2005; Pinquart & Sorensen, 2003). Bruce and colleagues (2005) suggested that younger caregivers may be more vulnerable to mental health problems from caregiving. Further investigation into this finding is warranted to identify caregiving groups that may be particularly vulnerable to the development of mental health problems.

The sample in the present study was comprised of spouse caregivers, a group that has been found to be especially at risk from the effects of caregiver burden, which may have contributed to the lower mental health scores (Covinsky, et al., 2003; Pinquart & Sorensen, 2003; Sherwood, Given, Given, & Von Eye, 2005). Explanations have included reduced access to resources, greater perceived burden, deterioration in relationship quality, and family conflict (Crespo, et al., 2005; Oyebode, 2003; Schulz & Martire, 2003; Sherwood, et al., 2005). In addition, Ankri and colleagues (2005) found that spouses may perceive the burden of caregiving differently in terms of deterioration in social and personal life than adult children or other caregivers.

In addition, in the present study women comprised 60% of the sample. It has been reported that women are at greater risk for negative health outcomes, including depression, due to caregiving responsibilities (Chumbler, et al., 2003; Mahoney, et al, 2005; Pinquart & Sorensen, 2003; Vitaliano, et al., 2003). This may be due to greater participation in direct physical care such as assistance with activities of daily living (bathing, toileting, dressing), greater willingness to report negative feelings, differences in coping styles, and less participation in respite care (Navaie-Waliser, Spriggs, & Feldman, 2003; Pinquart & Sorensen, 2003).
Measurement of the overall mental health of caregivers is important because mental health problems have been correlated with depression, a serious psychological disorder. Low scores on the SF-36 v2 mental health summary measure may be suggestive of clinical depression (McHorney, Ware, & Raczek, 1993; Ware, Kosinski, & Keller, 1996). Almost 30% of the sample in the present study had scores less than 42 on the mental health summary score, which may suggest the presence of clinical depression, and was slightly higher than the 25% reported in other dementia caregiver groups (Bruce, et al., 2005; Ware, et al., 1996). This may be because this group of caregivers was comprised of only spouses compared with the mixed caregiver group in the study by Bruce and colleagues (2005). Further investigation of differences between spouse caregivers, gender differences, and other types of caregivers and mental health problems is recommended. As well, an examination of this finding over time in longitudinal studies would advance the state of knowledge in this area.

As previously reported, the mean burden scores ($M = 30.72$, $SD = 14.0$) indicated mild levels of burden in this sample, however, 75% of the group reported some degree of burden ranging from mild to severe. This is similar to findings reported in the literature (McConaghy & Caltabiano, 2005; Pinquart & Sorensen, 2003). As anticipated, there was a moderate correlation between duration of caregiving and burden ($r = .371$, $p = .001$), indicating that duration of care contributed to the relationship between burden and mental health. Thus, even when the effect of duration of care was controlled, spouses who perceived higher levels of burden suffered greater mental health problems.

Although a causal relationship cannot be established in this cross-sectional study, evidence from a study by Sherwood and colleagues (2005) who used structural equation
modeling to examine significant pathways between the variables suggested that the
direction of the relationship was from burden towards depressive symptoms.
Longitudinal studies are needed to duplicate this finding but they lend support to stress-
process models such as the Alzheimer’s Caregiver Stress Model (Pearlin, et al., 1990).

Consistent with stress-process models, this study relied on a subjective measure of
caregiver burden to reflect primary stressors (Zarit Burden Scale). The Zarit Burden
Scale measured caregiver subjective burden; the caregiver appraisal of burden related to
their caregiving experience. Mahoney and colleagues (2005) described subjective burden
as associated more with the emotional consequences of caregiving while objective burden
referred to the physical and financial aspects. The Zarit Burden Scale, for example,
included questions to elicit information from caregivers about how stressed they feel
when caring for their relative in addition to other responsibilities, whether they feel
angry, strained, embarrassed, or fearful, and about the loss of control over their lives.

In contrast, objective burden has been measured by assessing the amount of care
provided in terms of activities of daily living or hours of care provided (Bell, Araki, &
Neumann, 2001; Crespo, et al., 2005). Other aspects of objective burden have included
the presence of care recipient behavior problems and level of cognitive impairment
(Covinsky, et al., 2003; Crespo, et al., 2005). In the present study, to include a measure of
objective burden would likely have contributed additional information about the
complexity of the caregiving experience but also would have required resources beyond
the capacity of the present study.

In a meta-analysis of the literature about differences in health between caregivers
and noncaregivers, Pinquart and Sorensen (2003) reported that five indicators (stress,
depression, well-being, physical health, and self-efficacy) explained only 8% of the variance between the two groups. One explanation offered for this finding was that negative effects of caregiving may have been under-assessed in the research studies due to the exclusion of caregiver-specific stressors. For example, there is a some literature to indicate that care recipient behaviors may contribute to declines in the mental health of caregivers (Covinsky, et al., 2003; Hooker, et al., 2002; Kim, Knight, & Longmire, 2007; Mahoney, et al., 2005; Oyebode, 2003).

Another possibility to account for the relatively small effect size (Cohen, 1992) in the meta-analysis was that stress-buffering factors such as the positive effect of caregiving have been under-assessed (Pinquart & Sorensen, 2003). This has similarly been reported by others (Farran, et al., 1991; Farran, et al., 1997; Kramer, 1997; Noonan & Tennstedt, 1997; Roff, et al., 2004). For this reason, the current study explored the potential of a positive aspect of caregiving, finding meaning through caregiving, as a way of coping and potential mediator of burden on health outcomes in spouse caregivers, which will be discussed in the next section.

To summarize, the hypothesis that greater caregiver burden would predict poorer mental health outcomes, controlling for the effect of duration of caregiver was supported in the present study. The correlation between mental health, measured with the SF-36 v2, and depressive symptoms highlights the importance of recognizing at-risk caregivers. Consistent with the literature, this group of caregivers reported lower mental health scores than the general community, particularly among younger spouses. This suggests that younger spouse caregivers may be particularly vulnerable to the mental health effects of caregiving. In the next section, the findings for the final three hypotheses, that finding
meaning would mediate the relationship between caregiver burden and physical and mental health will be discussed.

**Mediation testing.** Hypotheses 3 through 5 consisted of the steps for mediation testing of finding meaning through caregiving (FMTCG) on the physical and mental health of spouse caregivers. In the present study, FMTCG scores ranged from 93 to 193 ($M = 150.56$, $SD = 20.02$). Higher scores indicated finding more meaning in caregiving. This is similar to previous research where scores ranged from 76 to 198 ($M = 144.35$, $SD = 19.07$) in a sample of 215 spouse caregivers in dementia (Farran, et al., 1999). The results of the current study suggest that the effect of burden on the mental health of people who were caring for their spouse with dementia was lessened by the process of finding meaning. Specifically, in the present study, 64% of the variance in mental health was explained by caregiver burden. When finding meaning was entered into the model, there was a 23% reduction in the amount of variance explained by burden (23% of 64%). Thus, caregivers who found meaning in caregiving were able to reduce the effect of burden on their mental health by 15%. This contribution to the caregiving literature offers new information for use in identifying at-risk caregivers and for intervention designs. Replication of the findings in a larger, more representative sample would help to confirm the results.

For comparison, only one other study was found that proposed finding meaning as a mediator variable. Similar to the present study, Noonan and Tennstedt (1997) conceptualized finding meaning in caregiving as a coping resource within the context of the caregiving model of Pearlin and colleagues (1990). However, the participants in their
sample were caregivers for disabled elders. While finding meaning was also proposed as a coping resource and mediator variable, the researchers assessed objective burden (measured as amount and frequency of care, cognitive impairment, and behavior problems) and the outcome of well-being. However, when analysis of the variables showed no association between finding meaning and measures of objective burden the steps in mediation testing could not be performed. Several differences between the Noonan and Tennstedt (1997) study and the present study may explain these seemingly contradictory findings.

First, the Pearlin model (1990) was developed specifically for application in studies of Alzheimer’s disease caregivers because dementia caregiving was thought to be unique from other types of caregiving. In addition to loss of the relationship and stress of caregiving, specific aspects of dementia caregiving thought to make it unique from other types of caregiving stem from the unrelenting cognitive deterioration that results in unilateral, overwhelming, and unbalanced care provision by the caregiver to the family member who becomes increasingly unaware and dependent (Pearlin, et al., 1990). Components of the model were derived from interviews at several points in time with 555 Alzheimer’s disease caregivers. Therefore, the model, its components, and measures, as conceptualized by Pearlin and colleagues, may not have been as applicable to caregivers of elders with disabilities, of which only 31% were cognitively impaired.

Second, the measurement of finding meaning resulted from a combination of two different constructs of meaning in caregiving: 1) the Meaning in Caregiving Scale (Giuliano, Mitchell, Clark, Harlow, & Rosenbloom, 1990), a 25-item scale which was reduced to a 12-item version (reliability not reported), which was then reduced to one
summary score to represent caregiver’s overall ability to find meaning, and 2) the Management of Meaning subscale from the Pearlin model (1990). However, Pearlin and colleagues (1990) recommended using caution with the management of meaning subscale (4-item) due to low reliability coefficients. Although the researchers did not actually test this construct of meaning as a mediator, there were conceptual and methodological inconsistencies that may have influenced the lack of association between objective burden and their construct of finding meaning. Last, measures of objective burden do not reflect caregiver’s perceptions or appraisals of the burden they feel in their situation. Instead, measures of subjective burden might better reflect individual perceptions about their own caregiving situation which theoretically would be more consistent with measures of meaning in caregiving.

In another dementia caregiver study (Farran, et al., 1997) that measured finding meaning in caregiving with the FMTCG scale, finding meaning was conceptualized as a positive psychological resource variable and measured using only the provisional meaning subscale. It contributed an additional 3% of the variance toward predicting depression. In contrast, in a study of 58 caregivers of people with Parkinson’s disease, Konstam and colleagues (2003) reported that FMTCG did not contribute any additional variance over and above that already contributed by the Life Attitude Profile-revised subscales of Purpose and Existential Vacuum (Reker, 1981) when predicting caregiver well-being. The Life Attitude Profile measures an overall construct of searching for and attaining general meaning in life (Reker, 1981).

In the first study (Farran, et al., 1997), the provisional meaning subscale did contribute an additional 3% to the model, and it is unknown whether the full scale would
have contributed any additional variance. Replication of this study using the full scale might produce additional information about the contribution of FMTCG to depression in dementia caregivers. In the second study (Konstam, et al., 2003), because the sample was comprised of caregivers in Parkinson’s disease, whether the outcomes would be similar in a group of dementia caregivers remains unclear. It is interesting to note that when general meaning in life was already in the regression model, that finding meaning specific to caregiving did not contribute anything further to the model. Additional exploration of these two concepts as they relate to particular groups of caregivers would help to clarify this finding.

**Correlates of finding meaning.** Regarding the results of the bivariate correlation analyses, there were strong associations between burden and FMTCG ($r = -0.757, p < .001$) and mental health and FMTCG ($r = 0.720, p < .001$), while duration of caregiving was weakly associated with FMTCG ($r = -0.226, p < .05$). The negative association between burden and FMTCG was not unexpected and similar to the findings reported in the literature (Farran, et al., 1997). Caregivers who perceived their burden as low also reported greater meaning in caregiving. In addition, caregivers who described finding more meaning in caregiving reported better mental health. The weak association between duration of caregiving and FMTCG suggests that caregivers may perceive their situation as less meaningful over longer periods of time. However, because these are correlational findings, causality cannot be determined.

This study contributes to the current conceptualization of the Alzheimer’s Caregiver Stress Model (Pearlin, et al., 1990) by proposing and testing the idea that
finding meaning in caregiving (Farran, 1997) may operate as a way of coping and mediator variable. According to the model, coping represents personal management of a stressful situation that changes the meaning and reduces the threat (Pearlin, et al., 1990). Previous researchers have reported that coping strategies partially or completely ameliorate the effects of perceived stressors on negative caregiving outcomes such as physical and mental health (Gottlieb & Rooney, 2004; Kneebone & Martin, 2003). Findings from the present study suggest that caregivers who are able to find meaning in their situation may reduce the threat of the stressful situation and improve their mental health. Next, study limitations, implications, additional recommendations for future research and conclusions will be discussed.

**Limitations**

When evaluating the findings from this study, several limitations should be taken into account. First, because this was a cross-sectional design, conclusions about the direction of the relationships between burden, finding meaning and health cannot be clearly established. A longitudinal design would allow greater understanding of whether, and in which direction, caregiver burden changes over time, how caregivers go about the process of finding meaning, and at which points or stages in the caregiving trajectory that these processes occur. In addition, longitudinal designs could also answer questions about care recipient factors that change over time such as stage of disease, disease symptoms, behavioral problems, and functional decline and their effect on perceptions of burden and meaning in caregiving.
Because this was a convenience sample from the north-central Florida area, generalizations to the larger population of caregivers are limited. As previously discussed, 60% of the sample in the present study were recruited through support groups and day care centers which may have resulted in an over-selection of caregivers in need. In addition, because the sample was largely from a group of help-seeking caregivers, it may not adequately represent the caregiving community in general. Because this was a sample of caregivers who volunteered to participate, there may have been others who were too stressed or overburdened to be able to participate, thus limiting results.

In this study, there was no differentiation made between various types of dementia when recruiting the sample. However, there is evidence that the behaviors of people with different types of dementia are varied (deVught, et al., 2006; Moretti, Torre, Antonello, & Cazzato, 2006). For example, frontotemporal dementia (FTD) can be distinguished from Alzheimer’s disease (AD) by specific types of behavior changes, such that greater general burden has been reported among caregivers of FTD patients (deVught, et al., 2006). As well, among people with vascular dementia, more behavioral problems were exhibited by a group of people with multi-infarct dementia when compared with a second group with subcortical vascular dementia. Thus, there may have been participants in the current study, caring for their spouse with several different types of dementia with varying behavioral problems which may have influenced the results.

The data were obtained from self-report questionnaires which may be more subjective than other objective measures. The questionnaires were obtained by direct interview with the researcher, which may have influenced the participant to answer in a way that they thought might please the examiner. In a few cases, the care recipient was
nearby while the interviews were taking place and, although attempts were made to minimize this, it could have influenced the answers that participants were willing to disclose.

Conclusions

The findings of the present study indicate that caregivers of spouses with dementia may be at risk for mental health problems from the burden of caregiving, and that the negative effects may be less in people who are able to find meaning in their situation. Identification of caregivers at risk and assistance given, particularly psychosocial interventions, to reduce burden may be helpful (Sorensen, et al., 2002). Further investigation into how caregivers find meaning in their caregiving experiences and optimal ways to disseminate this information to others is needed. Although in the present study caregiver burden did not predict caregiver physical health this may have been due to methodological issues rather than an actual indication of the state of their physical health. For example, because the trajectory of dementia is downward, it may be that as care recipients reach the later stages of the disease requiring more direct care and exhibiting greater behavioral problems, that caregivers, particularly spouse caregivers, would demonstrate more physical health problems due to age as well. Because caregivers have an increased risk for mortality, the physical health effect of caregiving needs further exploration.
Implications

Alzheimer’s disease is expected to become an epidemic in this century. Informal caregivers, spouses and adult children, will provide the majority of the care for individuals with AD over an extended period of time. As such, they play and will continue to play an important role in society. Unfortunately, it is anticipated that because of the stress, caregivers will be at risk to suffer from adverse health effects, particularly later in the caregiving course, and caregivers with preexisting health problems may be particularly at risk (Hooker, et al, 2000; Vitaliano, et al., 2003). Systems to protect the health of informal caregivers can be beneficial, not only to the caregivers, but also to the care recipient and society as a whole.

Health care providers need to be aware of the risks associated with caregiving and knowledgeable of effective interventions and treatments for this vulnerable group. For example, psychotherapeutic interventions, specifically reducing negative thoughts about caregiving, have been found to improve caregiver mental health (Chang, 1999; Sorensen, et al., 2002). In the present study, one mechanism was identified that might assist spouse caregivers to cope with the stress of caregiving. Spouses who found their experiences to be meaningful had better mental health outcomes. Perhaps finding meaning in caregiving is one way to assist with reducing negative thoughts about caregiving and improve outcomes. As well, the idea of finding meaning could be incorporated into a larger, multidimensional intervention as one mechanism to increase the effect of interventions. By addressing several different problems associated with caregiving simultaneously in an intensely therapeutic intervention, the best outcome would be most likely achieved (Schultz & Martire, 2004). In summary, health care providers can be important resources
for informal caregivers. By identifying caregivers at risk for detrimental effects of caregiving, health care providers may intervene to reduce negative outcomes not only for the caregiver, but also for the care recipient.

Future Research

As the result of this study, several areas for further research have been identified. Identification of caregivers at risk for health care problems and interventions to reduce risk and improve health outcomes should remain the focus of future research. One intervention identified in the present study is finding meaning, which might function as a way of coping with the stress of caregiving. However, replication of this study in a more representative sample, with a larger number of participants that would allow enough power to include a number of covariates, would greatly increase the generalizability and applicability of the results.

In addition, exploration of the role of finding meaning in caregivers other than spouses, for example adult children and other relatives, would be valuable. It may be that there would be variations in responses between spouse and adult children to the questionnaire. For example, adult children may perceive the loss of their parent differently than spouses. Specifically, responses to questions about “missing the little things that we did together in the past” and “missing our previous social life” and “we had plans for the future that just folded up” would likely be answered differently depending on the type of relationship with the care recipient.

A prospective, longitudinal design would validate the current findings about the relationships between burden, finding meaning, and mental health. In addition, further
work in the area of measurement of caregiver physical health would be beneficial. In particular, the effect of caregiving stress over time in caregivers with pre-existing health problems and their ability to participate in healthy behaviors needs further investigation.

A larger sample of informal caregivers that included spouses, adult children, other relatives and friends, from different geographic areas residing in the community, perhaps recruited through health care settings such as physician’s offices, memory disorder clinics, churches or other community centers would allow a more representative sample thus increasing generalizability. As well, because different types of dementia may be associated with different stressors, caregiver studies targeted towards understanding the problems associated with specific types of dementia would be beneficial in designing more precise interventions.
REFERENCES


APPENDIX A

DEMOGRAPHIC SURVEY
DEMOGRAPHIC SURVEY

In order to help me understand your answers better, would you please tell me a little bit more about yourself and your spouse?

CAREGIVER INFORMATION

1. Date of birth

2. Education

What is the highest level of education that you have completed?

- 1st grade
- 2nd grade
- 3rd grade
- 4th grade
- 5th grade
- 6th grade
- 7th grade
- 8th grade
- 9th grade
- 10th grade
- 11th grade
- 12th grade
- 1 -2 years college
- 3-4 years college
- 5 or more years college

3. Sex
   a. male
   b. female

4. Race
   What race do you consider yourself?
   a. white/Caucasian

   b. black/African American

   c. American Indian/Alaskan Native

   d. Asian/Pacific Islander

   e. Other
5. Duration of caregiving

How long have you been the main caregiver for your spouse?

   a. number of months _______

6. Income

What is your current annual income?

   a. 0 to $10,000 per year
   b. $10,000 - $25,000 per year
   c. $26,000 - $40,000 per year
   d. $41,00 - $55,000 per year
   e. $56,00 - $70,000 per year
   f. more than $70,000 per year

CARE RECIPIENT INFORMATION

7. Date of birth_________________

8. Education

What is the highest level of education your spouse completed?

   □ 1st grade
   □ 2nd grade
   □ 3rd grade
   □ 4th grade
   □ 5th grade
   □ 6th grade
   □ 7th grade
   □ 8th grade
   □ 9th grade
   □ 10th grade
   □ 11th grade
   □ 12th grade
   □ 1 - 2 years college
   □ 3 – 4 years college
   □ 5 or more years college
9. Sex
   a. male
   b. female

10. Race
    What race does your spouse consider him/herself?
    a. white/Caucasian
    b. black/African American
    c. American Indian/Alaskan Native
    d. Asian/Pacific Islander
    e. Other

Is there anything else that you would like to add that was not have been covered today?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for participating in this study. Your time and effort is greatly appreciated.
APPENDIX B

ZARIT BURDEN INTERVIEW
ZARIT BURDEN INTERVIEW

Circle the response that best describes how you feel.

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>rarely</th>
<th>sometimes</th>
<th>quite frequently</th>
<th>nearly always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behavior?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
12. Do you feel that your social life has suffered because you are caring for your relative?  
0 1 2 3 4

13. Do you feel uncomfortable about having friends over because of your relative?  
0 1 2 3 4

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?  
0 1 2 3 4

15. Do you feel that you don’t have enough money to take care of your relative in addition to the rest of your expenses?  
0 1 2 3 4

16. Do you feel that you will be unable to take care of your relative much longer?  
0 1 2 3 4

17. Do you feel you have lost control of your life since your relative’s illness?  
0 1 2 3 4

18. Do you wish you could leave the care of your relative to someone else?  
0 1 2 3 4

19. Do you feel uncertain about what to do about your relative?  
0 1 2 3 4

20. Do you feel you should be doing more for your relative?  
0 1 2 3 4

21. Do you feel you could do a better job in caring for your relative?  
0 1 2 3 4

22. Overall, how burdened do you feel in caring for your relative?  
0 1 2 3 4

(Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.)

(Scoring Instructions: Add the scores for the 22 questions. The total score ranges from 0-88. A high score correlates with higher level of burden.)
APPENDIX C

FINDING MEANING THROUGH CAREGIVING SCALE
FINDING MEANING THROUGH CAREGIVING SCALE

This questionnaire contains a number of statements related to opinions and feelings about yourself, your impaired relative, and your caregiving experience. Read each statement carefully, then indicate the extent to which you agree or disagree with the statement. Circle one of the alternative categories.

<table>
<thead>
<tr>
<th></th>
<th>STRONGLY AGREE</th>
<th>A AGREE</th>
<th>UNDECIDED</th>
<th>D DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I miss the communication and companionship that my family member and I had in the past.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>I miss my family member’s ability to love me as he/she did in the past</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>I am sad about the mental and physical changes I see in my relative</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>I miss the little things my relative and I did together in the past.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>I am sad about losing the person I once knew.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I miss not being able to be spontaneous in my life because of caring for my relative.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>My situation feels endless.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>I enjoy having my relative with me; I would miss it if he/she were gone.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>I count my blessings.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Caring for my relative gives my life a purpose and sense of meaning.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>The Lord won’t give you more than you can handle.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>I miss not having more time for other family members and /or friends.</td>
<td>A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>I have no hope, I am clutching at straws.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>I cherish the past memories and experiences that my relative and I have had.</td>
<td>SA A U D SD</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
15. I am a strong person.  
16. Caregiving makes me feel good that I am helping.  
17. I believe in the power of prayer; without it I couldn’t do this.  
18. I miss our previous social life.  
19. I have no sense of joy.  
20. The hugs and “I love you” from my relative make it worth it all.  
21. I am a fighter.  
22. I am glad I am here to care for my relative.  
23. I believe that the Lord will provide.  
24. I miss not being able to travel.  
25. I wish I were free to lead a life of my own.  
26. Talking with others who are close to me restores my faith in my own abilities.  
27. Even though there are difficult things in my life, I look forward to the future.  
28. Caregiving has helped me learn new things about myself.  
29. I have faith that the good Lord has reasons for this.  
30. I miss having given up my job or other personal interests to take care of my family member.  
31. I feel trapped by my relative’s illness.  
32. Each year, regardless of the quality, is a blessing.
33. I would not have chose the situation I’m in, but I get satisfaction out of providing care.
34. We had goals for the future but they just folded up because of my relative’s dementia.
35. God is good.
36. I miss my relative’s sense of humor.
37. I wish I could run away.
38. Every day is a blessing.
39. This is my place; I have to make the best out of it.
40. I am much stronger than I think.
41. I feel that the quality of my life has decreased.
42. I start each day knowing we will have a beautiful day together.
43. Caregiving has made me a stronger and better person.
APPENDIX D

SF36V2 HEALTH SURVEY
SF36V2 HEALTH SURVEY

The following questions ask for your views about your health and how you feel about life in general. If you are unsure about how to answer any question, try and think about your overall health and give the best answer you can. Do not spend too much time answering, as your immediate response is likely to be the most accurate.

1. In general, would you say your health is:
   - [ ] Excellent
   - [ ] Very good
   - [ ] Good
   - [ ] Fair
   - [ ] Poor

2. Compared to one year ago, how would you rate your health in general now?
   a. Much better than one year ago
   b. Somewhat better now than one year ago
   c. About the same as one year ago
   d. Somewhat worse now than one year ago
   e. Much worse now than one year ago

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
      - [ ] Yes, limited a lot
      - [ ] Yes, limited a little
      - [ ] No, not limited at all
   b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
      - [ ] Yes, limited a lot
      - [ ] Yes, limited a little
      - [ ] No, not limited at all
   c. Lifting or carrying groceries
      - [ ] Yes, limited a lot
      - [ ] Yes, limited a little
      - [ ] No, not limited at all
d. Climbing several flights of stairs
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

e. Climbing one flight of stairs
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

f. Bending, kneeling, or stooping
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

g. Walking more than a mile
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

h. Walking several hundred yards
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

i. Walking one hundred yards
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all

k. Bathing or dressing yourself
   - Yes, limited a lot
   - Yes, limited a little
   - No, not limited at all
4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
   a. Cut down on the amount of time you spend on work or other activities
      - all of the time
      - most of the time
      - some of the time
      - a little of the time
      - none of the time
   b. Accomplished less than you would like
      - all of the time
      - most of the time
      - some of the time
      - a little of the time
      - none of the time
   c. Were limited in the kind of work or other activities
      - all of the time
      - most of the time
      - some of the time
      - a little of the time
      - none of the time
   d. Had difficult performing the work or other activities (for example, it took extra effort)
      - all of the time
      - most of the time
      - some of the time
      - a little of the time
      - none of the time

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
   a. Cut down on the amount of time you spent on work or other activities
      - all of the time
      - most of the time
      - some of the time
      - a little of the time
      - none of the time
b. Accomplished less than you would like

☐ all of the time
☐ most of the time
☐ some of the time
☐ a little of the time
☐ none of the time

c. Did work of other activities less carefully than usual

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ A little of the time
☐ None of the time

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

7. How much bodily pain have you had during the past 4 weeks?

☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐ Not at all
☐ A little bit
☐ Moderately
☐ Quite a bit
☐ Extremely
9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks….

a. Did you feel full of life?
   - All of the time
   - Most of the time
   - Some of the time
   - A little bit of the time
   - None of the time

b. Have you been very nervous?
   - All of the time
   - Most of the time
   - Some of the time
   - A little bit of the time
   - None of the time

c. Have you felt so down in the dumps that nothing could cheer you up?
   - All of the time
   - Most of the time
   - Some of the time
   - A little bit of the time
   - None of the time

d. Have you felt calm and peaceful?
   - All of the time
   - Most of the time
   - Some of the time
   - A little bit of the time
   - None of the time

e. Did you have a lot of energy?
   - All of the time
   - Most of the time
   - Some of the time
   - A little bit of the time
   - None of the time
f. Have you felt downhearted and depressed?
   □ All of the time
   □ Most of the time
   □ Some of the time
   □ A little bit of the time
   □ None of the time

g. Did you feel worn out?
   □ All of the time
   □ Most of the time
   □ Some of the time
   □ A little bit of the time
   □ None of the time

h. Have you been happy?
   □ All of the time
   □ Most of the time
   □ Some of the time
   □ A little bit of the time
   □ None of the time

i. Did you feel tired?
   □ All of the time
   □ Most of the time
   □ Some of the time
   □ A little bit of the time
   □ None of the time

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?
   □ All of the time
   □ Most of the time
   □ Some of the time
   □ A little bit of the time
   □ None of the time
11. How TRUE or FALSE is each of the following statements for you?

   a. I seem to get sick a little easier than other people
      - Definitely true
      - Mostly true
      - Don’t know
      - Mostly false
      - Definitely false

   b. I am as healthy as anybody I know
      - Definitely true
      - Mostly true
      - Don’t know
      - Mostly false
      - Definitely false

   c. I expect my health to get worse
      - Definitely true
      - Mostly true
      - Don’t know
      - Mostly false
      - Definitely false

   d. My health is excellent
      - Definitely true
      - Mostly true
      - Don’t know
      - Mostly false
      - Definitely false
APPENDIX E

COGNITIVE STATUS SCALE
COGNITIVE STATUS SCALE

Now, I’d like to ask you some questions about your spouse’s memory and the difficulty he/she may have doing some things. How difficult is it for your spouse to:

A. Remember recent events
   - Can’t do at all
   - Very difficult
   - Fairly difficult
   - Just a little difficult
   - Not at all difficult

B. Know what day of the week it is
   - Can’t do at all
   - Very difficult
   - Fairly difficult
   - Just a little difficult
   - Not at all difficult

C. Remember his/her home address
   - Can’t do at all
   - Very difficult
   - Fairly difficult
   - Just a little difficult
   - Not at all difficult

D. Remember words
   - Can’t do at all
   - Very difficult
   - Fairly difficult
   - Just a little difficult
   - Not at all difficult

E. Understand simple instructions
   - Can’t do at all
   - Very difficult
   - Fairly difficult
   - Just a little difficult
   - Not at all difficult

F. Find his/her way around the house
G. Speak sentences

- Can’t do at all
- Very difficult
- Fairly difficult
- Just a little difficult
- Not at all difficult

H. Recognize people that he/she knows

- Can’t do at all
- Very difficult
- Fairly difficult
- Just a little difficult
- Not at all difficult

(Scoring: 1 = can’t do at all, 2 = very difficult, 3 = fairly difficult, 4 = just a little difficult, 5 = not at all difficult. Higher scores indicate greater cognitive function).
APPENDIX F

SIX-ITEM SCREENER
SIX-ITEM SCREENER

I would like to ask you some questions that ask you to use your memory. I am going to name three objects. Please wait until I say all three words, then repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. Please repeat these words for me: APPLE – TABLE – PENNY. (Interviewer may repeat names 3 times if necessary but repetition not scored.)

Did patient correctly repeat all three words?  Yes  No

Incorrect  Correct

1. What year is this?  0  1
2. What month is this?  0  1
3. What is the day of the week?  0  1

What were the three objects I asked you to remember?

4. Apple  0  1
5. Table  0  1
6. Penny  0  1
APPENDIX G

IRB APPROVAL FORM
UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56 and ICH GCP Guidelines. The Assurance became effective on November 24, 2003 and expires on September 19, 2010. The Assurance number is FWA00005960.

Principal Investigator: MCLENNON, SUSAN
Co-Investigator(s): 
Protocol Number: X061116002
Protocol Title: Physical and Mental Health of Spousal Caregivers in Dementia: The Role of Finding Meaning as a Mediator of Burden

The IRB reviewed and approved the above named project on 11-02-07. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.
IRB Approval Date: 11-02-07
Date IRB Approval Issued: 11-02-07

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.