

UNDERSTANDING STRESS, IMMUNITY, AND SLEEP DISTURBANCES IN
CAREGIVERS OF PERSONS WITH DEMENTIA

By

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To my husband, who always provided support for my education with love,
Brandy L. Lehman

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LIST OF ABBREVIATIONS

ACTH	Adrenocorticotropin releasing hormone
ACS	Appraisal caregiving scale
ADL	Activities of daily living
AD	Alzheimer's disease
AUC	Area under curve
BMI	Body mass index
CBG	Corticosteroid binding globulin
CBI	Caregiver burden inventory
CES-D	Center for epidemiologic depression scale
CRF	Corticotropin releasing factor
CRH	Corticotrophin releasing hormone
DV	Dependent variable
EEG	Electroencephalogram
ESS	Epworth sleep scale
GAS	General adaptation syndrome
GR	Glucocorticoid receptor
HPA	Hypothalamic pituitary adrenal axis
IADL	Instrumental activities of daily living
IgA	Immunoglobulin A
IV	Independent variable
MMSE	Mini mental status exam
NPI	Neuropsychiatric inventory
NPI-Q	Neuropsychiatric inventory questionnaire

PSQI	Pittsburgh sleep quality index
PSS	Perceived stress scale
PWD	Person with dementia
RCT	Randomized control trials
REM	Rapid eye movement
SD	Standard deviation
SDB	Sleep disordered breathing
SEo	Actigraphy sleep efficiency
SEs	Sleep diary sleep efficiency
SNS	Sympathetic nervous system
SOLo	Actigraphy sleep onset latency
SOLs	Sleep diary sleep onset latency
SRRS	Social readjustment rating scale
TSTo	Actigraphy total sleep time
TSTS	Sleep diary total sleep time
TWTo	Actigraphy total wake time
TWTS	Sleep diary total wake time
VIF	Variance inflation factor
WAIS	Wechsler adult intelligence scale
WASOo	Actigraphy wake after sleep onset
WASOs	Sleep diary wake after sleep onset

Abstract of Dissertation Presented to the Graduate School
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Providing long-term care for a demented relative profoundly affects caregivers' lives. It puts the caregiver at risk for both mental and physical health problems. Caregiving of cognitively impaired individuals is a highly stressful activity associated with depression, impaired sleep, and immune and endocrine effects.

The purpose of the proposed study was (a) to explore sleep patterns in high and low stressed caregivers of cognitively impaired community-dwelling individuals and (b) to explore the proposed link between stress of caregiving role and the physiologic/psychologic awakened changes that occur in caregivers with high and low levels of stress.

A nonexperimental prospective cross-sectional design was used to explore sleep patterns and the physiologic/psychologic changes that occur in caregivers. Thirty caregivers were recruited and a series of instruments was used to measure stress, depression, sleep disturbances and immune and endocrine function.

Almost 40% of the caregivers showed signs of possible clinical depression. The caregivers tended to have a high level of stress and perceived their health as good or fair. The caregivers also displayed a high level of daytime sleepiness. There was no significant relationship between caregiving stress and sleep diary sleep efficiency ($r = -.073$, $p = .354$) and

actigraphy sleep efficiency ($r = -.127$, $p = .256$). There was no significant relationship between caregiving stress and area under curve mean daytime salivary cortisol in respect to ground ($r = -.094$, $p = .339$) and mean total salivary IgA ($r = .090$, $p = .328$). There was no significant relationship between high stressed caregivers and sleep diary sleep efficiency ($F = .171$, $p = .915$) and actigraphy sleep efficiency ($F = .598$, $p = .623$). Secondary analyses were conducted using the sleep data on nights 2 and 3 and the cortisol and IgA data on Days 3 and 4. On Day 3 the caregivers had increased actigraphy total wake time and decreased actigraphy sleep efficiency ($r = -.407$, $p = .014$) and Day 4 ($r = -.407$, $p = .014$). The caregivers also had increased actigraphy total wake time and decreased sleep diary sleep efficiency on Day 3 ($r = -.387$, $p = .021$) and Day 4 ($r = -.360$, $p = .033$). The caregivers also had increased cortisol after awakening and decreased actigraphy sleep efficiency ($r = -.590$, $p = .002$) on Day 3.

CHAPTER 1

INTRODUCTION

Alzheimer's Caregivers

Alzheimer's disease (AD) is a growing public health crisis. Every 72 seconds, someone in America develops Alzheimer's disease; by mid-century, someone will develop Alzheimer's disease every 33 seconds (Alzheimer's Association, 2007). It is an age-related disorder, with prevalence increasing in older populations. This is a particularly urgent problem in light of the fact that the elderly population in the United States and the world is growing rapidly. An estimated 5.1 million Americans had Alzheimer's disease in 2007. This number included 4.9 million people over age 65 and older (Alzheimer's Association, 2007).

More than 7 out of 10 people with Alzheimer's disease live at home, where family and friends provide almost 75% of their care (Alzheimer's Association, 2007). Almost 10 million Americans are caring for a person with Alzheimer's disease or another dementia (Alzheimer's Association, 2007). In the United States, care services to the elderly are provided by informal caregivers, such as spouses and adult children (Zhu et al., 2006). Informal caregivers of individuals with AD play a major role in supporting impaired elders throughout the course of the illness and are one of our health care system's greatest resources (Gibson & Houser, 2007). Although no standard definition of caregiving exists, there is general consensus that it involves provision of extraordinary care, exceeding the bounds of what is normative or usual in relationships (Mohr, Lafuze, & Mohr, 2000; Zhu et al., 2006).

Caring for a family member with AD is one of the most distressing and challenging experiences one can endure. Alzheimer's disease is a tragic, debilitating, chronic illness with unpredictable clinical courses that average nearly 10 years from diagnosis to death (Alzheimer's Association, 2005). The tragedy of AD is compounded by the toll it takes on the caregiver, who

must cope with the long-term disabling physical and behavioral problems associated with the care recipient's illness. Providing care to an elderly relative often restricts the personal life, social life, and employment of the caregiver. Their task is not an easy one and is fraught with emotional strain, distress, and physical exhaustion (Cohen, 1990; Schulz & Martire, 2004; Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Caregivers may have less time to spend with friends, to fulfill other family obligations, or to pursue leisure activities (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Kosberg & Cairl, 1986; Mohr et al., 2000). These challenges often affect the health and income of caregivers of people with Alzheimer's and other dementias. Over 40% of these caregivers report high levels of emotional stress (Alzheimer's Association, 2007). Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting.

Caregiver Burden

Caregiver burden is defined as "the physical, psychologic, or emotional, social and financial problems that can be experienced by family members caring for impaired elderly adults" (Gilleard et al., 1984; Kasuya, Polgar-Bailey, & Takeuchi, 2000; Sleath et al., 2005; Stuckey, Neundorfer, & Smyth, 1996). There is a substantial body of literature that documents the negative psychological, physical, and social consequences associated with providing care to a relative with AD (AARP, 2004; Alzheimer's Association, 2007; Kasuya et al., 2000). Informal caregivers are more likely to report that their health is in fair or poor condition than noncaregivers (Ho, Collins, Davis, & Doty, 2005; Pinquart & Sorensen, 2003; Schultz & Carnevale, 1996; Schulz & Beach, 1999; Schulz et al., 2002; Sherwood, Given, Given, & von Eye, 2005). They are also more likely to use psychotropic drugs (Baumgarten et al., 1992; Buhr,

Kuchibhatla, & Clipp, 2006; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Skjerve, Bjorvatn, & Holsten, 2004), engage in fewer health-promoting behaviors and self-care over the course of caregiving (Gallant & Connell, 1997; Savundranayagam, Hummert, & Montgomery, 2005) and report frequent utilization of medical care (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Kiecolt-Glaser et al., 1991; Savundranayagam et al., 2005). Most studies have found elevated rates of symptoms of anxiety and depression in caregivers (Ho et al., 2005; Kasuya et al., 2000; Sleath et al., 2005) compared to age-matched controls or population means, whether symptoms were measured by self-report or by structured diagnostic interviews (Schultz & Carnevale, 1996). Caregivers of demented patients also have financial problems and heightened levels of stress and psychological morbidity compared to caregivers of nondemented elderly persons (Alzheimer's Association, 2007; Bedard, Koivuranta, & Stuckey, 2004; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Furthermore, caregivers are often faced with difficult caregiving tasks and behavior problems of demented care recipients, such as verbal and physical aggression and confusion (Alzheimer's Association, 2007; Buhr et al., 2006; Teri et al., 1992).

One health area that has received little empirical study in caregiving research is sleep. Sleep is an important domain that is likely to be affected adversely by the task of providing care to a family member with cognitive impairments. Getting a good night's sleep is a high priority for most people. However, for those with AD and their caregivers, an uninterrupted night's sleep can be an unusual luxury. Problems sleeping at night can be very draining for the family members caring for AD patients living at home.

One possible explanation for the changes in caregiver sleep is a result of altered sleep-wake patterns in care recipient. Disturbed sleep in AD care recipient is a major medical problem (Allen, Seiler, Stahelin, & Spiegel, 1987; McCurry, Logsdon, Teri, & Vitiello, 2007; Pruchno,

Peters, & Burant, 1995; Pruchno & Potashnik, 1989; Wilcox & King, 1999). There is accumulating evidence that greater disease severity is associated with greater sleep disturbance (McCurry et al., 2007; Strine & Chapman, 2005; Vitiello & Borson, 2001). In persons with AD, sleep and nighttime behavioral disturbances include wandering, day/night confusion, getting up repeatedly during the night, and nightmares or hallucinations (Ayalon et al., 2006; Gaugler et al., 2000; Hope, Keene, Gedling, Fairburn, & Jacoby, 1998; McCurry et al., 2007; Pollak & Perlick, 1991; Smith, 2004; Strine & Chapman, 2005). The burden of nightly care of the AD patient taxes caregivers because of the unpredictability of the care recipient's behavior, the need for constant vigilance to monitor wandering outside the home, and the stress and depression that ensuing sleep loss can cause (Bliwise, 2004; McCurry et al., 1999; Moran et al., 2005). Finally, caregivers are likely to be awakened by sleep disruptions of their care recipients, with negative consequences of their own sleep.

Importance of Sleep

Sleep is an important component of mammalian homeostasis and is vital for the survival of self and species (Dew et al., 2003; McCurry et al., 1999; Vgontzas & Chrousos, 2002). It is also of great importance for health and the quality of life. It is estimated that 50 to 70 million Americans chronically suffer from a disorder of sleep and wakefulness, hindering daily functioning and adversely affecting their health and longevity. The cumulative effects of sleep loss and sleep disorders represent an under-recognized public health problem and have been associated with a wide range of health consequences including an increased risk of hypertension, diabetes, obesity, depression, heart attack, and stroke (Colten & Altevogt, 2006). Hundreds of billions of dollars a year are spent on direct medical costs related to sleep disorders such as doctor visits, hospital services, prescriptions, and over-the-counter medications (Colten & Altevogt, 2006).

There is a strong association between sleep and illness or early death (Anselm, Gauthier, Beanlands, & Haddad, 2008; Dew et al., 2003; Kripke, Simons, Garfinkel, & Hammond, 1979; Manocchia, Keller, & Ware, 2001; Morgan, Healey, & Healey, 1989; Strine & Chapman, 2005; Wingard & Berkman, 1983). Mortality is at least 1.6 to 2 times higher among elderly persons with sleep disorders than in those who sleep well, and the excess mortality is related to the predominant causes of death, such as heart disease, stroke, cancer and suicide (Dew et al., 2003; Ferrie et al., 2007; Morgan et al., 1989; Wingard & Berkman, 1983). The excess mortality is more pronounced in elderly persons who have begun to experience sleep problems later in life than in those who have slept poorly since earlier in life (Dew et al., 2003; Ferrie et al., 2007; Morgan & Clarke, 1997). However, poor sleep is not only associated with shortened life expectancy. It also shows a negative interaction with many somatic and psychiatric diseases and symptoms, as well as causing deterioration in the quality of life (Asplund, 1999; Manocchia et al., 2001; Strine & Chapman, 2005).

Sleep and Older Adult

Sleep quality is an important parameter of health-related quality of life in older adults, and it is possibly a correlate of continuing adaptability in later life (Dew et al., 2003; Dew et al., 1994; Ohayon, Carskadon, Guilleminault, & Vitiello, 2004). Sleep complaints are common in all age groups. Older adults, however, are particularly vulnerable. A series of studies of the sleep characteristics of healthy older adults suggest the importance of sleep quality as a marker of overall health, well-being, and adaptability in later life. In a 2-year observational study of laboratory-and diary-based sleep measures in two groups of healthy volunteers (ages 60-74 and age 75 and older), Hoch and colleagues (1994) found that sleep efficiency (defined as the amount of sleep, given the time in bed), deteriorated to a greater degree over 2 years among subjects ages 75 and older than in subjects ages 60 and 74.

In a study of over 9,000 community-dwelling adults over age 65 years, 42% of subjects reported difficulty in initiating and maintaining sleep (Foley et al., 1995). At follow up three years later, nearly 15% of the 4,956 participants without symptoms of difficulty sleeping at baseline reported chronic difficulties at baseline; approximately 50% no longer had symptoms. The discontinuation of insomnia symptoms was associated with improved self-perceived health (Foley, Monjan, Simonsick, Wallace, & Blazer, 1999). A recent comprehensive review reported that in noninstitutionalized elderly respondents, difficulties initiating sleep were reported in 15% to 45%, disrupted sleep in approximately 20% to 65%, early morning awakenings in 15% to 54%, and nonrestorative sleep in approximately 10% (Ohayon, 2002). In most studies, the prevalence of sleep did not significantly increase with age, but was higher in women than in men (Ohayon, 2002).

Sleep recordings of older adults, as compared with younger adults, have shown that older adults have less deep sleep and less REM (rapid eye movement) sleep. However, a recent meta-analysis looking at 65 studies, representing 3,657 subjects age 5 years to 102 years, suggested that these age-related sleep changes are already seen in young and middle-aged adults, with the percentage of slow-wave sleep linearly decreasing at a rate of approximately 2% per decade of age up to age 60 years (Ohayon et al., 2004). Studies that included only elderly participants did not find changes in percentage of slow-wave sleep. Rather, sleep remained relatively constant from age 60 to the mid-90s, except for sleep efficiency which continued to decrease. The meta-analysis also showed that as slow-wave sleep and REM sleep decreased, more of the night was spent in lighter stages of sleep (Ohayon et al., 2004).

Nevertheless, these changes in sleep, on their own, do not account for most of the sleep complaints of the older adult. Rather, the sleep difficulties are, in part, a result of the older

adults' decreased ability to maintain sleep. The causes of the decreased ability to maintain sleep are multifactorial and include the influence of medical and psychiatric illness and medications on sleep, changes in the timing and consolidation of sleep as a result of changes in the endogenous circadian clock, and the presence of other sleep disorders (Ancoli-Israel & Ayalon, 2006).

Sleep disturbances can have significant, serious consequences. Sleep problems are associated with increased risk of falls in the older adult, even after controlling for medication use, age, difficulty walking, difficulty seeing, and depression (Brassington, King, & Bliwise, 2000). Studies have shown that patients with difficulty sleeping reported as more symptoms of depression and anxiety, than those with no sleep difficulties. These patients were more likely to have slower reaction times, poorer balance, and worse memory than matched control subjects (Hauri, 1997). Chronic sleep difficulties at any age can lead to deficits in attention, response times, shortterm memory, and performance level (Walsh, Benca, & Bonnet, 1999).

Furthermore, another study (Dew et al., 1994) found that "inefficient" sleep (i.e., fragmented sleep with frequent interruptions) in the very old (age 75 and over) predicted future declines in measures of mental and physical adaptation in older age, including diminished subjective sleep quality, fewer social activities, greater depressive symptoms, and more chronic medical burden. Dew and colleagues (2003) also reported that after controlling for age, sex, and baseline medical burden, healthy elders with prolonged sleep latencies (>30 minutes) had 2.1 greater risk of death over a median follow-up interval of 13 years. Additionally, in the same study, participants with poor sleep efficiency ($<80\%$) had 1.9 greater risk of mortality; patients with either too much or too little REM sleep percent ($<16.1\%$ or $>25.7\%$) had 1.7 greater risk of mortality (Dew et al., 2003).

Sleep in older adults becomes lighter with age. However, healthy older adults rarely have sleep complaints (Foley, Ancoli-Israel, Britz, & Walsh, 2004). In a study of several thousand older adults, 57% had chronic insomnia, versus 12% with no insomnia, but the chronic insomnia was more prevalent among those with depressed mood, respiratory symptoms, fair-to-poor health, and physical disability (Foley et al., 1995). There was another study that concluded that aging, per se, does not cause the sleep disturbances (Foley et al., 1999). Rather, the sleep disruptions seen in this population are secondary to other factors, or comorbid with medical and psychiatric illness, medication use, circadian rhythm changes, and other sleep disorders such as sleep disordered breathing and REM behavior disorder (Foley et al., 1999).

Causes for Sleep Changes in Dementia Caregiver

Sleep is an important domain that is likely to be affected adversely by the task of providing care to a family member with cognitive impairments (McCurry et al., 2007; McKibbin et al., 2005; Pruchno & Potashnik, 1989; Wilcox & King, 1999). Several factors could lead to impaired sleep among caregivers, in addition to altered sleep-wake cycles of person with dementia (PWD). First, symptoms of stress and depression, commonly experienced by caregivers are associated with impaired sleep (Berkman & Breslow, 1983; Braekhus, Oksengard, Engedal, & Laake, 1998; Buysse, Reynolds, Monk, Berman, & Kupfer, 1989; Caswell et al., 2003; Kesselring et al., 2001; McCurry et al., 2007; McKibbin et al., 2005; Paulsen & Shaver, 1991). Second, it is well established that individuals with dementia commonly experience sleep disruptions, and these disruptions are viewed problematic by caregivers (McCurry et al., 2007; McKibbin et al., 2005; Prinz et al., 1982; P. Rabins, 1989; Rabins, Mace, & Lucas, 1982). Caregivers are likely to be awakened by the sleep disruptions of their care recipients, with negative consequences of their own sleep. Third, it has been reported that caregiver's inability to sleep is correlated with caregiver stress and patient institutionalization (Bergman-Evans, 1994;

Chenier, 1997; Hope et al., 1998; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005; McCurry et al., 2007; Pollak & Perlick, 1991).

Finally, these factors could interact to form a self-perpetuating cycle of sleep disturbance. That is, caregivers could experience negative thoughts and feelings that would interfere with resuming sleep (McCurry et al., 2007; Wilcox & King, 1999). Over time, the sleep deprivation could cause daytime fatigue, stress, and depression that could then further interfere with sleep, thus exacerbating the problem (McCurry et al., 2007; Teel & Press, 1999; Wilcox & King, 1999). Of all these problems being awakened by the patient at night has been identified as one of the most disturbing sleep irregularities faced by dementia caregivers (McCurry et al., 1999; McCurry et al., 2007) and as stated above is a major cause of patient institutionalization (Coehlo, Hooker, & Bowman, 2007; Hope et al., 1998; Pollak & Perlick, 1991). Next, the health consequences of disrupted sleep will be discussed.

Consequences of Fragmented Sleep

There are several studies that have documented health consequences due to fragmented sleep (Anselm et al., 2008; Schwartz et al., 1999; Strine & Chapman, 2005; Van Cauter, 2005; Vioque, Torres, & Quiles, 2000). Fragmented sleep has been linked to coronary heart disease, obesity, and diabetes mellitus. Cardiovascular risk is greater in individuals who perceive their sleep as poor (Anselm et al., 2008; Schwartz et al., 1999). Ayas and colleagues (2003) found in a prospective study of women a significant positive association between reported sleep duration and incidence of coronary heart disease. Short and long sleep durations were associated with an increased risk of incident coronary heart disease.

There has been an increase in the prevalence of both obesity and severe obesity linked to sleep disturbances. In recent years, an increasing number of epidemiological studies have reported an association between sleep duration and body mass index (BMI). A 2000 report from

Spain observed that those reporting sleeping 6 hours (h) or less per day had an increased risk of obesity after controlling for sex, age, and other factors, and this group also had a higher mean BMI (Schmid et al., 2007; Vioque et al., 2000).

Intriguingly, the dramatic increase in the incidence of obesity and diabetes seems to have developed over the same period of time as the progressive decrease in self-reported sleep duration (Flegal, Carroll, Kuczmarski, & Johnson, 1998; Flegal, Carroll, Ogden, & Johnson, 2002; Van Cauter, 2005). Taken together, sleep loss affects millions of individuals in our modern society, and recent studies have provided evidence in support of its deleterious impact on glucose metabolism and appetite regulation (Spiegel, Knutson, Leproult, Tasali, & Van Cauter, 2005).

Stress Response

Stress is defined as any stimulus that disturbs or interferes with the normal physiological equilibrium of an organism (Oxford, 1999). Stress is a state of threatened homeostasis provoked by a psychological, environmental, or physiologic stressor (Chrousos & Gold, 1992; Peterson et al., 1991).

There are two well recognized stress response systems that are activated when a stimulus is perceived as a stressor (King & Hegadoren, 2002). These are the sympathetic or autonomic response system and the hypothalamic pituitary adrenal (HPA) axis (King & Hegadoren, 2002; Kumsta, Entringer, Hellhammer, & Wust, 2007). The activation of the sympathetic system occurs within seconds with resultant increases in the secretion of epinephrine from the adrenal medulla and norepinephrine from peripheral and central sympathetic neurons (King & Hegadoren, 2002; Kumsta et al., 2007).

The activation of the HPA axis occurs more slowly within minutes or hours with increases occurring in release of corticotrophin-releasing hormone (CRH) from the

hypothalamus. CRH stimulates the pituitary to release adrenocorticotropin-releasing hormone (ACTH) into the systemic circulation, which in turn stimulates the adrenal cortex to release the glucocorticoid, cortisol (King & Hegadoren, 2002; Kumsta et al., 2007). Chronic or extreme activation can lead to changes in HPA axis activity, as evidenced by abnormal cortisol levels, which may in turn increase vulnerability to developing health problems (King & Hegadoren, 2002; Kumsta et al., 2007).

Uncontrollable, unpredictable, and constant stress has far-reaching consequences on our physical and mental health (Black, 2006). Many illnesses such as obesity, cardiovascular disease, and diabetes mellitus type II are influenced by chronic or overwhelming stress (Black, 2006).

One must remember that caring for a family member with AD is one of the most distressing and challenging experiences one can endure. Caregiving involves a significant expenditure of time, energy, and money over potentially long periods of time. It involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting. Informal caregivers are more likely to report that their health is in fair or poor condition than noncaregivers (Pinquart & Sorensen, 2003; Schultz & Carnevale, 1996; Schulz & Beach, 1999; Schulz & Martire, 2004; Schulz et al., 2002; Sherwood et al., 2005; Sleath et al., 2005).

Statement of the Problem

The purpose of the proposed study is to explore sleep patterns in stressed caregivers of cognitively impaired community-dwelling individuals who worry about nighttime activity and to explore the proposed link between stress of caregiving role and the physiologic/psychologic changes that occur in stressed caregivers with high and low levels of stress that worry about nighttime activity.

- **Specific aim 1:** To describe differences in sleep patterns between caregivers with high and low levels of stress.
 - **Hypothesis 1a:** Caregivers with higher levels of stress will have more sleep fragmentation (lower sleep efficiency and higher number of awakenings) and more daytime sleepiness.
- **Specific aim 2:** To describe daytime salivary cortisol levels among caregivers with high and low levels of stress.
 - **Hypothesis 2a:** Caregivers with higher levels of stress will have more abnormal daytime salivary cortisol levels.
- **Specific aim 3:** To describe IgA levels among caregivers with high and low levels of stress.
 - **Hypothesis 3a:** Caregivers with higher levels of stress will have decreased salivary IgA levels.
- **Specific aim 4:** To test whether the Caregiver and Ineffective Sleep model predicts the relationship between caregivers with high and low levels of stress, fragmented sleep, and caregiver well-being.
 - **Hypothesis 4a:** The relationship between high stressed caregivers and fragmented sleep will be moderated by worrying about sleeping through nighttime activity.
 - **Hypothesis 4b:** Fragmented sleep will mediate the relationship between level of caregiver stress and daytime salivary cortisol levels.
 - **Hypothesis 4c:** Fragmented sleep will mediate the relationship between level of caregiver stress and salivary IgA levels.

Introduction to Stress, Coping, and Adaptation

Conceptual Framework

In order to contribute to a more coherent and comprehensive body of knowledge and to advance nursing science, it is recommended that studies should be based on a conceptual and theoretical model (Fawcett, 1995). A theoretical model is a description of the variables being analyzed in a given situation, together with a statement of the researcher's hypotheses concerning the relationships among the variables. Models are typically accompanied by a pictorial representation of these variables and their interrelationships (Britt, 1997). The Stress,

Coping, and Adaptation Model has been used to conceptualize the important constructs for this study. The theoretical framework of this study is constructed from specific concepts identified in the empirical and theoretical literature on stress, coping, and adaptation (Lazarus & Folkman, 1984).

Lazarus and Folkman began to develop their model in 1966, and it is one of the most prominent theories of stress (Lazarus & Folkman, 1984). The Stress, Coping, and Adaptation Model presents stress as a transaction between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984). At the heart of this model are two processes: appraisal and coping. Appraisal has to do with the individual's evaluation of the personal significance of a given event and the adequacy of the individual's resources for coping. It influences emotion and subsequent coping. Coping refers to the thoughts and behaviors a person uses to regulate distress (emotion-focused coping), manage the problem causing distress (problem-focused coping), and maintain positive well-being (meaning-based coping) (Lazarus & Folkman, 1984). Coping influences the outcome of the situation and the individual's appraisal of it (Lazarus & Folkman, 1984).

The Stress, Coping, and Adaptation model was chosen because the assumptions, conceptions, relational statements, and propositions are logically congruent with the phenomenon of interest, and the mid-range theory is well represented in the caregiver literature (Bakas, Champion, Perkins, Farran, & Williams, 2006; Coon et al., 2004; DiBartolo & Soeken, 2003; Haley et al., 2004; Hebert et al., 2003; Huang, Musil, Zauszniewski, & Wykle, 2006). There have also been several books published by Lazarus further explaining the theoretical model (Lazarus, 1994, 1999). The theoretical model will be presented by explaining stress, appraisal and coping by synthesizing relevant literature.

Stress, Coping, and Adaptation model

Figure 1-1 displays the Stress, Coping, and Adaptation model in pictorial format showing the variables and their interrelationships. This model has a transactional, process-oriented outlook, because the authors are looking at the same persons at different times or under different conditions (Lazarus & Folkman, 1984). This model allows the researcher to observe or infer what the person is thinking and doing at various points during an encounter or in different encounters. It looks at phenomena within persons as well as across persons within the same research design (Lazarus & Folkman, 1984). The authors have also developed this model to be used in interdisciplinary research. There are five types of major variables in this model: stress, appraisal, coping, person and environment antecedents of stress and coping and short-and long-term adaptational outcomes. Next, these five major variables will be defined in further detail.

Stressor

Stressors are demands made by the internal or external environment that upset balance or homeostasis, thus affecting physical and psychosocial well-being and requiring action to restore balance or equilibrium (Lazarus & Cohen, 1977). Early work on stress focused on physiological reactions to stressful stimuli. Cannon (1932) is credited with first describing the “fight-or-flight” reaction to stress. Hans Selye, the father of modern stress research, extended Cannon’s studies with clinical observations and laboratory research. He hypothesized that living organisms (rats and people) exhibited nonspecific changes in response to stressors, labeled as a three-stage General Adaptation Syndrome (GAS). This syndrome consists of an alarm reaction, resistance, and exhaustion (Selye, 1956). Each stage evokes both physiological and behavioral responses, and without curative measures, physical and psychological deterioration will occur.

Another major stream of stress research in the 1960s and 1970s focused on identifying and quantifying potential stressors, or stressful life events. Holmes and Rahe (1967) developed

the Social Readjustment Rating Scale (SRRS), a tool to measure stressful life events. Studies showed that people with high scores on the SRRS had more illness episodes than did those with low scores. This scale stimulated a substantial body of research despite numerous methodological limitations (Dohrenwend & Dohrenwend, 1981).

Beginning in the 1960s and 1970s, stress was considered to be a transactional phenomenon dependent on the meaning of the stimulus to the perceiver (Antonovsky, 1979; Lazarus, 1966). The central concept in models developed during this time is that a given event or situation is perceived in different ways by various individuals. Moreover, these perceptions—rather than the objective stressors—are the main determinants of effects on subsequent behaviors and on health status. Some researchers in the field of occupational stress and health used this concept as a foundation for a model that viewed occupational stress as a result of the interaction between individual workers' characteristics and the work environment, or the "person-environment fit" (French & Kahn, 1962; House, 1974). These lines of theory led to an examination of possible buffering, or moderating factors, and in particular to a focus on the role of social support (Cohen & Wills, 1985). Next, appraisal will be defined.

Appraisal

The appraisal process is based on the assumption that people are constantly appraising their relationship to the environment. The stress process begins when the person becomes aware of a change or a threatened change in the status of current goals and concerns (Folkman & Greer, 2000). Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984). The appraisal of this actual or threatened change includes an evaluation of its personal significance, which is called primary

appraisal, and evaluation of the options for coping, which is called secondary appraisal (Folkman & Greer, 2000).

The theory approaches psychological stress through the examination of two critical processes that mediate the person-environment relationship: cognitive appraisal and coping (Lazarus & Folkman, 1984). Cognitive appraisal can be most readily understood as the process of categorizing an encounter, and its various facets, with respect to its significance for well-being. It is not information processing per se, in the sense used by Mandler (1975) and others, although it partakes of such processing. Rather, it is largely evaluative, focused on meaning or significance, and takes place continuously during waking life (Lazarus & Folkman, 1984). It is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and if so, in what ways. Lazarus and Folkman (1984) have made a basic distinction between primary and secondary appraisal identifying the two main evaluative issues of appraisal, namely, “Am I in trouble or being benefited, now or in the future, and in what way?” and “What if anything can be done about it?”

Person and Environment Antecedents

The two main sets of variables jointly influencing whether the appraisal is that of threat or challenge are environmental and personality centered (Lazarus & Folkman, 1984). These variables influence appraisal by (a) determining what is salient for well-being in a given encounter, (b) shaping the person’s understanding of the event, and in consequence his or her emotions and coping efforts; and (c) providing the basis for evaluating outcomes (Lazarus & Folkman, 1984).

Some environmental circumstances impose too great a demand on a person’s resources, whereas others provide considerable latitude for available skills and persistence, thereby influencing whether threat or challenge will occur. The substantive environmental content

variables having an influence consist of diverse situational demands, constraints, and opportunities (Lazarus & Folkman, 1984). Formal environmental variables consist of situational dimensions, such as novelty versus familiarity, predictability versus unpredictability, clarity of meaning versus ambiguity, and temporal factors such as imminence, timing, and duration (Lazarus & Folkman, 1984).

Personality dispositions influencing whether a person is more prone to a threat or challenge include self-confidence or self-efficacy (Lazarus & Folkman, 1984). The more confident we are of our capacity to overcome dangers and obstacles, the more likely we are to be challenged rather than threatened; a sense of inadequacy, however, promotes threat. Nevertheless, and consistent with a relational analysis of stress, in any transaction both the environmental circumstances and the personality dispositions combine in determining whether there will be a threat or challenge appraisal (Lazarus & Folkman, 1984). Primary appraisal will now be further defined.

Primary appraisal

In primary appraisal, the person evaluates whether he or she has anything at stake in this encounter. For example, is there potential harm or benefit with respect to commitments, values, or goals? Is the health or well-being of a loved one at risk? Is there potential harm or benefit to self-esteem? (Lazarus & Folkman, 1984). Primary appraisal is influenced by the person's beliefs, values, and commitments. There are three kinds of primary appraisal, irrelevant, benign-positive, and stressful.

An irrelevant encounter has no significance for one's well-being, and the person has no stake in its outcome; in a benign-positive encounter only a good outcome is signaled (Lazarus & Folkman, 1984). Stressful appraisals are characterized by threat, challenge, or harm-loss. Threat refers to the potential for harm or loss; challenge refers to the potential for growth, mastery, or

gain; and harm-loss refers to injury already done, as in harm to a friendship, health, or self-esteem (Lazarus & Folkman, 1984). Because people vary in these attributes, a given situation, such as a spouse diagnosed with Alzheimer's Disease, is appraised by some primarily as harm, by others as a threat, and by others as primarily a challenge. Next, secondary appraisal will be discussed in greater detail.

Secondary appraisal

When we are in jeopardy, whether it be a threat or a challenge, something must be done to manage the situation. In that case, a further form of appraisal becomes salient, that of evaluating what might and can be done, which is secondary appraisal (Lazarus & Folkman, 1984). In secondary appraisal, the person evaluates what if anything can be done to overcome or prevent harm or to improve the prospects for benefit. Various coping options are evaluated, such as altering the situation, accepting it, seeking more information, or holding back from acting impulsively and in a counterproductive way (Lazarus & Folkman, 1984).

Secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality (or content) of the emotional reaction. Primary and secondary appraisal converge to determine whether the person-environment transaction is regarded as significant for well-being, and if so, whether it is primarily threatening (containing the possibility of harm or loss), or challenging (holding the possibility of mastery or benefit) (Lazarus & Folkman, 1984). Next, coping will be discussed in greater detail.

Coping is defined as the person's constantly changing cognitive behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources. There are three key features of this definition (Lazarus & Folkman, 1984). First, it is process oriented, meaning that it focuses on what the person actually thinks and does

in a specific stressful encounter, and how this changes as the encounter unfolds. Second, coping is contextual, that is it is influenced by the person's appraisal of actual demands in the encounter and resources for managing them. The emphasis on context means that particular person and situation variables together shape coping efforts. Third, there are no a priori assumptions about what constitutes good or bad coping; coping is defined simply as a person's efforts to manage demands, whether or not the efforts are successful (Lazarus & Folkman, 1984).

Coping has two widely recognized major functions: regulating stressful emotions (emotion-focused coping) and altering the troubled person-environment relation causing the distress (problem-focused coping) (Lazarus & Folkman, 1984). Two studies have provided strong empirical support for the idea that coping usually includes both functions. Both forms of coping were represented in over 98% of the stressful encounters reported by middle-aged men and women (Folkman & Lazarus, 1980) and in an average of 96% of the self-reports of how college students coped with a stressful examination (Folkman & Lazarus, 1985). Problem-focused coping was used more frequently in encounters that were appraised by the person as changeable. In contrast, emotion-focused coping was used more frequently in encounters that were appraised as unchangeable.

Emotion-focused coping

A wide range of emotion-focused forms of coping is found in the literature. One large group consists of cognitive processes directed at lessening emotional distress and includes strategies such as avoidance, minimization, distancing, selective attention, positive comparisons, seeking emotional support, wishful thinking, self-blame and wresting positive value from negative events (Lazarus & Folkman, 1984). A smaller group of cognitive strategies is directed at increasing emotional distress. Some individuals need to feel worse before they can feel better;

in order to get relief they first need to experience their distress acutely and to this end engage in self-blame or some other form of punishment (Lazarus & Folkman, 1984).

Certain cognitive forms of emotion-focused coping lead to a change in the way an encounter is construed without changing the objective situation. These strategies are equivalent to reappraisal. Consider the following cognitive maneuvers that are commonly used to reduce threat, "I decided there are more important things to worry about" and "I considered how much worse things could be" (Lazarus & Folkman, 1984). In each case, threat is diminished by changing the meaning of the situation-a coping effort qua reappraisal (Lazarus & Folkman, 1984).

Problem-focused coping

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. Problem-focused efforts are often directed at defining the problem, generating alternative solutions, weighting the alternative solutions in terms of their costs and benefits, choosing among them, and acting (Lazarus & Folkman, 1984). It includes strategies for gathering information, making decisions, planning, and resolving conflicts; it includes efforts directed at acquiring resources (e.g., skills, tools, and knowledge) to help deal with the underlying problem. It also includes instrumental, situation specific, and task-oriented actions (Lazarus & Folkman, 1984).

Greater control (secondary appraisal) is associated with higher levels of problem-focused coping, such as information search, problem solving, and direct action to solve a problem. Less control is associated with higher levels of emotion-focused coping, such as escape and avoidance, the seeking of social support, distancing, or cognitive reframing (Lazarus & Folkman, 1984). People vary their coping depending on the intensity of their emotion response and their

ability to regulate it, the opportunities inherent in the situation for problem solving, and changes in the person-environment relationship as the situation unfolds (Lazarus & Folkman, 1984).

Whether as a result of coping, changes in the environment that may or may not be related to the event, or changes in the individual, the relationship between the person and the environment continues to unfold. Events that are brought to a clear conclusion lead to an appraisal of the outcome as favorable or unfavorable. A favorable event outcome is likely to lead to a benefit appraisal, positive emotion, and the conclusion of coping activity (Lazarus & Folkman, 1984). The final variables of the model, immediate and long-term effects, will be discussed.

Immediate and Long-Term Affects

The issue of great concern to researchers in this field is how appraisal and coping affect three major classes of adaptational outcomes—social functioning, morale, and somatic health/illness (Lazarus & Folkman, 1984). Social functioning can be defined as the ways the individual fulfills his/her various roles, as satisfaction with interpersonal relationships, or in terms of the skills necessary for maintaining roles and relationships. A person's overall social functioning is largely determined by the effectiveness with which he or she appraises and copes with the events of day-to-day living (Lazarus & Folkman, 1984). Social functioning is thus influenced by many factors, including the person's autonomy, trust, intimacy, and so on, and cultural values and expectations regarding social roles and how they should be enacted.

Social functioning over the long term is an extension of coping effectiveness in many specific encounters over the life course (Lazarus & Folkman, 1984). Problems exist in the assessment of social functioning, many of which have to do with value judgments as to what constitutes good social functioning. Many relationships can withstand occasional errors of

appraisal, but any relationship will be put to a severe test if inappropriate appraisals are frequent (Lazarus & Folkman, 1984).

Morale is concerned with how people feel about themselves and their conditions of life (Lazarus & Folkman, 1984). Morale over the long run probably depends on a tendency to appraise encounters as challenges, to cope with negative outcomes by putting them in a positive light, and, overall, effectively managing a wide range of demands (Lazarus & Folkman, 1984).

An essential theme of the analysis of stress, coping, and health that dominates thinking in behavioral medicine is that emotional states of all kinds and intensities accompany appraisals of harm, threat, and challenge (Lazarus & Folkman, 1984). The link with illness is the conventional one that massive bodily changes are associated with emotions, especially strong, negative ones such as fear and anger. It is this theme that has given Selye's (1956, 1976) work on the physiology of stress great influence in behavioral medicine and psychosomatics. There are three routes through which coping can affect health including influencing the frequency, intensity, duration, and patterning of neurochemical stress reactions; using injurious substances or carrying out activities that put the person at risk; and impeding adaptive health/illness-related behavior (Lazarus & Folkman, 1984).

Overall, the relationships among morale, social functioning, and somatic health are complex. It is important to recognize that good functioning in one sphere may be directly related to poor functioning in another and that good functioning in one area does not necessarily mean that the person is functioning well in all areas (Lazarus & Folkman, 1984).

Conclusion

In conclusion, the Stress, Coping, and Adaptation model was chosen because it is one of the most prominent theories of stress (Lazarus & Folkman, 1984). The assumptions, conceptions, relational statements, and propositions of this model are logically congruent with

the phenomenon of interest, and the mid-range theory is well represented in the caregiver literature (Bakas et al., 2006; Coon et al., 2004; DiBartolo & Soeken, 2003; Haley et al., 2004; Hebert et al., 2003). The concepts from the Stress, Coping, and Adaptation model will now be used to form the theoretical framework of this study, Caregiver and Ineffective Sleep, which will be discussed next.

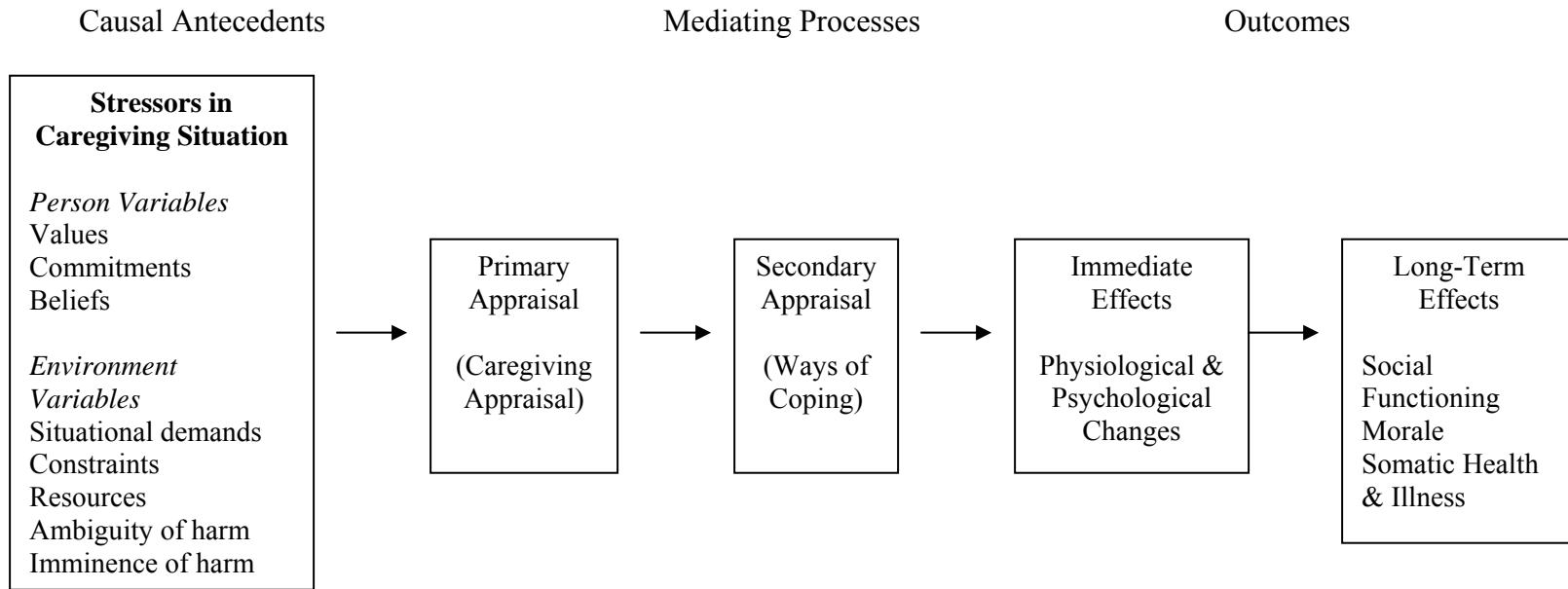


Figure 1-1. Theoretical framework for caregivers (adapted from Lazarus & Folkman's Theory of Stress & Coping, 1984)

CHAPTER 2

THEORETICAL MODEL AND REVIEW OF LITERATURE

Introduction

The theoretical framework of this study builds on the Stress, Coping, and Adaptation model. The theoretical framework, the Caregiver and Ineffective Sleep, encompasses the desired components of the Stress, Coping, and Adaptation model and interprets them in a conceptually meaningful way. The Caregivers and Ineffective Sleep framework has the potential to further our understanding of the challenges associated with caregiving and fragmented sleep. Next, the theoretical framework will be discussed in greater detail (Figure 2-1).

Stressors in Caregiving Situation

Person Variables

The first two variables in the model, person and environment, will now be discussed. The two main sets of variables jointly influencing whether the appraisal is that of a threat or challenge are environment and personality centered (Lazarus & Folkman, 1984). These variables influence appraisal by (a) determining what is salient for well-being in a given encounter; (b) shaping the person's understanding of the event, and in consequence his or her emotions and coping efforts; and (c) providing the basis for evaluating outcomes (Lazarus & Folkman, 1984). The person variables that will be examined in this model are age, gender, and race.

The age, gender, and race differences of the human system have been found to be significantly related to the perception of caregiver burden and the system's abilities. Thus, background demographic factors of human systems can vary the magnitude of caregiver burden and caregiver stress. By being aware of possible racial, ethnic, and cultural variations in the caregiving experience, health care professionals and policy makers can better meet the needs of

the diverse groups of caregivers whom they serve. In addition to these practical benefits, contrasting the caregiving experience of different groups can also enhance the theoretical understanding of this experience by distinguishing its universal elements from those that are mediated by norms, expectations, or experiences of a given cultural group (Chun, Knight, & Youn, 2007; Gallagher-Thompson, Rabinowitz et al., 2006; Gallagher-Thompson, Shurgot et al., 2006; McCallum, Sorocco, & Fritsch, 2006; Patterson et al., 1998). Person variables in this study are race, age, and gender.

Connell and Gibson (1997) reviewed 12 articles published between 1985 and 1996 that examined the impact of race, ethnicity, and culture on the caregiving experience. In their review, Connell and Gibson (1997) concluded that, compared with Caucasian caregivers, non-white caregivers tend to report lower burden and more strongly-held beliefs about familial support. Since this time period another 21 articles on this topic have been published. The studies reviewed by Janevic and colleagues (2001) also suggest that there are differences in the stress process, in psychosocial outcomes, and in variables related to service utilization among caregivers of different racial, ethnic, national, and cultural groups. Depp and colleagues (2005) reported higher self-efficacy among Hispanic/Latino caregivers in their study which parallels previous research on cultural values regarding caregiving among Mexican Americans (Phillips, Torres de Ardon, & Komenich, 2000). Another study by McCallum and colleagues compared European caregivers and African American caregivers. The study found that African American caregivers reported deriving more meaning in the act of caregiving, used their religious convictions more often while caregiving, and held stronger beliefs in the importance of caregiving, but these culturally based beliefs and behaviors failed to result in (comparatively) better mental health (McCallum et al., 2006).

Spouses make up the majority of caregivers (Adams, 2007; S. M. Allen, Goldscheider, & Ciambrone, 1999; Croog, Burleson, Sudilovsky, & Baume, 2006), with wives more likely to be the primary caregiver (Houde, 2002). This may be due to social expectations as women may be perceived as more suitable to care for an ill spouse (Collins & Jones, 1997; Taylor, Ezell, Kuchibhatla, Ostbye, & Clipp, 2008). Husbands and wives who are caregivers appear to react differently to the caregiving role, with wives more negatively affected. Women often report a more negative impact of caregiving than do men on measures related to quality of life (Thomas et al., 2006; Yee & Schulz, 2000), burden (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Shanks-McElroy & Strobino, 2001; Simonelli et al., 2008), and strain and stress (Almberg, Jansson, Grafstrom, & Winblad, 1998; Pinquart & Sorensen, 2006). Compared to men, women have reported greater psychological and emotional symptoms such as worry, anxiety (Thomas et al., 2006; Yee & Schulz, 2000), and depression (Bookwala & Schulz, 2000; Pinquart & Sorensen, 2006; Yee & Schulz, 2000). There is some evidence that women caregivers experience negative physical responses and health problems more than men (Lieberman & Fisher, 2001). Lieberman and Fisher (2001) reported that the health and well-being of female caregivers declined more than that of male caregivers following nursing home placement for their spouses.

However, findings of greater impact on women are not universal. Other studies have found no difference by sex for burden, anxiety (Sparks, Farran, Donner, & Keane-Hagerty, 1998), or strain and stress. The differences in findings may be due to the different outcomes used to measure the consequences of caregiving stress. Men have not been studied adequately because of limitations in sampling design, with too few men in many caregiving samples (Houde, 2002). Many of the caregiving samples have been convenience samples, limiting the

generalizability of the findings (Houde, 2002). Next, the environmental variables will be discussed in further detail.

Environment Variables

As stated earlier, some environmental circumstances impose too great a demand on a person's resources, whereas others provide considerable latitude for available skills and persistence, thereby influencing whether threat or challenge will occur. The substantive environmental content variables having an influence consist of diverse situational demands, constraints, and opportunities (Lazarus & Folkman, 1984). In this study, the environment variables according to the model are defined as caregiver burden, caregiver with disturbed sleep and perceived stress.

It is well known that providing care for a patient with dementia is stressful and has substantial demands on relatives (Bedard, Pedlar, Martin, Malott, & Stones, 2000; Burns & Rabins, 2000; Pinquart & Sorensen, 2006). The nature of the disease and its symptomatology are such that the demands placed on caregivers are heavy and their consequences diverse. The caregiver burden results from the physical, psychosocial or emotional, social and financial problems that can be experienced by family members caring for persons with dementia (Bruce et al., 2005; Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999; Mahoney, Regan, Katona, & Livingston, 2005). It also includes embarrassment, overload, feelings of entrapment, resentment, isolation from society (Pinquart & Sorensen, 2003, 2006; Zarit, Reever, & Bach-Peterson, 1980), loss of control, poor communication (Gonzalez-Salvador et al., 1999; McGinnis, Schulz, Stone, Klinger, & Mercurio, 2006; R. G. Morris, Morris, & Britton, 1988), and work pressures (Bruce et al., 2005; Covinsky et al., 2001; Stephens, Kinney, & Ogorcki, 1991).

The amount of or perception of caregiver burden is determined by many factors, including care recipient, caregiver, and environmental variables (Burns & Rabins, 2000; Oyebode, 2003; Pinquart & Sorensen, 2003, 2006; Rymer et al., 2002). The care recipient variables include the severity and duration of the dementia, behavior problems, functional status, cognitive status, and activities of daily living. The caregiver variables are the age, gender, and health of caregiver, the competing demands on the caregiver's time, religious beliefs, problem-solving ability, and the perception of disease. The environmental variables in relation to caregiver burden include financial resources, social supports, and the quality of the prior relationship (Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Burns & Rabins, 2000; Oyebode, 2003; Pinquart & Sorensen, 2003; Rymer et al., 2002). First, the care recipient variables (functional status, cognitive status, and behavior problems) will be discussed in greater detail.

The care recipient's functional status is the ability to perform activities of daily living, such as eating and bathing, as well as instrumental activities of daily living, such as housework and transportation (Katz, 1976). Declines in functional status can increase the number of care activities that the caregiver is required to perform. Caregivers who are confronted with multiple new, or rapidly increasing numbers of, demands to assist with a patient's loss of function have less time to adjust their work, family, and social obligations and may experience more burden in response to providing care (Perren, Schmid, Herrmann, & Wettstein, 2007; Sherwood et al., 2005). Deficits in the care recipient's functional status have also been consistently linked with caregiver burden (Clyburn et al., 2000; Given, Given, Stommel, & Azzouz, 1999; Pinquart & Sorensen, 2003, 2006).

The care recipient's cognitive status which is defined as the care recipient's presence or absence of neuropsychiatric symptoms has also been consistently linked to caregiver burden

(Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Matsuda, 1995; Nagatomo et al., 1999; Pinquart & Sorensen, 2006; Prescop, Dodge, Morycz, Schulz, & Ganguli, 1999). The diminishing cognitive status on the part of the care recipient can be defined as confusion or forgetfulness. This diminishing cognitive status can increase caregiver burden as caregivers find that they must supervise the care recipient more closely and have less time to fulfill other role obligations (Annerstedt, Elmstahl, Ingvar, & Samuelsson, 2000; Gonzalez-Salvador et al., 1999; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtsou, 2007).

Behavior problems are another care recipient variable that contributes to caregiver burden. Virtually all patients with dementia will develop changes in behavior and personality as the disease progresses (Holtzer et al., 2003; Ikeda, 2005). The nature and frequency of symptoms vary over the course of the illness, and psychotic features tend to present later, particularly when the patient becomes more dependent. Psychotic manifestations and other behavior problems may be more troubling and challenging than cognitive losses; these features result in an increased burden for caregivers, earlier institutionalization, and acceleration in cognitive decline (Gaugler, Kane, Kane, & Newcomer, 2006; Leroi, Voulgari, Breitner, & Lyketsos, 2003; Rozzini et al., 2006). Bedard and colleagues (2000) found that in 74% of the studies reviewed, behavior problems of the care recipient showed the strongest relationship with caregiver burden. Similarly, Schulz and colleagues (1995) reported that behavior problems are consistently related to caregiver distress.

Behaviors that are most common or most serious to caregivers include behaviors related to restlessness and agitation, psychotic manifestations, day/night disturbances, delusions, wandering, and physical violence. Indeed, it is thought that the unpredictability of the course of behavioral problems may be why these behaviors cause high levels of stress among caregivers

(Caron, Ducharme, & Griffith, 2006; Hooker et al., 2002; Rozzini et al., 2006). These psychotic features of dementia include hallucinations (usually visual), delusions, and delusional misidentifications. Delusions are very common in AD patients, and they contribute to the deterioration in the patient's quality of life. Several studies have demonstrated that about 50% of PWD have or have had delusions, particularly of the paranoid type that is evident in theft and betrayal (Chiu & Chung, 2006; Gill, 2006; Hart et al., 2003; Migliorelli et al., 1995). Delusions are associated with functional decline and a more rapid downhill course, and they seem to play a critical role in patient's institutionalization (Chiu & Chung, 2006; Donaldson & Burns, 1999; Gill, 2006).

The most potentially dangerous behavior among persons with dementia is the tendency to wander. Persons with dementia who wander pose a danger to themselves and are of considerable concern to their care providers and family members (Baker, Kokmen, Chandra, & Schoenberg, 1991; Hermans, Htay, & McShane, 2007; Logsdon et al., 1998). Wandering occurs in up to 65% of patients with dementia in nursing homes or dementia-based clinic samples (Logsdon et al., 1998) and in approximately 35% of community samples (Devanand et al., 1992). The fear that the person with dementia will wander away from home and become lost has led many caregivers to search for systems to enable them to monitor the individual, including latches and alarms on doors, barring or disguising exits, and constant personal supervision. In addition, concern about wandering in other settings, such as in shopping centers or the community at large, may lead caregivers to restrict both their own activities and the activities of their care recipient (Hermans et al., 2007; Hindelang, 2006; Logsdon et al., 1998). Another aspect that contributes to caregiver burden is the caregiver variables.

As mentioned above, the caregiver variables that affect the level of burden are the age, gender, and health of caregiver, the competing demands on the caregiver's time, religious beliefs, problem-solving ability, and the perception of disease. Because of the demographics of the aging population, as well as societal role expectations, family caregivers overwhelmingly tend to be women and are most often spouses (Gallicchio et al., 2002; Mausbach et al., 2007). In most studies, female caregivers report a higher level of burden than male caregivers (Gallicchio et al., 2002; Mausbach et al., 2007; Miller & Cafasso, 1992; Neal, Ingersoll-Dayton, & Starrels, 1997). This finding has been interpreted in many ways, including the possibility that it represents women's greater comfort with expressing feelings, or that there are caregiving task differences between male and female caregivers or the possibility that female caregivers have greater stress from multiple social roles than male caregivers (Adams, 2007; Gallicchio et al., 2002; Miller & Cafasso, 1992; Neal et al., 1997).

A substantial body of literature documents the negative psychological, physical, and social consequences associated with high levels of perceived burden. A high level of burden correlates with poor caregiver well-being and increased use of health services. Informal caregivers are more likely to report that their health is in fair or poor condition than are noncaregivers (Baumgarten et al., 1992; Clark, Bond, & Hecker, 2007; Haley, 1997; Schulz & Beach, 1999; Schulz et al., 2001; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Lastly, environmental variables are another aspect that contributes to caregiver burden.

Environmental variables that contribute to caregiver burden are financial resources, social supports, and the quality of the prior relationship. A significant component of caregiver burden is financial in origin. Caregivers may suffer an unavoidable depletion in personal savings and are often forced to give up or scale back their work which may produce feelings of resentment

and isolation (Burns, 2000; Zhu et al., 2006). Some family caregivers who are employed report missing work, taking personal days, and quitting or retiring early to provide care (Lim & Zebrack, 2004). Also predictive of higher caregiver burden is a poor relationship with the care recipient. The poor-quality relationship between the caregiver and care recipient predicts both caregiver depression and anxiety (Mahoney et al., 2005; Zhu et al., 2006).

The degree of social support available to the caregiver is another environmental variable that has been investigated in the context of predicting caregiver outcomes. Social support has been a consistent mediator of stress-related outcomes in that the presence of a strong social network and satisfaction with support is a powerful predictor of positive outcomes. Caregivers reporting larger social networks and greater satisfaction with the support they receive report significantly less burden, less depression, greater life satisfaction and fewer health problems than caregivers with fewer social ties (Chang, Brecht, & Carter, 2001; Clyburn et al., 2000; Huang et al., 2006). The next variable that will be discussed is the caregiver with disturbed sleep.

Sleep and Nighttime Behavioral Disturbances in the Care Recipient

In persons with AD, sleep and nighttime behavioral disturbances such as wandering, day/night confusion, getting up repeatedly during the night, and nightmares or hallucinations are a significant source of caregiver burden and a primary cause of patient institutionalization (Pollak & Perlick, 1991). Gaugler and colleagues (2000 & 2003) found one primary stressor that reliably predicted institutionalization, behavior problems. These troublesome behavior problems include wandering, getting lost, becoming agitated, exhibiting inappropriate behavior, and overnight problems. Findings also have suggested that the amount of family help provided to caregivers prior to placement is not as important as getting specific types of assistance (i.e., help with ADL dependencies and overnight problems) (Gaugler et al., 2000; Gaugler, Kane, Kane, Clay, & Newcomer, 2003). Another study had primary findings that two conditions are strongly

associated with worse mental and physical health for the caregiver (a) the amount of increase in problematic behaviors among persons with dementia and (b) caregiving from someone who is in a long-term care setting (Hooker et al., 2002). The abnormal sleep pattern of the PWD has been particularly resistant to treatment.

Sedative/hypnotic medications, light therapy, cognitive behavioral therapy, physical exercise, and sleep hygiene interventions, have been frequently prescribed to treat sleep problems in AD (McCurry et al., 2005; McCurry, Logsdon, Vitiello, & Teri, 2004; Skjerve et al., 2004). Most research on the use of pharmacologic and non-pharmacologic interventions to improve sleep has been focused on the AD patient (Prinz et al., 1982; Prinz, Vitiello, Raskind, & Thorpy, 1990; Tractenberg, Singer, & Kaye, 2005). There are reasons why sleep hygiene recommendations might not be effective with PWD. The components that have proven most effective, stimulus control and sleep restriction, require adherence to a structured routine that may not be feasible with PWD (Dowling & Wiener, 1997; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2003; Morin, Culbert, & Schwartz, 1994). Caregivers might find that it is excessively burdensome to try to change established patient sleep habits. Finally, the neurobiological and circadian timing changes associated with progressive dementia might undermine behavioral attempts to regularize patient sleep routines (Dowling & Wiener, 1997; Hoekert, der Lek, Swaab, Kaufer, & Van Someren, 2006; McCurry et al., 2003; Morin et al., 1994; Van Someren, 2000).

The next variable that will be discussed is perceived stress in the caregiver.

Perceived Stress in Caregiver

Caring for disabled or chronically ill adults is stressful (Andren & Elmstahl, 2008; Fredman & Daly, 1997; Kiecolt-Glaser et al., 1987); moreover, it is especially stressful for caregivers to persons with Alzheimer's Disease or other dementias (Andren & Elmstahl, 2008; Schulz et al., 1995; Sugiura, Ito, & Mikami, 2007). Dementia caregivers in the National

Caregiver Survey reported higher levels of emotional strain than nondementia caregivers and were likely to report mental or physical problems as a result of caregiving (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Other studies also reveal increased stress in caregivers based on a diagnosis of mental impairment including dementia (Bass, McClendon, Deimling, & Mukherjee, 1994; Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001).

Numerous studies have documented a direct association between care-related factors, such as intensity of the caregiver role (e.g., caregiving hours/day, amount of help with ADL and IADL tasks) and care-recipient problems (e.g., behavioral problems, cognitive problems) with caregiving stress and burden (Andren & Elmstahl, 2008; Bertrand, Fredman, & Saczynski, 2006). Providing more care in general (Signe & Elmstahl, 2008; Yates, Tennstedt, & Chang, 1999) and spending more hours per day caregiving (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001; Signe & Elmstahl, 2008) were related to more burden in cross-sectional analyses (Yates et al., 1999) and higher rates of stress in prospective analyses (Cotter, 2007; Desbiens et al., 2001; Signe & Elmstahl, 2008). Likewise, caregivers experienced more stress and burden if they cared for someone with more behavioral problems (Hooker et al., 2002; Schulz et al., 1995) and who had a more rapid rate of cognitive decline (Gallagher-Thompson, Brooks, Bliwise, Leader, & Yesavage, 1992). These associations were observed in prospective studies of caregivers to persons with dementia (Boutoleau-Bretonniere, Vercelletto, Volteau, Renou, & Lamy, 2008; Gallagher-Thompson et al., 1992; Hooker et al., 2002; Montgomery, Mayo-Wilson, & Dennis, 2008), a group that is likely to spend more time providing care, help with more activities of daily living (ADL) and instrumental activities of daily living (IADL) tasks, and deal with more cognitive and behavioral problematic behavior problems than caregivers to persons without dementia.

The high correlation between caregiving intensity and care recipient cognitive status is underscored by a recent meta-analysis that integrated 228 studies examining the effects of caregiving on burden, including stress (Pinquart & Sorensen, 2003). The result showed significant, positive correlations between caregiver burden and recipient cognitive impairment, hours of care provided per week, and number of caregiving tasks. Care recipient behavioral problems were more strongly related to caregiver burden than any of the other variables included in their analyses. Furthermore, the number of hours of caregiving and cognitive impairment were more consistently associated with burden among caregivers to adults with dementia than other caregivers. However, the number of caregiving tasks performed was more consistently related to burden in combined caregiver samples than in samples restricted to dementia caregivers alone (Bertrand et al., 2006). As one can plainly see, caring for a disabled or chronically ill adult is stressful (Fredman & Daly, 1997; Hooker et al., 2002; Kiecolt-Glaser et al., 1987; O'Rourke, Cappeliez, & Neufeld, 2007; Papastavrou et al., 2007); moreover, it is especially stressful for caregivers to persons with Alzheimer's Disease or other dementias (Schulz & Martire, 2004; Schulz et al., 1995; Vickrey et al., 2006). The next concept that will be discussed is the primary appraisal.

Primary Appraisal

In primary appraisal, the person evaluates whether he or she has anything at stake in this encounter. For example, is there potential harm or benefit with respect to commitments, values, or goals? Is the health or well-being of a loved one at risk? Is there potential harm or benefit to self-esteem? (Lazarus & Folkman, 1984). Primary appraisal is influenced by the person's beliefs, values, and commitments. There are three kinds of primary appraisal, irrelevant, benign-positive, and stressful. When an encounter with the environment carries no implication for a person's well-being, it falls within the category of irrelevant (Lazarus & Folkman, 1984). The

person has no investment in the possible outcomes, which is another way of saying that it impinges on no value, need, or commitment; nothing is to be lost or gained in the transaction.

Benign-positive appraisals occur if the outcome of an encounter is construed as positive, that is, if it preserves or enhances well-being or promises to do so. These appraisals are characterized by pleasurable emotions such as joy, love, happiness, exhilaration, or peacefulness (Lazarus & Folkman, 1984). Totally benign-positive appraisals that are without some degree of apprehension may be rare, however. For some people there is always the prospect that the desirable state will sour, and for those who believe that one must ultimately pay for feeling good with some later harm, benign appraisals can generate guilt or anxiety. These illustrations anticipate the idea that appraisals can be complex and mixed, depending on person factors and the situational context (Lazarus & Folkman, 1984).

Stress appraisals include harm/loss, threat, and challenge. In harm/loss, some damage to the person has already been sustained, as in incapacitating injury or illness, recognition of some damage to self-or social esteem, or loss of a loved or valued person. The more damaging life events are those in which central and extensive commitments are lost (Lazarus & Folkman, 1984).

Threat concerns harm or losses that have not yet taken place but are anticipated. Even when a harm/loss has occurred, it is always fused with threat because every loss is also pregnant with negative implications for the future (Lazarus & Folkman, 1984). The primary adaptational significance of threat, as distinguished from harm/loss, is that it permits anticipatory coping. To the extent that humans can anticipate the future, they can plan for it and work through some of the difficulties in advance, as in anticipatory grief work (Lazarus & Folkman, 1984).

The third type of stress appraisal, challenge, has much in common with threat in that it too calls for the mobilization of coping efforts (Lazarus & Folkman, 1984). The main difference is that challenge appraisals focus on the potential for gain or growth inherent in an encounter and they are characterized by pleasurable emotions such as eagerness, excitement, and exhilaration, whereas threat centers on the potential harms and is characterized by negative emotions such as fear, anxiety, and anger (Lazarus & Folkman, 1984).

Threat and challenge are not necessarily mutually exclusive. A spouse diagnosed with Alzheimer's Disease is likely to be appraised as holding potential gains in knowledge and skills, responsibility, and dedication. At the same time, it entails the risk of the person being swamped by new demands and not performing as a spouse as well as expected. Therefore, caring for a spouse who has been diagnosed with AD is likely to be appraised as both a challenge and a threat. Although threat and challenge appraisals are distinguished from one another by their cognitive component, the judgment of potential harm or loss versus mastery or gain, and their affective component, negative versus positive emotions, they can occur simultaneously (Lazarus & Folkman, 1984).

Lazarus and Folkman (1984) emphasize that threat and challenge appraisals are not poles of a single continuum. Threat and challenge can occur simultaneously, and must be considered as separate, although often related, constructs. Moreover, the relationship between threat and challenge appraisals can shift as an encounter unfolds. A situation that is appraised as more threatening than challenging can come to be appraised as more challenging than threatening because of cognitive coping efforts which enable the person to view the episode in a more positive light, or through changes in the environment that alter the troubled person-environment relationship for the better (Lazarus & Folkman, 1984).

Challenge, as opposed to threat, has important implications for adaptation. For example, people who are disposed or encouraged by their circumstances to feel challenged probably have advantages over easily threatened people in morale, quality of functioning, and somatic health (Lazarus & Folkman, 1984). Challenged persons are more likely to have better morale, because to be challenged means feeling positive about demanding encounters, as reflected in the pleasurable emotions accompanying challenge. The quality of functioning is apt to be better in challenge because the person feels more confident, less emotionally overwhelmed, and more capable of drawing on available resources than the person who is inhibited or blocked. Finally, it is possible that the physiological stress response to challenge is different from that in threat, so that diseases of adaptation are less likely to occur (Lazarus & Folkman, 1984).

Secondary Appraisal

When we are in jeopardy, whether it be a threat or a challenge, something must be done to manage the situation. In that case, a further form of appraisal becomes salient, that of evaluating what might and can be done, which is secondary appraisal (Lazarus & Folkman, 1984). Secondary appraisal activity is a crucial feature of every stressful encounter because the outcome depends on what, if anything, can be done, as well as on what is at stake.

Secondary appraisal is more than a mere intellectual exercise in spotting all things that might be done. It is a complex evaluative process that takes into account which coping options are available, the likelihood that a given option will accomplish what it is supposed to, and the likelihood that one can apply a particular strategy or set of strategies effectively (Lazarus & Folkman, 1984). Bandura (1977, 1982) emphasizes the distinction between these two expectancies. He uses the term outcome expectancy to refer to the person's evaluation that a given behavior will lead to certain outcomes and efficacy expectation to refer to the person's conviction that he or she can successfully execute the behavior required to produce the

outcomes. In addition, the appraisal of coping options includes an evaluation of the consequences of using a particular strategy or set of strategies vis-à-vis other internal and/or external demands that might be occurring simultaneously (Lazarus & Folkman, 1984).

Secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality (or content) of the emotional reaction (Lazarus & Folkman, 1984). This interplay can be quite complex, although our understanding here is still rudimentary. For example, other things being equal, if the person is helpless to deal with a demand such as caring for a spouse with AD, stress will be relatively great because the harm/loss cannot be overcome or prevented. If the person has a high stake in the outcome, meaning that it touches a strong commitment, helplessness is potentially devastating. Even when people believe they have considerable power to control the outcome of an encounter, if the stakes are high any doubt can produce considerable stress (Lazarus & Folkman, 1984).

Challenge appraisals are more likely to occur when the person has a sense of control over the troubled person-environment relationship (Lazarus & Folkman, 1984). Challenge will not occur, however, if what must be done does not call for substantial efforts. The joy of challenge is that one pits oneself against the odds (Lazarus & Folkman, 1984).

We need to look closely at what it means to speak of a sense of control in a stressful encounter with respect to challenge (Lazarus & Folkman, 1984). There are numerous situations in which there seems to be little opportunity to enhance a value or commitment and/or which the person feels helpless. Yet people can appraise these situations as challenges because challenges can also be defined as controlling oneself in the face of adversity, and even transcending adversity. An example is a life-threatening, incapacitating illness such as AD in which the

person reports being challenged by the task of maintaining a positive outlook, or tolerating pain and distress without falling apart (Lazarus & Folkman, 1984). In order to understand how people can feel challenged even under the bleakest conditions, control is defined as control over oneself and one's emotions as well as control over environmental conditions (Lazarus & Folkman, 1984). Next, emotion-focused coping will be discussed in further detail.

Coping is defined as the person's constantly changing cognitive behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources. Coping has two widely recognized major functions: regulating stressful emotions (emotion-focused coping) and altering the troubled person-environment relation causing the distress (problem-focused coping) (Lazarus & Folkman, 1984).

Emotion-Focused Coping

A wide range of emotion-focused forms of coping is found in the literature. One large group consists of cognitive processes directed at lessening emotional distress and includes strategies such as avoidance, minimization, distancing, selective attention, positive comparisons, and uncovering positive value from negative events (Lazarus & Folkman, 1984). Many of these strategies derive from theory and research on defensive processes and are used in virtually every type of stressful encounter. A smaller group of cognitive strategies is directed at increasing emotional distress (Lazarus & Folkman, 1984). Some individuals need to feel worse before they can be better; in order to get relief they first need to experience their distress acutely and to this end engage in self-blame or some other form of self-punishment. In still other instances, individuals deliberately increase their emotional distress in order to mobilize themselves for action, as when athletes "psych themselves up" for a competition (Lazarus & Folkman, 1984).

Certain cognitive forms of emotion-focused coping lead to a change in the way an encounter is construed without changing the objective situation (Lazarus & Folkman, 1984).

Consider the following cognitive maneuvers that are commonly used to reduce threat: “I decided there are more important things to worry about”; “I considered how much worse things could be”; and “I decided I didn’t need him nearly as much as I thought.” In each case, threat is diminished by changing the meaning of the situation (Lazarus & Folkman, 1984).

Other emotion-focused coping strategies do not change the meaning of an event directly. For example, whether selective attention or avoidance changes meaning depends on what is attended to, or what is being avoided. The meaning of an encounter can remain the same even if some of its aspects are screened out, or thoughts about the encounter are put aside temporarily.

Although emotion-focused processes may change the meaning of a stressful transaction without distorting reality, we must still consider the issue of self-deception, which is always a potential feature of this type of coping process (Lazarus & Folkman, 1984). We use emotion-focused coping to maintain hope and optimism, to deny both fact and implication, to refuse to acknowledge the worst, to act as if what happened did not matter, and so on. These processes lend themselves to an interpretation of self-deception or reality distortion (Lazarus & Folkman, 1984). We are inclined to argue that self-deception extends on a continuum from personal or social illusions to major distortions, with a sharp dividing line between so-called healthy and pathological forms. We must be aware of the contexts in which self-deception occurs, and the short and long term costs and benefits that accrue from it (Lazarus & Folkman, 1984).

In this study, the emotion-focused variable is the caregiver who is worried about an unsafe situation when PWD is up during night without supervision. In order to understand this variable, one must first be aware of the sleep patterns of the AD care recipient.

Alzheimer’s disease and sleep

The cause of sleep disturbance in AD is thought to be multifactorial. Pathophysiological changes resulting from the disease itself interfere with the maintenance of normal sleep (Bliwise,

2004; Craig, Hart, & Passmore, 2006). Damage to neuronal pathways, such as the cholinergic pathways, that initiate and maintain sleep is thought to contribute to sleep changes in AD (Craig et al., 2006; Vitiello & Borson, 2001). The circadian pacemaker, in the suprachiasmatic nucleus, is also important in maintaining a normal sleep-wake-cycle. Researchers have demonstrated dysregulation of the circadian timing system in AD, and this may play a role in the development of sleep disturbance (Craig et al., 2006; Mishima, Okawa, Hozumi, & Hishikawa, 2000). Sleep disturbance is also known to occur as part of associated medical and psychiatric illnesses, such as sleep-disordered breathing (SDB), or sleep apnea, disrupted chronobiology (most often characterized by excessive daytime napping), disorientation, medication use, depression, bedrest, nocturia, arthritis, depression, and circadian rhythm changes (Ancoli-Israel, Klauber, Gillin, Campbell, & Hofstetter, 1994; Bliwise, 2004; Craig et al., 2006).

Increased duration and frequency of awakenings, decreased slow-wave sleep and rapid eye movement (REM) sleep, and daytime napping mark the sleep of AD patients (Park et al., 2006; Prinz et al., 1982; Vitiello, Prinz, Williams, Frommlet, & Ries, 1990). The sleep patterns observed in AD patients are consistent with changes found in the sleep of non-demented older adults, although they occur more frequently and tend to be more severe in AD patients than in the general population (McCurry, Reynolds, Ancoli-Israel, Teri, & Vitiello, 2000). The loss or damage to neuronal pathways that initiate and maintain sleep in AD patients is most likely the cause of this exacerbation of age-related sleep changes. Brainstem regions and pathways that regulate sleep-wake cycles undergo degenerative change in AD, as do the cortical tissues that generate EEG slow-wave activity during sleep (Bliwise, 1993; Moe, Vitiello, Larsen, & Prinz, 1995; Park et al., 2006).

Patients with dementias, such as AD, often have nocturnally disrupted sleep (Bliwise, 2004; McCurry et al., 2007). Clinically, this may present as agitation during the nighttime hours, which may affect as many as a quarter of AD patients during some stage of their illness (Bliwise, 2004; McCurry et al., 2007). For patients with dementia, sleep disturbance will also reduce the quality of life (Cole & Richards, 2006). It may also contribute to the behavioral, functional, and cognitive status of persons with AD, as well as to the burden and health status of the caregiver (Pollak & Perlick, 1991; Pollak & Stokes, 1997). For family caregivers, being awakened at night by patient behaviors such as wandering, getting out of bed repeatedly, and talking in bed is one of the most disturbing aspects of care (McCurry et al., 1999; McCurry et al., 2007) and is a major cause of patient institutionalization (Buhr et al., 2006; Hope et al., 1998; Pollak & Perlick, 1991; Spitznagel, Tremont, Davis, & Foster, 2006). For these reasons, sleep disturbance has recently been of particular interest in the AD population. First, AD and circadian rhythm changes will be discussed in greater detail.

Alzheimer's disease and circadian rhythm changes

As stated above, sleep regulation is generally considered to be an interaction of two distinct processes that can be expressed as discrete mathematical functions (Borbely, 1982). One, a circadian oscillatory process, promotes wakefulness as a function of time-of-day. Opposing this alerting circadian rhythm is a homeostatic process that builds the need to sleep as a function of the duration of previous wakefulness (Jewett & Kronauer, 1999). Sleep disturbance in patients with AD is characterized by increases seen in both the frequency and duration of nocturnal awakenings and daytime naps, suggesting that disturbance of the circadian system may be involved in the etiology of these symptoms (McCurry et al., 1999; McCurry et al., 2007; Vitiello, Bliwise, & Prinz, 1992).

Changes in the hypothalamic suprachiasmatic nucleus and other parts of the circadian-timing system that determine tendency towards sleep and wakefulness have also been implicated in the sleep disturbances of both normal elderly and dementia patients (Park et al., 2006; Swaab, Fliers, & Partiman, 1985; Van Someren, 2000; Vitiello & Borson, 2001). Shifts in the basic circadian sleep-wake rhythm of dementia patients can be severe, and in extreme cases may lead to complete day/night sleep pattern reversals. It has been estimated that in the later stages of disease, AD patients spend approximately 40% of their time in bed awake, and a significant portion of their daytime hours asleep (Ancoli-Israel, Parker, Sinaee, Fell, & Kripke, 1989; Park et al., 2006; Vitiello & Borson, 2001; Vitiello, Poceta, & Prinz, 1991). This increased daytime sleep consists almost exclusively of stage 1 and 2 sleep, and poorly compensates for night-time losses of slow-wave sleep and REM sleep (Park et al., 2006; Vitiello et al., 1991).

The tendency for agitation to occur at night suggests that some changes in sleep and wakefulness in the AD patient reflect alterations in the body's ability to regulate the timing of certain physiological events, i.e, the changes represent an altered circadian timing system (Bliwise, 2004; Park et al., 2006). Numerous studies have described chronobiologic changes in sleep/wakefulness and other physiological markers of circadian rhythmicity such as body temperature, melatonin, blood pressure, and heart rate occurring over the 24-hour day (Bliwise, 2004; Park et al., 2006). Harper and colleagues (2005) found that both age-related and disease-specific changes play a role in driving the circadian rhythms observed in AD patients. Studies have also shown for typical nursing home patients that no nocturnal hour is represented by continuous sleep, and that no daytime hour is completely devoid of brief naps or unintended sleep episodes (Pat-Horenczyk, Klauber, Shochat, & Ancoli-Israel, 1998). Another explanation of the AD recipient's impaired sleep is environmental influences.

Environmental influences such as light levels and social/institutional factors also affect the extent to which dementia patients sleep during the daytime. Light level is an important factor in synchronizing the circadian timing system; regardless of the setting, AD patients often receive minimal exposure to light (Bliwise, 2004; Dowling, Mastick, Hubbard, Luxenberg, & Burr, 2005). In addition, an often overlooked component of AD is macular and optic nerve degeneration which may limit the extent to which external light can favorably impact circadian rhythms (Hinton, Sadun, Blanks, & Miller, 1986). Next, the caregiver who worries about sleeping through nighttime activity will be discussed in further detail.

Caregiver worrying about sleeping through nighttime activity

Due to these troublesome behaviors (wandering, day/night confusion, getting up repeatedly during the night, and nightmares or hallucinations) displayed by the care recipient, the caregiver cannot count on the fact that the care recipient will sleep throughout the night. The caregiver may worry at night about sleeping through the care recipient wandering through the home. While wandering through the home, the care recipient could exit, fall, swallow something harmful, burn or cut himself. Of these troublesome behaviors, wandering will be discussed first.

Wandering is a common behavior disturbance during AD and one of the most exhausting for the caregiver (Creese, Bedard, Brazil, & Chambers, 2008; Rolland et al., 2003; Scarmeas et al., 2007). Because of this behavior, caregivers may worry at night that the care recipient may exit the home and begin to wander. People with AD can wander away from their home and the prevalence of such wandering incidents is expected to grow as aging populations increase (Rowe, 2003; Rowe & Bennett, 2003; Rowe & Glover, 2001). About 12% of AD subjects living at home (Logsdon et al., 1998; Rolland et al., 2003) to 39% of those living in nursing homes present this aberrant motor behavior (Cohen-Mansfield, Werner, Marx, & Freedman, 1991).

Wandering causes worry and stress for the caregiver. The next troublesome behavior that will be discussed is falls.

Falls are among the most serious and common problems faced by the elderly persons and can be life changing events. Compared to cognitively intact elderly, individuals with dementia are at an even higher risk of increased morbidity and mortality due to falls (Fick, Kolanowski, & Waller, 2007; Gales & Menard, 1995; Tinetti, Inouye, Gill, & Doucette, 1995; Waldorff & Andersen, 2007). This increased risk is present for individuals in both community (Fick et al., 2007; Melton, Beard, Kokmen, Atkinson, & O'Fallon, 1994; Morris, Rubin, Morris, & Mandel, 1987; Oleske, Wilson, Bernard, Evans, & Terman, 1995; Waldorff & Andersen, 2007) and institutional (Holmes et al., 2007; Luukinen, Koski, Laippala, & Kivela, 1995; Rubenstein, Robbins, Josephson, Schulman, & Osterweil, 1990; Waldorff & Andersen, 2007) settings.

A number of researchers have confirmed this increased risk of falls and fractures in individuals with dementia. Melton and colleagues (1994) found that the risk of an individual sustaining a fracture increased twofold during the year in which he or she was diagnosed with AD as compared to the year before diagnosis. The largest increase was in hip fractures, which may indicate an increased incidence of certain types of falls (Oleske et al., 1995). Rowe and Fehrenbach (2004) also found that the falls are a major cause of nighttime injuries.

Sattin and colleagues (1990) found that 50% of the elderly requiring hospitalizations subsequent to a fall were discharged to a nursing home; Alexander and colleagues (1992) found a rate of 42% and Rowe and Fehrenbach (2004) found a rate of 65%. The rate was even higher (76%) for those subjects who had sustained a hip fracture and were discharged from the hospital (Rowe & Fehrenbach, 2004). These alarming statistics indicate that the risk of loss of community tenure after injury is greater for persons with dementia. Rowe and Fehrenbach

(2004) also found that falls are a major cause of nighttime injuries. Health care professionals should assist caregivers in providing a safer environment for PWD at night and researchers need to work to identify strategies to assist caregivers in improving the safety of the nighttime environment. Next, problem-focused coping will be discussed in further detail.

Problem-Focused Coping

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. Problem-focused efforts are often directed at defining the problem, generating alternative solutions, weighting the alternative in terms of their costs and benefits, choosing among them, and acting (Lazarus & Folkman, 1984). It includes strategies for gathering information, making decisions, planning, and resolving conflicts; it includes efforts directed at acquiring resources (e.g., skills, tools, and knowledge) to help deal with the underlying problem. It also includes instrumental, situation specific, and task-oriented actions (Lazarus & Folkman, 1984).

Caregiver and sleep

One health area that has received little empirical study in caregiving research is sleep. Sleep is an important domain that is likely to be affected adversely by the task of providing care to a family member with cognitive impairments. Getting a good night's sleep is a high priority for most people. However, for those with AD and their caregivers, an uninterrupted night's sleep can be an unusual luxury. Problems sleeping at night can be very draining for the family members caring for AD patients living at home.

Sleep is the natural periodic suspension of consciousness during which the powers of the body are restored (Oxford, 1999). Sleep is an active multiphase process. Normal sleep has two phases that can be documented by electroencephalogram (EEG): REM sleep and non-REM, or slow wave, sleep (Huether & McCance, 2000). Non-REM sleep is initiated when

neurotransmitters withdraw from the reticular formation and arousal mechanisms are blocked. REM is characterized by desynchronized fast activity that occurs about every 90 minutes beginning 1 to 2 hours after non-REM sleep begins. This sleep pattern is known as paradoxical sleep because the EEG pattern is similar to the normal wake pattern (Huether & McCance, 2000). REM and non-REM sleep alternate throughout the night, with lengthening intervals of REM sleep and fewer intervals of deeper states of non-REM sleep toward morning (Huether & McCance, 2000).

Fragmented sleep is defined as periods of wakefulness throughout the sleep period and the lack of deep-stage sleep (Oxford, 1999). In this study, fragmented sleep of the caregiver will be further investigated. As mentioned above, getting a good night's sleep is a high priority for caregivers of PWD. Disturbed sleep is one of the most common reasons why caregivers are no longer able to care for a patient, resulting in institutionalization (Pollak & Perlick, 1991). It is important to study fragmented sleep of the caregiver because of the physiologic and psychologic consequences (Prinz et al., 1982; Prinz et al., 1990; Tractenberg et al., 2005). Several factors could lead to impaired sleep among caregivers.

First, it is well established that individuals with dementia commonly experience sleep disruptions, and these disruptions are viewed as problematic by caregivers (Kochhar, Fredman, Stone, & Cauley, 2007; McCurry et al., 1999; Pinquart & Sorensen, 2003; Rabins et al., 1982). Caregivers can be wakened at night by the AD care recipient who may get out of bed repeatedly, wander around, and talk while in bed. These sleep disruptions from the care recipient can cause negative consequences for their own sleep (Creese et al., 2008). A study conducted by McKibbin and colleagues (2005) found that caregivers of patients with moderate to severe AD

reported significantly more sleep problems and more functional impairment as a result of sleepiness than noncaregivers.

Second, symptoms of stress and depression, commonly experienced by caregivers, are associated with impaired sleep (Buysse et al., 1989; Creese et al., 2008; Donaldson, Tarrier, & Burns, 1998; Gallant & Connell, 1997; McCurry et al., 1999; McCurry et al., 2000; Pinquart & Sorensen, 2003). It is important for caregivers of PWD to get enough sleep. If they are sleep deprived, they will not have the patience and energy needed to take care of the person with AD. For caregivers, disturbances in the patient's sleep and night-time behavior, particularly reduced night-time sleep, increased night-time wakefulness and wandering requiring caregiver attention, are a significant source of physical and psychological burden and are often cited as a reason for a family's decision to institutionalize a patient with dementia (Buhr et al., 2006; Donaldson et al., 1998; Gaugler et al., 2000; Hope et al., 1998; Pollak & Perlick, 1991)

Wilcox and King (1999) found that caregivers experiencing more psychological distress reported more overall sleep problems and greater impairments in sleep quality and daytime dysfunction. These results were consistent with results from community samples and with a report focused specifically on caregivers (Creese et al., 2008; Foley et al., 1995; Newman, 1997; Teri, McCurry, Edland, Kukull, & Larson, 1995).

Finally, these two factors could interact to form a self-perpetuating cycle of sleep disturbance. That is, caregivers might be awakened regularly by their care recipients. Once awake, caregivers would experience negative thoughts and feelings that would interfere with resuming sleep. Over time, the sleep deprivation can cause daytime fatigue, stress, and depression that can further interfere with sleep, thus exacerbating the problem (Pinquart & Sorensen, 2003, 2006; Thommessen et al., 2002).

Disturbed sleep is one of the most common reasons why caregivers are no longer able to care for a patient, resulting in institutionalization (Pollak & Perlick, 1991). Pollack and Perlick (1991) examined the role of sleep problems in decisions of families to institutionalize elderly relatives. Seventy-three primary caregivers of elders recently admitted to a nursing home or psychiatric hospital were asked to identify the problems the elder was having during the night and day. Seventy percent of the caregivers in each sample cited nocturnal problems in their decision to institutionalize, often because their own sleep was disrupted (Pollak & Perlick, 1991). These symptoms of sleep deprivation, including fatigue, stress, and depression, not only affects the quality of life and health of the caregiver, but could also affect the quality of care provided to the care recipient.

Consequences of fragmented sleep

Cardiovascular risk is greater in individuals who perceive their sleep as poor (Anselm et al., 2008; Schwartz et al., 1999). Ayas and colleagues (2003) found in a prospective study of women a significant positive association between reported sleep duration and incidence of coronary heart disease. Short and long sleep durations were associated with an increased risk of incident coronary heart disease. After controlling for smoking status, body mass index (BMI), and other relevant covariates, a significant positive association between sleep duration and coronary heart disease persisted (Ayas et al., 2003).

Previous studies have also demonstrated an increased risk of coronary artery disease morbidity and death in subjects with sleep complaints. Kirpke and colleagues (1979) studied the mortality rate of a large cohort of American Cancer Society volunteers who had completed a survey that contained a question about sleep duration. Although they were not able to control for various relevant confounders, they demonstrated that reported sleep duration of fewer than 4

hours per night was associated with an increased 6-year all-cause mortality rate in men and women.

In addition in males, reports of bad sleep quality increased the risk of death or hospitalization because of ischemic heart disease (Koskenvuo, Kaprio, Lonnqvist, & Sarna, 1986) and problems falling asleep increased the risk of myocardial infarction and cardiac death (Appels et al., 1987; Aronow, 2007). Siegrist (1987) also found that a higher risk of developing a myocardial infarction was found in males with severe sleep disturbances. Next, the effects of sleep changes on one's physical health will be discussed.

Effects of Sleep Changes on Physical Health

In concert with sleep disturbances, there has been an increase in the prevalence of both obesity and severe obesity. A comparison of studies conducted from 1988 to 1994 and from 1999 to 2000 determined that the prevalence of obesity has increased from 23% to 31% and the prevalence of severe obesity from 3% to 5% between the 2 periods (Flegal et al., 2002). In recent years, an increasing number of epidemiological studies have reported an association between sleep duration and BMI. A 2000 report from Spain observed that those reporting sleeping 6 hours (h) or less per day had an increased risk of obesity after controlling for sex, age, and other factors, and this group also had a higher mean BMI (Vioque et al., 2000). The Wisconsin Sleep Cohort Study, which was a population based study that included over 1,000 subjects, found that a sleep duration of 7.7 h predicted the lowest mean BMI (Taheri, Lin, Austin, Young, & Mignot, 2004).

Two recent studies from Japan have explored the relationship between insufficient sleep and obesity. In 8,274 children aged from 6 to 7 years, Sekine and colleagues (2002) found an inverse relationship between hours of sleep and risk of childhood obesity. Shigeta and colleagues (2001) noted in a study of 321 men and 132 women that sleeping less than 6 hours per

night and remaining awake beyond midnight increased the likelihood of obesity. Recent findings suggest that endocrine changes may mediate this relationship (Lusardi et al., 1999; Spiegel et al., 2000; Spiegel, Leproult, & Van Cauter, 1999). Sleep and diabetes will now be further examined.

Intriguingly, the dramatic increase in the incidence of obesity and diabetes seems to have developed over the same period of time as the progressive decrease in self-reported sleep duration (Flegal et al., 1998; Flegal et al., 2002; Laposky, Bass, Kohsaka, & Turek, 2008; Van Cauter, 2005). The two secular trends mirror each other over the second half of the 20th century. Taken together, sleep loss affects millions of individuals in our modern society, and recent studies have provided evidence in support of its deleterious impact on glucose metabolism and appetite regulation (Laposky et al., 2008; Spiegel et al., 2005).

A recent study demonstrated that sleep deprivation can adversely affect endocrine function. Spiegel and colleagues (1999) limited 11 young men to 4 h of sleep per night for 6 nights followed by 6 days of recovery sleep (10 h per night). Despite the short duration of partial sleep deprivation, the subjects demonstrated impaired glucose tolerance during sleep deprivation compared with their recovery period. Ayas and peers (2003) also found that short self-reported sleep duration is associated with an increased risk of being diagnosed with diabetes. This association persists even after adjustment for age, smoking, hypertension and other risk factors. Sleep restriction was a significant predictor of symptomatic diabetes even after controlling for body mass index (Ayas et al., 2003; Laposky et al., 2008). Next, the caregiver's physiological well-being will be discussed in greater detail.

Caregiver's Physiological Well-Being

Stress is defined as any stimulus that disturbs or interferes with the normal physiological equilibrium of an organism (Oxford, 1999). Stress is a state of threatened homeostasis provoked by a psychological, environmental, or physiologic stressor (Chrousos & Gold, 1992; Peterson et

al., 1991). One can also define stress as a stimulus, either internal or external, that activates the hypothalamic-pituitary-adrenal axis (HPA) and the sympathetic nervous system (SNS), resulting in a physiological change or adaptation so that the organism can deal with the threat (Maier, Goehler, Fleshner, & Watkins, 1998). In addition to these aspects, stress is now construed more broadly to include personality and socioenvironmental factors that are pertinent to individual adaptation (Francis, Champagne, Liu, & Meaney, 1999; Manuck, Marsland, Kaplan, & Williams, 1995).

In stress, a demand exceeds a person's coping abilities, resulting in reactions such as disturbances of cognition, emotion, and behavior that can adversely affect well-being (Huether & McCance, 2000). There are two well recognized stress response systems that are activated when a stimulus is perceived as a stressor (King & Hegadoren, 2002). These are the sympathetic or autonomic response system and the HPA axis (King & Hegadoren, 2002).

The activation of the sympathetic system occurs within seconds with resultant increases in the secretion of epinephrine from the adrenal medulla and norepinephrine from peripheral and central sympathetic neurons (King & Hegadoren, 2002). This reaction is referred to as "fight or flight" response. The "fight or flight" response is a short intense stress reaction that is an emergency reaction for survival (Huether & McCance, 2000).

The activation of the HPA axis occurs more slowly within minutes or hours with increases occurring in release of corticotrophin-releasing hormone (CRH) from the hypothalamus. CRH stimulates the pituitary to release adrenocorticotropin-releasing hormone (ACTH) into the systemic circulation, which in turn stimulates the adrenal cortex to release the glucocorticoid, cortisol (King & Hegadoren, 2002). The HPA system plays an important role in physiological and psychological coping with a stressor and in moderating the effects of stress on

health, mood, behavior and the development of stress related diseases (Black, 2006; Breier, 1989; Meaney, Aitken, van Berkel, Bhatnagar, & Sapolsky, 1988).

Stress can be divided into two subtypes: acute and chronic. Acute stress prepares us for “fight or flight” and is generally short-term. Chronic stress lasts longer and is the main cause of stress-related health problems (Black, 2006). Chronic stress occurs when continuous acute stress responses keep the body on alert continuously, negatively affecting health (Black, 2006).

Chronic or extreme activation can lead to changes in HPA axis activity, as evidenced by abnormal cortisol levels, which may in turn increase vulnerability to developing health problems (King & Hegadoren, 2002). Ideally, the exposure to the stressor is eliminated and the endocrine and immune systems quickly restore hormonal balance (Black, 2006). The normalization of the acute cortisol response after the termination of a stressful event protects against the potentially detrimental effects of glucocorticoids on hippocampus neurons, immune function, and mental health (King & Hegadoren, 2002) (Black, 2006).

Stress can serve as a catalyst for physical changes, either strengthening the body’s resilience or weakening its resistance to illness. Paradoxically, the added stress created when one is afflicted with disease perpetuates the illness, further weakening the immune system (Black, 2006). Uncontrollable, unpredictable, and constant stress has far-reaching consequences on our physical and mental health (Black, 2006). Many illnesses such as obesity, cardiovascular disease, and diabetes mellitus type II are influenced by chronic or overwhelming stress (Black, 2006). Salivary cortisol will now be discussed in greater detail.

Salivary Cortisol and Physiologic Changes

Cortisol is the most potent glucocorticoid produced by the human adrenal. It is the primary hormonal product of the HPA axis and plays a critical role in the metabolism of proteins, gluconeogenesis, and lipid metabolism (Ice, Katz-Stein, Himes, & Kane, 2004). In

addition, it supports vascular responsiveness, skeletal turnover, muscle function, immune response, and renal function (Berne & Levy, 1997). It is synthesized from cholesterol and its production is stimulated by pituitary adrenocorticotrophic hormone (ACTH) which is regulated by corticotrophin releasing factor (CRF) (Berne & Levy, 1997). ACTH and CRF secretions are inhibited by high cortisol levels in a negative feedback loop. In plasma a majority of cortisol is bound with high affinity to corticosteroid binding globulin (CBG or transcotin)(Berne & Levy, 1997).

Cortisol has a well-documented circadian pattern, which is established as early as 3 months of age (Price, Close, & Fielding, 1983). Cortisol levels are lowest between 20:00 and 02:00h; levels increase thereafter, with the highest levels shortly after awakening (Pruessner et al., 1997; Weitzman et al., 1971). In the absence of external stimuli, cortisol levels typically decrease throughout the day. Cortisol is secreted in intermittent pulses at 1-2 h intervals; the observed circadian pattern is produced by the height of successive pulses (Ice et al., 2004).

The HPA and cortisol have been extensively studied in relation to psychosocial stressors. Cortisol increases in response to laboratory stressors (Bohnen, Houx, Nicolson, & Jolles, 1990; Kirschbaum & Hellhammer, 1994; Kirschbaum et al., 1995), stressful jobs (Benjamins, Asschelman, & Schuurs, 1992; Hennig, Laschefski, & Opper, 1994) and daily hassles (Smyth et al., 1998). Although cortisol allows an individual to respond to environmental stressors by supporting energy mobilization and mental alertness, chronic elevation of cortisol has been implicated in the pathogenesis of several psychiatric and somatic disorders including, depression (Michopoulos et al., 2008; Steckler, Holsboer, & Reul, 1999), immunosuppression (Difrancesco et al., 2007; McEwen et al., 1997), obesity (Bjorntorp & Rosmond, 2000; Vgontzas et al., 2007), cardiovascular disease (Rosmond & Bjorntorp, 2000; von Kanel et al., 2008), diabetes (Cunha et

al., 2008; Rosmond & Björntorp, 2000), and osteoporosis (Chehab, Ouertani, Chaieb, Haouala, & Mahdouani, 2007; Manelli & Giustina, 2000).

Although cortisol activation in response to stress is protective in short term chronic or extreme activation may have long-term negative consequences (Ganzel et al., 2007; Heim, Ehlert, & Hellhammer, 2000; Martí, García, Valles, Harbuz, & Armario, 2001). Chronic or extreme activation can lead to changes in HPA axis activity, as evidenced by abnormal cortisol levels, which may in turn increase vulnerability to developing health problems. The normalization of the acute cortisol response after the termination of a stressful event protects against the potentially detrimental effects of glucocorticoids on hippocampus neurons, immune function, and health (King & Hegadoren, 2002). Cortisol stimulates the immune system and counteracts inflammatory and allergic reactions at normal levels, but can suppress the immune system at excessive levels (King & Hegadoren, 2002).

As with other circadian rhythms, cortisol appears to be influenced by sleep (Born & Fehm, 1998; Vgontzas et al., 2007) and light conditions (Levine, Milliron, & Duffy, 1994) and is ultimately controlled by the suprachiasmatic nucleus of the hypothalamus (Ice et al., 2004). Although this diurnal pattern has been considered robust, alterations have been observed in disease states such as rheumatoid arthritis (Dekkers, Geenen, Godaert, van Doornen, & Bijlsma, 2000; Motivala, Khanna, Fitzgerald, & Irwin, 2008), colic (White, Gunnar, Larson, Donzella, & Barr, 2000), among institutionalized children (Carlson & Earls, 1997; Motivala et al., 2008), populations living in circumpolar environments (Levine et al., 1994), and shift workers (Goh, Tong, Lim, Low, & Lee, 2000; Zefferrino et al., 2006). Thus, it has been suggested that diurnal cycle variation may provide valuable information on physiological and environmental influences on the HPA axis (Stone et al., 2001).

A number of studies have investigated the effects of chronic stress on HPA activity in caregivers of PWD. Among these studies, the researchers found elevated daytime cortisol levels in caregivers as compared with healthy comparison subjects (Bauer et al., 2000; Cacioppo et al., 2000; Da Roza Davis & Cowen, 2001; de Vugt et al., 2005; Hugo et al., 2008; Neri et al., 2007; Vedhara et al., 1999). De Vugt and colleagues (2005) supported the hypothesis that salivary cortisol patterns change in relation to the stress of caregiving. Caregivers showed significantly higher levels of cortisol at the time of morning awakening than comparison subjects, with smaller increases after awakening. In the caregiver group, a higher cortisol awakening response was found in caregivers of PWD with high levels of behavioral and psychological symptoms of dementia (de Vugt et al., 2005). These findings provide evidence for physiological changes as indicators of chronic stress in caregivers.

Gallagher-Thompson and colleagues also found higher morning cortisol in both Hispanic and non-Hispanic caregivers relative to noncaregivers of both ethnicities. In addition, they found that the distressed sample of caregivers, and the finding of greater cortisol levels throughout the day in caregivers of both ethnicities relative to noncaregivers, lends further support to the relationship between chronic stress and HPA axis dysregulation (Gallagher-Thompson, Shurgot et al., 2006). It was reinforced by the fact that the 9_{PM} levels were still significantly different between caregivers and noncaregivers despite the fact that this time of day has been characterized as the “quiescent period” of cortisol secretion when secretory bursts are less probable and when transient everyday stress is likely to be minimal (Clow, Thorn, Evans, & Hucklebridge, 2004).

Bauer and colleagues (2000) revealed evidence of both increased HPA activity and impaired immunity in elderly spousal caregivers of PWD. This finding was consistent with their

previous research (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990), which observed elevated levels of stress, anxiety, and depression. This increased distress was also associated with elevated salivary cortisol levels, indicating HPA axis activation. Vedhara and colleagues (1999) also found increased levels of distress in caregivers of PWD compared with controls. This increased distress was also associated with significantly raised concentrations of cortisol. Furthermore, the chronic activation of the HPA axis was associated with significantly impaired antibody responses to influenza vaccination (Vedhara et al., 1999). Lastly, salivary immunoglobulin A (IgA) will be discussed in further detail.

Salivary Cortisol and Older Adults

Links between cumulative exposure to stress and aging have now been well established in rodents and primates, from the perspective of stress as both an accelerator of aging changes and aging as a contributor to the impairments in stress responsivity (Meaney, O'Donnell, & Rowe, 1996; Sapolsky, Krey, & McEwen, 1986). Age-altered stress responses are often accompanied by longer-lasting increases in circulating glucocorticoid levels (Lawlor et al., 1992; Sapolsky et al., 1986; Sapolsky, Zola-Morgan, & Squire, 1991). Hypercortisolemia with increasing age has also been demonstrated in both rodents and primates (Sapolsky et al., 1986; Sapolsky et al., 1991), particularly as regards a decreased ability of the HPA axis to recover from a challenge with age (slower termination of the stress response). This decreased ability of the HPA axis to return to baseline is thought to be due to an age-related decreased in glucocorticoid receptor (GR) sensitivity at the hippocampus, hypothalamus, and other brain sites (McEwen, Brinton, & Sapolsky, 1988).

In contrast to these studies of stress, studies of basal daytime cortisol levels and age in humans are inconclusive (Sherman, Wysham, & Pfahl, 1985; Waltman, Blackman, Chrousos, Riemann, & Harman, 1991). However, basal nighttime cortisol appears to be age influenced.

The level at the nadir increases progressively with age, whereas the amplitude of the rhythm decreases with age for both men and women (Copinschi & Van Cauter, 1995; Lupien et al., 1996). Taken together, these studies reveal age increases in total plasma cortisol at times when cortisol would normally be restored to lower baseline levels in young subjects (following resolution of a stressor and at the circadian nadir). These age changes are in a direction that is predicted by the theories of increased glucocorticoid receptor insensitivity with aging.

Another study explored the question of greater female HPA axis reactivity at older ages. This study examined the distributions of ACTH and cortisol responses which indicated that women tended to exhibit greater responses in terms of total “area under the curve” as well as their maximal increases for ACTH and cortisol, with a larger proportion of women showing responses above the respective sample medians for ACTH and cortisol (Seeman, Singer, & Charpentier, 1995). Examination of cortisol and ACTH levels throughout the post-challenge recovery period also indicated that women experienced more prolonged elevations in their cortisol levels and a similar, although somewhat more variable pattern for their ACTH responses (Seeman et al., 1995).

In addition to higher nighttime cortisol levels, older adults also undergo well known age impairments in sleep; decreased slow-wave sleep and increased sleep fragmentation (Bliwise, 1993; Prinz et al., 1990). In a prior pilot study, we reported that cortisol (as indexed by 24 hour free urine cortisol levels) was associated significantly with impaired sleep in healthy seniors under conditions of a mild stress (Prinz, Bailey, Moe, Wilkinson, & Scanlan, 2001).

Furthermore, another study found that cortisol was generally unrelated to sleep in the baseline condition, in the intravenous stress condition (intravenous device inserted in the hand), cortisol correlated inversely with indices of quality sleep (stages 2, 3, and 4 sleep, and sleep

efficiency) and positively with a measure of impaired sleep (EEG β activity during slow-wave sleep) in both women and men (Prinz, Bailey, & Woods, 2000). Similar results were obtained when examining cortisol and sleep responses to stress, as indexed by residuals of baseline values regressed on intravenous stress values. These results confirmed an extend earlier observations in a smaller subset of this population (Prinz et al., 2001) and are congruent with published studies that showed that sleep is impaired in a variety of clinical and experimental conditions characterized by heightened HPA activity (Dubrovsky, 1993; Ferrari et al., 1997; Montplaisir, Petit, Gauthier, Gaudreau, & Decary, 1998). These results indicate that the HPA-sleep relationships are also detectable in healthy seniors (explaining up to 36% of the variance) when free 24 hour cortisol is used to index overall HPA activity in response to a mild 24 hour stress (Prinz et al., 2000).

Salivary IgA and Physiologic Changes

An important parameter of immune status is salivary secretory IgA. Secretory IgA is the main immunological defense of mucosal surfaces and levels measured in saliva are thought to be representative of functional status of the entire mucosal immune system (Mestecky, 1993). The primary functional role of IgA antibodies is to protect epithelial surfaces from infectious agents (Janeway, Travers, Walport, & Shlomchik, 2005). IgA antibodies prevent the attachment of bacteria or toxins to epithelial cells and the absorption of foreign substances. The principal sites of IgA synthesis and secretion are the gut, the respiratory epithelium, the lactating breast, and various other exocrine glands such as the salivary and tear glands (Janeway et al., 2005).

Secretory IgA thus acts as a first line of defense against colonization of infectious agents on mucosal surfaces by neutralization and elimination of viral pathogens (Gleeson & Pyne, 2000). It has been suggested that low levels of salivary IgA reduce the resistance to infection as

indicated by the finding of a precise relationship between IgA concentrations and the risk of infection (Gleeson et al., 1999; Pyne & Gleeson, 1998).

Studies have explored the relationship between salivary IgA and chronic exposure to psychological stress or individuals particularly prone to stress. Such studies consistently revealed stress-related down regulation (Evans, Hucklebridge, Clow, & Doyle, 1995; Lucas, Ponsonby, & Dear, 2007). Hucklebridge and colleagues (1998) have shown that the acute response to a psychological challenge is a rise in IgA. This mobilization of IgA has been reported in response to acute laboratory psychophysiological stress tests, such as public speaking (Bristow, Hucklebridge, Clow, & Evans, 1997), computer game challenge (Carroll et al., 1996), and mental arithmetic (Willemsen et al., 1998). It has also been reported in response to music (Ramos Goyette & DeLuca, 2007), and relaxation training on medical workers (Taniguchi, Hirokawa, Tsuchiya, & Kawakami, 2007). Since cortisol can also be measured in saliva and reflects circulating free cortisol levels it is possible to measure simultaneously the secretory immune system and HPA neuroendocrine responses to psychological manipulation.

In summary, the theoretical framework for Caregivers and Ineffective Sleep builds on the Stress, Appraisal, and Coping model. It encompasses the desired components of the Stress, Appraisal, and Coping model and interprets them in a conceptually meaningful way. The theoretical framework will without a doubt explore the sleep patterns in high and low stressed caregivers of cognitively impaired community-dwelling individuals who worry about nighttime activity. It will also absolutely explore the proposed link between stress of caregiving role and the physiologic/psychologic changes that occur in high and low stressed caregivers who worry about nighttime activity.

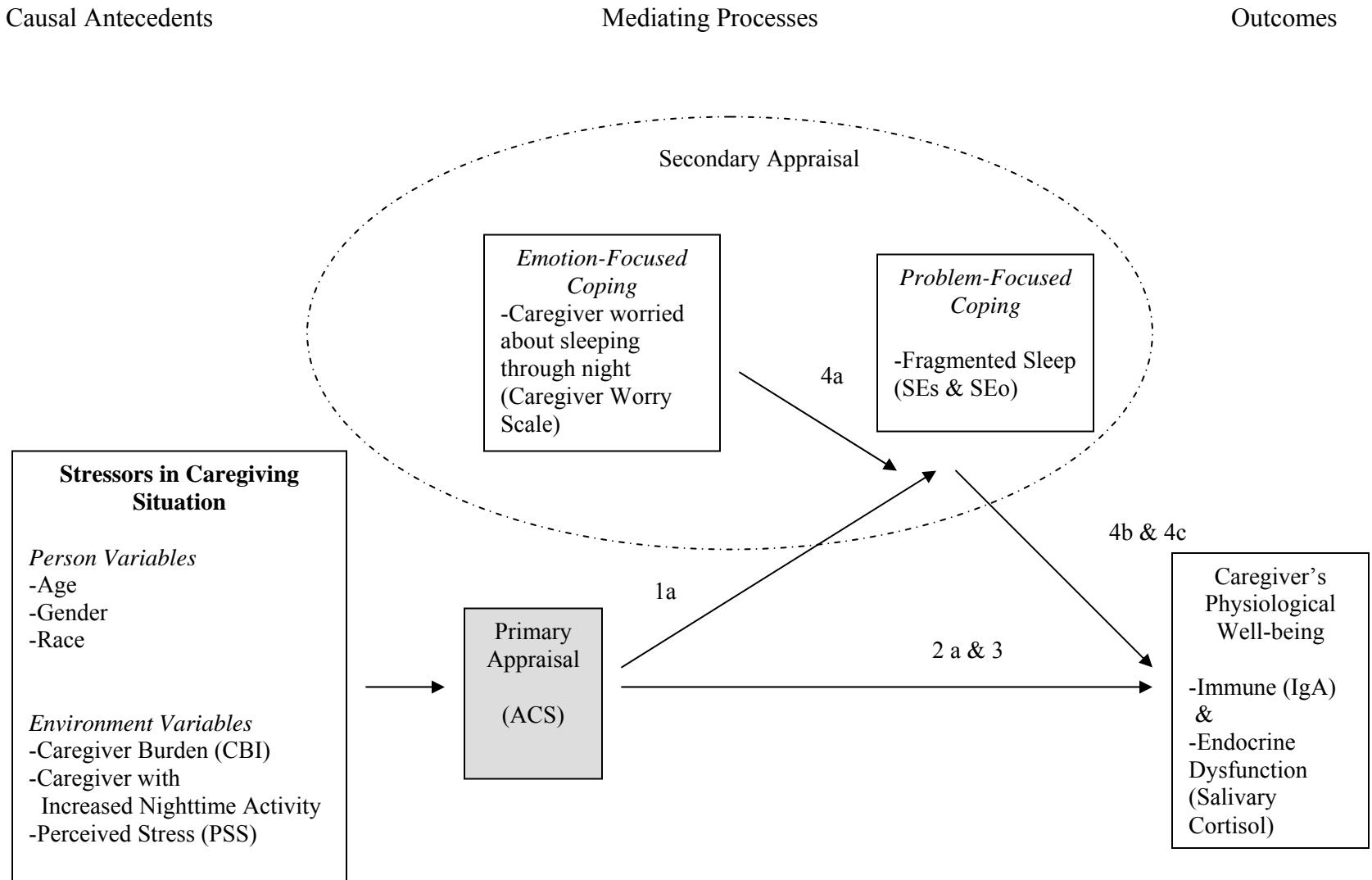


Figure 2-1. Theoretical framework for caregivers and ineffective sleep (adapted from Lazarus & Folkman's Theory of Stress & Coping, 1984)

CHAPTER 3

MATERIALS AND METHODS

The purpose of the proposed study is to explore sleep patterns in high and low stressed caregivers of cognitively impaired community-dwelling individuals who worry about nighttime activity and to explore the proposed link between stress of caregiving role and the physiologic/psychologic changes that occur in caregivers with high and low levels of stress that worry about nighttime activity. In this chapter, the methodological issues in relation to the study will be discussed, including specific issues about design, sampling, and data collection procedures. The instrumentation and measurements are also presented. Finally, the protection of human subjects, data management, and statistical analysis issues will be discussed.

- **Specific aim 1:** To describe differences in sleep patterns between caregivers with high and low levels of stress.
 - **Hypothesis 1a:** Caregivers with higher levels of stress will have more sleep fragmentation (lower sleep efficiency and higher number of awakenings) and more daytime sleepiness.
- **Specific aim 2:** To describe daytime salivary cortisol levels among caregivers with high and low levels of stress.
 - **Hypothesis 2a:** Caregivers with higher levels of stress will have more abnormal daytime salivary cortisol levels.
- **Specific aim 3:** To describe IgA levels among caregivers with high and low levels of stress.
 - **Hypothesis 3a:** Caregivers with higher levels of stress will have decreased salivary IgA levels.
- **Specific aim 4:** To test whether the Caregiver and Ineffective Sleep model predicts the relationship between caregivers with high and low levels of stress, fragmented sleep, and caregiver well-being.
 - **Hypothesis 4a:** The relationship between high stressed caregivers and fragmented sleep will be moderated by worrying about sleeping through nighttime activity.
 - **Hypothesis 4b:** Fragmented sleep will mediate the relationship between level of caregiver stress and daytime salivary cortisol levels.

- **Hypothesis 4c:** Fragmented sleep will mediate the relationship between level of caregiver stress and salivary IgA levels (Figure 2-1).

Design

A nonexperimental prospective cross-sectional design was used to examine sleep patterns in stressed caregivers of cognitively impaired community dwelling individuals and to examine the physiologic changes that occur in caregivers who worry about nighttime activity. Cross-sectional studies are especially appropriate for describing the status of phenomena or for describing relationships among phenomena at a fixed point in time (Polit & Hungler, 1995). The phenomena under investigation are captured, as they manifest themselves, during one period of data collection.

Data for this study was collected over a one-week time period. Researchers visited each caregiver two times on Day 1 and Day 7 (Table 3-1 represents a schema of the design).

Sample

Purposive sampling was used to recruit 30 caregivers. Purposive sampling is a type of non-probability sampling that targets a particular group of people (Polit & Hungler, 1995). It is characterized by the use of judgment and a deliberate effort to obtain representative samples by including typical areas or groups in the sample (Polit & Hungler, 1995). In purposive sampling, researchers sample with a *purpose* in mind. Researchers usually have one or more specific predicated groups they are seeking. Purposive sampling does not produce a sample that is representative of a larger population, but it can be exactly what is needed in some cases-study of organization, community, or some other clearly defined and relatively limited group (Polit & Hungler, 1995).

Participant Characteristics/Caregiver

Inclusion criteria

The inclusion criteria for the caregivers in the study were the following:

- Able to speak and read English
- 21 years of age or older
- Living with the care recipient
- Providing informal (unpaid) care only to the care recipient on a daily basis
- Functioning independently
- Using sleep medication less than 3 nights per week
- Willing to provide saliva samples.

The rationale for these inclusions is to control for extraneous factors that could influence the salivary cortisol and salivary IgA.

Exclusion criteria

The exclusion criterion for the caregivers were the following

- Experiencing a major life event within the past 6 months such as a death of a first degree relative, divorce, surgery, or a change in primary residence
- Chronic illness requiring daily or weekly professional care such as diabetes, congestive heart failure, cancer, or renal failure or immunosuppressive therapies except physical therapy and/or occupational therapy
- Taking beta blockers
- Treatments containing glucocorticoids
- Diagnosed with a sleep disorder such as sleep apnea or restless leg syndrome.

The rationale for these exclusions is to control for extraneous factors that could influence the salivary cortisol and salivary IgA.

Participant Characteristics/Care Recipient

Inclusion criteria

The inclusion criteria for the care recipient were the following:

- Able to speak and read English
- 21 years of age or older
- Living with a primary caregiver
- A confirmed diagnosis of dementia.

Exclusion criteria

The exclusion criteria for the care recipient were the following:

- Experiencing a major life event within the past 6 months such as a death of a first degree relative, divorce, surgery, or a change in primary residence
- Chronic illness requiring daily or weekly professional care such as diabetes, congestive heart failure, cancer, or renal failure.

Sample Size

A pilot study is a small-scale version or trial run of a major study (Polit & Hungler, 1995). Pilot studies play an important role in health research, in providing information for the planning and justification of randomized controlled trials (RCTs) (Anderson & Prentice, 1999). RCTs are costly and time-consuming and major funding bodies such as the National Institute of Nursing Research require this evidence before large amounts of money will be allocated.

A major reason for conducting a pilot study is to determine initial data for the primary outcome measure, in order to determine effect sizes to estimate a sample size with adequate power for a larger trial (Ross-McGill et al., 2000; Stevenson & Ernst, 2000). This can be in the form of an estimate of location (mean) and variability (standard deviation) of measurements for those in the control group for a continuous outcome measure, or an estimate of the proportion on the standard treatment for a categorical outcome measure (Lancaster, Dodd, & Williamson, 2004). The number of patients to be included in a pilot study will depend on the parameter(s) to be estimated. A general rule of thumb is to take 30 patients or greater to estimate a parameter (Browne, 1995). The principal investigator chose 30 stressed caregivers to estimate the outcome measures, sleep patterns, salivary cortisol and IgA. This pilot study will estimate an effect size that can be used in future subsequent full-scale clinical trials and determine potential variables that may improve sleep in caregivers of PWD.

Subject Retention

All subjects were paid \$25.00 upon completion of the study. All appointments were made at the convenience of the subjects and were conducted in the subject's home when necessary.

Measurements

In this study 13 instruments were used for measuring the variables of interest which included the following:

- Demographic questionnaire
- Center for Epidemiologic Depression Scale (CES-D)
- Perceived Stress Scale (PSS)
- Appraisal Caregiving Scale (ACS)
- Caregiver Nighttime Worry Scale
- Epworth Sleep Scale (ESS)
- Pittsburgh Sleep Quality Index (PSQI)
- Sleep diary
- Actigraphy
- Salivary cortisol
- Salivary IgA
- Mini-Mental Status Examination (MMSE)
- Neuropsychiatric Inventory Questionnaire (NPI-Q) (Table 3-1).

The characteristics of the instruments including the number of items, the formats, the scoring, and the psychometric properties are described individually in this section. Examples of uses of the instruments found in recent literature are also explained.

Caregiver Questionnaire Measures

Demographic questionnaire. A researcher-developed demographic questionnaire was used to describe the characteristics of the care recipient as well as the caregiver. The characteristics of the caregiver were represented as control variables and were measured by the Demographic Questionnaire. The Demographic Questionnaire included age, gender, race, educational level, marital and employment status, duration of caregiving, medications, and

chronic health conditions. The general health questionnaire was also included in the Demographic Questionnaire. The single question asked caregivers to rate their overall health for the past year on a scale from excellent to poor. There is widespread agreement that this simple global question provides a useful summary of how patients perceive their overall health status. This view is also borne out by the large number of studies that have consistently shown, in a wide range of disease areas, that self-reported health is a powerful predictor of clinical outcome and mortality (Fayers & Sprangers, 2002).

Center for Epidemiologic Studies depression scale. Depression was measured by using the CES-D, which is a self-administered instrument that asks subjects about the frequency of symptoms during the past week. The CES-D (Radloff, 1977) is a well-known measure of depression. The content of its 20 items was gleaned from previous items used to measure depression such as those used in the Beck Depression Inventory and Zung Depression Scale (Zung, 1967).

Each question uses a 4-point scale; except for four positive questions, a higher score indicates greater depression. Question scores will be summed to provide a total depression symptom score from 0 to 60 and it will be computed that higher scores indicate a greater frequency of depressive symptomatology during the previous week. Although the scale does not diagnose clinical depression, a CES-D score equal or greater than 16 on the range of 0 to 60 has been used to identify those with significant depressive symptomatology (Myers & Weissman, 1980).

If more than five items on a scale are missing, a score is generally not calculated (Sayetta & Johnson, 1980). If one to five items are missing, scores on the completed items will be summed; this total score is divided by the number of items answered and multiplied by 20. This

20-item measure has a high alpha reliability (Cronbach's alpha is .85 to .91) as well as discriminant validity (Haug, Musil, Warner, & Morris, 1997; Rose-Rego, Strauss, & Smyth, 1998).

For validity, researchers compared CES-D scores with the scores from a community sample, a group of depressed patients, and patients with other psychiatric conditions. The average scores were 38.1 for 148 acutely depressed patients, 14.9 for 87 recovered depressives, 13 for 50 schizophrenics, and 9.1 for 3,932 adults in the community (Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977).

The CES-D has been widely used to assess depression in caregivers who are living in the community (Cohen, Colantonio, & Vernich, 2002; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Loewenstein et al., 2001). Hooker and colleagues (2000) studied 175 spouse caregivers for patients with AD and Parkinson's disease. Wives in the AD group reported significantly greater depression and were significantly more stressed and anxious than were AD caregiving husbands.

Gallicchio and colleagues (2002) studied 320 informal community caregivers of dementia patients. They discovered that poor perceived caregiver's health and more behavior disturbance in the care recipient was associated with significantly higher odds of high levels of caregiver burden and depression.

O'Rourke and colleagues (2007) also supported that depressive symptomatology is significantly associated with reduced physical well-being among family or unpaid caregivers of persons with dementia. Depressive symptomatology was measured over time and appeared to be significantly associated with reports of poorer health status at all points of measurement (O'Rourke et al., 2007).

Perceived Stress Scale. The Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1983) is a 14-item, self-reported unidimensional instrument developed to measure perceived stress in response to situations in a person's life. Respondents report the prevalence of an item within the last month on a 5-point scale, ranging from never to very often (Cohen et al., 1983). It is a measure of the degree to which situations in one's life are appraised as stressful. Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress (Cohen et al., 1983).

The PSS was designed for use in community samples with at least a junior high school education. The items are easy to understand and the response alternatives are simple to grasp. Moreover, the questions are of a general nature and hence are relatively free of content specific to any subpopulation group (Cohen et al., 1983). The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way. It is an economical scale that can be administered in only a few minutes and is easy to score.

McCallum and colleagues (2006) studied 30 African American and 24 European American female dementia caregivers and noncaregivers (48 African American and 15 European American). As compared with the European caregivers, African American caregivers were higher in stress-related growth, religious coping and cultural justification for caregiving. Despite these differences, levels of depressive symptoms and perceived stress were similar between the two groups ($r = -0.261$).

A study conducted by Glaser and colleagues (2000) measured antibody titers of current caregivers, former caregivers, and control subjects after vaccination with a pneumococcal

bacterial vaccine. Group differences in self-report stress on the PSS at baseline were in the expected direction, although they did not reach significance; caregivers had a mean of 16.73 ± 2.82 , compared with 10.46 ± 2.44 for former caregivers and 9.61 ± 1.73 for controls.

Kiecolt-Glaser and colleagues (1995) studied 13 women caring for demented relatives and 13 age-matched controls and found that caregivers reported significantly more stress on the PSS than did controls on baseline. Vedhara and colleagues (1999) studied 50 spousal caregivers of PWD and 67 controls and found significantly higher scores of emotional distress on the PSS in caregivers versus controls.

Appraisal Caregiving Scale. The Appraisal Caregiving Scale (ACS) is a 53-item self-report instrument designed to measure the meaning of the illness-caregiving situation in terms of intensity of each of four appraisal dimensions: harm/loss (15 items), and benign (8 items) (Oberst, Thomas, Gass, & Ward, 1989). It was developed based on the Lazarus and Folkman stress model (1984). The ACS measures elements of primary, secondary, and initial reappraisal and is most appropriately used after an initial stressful encounter has occurred and coping has begun. The items were written to address appraisal in five broadly defined areas reflecting potential stress responses associated with caregiving: caregiving tasks, relationships, and interpersonal support, lifestyle, emotional and physical health, and overall personal impact (Oberst et al., 1989). An earlier 36-item version of the ACS was validated with seven persons engaged in caring for a family member with Alzheimer's disease, and their suggestions were used in revising and adding items.

The current 53-item scale was validated by six clinical experts familiar with the underlying theoretical model and with the caregiving literature (Oberst et al., 1989). All were able to classify 51 of the items; two items incorrectly classified by three experts were revised to

reflect the intended appraisal more accurately. A 5-point Likert-type response format was used, with choices ranging from 1 (very untrue) to 5 (very true). Higher scores on each of the subscales represent greater intensity of that appraisal dimension (Oberst et al., 1989). The alpha coefficients in this study were: harm/loss, $r = 0.87$; threat, $r = 0.91$, challenge, $r = 0.72$; benign, $r = 0.77$; and caregiver load: $r = 0.87$.

Carey and colleagues (1991) used the ACS on 49 family caregivers who were caring for adult family members receiving outpatient chemotherapy at a midwestern cancer center. Alpha coefficients in this study were: harm/loss $r = 0.91$; threat, $r = 0.91$; challenge, $r = 0.85$; benign, $r = 0.74$; and benefit, $r = 0.85$.

Alpha reliabilities for ACS subscales (threat=.90, benign=.73, benefit=.74), as well as content and construct validity, were reported as being acceptable in a sample of 240 family caregivers of cancer patients (Carey, Oberst, McCubbin, & Hughes, 1991).

Caregiver nighttime worry scale. A tool developed by Dr. Meredith Rowe was used to measure caregiver worry about nighttime activity. The tool contains five questions displayed on a 100 cm visual analog scale. This tool has been used previously by Dr. Meredith Rowe in two other studies. The caregivers are asked to indicate on the visual analog scale how worried or concerned they are about problems associated with nighttime activity.

Sleep diary. Subjects completed a sleep diary for each day of actigraphy data collection (7 days), which provided subjective estimates of eight sleep-wake variables: 1. sleep onset latency (time from initial lights out until sleep onset); 2. number of nighttime awakenings (number of total awakenings during night); 3. wake time after sleep onset (time spent awake after initial sleep onset until last awakening); 4. total sleep time (computed by subtracting total wake time from time in bed); 5. sleep efficiency percentage (ratio of total sleep time (TST) to total

sleep time spent in bed \times 100); 6. total wake time (time spent awake from initial lights out until time out of bed in the morning); 7. sleep quality rating (scaled from 1=very poor to 5=excellent); and 8. total nap time (total amount of time spent sleeping prior to bedtime) (Lichstein, Riedel, & Means, 1999; K. L. Lichstein, Durrence, Taylor, Bush, & Riedel, 2003).

It is important to have both objective and subjective sleep measures for these sleep parameters because one may be a better predictor of the perception of sleep quality and fatigue (Yamadera, 1995). Very little prior research exists comparing the two measures' effects on these perceptions in the caregiver population.

Epworth Sleepiness Scale. The Epworth Sleepiness Scale (ESS) is a brief self-administered retrospective questionnaire of the behavioral aspects of sleepiness to evaluate self-reports of sleep tendency (Johns, 1991). It is an 8-item scale that rates the likelihood of dozing off or falling asleep in a variety of everyday settings (e.g., watching television) (Johns, 1991). The ESS is a four-point scale with 0=never doze off and 3=high chance of dozing off.

The ESS has been used for proxy reports in demented and nondemented geriatric populations (DJ Foley, Masake, & White, 2003; Kingshott, Sime, Engleman, & Douglas, 1995). A score of 10 or more is considered sleepy. ESS scores of 16 or higher are indicative of a high level of daytime sleepiness. The scores were summed and varied from 0 to 24 with higher scores indicating greater sleepiness. This measure has high 5-month-test-retest reliability in “normals” ($r=.82$) as well as high internal consistency (Cronbach’s alpha=.88) (Johns, 1991). McCurry and colleagues (2000) studied 17 caregivers and found that 36% of patients scored a 16 or higher.

Pittsburgh Sleep Quality Index. The Pittsburgh Sleep Quality Index (PSQI) is a self-reported questionnaire that consists of 19 questions. These 19 questions assess a wide variety of

factors relating to sleep quality, including estimates of sleep duration and latency and of the frequency and severity of specific sleep-related problems (Buysse et al., 1989). These 19 items are grouped into seven component scores each weighted equally on a 0-3 scale. The seven component scores are then summed to yield a global PSQI score, which has a range of 0-21; higher scores indicate worse sleep quality (Buysse et al., 1989).

The seven components of the PSQI are standardized versions of areas routinely assessed in clinical interviews of patients with sleep/wake complaints (Buysse et al., 1989). These components are subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction. The PSQI requires 5-10 minutes for the subject to complete and 5 minutes to score (Buysse et al., 1989). The PSQI has been widely used to assess sleep problems in the elderly (King, Oman, Brassington, Bliwise, & Haskell, 1997; McCurry et al., 2005; McKibbin et al., 2005; Singh, Clements, & Fiatarone, 1997).

During 18 months of field testing with the PSQI, Buysse and colleagues (1989) demonstrated that (a) subjects and patients find the index easy to use; (b) the seven major components of the index as well as the 19 individual questions, are internally consistent; c) the global scores, component scores, and individual question responses are stable across time; (d) the validity of the index is supported by its ability to discriminate patients from controls and, to a more limited degree, by concurrent polysomnographic findings (Buysse et al., 1989).

Buysse and colleagues (1989) found that the PSQI had an overall reliability coefficient (Cronbach's α) of 0.83 in the seven component scores which indicates a high degree of internal consistency. In other words, each of the seven components appears to measure a particular aspect of the same overall construct, such as sleep quality. The largest component-total

correlation coefficients were found for habitual sleep efficiency and subjective sleep quality (0.76 for each), and the smallest correlation coefficient was found for sleep disturbances (0.35).

Overall consistency (test-retest reliability) of the PSQI was better for the entire subject pool than for any specific group (Buysse et al., 1989). Ninety-one patients completed the PSQI on two separate occasions. Paired *t*-tests for the global PSQI score, as well as the seven individual component scores, showed no significant differences between T₁ and T₂ (Buysse et al., 1989).

The identification of “good” and “poor” sleepers for research studies relies on subjective assessments of sleep quality, clinical interviews, and polysomnographic studies (Buysse et al., 1989). The PSQI provides a standardized, quantitative measure of sleep quality that quickly identifies good and poor sleepers, and compares favorably with the “gold standard” of clinical and laboratory diagnosis.

Good and poor sleepers consisted of healthy control subjects and depressed or sleep-disordered patients. A global PSQI score >5 provided a sensitive and specific measure of poor sleep quality, relative to clinical and laboratory measures. Age and sex did not strongly correlate with the PSQI component scores, but they were significant covariates for the global score (Buysse et al., 1989).

The PSQI is primarily intended to measure sleep quality and to identify good and bad sleepers, not to provide accurate clinical diagnoses (Buysse et al., 1989). Nevertheless, responses to specific questions can point the clinician toward areas for further investigation. This is particularly true for the “sleep disturbances” component, which may guide clinical evaluations for specific patients, even though mean scores do not discriminate between groups. Furthermore, a PSQI global score > 5 indicates that a subject is having severe difficulties in at

least two areas, or moderate difficulties in more than three areas (Buysse et al., 1989). The global score is therefore “transparent”, i.e., it conveys information about the severity of the subject’s problem, and the number of problems present through a single simple measure (Feinstein, 1987).

McKibbin and colleagues (2005) examined the differences in objective and subjective measures of sleep between caregivers and noncaregivers. They used the PSQI and found that in the caregiver-severe, caregiver-mild, and noncaregivers groups all reported difficulty with sleep, as reflected by mean Global PSQI scores > 5 . Analyses of PSQI revealed a significant age x caregiver status interaction for the Sleep Latency subscale ($F_{2,104} = 3.28$, df, $P < .05$). Specifically, the older caregiver-severe group reported longer latency than those in older noncaregivers group ($P < .01$). Main effects were also found for caregiver status on the PSQI total score ($F_{2,102} = 5.35$, 2/102 df, $P < .01$), with the caregiver-severe group reporting poorer sleep quality than noncaregivers ($P < .05$), and both the caregiver-severe ($P < .05$) and caregiver mild ($P < .01$) groups reporting greater daytime dysfunction than the noncaregivers group.

McCurry and colleagues (2006) examined the relationship between caregivers’ reports of sleep disturbances in persons with Alzheimer disease and actigraphic records of patients’ sleep-wake activity, and explored the factors associated with discrepancies in this relationship. They used the PSQI and found that 46 caregivers had a mean of 8.6 on the Global PSQI scores. This PSQI global score is > 5 which indicates that the 46 caregivers had severe difficulties in at least two areas, or moderate difficulties in more than three areas.

Actigraphy. Actigraphy is a reliable and valid measure of sleep as compared to polysomnography and has been used in previous studies involving older adults and in populations with dementia (Friedman et al., 1997; McCrae et al., 2005; Sadeh, Sharkey, &

Carskadon, 1994). Actigraphy was used as the objective sleep measure which was collected using the ActiWatch-L® (Figure 3-1). Actigraphy data was collected using the two-channel ActiWatch-L® that has an internal ambient light sensor (max 150,000 lux) and an omnidirectional accelerometer with a sensitivity of ≥ 0.01 g-force (Mitter, 2001). The ActiWatch-L® was worn on the subjects' non-dominant wrist.

The integrated degree and speed of motion sensed was used to calculate 'counts' or values of activity. This "digitally integrated" method of examining motion is recommended as the most accurate, reflecting intensity of movement as well as number of motions (Ancoli-Israel et al., 2003; Gorny & Allen, 1999; Mitter, 2001). A 30-second recording epoch will be used which allows storage of 7.5 continuous 24-hour periods of data. In the study, seven days and nights of sleep data was collected. This minimum was chosen because recommendations made by the American Association of Sleep Medicine indicate that actigraphic studies should collect at least three days/nights of data for adequate representation of the subject's sleep patterns (Kushida et al., 2001).

Data was downloaded into a PC and analyzed using Actiware-Sleep v. 5.0 (Mini Mitter, 2001). The medium threshold/sensitivity setting was used, where total activity values of > 40 are necessary in order to score an epoch as 'wake.' This setting was chosen to take advantage of both sensitivity and specificity without loss of accuracy, as compared to polysomnography (Kushida et al., 2001), since both sleep and wake parameters are important in older adults and caregivers.

Sleep diary recordings, ambient light, and activity were used in conjunction to help determine a *Bedtime* and *Out-of-Bed* analysis window. Because of problems relying on subjects to consistently press an event marker button at these times, the researchers used ActiWatch-L® (Figure 3-1) with a light channel that indicates a sudden decrease in light when a person retires

(*Bedtime*) and an increase when he/she leaves the bed (*Out-of-Bed*). The principal investigator will be responsible for establishing all *Bedtime*—*Out-of-Bed* analysis windows to ensure they were set similarly across all subjects. The principal investigator was trained in the use of the ActiWatch-L® by the same senior researcher.

Fragmented sleep was measured using these variables from the actigraphy analysis as produced by Actiware software: sleep efficiency (percent of time in bed scored as sleep), number of sleep bouts (time of sleep between awakenings), and movement and fragmentation index (ration of mobile and immobile minutes during bedtime). Insomnia was measured using these variables: sleep latency (time in bed before initial sleep period) and actual awake time (total minutes awake after sleep onset).

Caregiver Immune and Endocrine Measures

Salivary cortisol. Salivary cortisol has been used frequently to measure the impact of stress on the endocrine system (King & Hegadoren, 2002; G. E. Miller et al., 2004). Since the natural secretion of cortisol has a diurnal pattern it is important to sample several times each day and use the pattern of cortisol secretion throughout the day as the variable.

The participant was provided a salivary cortisol kit and was instructed to engage in the collection procedure on Days 3 and 4. The collection kit consisted of (a) 8 polypropylene 50 mL tubes pre-labeled with the date and time of each scheduled collection, (b) a permanent marker, (c) a specimen transport bag with a biohazard symbol, and (d) a brochure detailing instructions for collecting the salivary cortisol specimens. Specifically, the participant was asked to provide 4 saliva samples on Days 3 and 4. The participant was instructed to collect samples upon awakening, 30 minutes after awakening, 1100, and 1700 hours on each day. The subject was asked to abstain from eating, smoking, or drinking for 30 minutes prior to obtaining the specimen.

At the appropriate time, the participant swallowed to dry her mouth and then took one polypropylene tube from the collection kit; and provided a nonstimulated saliva sample. Participants were instructed to refrigerate all samples they collected.

On Day 7, the samples were collected from participants and were transferred to the USF College of Public Health Biobehavioral Nursing Laboratory. Once transferred, samples were pipetted into microcentrifuge tubes (Fisher Scientific) and then centrifuged at 3000 R.P.M. for 15 minutes. They were then pipetted into Fisherbrand siliconized/low retention microcentrifuge tubes (Fisher Scientific), and stored in the -80° C freezer in the College of Public Health Biobehavioral Nursing Laboratory until assayed.

Saliva was assayed under the supervision of Dr. Maureen Groer using a High Sensitivity Salivary Cortisol Enzyme Immunoassay Kit from Salimetrics, Inc. (State College, PA) according to kit instructions (Salimetrics Inc 96-Well Kit). Intra-assay coefficients of variation, inter-assay values, and assay sensitivity were calculated. Cortisol values were examined for outliers and any raw data that fell outside the physiological range (0.01-2.54 μ g/dl) was excluded from analyses.

Salivary IgA. The same kit as described above was also used for the salivary IgA collection. The collection kit consisted of (a) 8 polypropylene 50 mL tubes prelabeled with the date and time of each scheduled collection, (b) a permanent marker, (c) a specimen transport bag with a biohazard symbol, and (d) a brochure detailing instructions for collecting the salivary IgA specimens. Specifically, the participant was asked to provide 4 saliva samples on Days 3 and 4. The participant was instructed to collect samples upon awakening, 30 minutes after awakening, 1100, and 1700 hours on each day. The subject was asked to abstain from eating, smoking, or drinking for 30 minutes prior to obtaining the specimen.

At the appropriate time, the participant swallowed to dry her mouth and then took one polypropylene tube from the collection kit; and provided a non-stimulated saliva sample. Participants were instructed to refrigerate all samples they collected.

On Day 7, the 8 samples were collected from participants and were transferred to the USF College of Public Health Biobehavioral Nursing Laboratory. Once transferred, samples were pipetted into microcentrifuge tubes (Fisher Scientific) and then centrifuged at 3000 R.P.M. for 15 minutes. They were then pipetted into Fisherbrand siliconized/low retention microcentrifuge tubes (Fisher Scientific), and stored in the -80° C freezer in the College of Public Health Biobehavioral Nursing Laboratory until assayed.

Saliva was assayed under the supervision of Dr. Maureen Groer using a High Sensitivity Salivary Secretory IgA Indirect Enzyme Immunoassay Kit from Salimetrics, Inc. (State College, PA) according to kit instructions (Salimetrics Inc 96-Well Kit). Intra-assay coefficients of variation, inter-assay values, and assay sensitivity were calculated. IgA values were examined for outliers and any raw data that fell outside the physiological range was excluded from analyses.

Care Recipient Questionnaire Measures

Neuropsychiatric Inventory Questionnaire. The Neuropsychiatric Inventory (NPI) is a validated informant-based interview that is widely used in clinical research studies to evaluate neuropsychiatric symptoms and their response to treatment in dementia patients (Cummings et al., 1994). The NPI was developed by Cummings and colleagues (1994) in order to thoroughly assess 12 neuropsychiatric symptom domains common in dementia. The NPI is a retrospective (to 1 month) caregiver informant interview covering the following domains: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation,

apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances (Cummings et al., 1994).

The NPI was originally designed to help distinguish between different causes of dementia. The scripted NPI interview includes a compound screening question for each symptom domain, followed by a list of interrogatives about domain specific behaviors that is administered when a positive response to a screening question is elicited (Cummings et al., 1994). This is a brief semistructured interview administered by a clinician to a caregiver rating the severity and frequency of the behavior. Severity of behavior is scored (1-3) and frequency of behavior is scored (1-4). A maximum score of 12 (frequency X severity) is possible for each domain. Frequency and severity rating scales have defined anchor points to enhance the reliability of caregiver responses. Caregiver distress is rated for each positive neuropsychiatric symptom domain on a scale anchored by scores of 0 (not distressing at all) and 5 (extremely distressing).

The NPI has been shown to have adequate test-retest interrater reliability, as well as good concurrent validity with the relevant items from the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD) (Reisberg et al., 1987) and the Hamilton Rating Scale for Depression (Hamilton, 1967).

The Neuropsychiatric Inventory-Questionnaire (NPI-Q) was designed to expand the applicability of the NPI to routine clinical settings (Kaufer et al., 2000). The NPI-Q differs from the standard NPI in several ways. It is given as a two-page self-administered questionnaire, as opposed to an interview. The NPI-Q was cross-validated with the NPI in 60 Alzheimer's patients (Kaufer et al., 2000). The NPI-Q is a brief, informant-based, 2-page, self-administered assessment of neuropsychiatric symptoms and associated caregiver distress. Written instructions

are provided to the caregiver who then uses anchor points to rate symptom severity and caregiver distress. There is a screening question from the NPI that covers each of the 12 core symptom manifestations. The wording of the screening question used in the NPI-Q (e.g., Apathy: Does he/she seem less interested in his/her usual activities or in the activities of others?) is taken directly from the NPI screening questions, although in some cases the compound screening questions were shortened. Informants are asked to circle “yes” or “no” in response to each screening question, and to either proceed to the next question if the answer is “no” or to rate the symptoms present in the last 4 weeks if the answer is “yes.”

Neuropsychiatric symptoms are assessed in terms of severity on the same three-point scale as the NPI (1-mild, 2-moderate, 3-severe) using similar anchor points. Frequency of symptoms is not assessed. The rationale for assessing only symptom severity is more strongly correlated with caregiver distress (i.e. more clinically significant) than how often the symptom occurs (Kaufer et al., 1998). In addition, severity and frequency scores are highly correlated on the NPI (Cummings et al., 1994).

The total NPI-Q severity score represents the sum of individual scores and ranges from 0 to 36. Caregiver distress associated with the symptoms is rated 0-5 on an anchored 0 to 5 point scale identical to that used in the NPI (Kaufer et al., 1998). The total NPI-Q distress score represents the sum of individual symptom scores and ranges from 0 to 60. Informants typically complete the NPI-Q in 5 minutes or less.

Kaufer and colleagues (2000) found that in 60 caregivers the NPI-Q showed adequate test-retest reliability and convergent validity with respect to total and individual symptom domain scores and caregiver distress ratings on the NPI. The NPI-Q symptom severity scale was highly correlated with both the composite frequency X severity score from the NPI and the

analogous NPI severity score. The degree to which NPI and NPI-Q total symptom scores were correlated was greater in subjects with more severe dementia (Low MMSE group compared with High MMSE group) but was still robust in the group with less severe dementia (Kaufer et al., 2000). Both NPI and NPI-Q total scores were significantly correlated to MMSE score in Low MMSE group ($r=0.44$ for both), whereas no association between MMSE score and NPI or NPI-Q ratings of neuropsychiatric symptoms was observed in the High MMSE group (Kaufer et al., 2000). These findings suggest that neuropsychiatric symptom manifestations in community-dwelling AD patients may become a more consistent feature of the disease as it progresses over time. Alternatively, informants may become more attuned to observing and reporting neuropsychiatric symptoms as they gain more experience in the caregiver role (Kaufer et al., 2000).

Neuropsychiatric symptom prevalence as assessed by the two scales differed by 5% overall, and it tended to be higher on the NPI-Q (Kaufer et al., 2000). This finding is consistent with the approximately 5% false-positive rate observed on NPI screening questions (Cummings et al., 1994). However, interscale differences were less than 2% for symptoms that were moderate to severe in intensity, suggesting that the two scales are similar in capturing clinically significant neuropsychiatric manifestations (Kaufer et al., 2000). The NPI-Q rated symptom prevalence was >5% higher compared with the NPI on four domains (hallucinations, dysphoria, aberrant motor behaviors, and appetite/eating disturbances). However, moderate to severe symptom ratings in all four differed by less than 2% (Kaufer et al., 2000).

Mini-Mental Status Examination. The Mini-Mental Status Examination (MMSE) is a brief cognitive screening measure that is divided into two sections. The first section requires only verbal responses; assesses orientation to time and place, immediate and recall memory, and

attention; and has a maximum score of 21 (Folstein, Folstein, & McHugh, 1975). The second part assesses the ability to name, follow verbal and written commands, write a sentence spontaneously, and copies a simple line drawing and has a maximum score of 9. Subjects can obtain a score between 0 and 30. The lower the score is, the higher the cognitive impairment.

Folstein and colleagues (1975) established reliability and validity for their instrument. The MMSE was given to 63 normal subjects and to a group of 206 patients with a variety of mental disorders, including dementia syndromes, schizophrenia, personality disorders, depression with cognitive impairment, and affective disorders of the depressed type, and to 63 normal subjects. The MMSE was found to be reliable on a 24-hour and 28-day retest by single or multiple examiners. When the MMSE was given twice, 24 hours apart, by the same tester on both occasions, a Pearson coefficient of .887 was obtained. To determine examiner effect on 24-hour test-retest reliability, the MMSE was given twice, 24 hours apart, by two examiners (Folstein et al., 1975). The Pearson *r* remained high at .827. When elderly depressed and demented patients were given the MMSE twice, an average of 28 days apart, the product moment correlation coefficient for test 1 and test 2 was .98.

The MMSE separated the three diagnostic groups (dementia, depressed with cognitive impairment, and affective disorders of depressed type) from the normal group. Of a total possible score of 30, the following mean scores were obtained for persons with the three diagnoses: dementia, 9.7; depression with cognitive impairment, 19.0; and affective disorder with depression, 25.1 (Folstein et al., 1975). The mean score for normal subjects was 27.6. To determine that these scores were not due to the effects of age, an age-matched group was selected with the same distribution of scores according to diagnosis. The mean initial MMSE score for depressed patients less than 60 years of age was 24.5 and for depressed patients over 65

was 25.7, which were not significantly different. Scores below 20 were found only in dementia and functional psychoses, except for a score of 19 in a patient who had a history of drug abuse (Folstein et al., 1975).

Folstein and colleagues (1975) determined concurrent validity by correlating the MMSE with the Wechsler Adult Intelligence Scale (WAIS) using normal subjects along with a group of patients with a variety of neurological and psychiatric disorders. On the Verbal IQ portion of the WAIS, the Pearson *r* was .78. For the Performance IQ portion of the WAIS, the Pearson *r* was .66. Folstein et al. (1975) concluded that the MMSE separated patients with cognitive impairment from those without cognitive impairment.

Dick and colleagues (1984) studied 126 neurological patients with one or more brain lesions using the MMSE and WAIS. A Pearson correlation coefficient of .92 was found in patients tested by the same observer and one of .95 in patients retested by a different observer. The authors also found that there was a relationship between the total score on the WAIS and the total score on the MMSE with a Spearman rho correlation of .52.

Ashford, Kohm, Colliver, Bekian, and Hsu (1989) examined the items on the MMSE using an item characteristic curve analysis with 86 subjects with a clinical diagnosis of possible or probable AD. Results of the analysis indicated a progression of the development of symptoms of AD related to the decline in mental function. The earliest loss was recent memory items on the MMSE (score of 20 or above). Items related to time and place orientation and those items requiring more cues for acquisition become impaired in the middle category of severity (MMSE greater than 10 and less than 20). Those items requiring the use of the more solidly stored memories, such as the repeating of simple words and following simple commands, are lost in later stages of AD (MMSE of 10 or less).

Ashford and colleagues (1989) compared the results between the repeating the names of three objects and recalling them later. Those with mild to moderate impairment could repeat the three words (87%, 84%, 86% correct, respectively), but only a few of the patients were able to recall the words later (24%, 9%, and 16% correct, respectively). The investigators concluded that the pattern of performance loss on the MMSE was consistent with the observed clinical observation of AD.

According to Ashford and colleagues (1989), the MMSE has two weaknesses. First, the MMSE is not an adequate test to distinguish between normal subjects and those with very mild AD. The second weakness is that the score reaches zero at a stage in the disease after which the person with AD may continue to deteriorate for several years. At this phase, the cognitive functioning of the person with AD becomes unstable. The MMSE is a reliable and valid instrument for use in measuring cognitive function (Ashford, Kolm, Colliver, Bekian, & Hsu, 1989).

Data Management

A data codebook was developed for each instrument. Each subject was assigned an identification number in order to ensure that the principal investigator could attribute data to the correct participant. Only the subject identification number was used on all study related materials. Carefully inspecting completeness and clarity of each questionnaire was performed immediately after the survey was completed. Subjects were offered the opportunity to complete any missed items.

The SPSS statistical software program (version 15.0 for Windows) was used for storing the data base file, analyzing the data, and computing the statistical tests in this study (SPSS, 2004). This statistical program was selected because it is a standard program for statistical analysis. In this study, the data cleaning, descriptions of the sample and study variables,

assessment of outliers and multicollinearity, and evaluation of the reliabilities of the measurements were performed.

The questionnaires were independently double coded and their differences were reconciled. The principal investigator double-checked 15% of data, if the error rate was greater than 3% then all data were double-checked. The data was entered and checked for errors and outliers by double keying the data with a separate editing program.

Skipped items on the questionnaires were identified, and decisions were made in order to recode for missing data. When missing values were reasonably random and the extent of the problem was not large, the investigator performed a mean substitution. If an item on a questionnaire is truly missing, the following rules were used to impute a total score for that item:

- (a) if greater than 25% of the items were missing, the score for the questionnaire was missing;
- (b) if less than 25% of the item scores were missing, and the total score for the questionnaire was represented as a mean, then the mean of the present items were used for the total score; and
- (c) if less than 25% of the item scores were missing, and the total score for the questionnaire was represented as a sum, then the average for the completed items were multiplied by the total number of items to get a prorated score.

The investigator used a computer program to construct frequency distributions on all variables in order to inspect outliers and missing data. After all the errors and discrepancies were corrected and validity checks were completed, the edited records were stored on an SPSS master file for data analysis. All missing data points were identified to determine whether the information could be obtained and entered into the data file.

Plan for Data Analysis

Univariate. Univariate analysis was calculated for each variable in the data set, separately. Next, the measures for central tendency were computed. The central tendency is the

statistical measure that identifies a single score as representative of an entire distribution of scores (Polit, 1996). Central tendency finds the single score that is most typical or most representative of the entire distribution. There are three main measures of central tendency: mean and weighted mean, median, and mode. A mean was used for variables that are normally distributed, a median for categorical data, and a mode for nominal data (Polit, 1996). After computing the central tendency, the shape of the distribution was examined for symmetric or skewed distributions.

Lastly, the measures of dispersion were examined. The measures of dispersion are important for describing the spread of the data or its variation around a central value (Polit, 1996). The measures of dispersion describe the amount of heterogeneity or variety within distribution scores. The range, standard deviation, and variance were computed to examine the measures of dispersion. The range is the difference between the highest and lowest values in an ordered distribution of the values of a variable and the standard deviation is a measure of the average difference of each observation in a distribution from the average (mean) of the distribution (Polit, 1996). The variance is an expression of the total amount of variability of the observations for a variable. After computing the measures of dispersion, the shape of the distribution was examined for symmetric or skewed distributions.

Bivariate. After examining the univariate frequency distribution of the values of each variable separately, the bivariate distribution was computed. The bivariate distribution is the joint occurrence and distribution of the values of the independent and dependent variable together. The differences between the high and low stressed caregivers were examined by contingency tables, cross tabulations, and correlations.

The difference between high stressed caregivers, sleep fragmentation, and daytime sleepiness was examined by correlation (Table 3-2). Correlation is a central measure within the general linear model of statistics (Polit, 1996). In order to complete a correlation, the data must be interval. There are three assumptions that must be met when using correlations. First, is the assumption of normality which requires that the distribution of both variables approximates the normal distribution and is not skewed in either the positive or negative direction. Second, it is assumed that the x-y scattergraph points for the two variables being correlated can be better described by a straight line than by any curvilinear function. Linearity was checked visually by plotting the data. Third, it is assumed that the error variance is to be the same at any point along the linear relationship (Polit, 1996). Descriptive statistics, Levene's test, and the Pearson's r was reported.

Regression. Regression analysis is a statistical tool for evaluating the relationship of one or more independent variables to a single continuous dependent variable (Polit, 1996). Multiple regression allows researchers to improve their predictive power by using two or more independent variables to predict a dependent variable (Polit, 1996). Multiple regression analysis was used to test the hypothesized path model.

The multiple regression model was run, checked for outliers and multicollinearity, and then the assumptions were tested. The first assumption that was examined was the linearity of the relationship between the dependent and independent variables (Polit, 1996). Next, the constant variance of the error terms and the normality of the error term distribution were examined. Lastly, the independence of the error terms was examined (Polit, 1996). If any of the assumptions were violated, transformations were considered. If any variables were transformed,

the model was re-run. Lastly, the final model was interpreted using the R^2 , F -ratio, and the betas (Polit, 1996).

Test for moderating effect. Moderator is an independent variable that affects the strength and/or direction of the association between another independent variable and an outcome variable (Bennett, 2000). Figure 3-2 illustrates the moderator effect. The moderator interacts with the independent variable of interest so that the independent variable's association with the outcome variable is stronger or weaker at different levels of the moderator variable (Bennett, 2000). The association of the independent variable with the outcome variable does depend on the value (or level) of the moderator variable (Cohen & Cohen, 1983).

After the data was collected, it was then analyzed. The steps involved in analyzing the moderator data included creating or transforming predictor and moderator variables (e.g., coding categorical variables, centering or standardizing continuous variables, or both), creating product terms, and structuring the equation (Frazier, Tix, & Barron, 2004). If either the predictor or moderator variable was categorical, the first step was to represent this variable with code variables.

The next step in formulating the regression equation involves centering the predictor and moderator variables that are measured on a continuous scale (Frazier et al., 2004). These variables were centered (i.e., put into deviation units by subtracting their sample means to produce revised sample means of zero). This is because the predictor and moderator variables generally are highly correlated with the interaction terms created from them. Centering reduces problems associated with multicollinearity among the variables in the regression equation (Baron & Kenny, 1986; Cohen, Cohen, West, & Aiken, 2003).

After product terms were centered, everything was in place to structure a hierarchical multiple regression equation using standard statistical software, SPSS, to test for moderator effects. The variables were entered into the regression equation through a series of specified blocks or steps (Baron & Kenny, 1986; Cohen et al., 2003). The first step included the code variables and centered variables representing the predictor and moderator variables. All individual variables contained in the interaction term were entered into the regression equation after the predictor and moderator variables from which they were created (Baron & Kenny, 1986; Cohen et al., 2003).

Next, the results of the hierarchical multiple regression analyses were interpreted by (a) interpreting the effects of the predictor and moderator variables, (b) testing the significance of the moderator effect, and (c) plotting significant moderator effects. The unstandardized (B) was reported when interpreting the effects of the predictor and moderator variables. If the moderator effect was significant, one then tested the statistical significance of the slopes of the simple regression lines. The slopes of the simple regression lines represent the relations between the predictor and the outcome at specific values of the moderator variable (Baron & Kenny, 1986; Cohen et al., 2003). Confidence intervals for the simple slopes was also calculated (Baron & Kenny, 1986).

Test for mediating effect. A mediator is a variable that specifies how the association occurs between an independent variable and an outcome variable (Bennett, 2000). A mediator effect is only tested when there is a significant direct effect between the independent variable and the outcome variable (Bennett, 2000). A mediator effect, shown in Figure 3-3, exists if the following conditions are met (a) variations in the independent variable predict variations in the mediator variable, (b) variations in the mediator variable predict variations in the outcome

variable, and (c) when associations in (a) and (b) are controlled in the model, the direct relationship between the independent variable and the outcome variable becomes nonsignificant (Baron & Kenny, 1986).

After the data was collected, it was then analyzed. The steps involved in analyzing the mediator data included four steps (performed with three regression equations): (a) show that there is a significant relation between the predictor and the outcome (Figure 3-3, Path c) (b) show that the predictor is related to the mediator (Figure 3-3, Path a), (c) show that the mediator is related to the outcome variable (Figure 3-3, Path b), and (d) show that the strength of the relation between the predictor and the outcome is significantly reduced when the mediator is added to the model (Figure 3-3, Path a, b, & c) (Baron & Kenny, 1986).

If the relation between the predictor and the outcome controlling for the mediator was zero, the data were consistent with a complete mediation model (i.e., the mediator completely accounts for the relation between the predictor and outcome) (Baron & Kenny, 1986). If the relation between the predictor and the outcome was significantly smaller when the mediator was in the equation (Path a, b, & c), but still greater than zero, the data suggest partial mediation (Baron & Kenny, 1986). However, it is not enough to show that the relation between the predictor and outcome is smaller or no longer is significant when the mediator is added to the model.

The method described by Kenny and colleagues (1998) to test significance of mediated effect is as follows: Because the difference between the total effect of the predictor on the outcome (Figure 3-3, Path c) and the direct effect of the predictor on the outcome (Figure 3-3, Path a, b, & c) is equal to the product of the paths from the predictor to the mediator (Figure 3-3, Path a) and from the mediator to the outcome (Figure 3-3, Path b), the significance of the

difference between Paths c and a, b, and c can be assessed by testing the significance of the products of Paths a and b. Specifically, the products of Paths a and b is divided by a standard error term. The mediated effect divided by its standard error yields a *z* score of the mediated effect. If the *z* score is greater than 1.96, the effect is significant at the .05 level. The error term used by Kenny and colleagues (Baron & Kenny, 1986; Kenny, Kashy, & Bolger, 1998) is the square root of $b^2sa^2 + a^2sb^2 + sa^2sb^2$, where *a* and *b* are unstandardized regression coefficients and *sa* and *sb* are their standard errors.

Procedures

Recruitment

Potential subjects received an invitation to participate through mailings or from staff from caregiver support organizations. Caregivers were recruited through caregiver support programs, USF Memory Disorder Clinic, newspaper articles, and health care provider offices. Anyone interested in participating was instructed to call principal investigator. The total sample size was 30 subjects.

Subjects were recruited once the University of Florida (UF) and the University of South Florida (USF) Health Science Center (HSC) Institutional Review Boards (IRB) provided the principal investigator with written approval. Subjects were recruited through the caregiver support groups and mailings to caregivers through organizations. Potential subjects received a flyer with information about the study and interested individuals were instructed to call the principal investigator's office for more information.

Individuals who called were screened for inclusion/exclusion criteria. For those who were eligible, an appointment was scheduled to review the study protocols and sign the informed consent. The appointment was either done in the office at the USF College of Nursing, USF

Memory Disorders Clinic, or at the subject's home. For consented subjects, data collection began at this appointment.

Data Collection

At the initial visit, the principal investigator screened the potential subject for inclusion in the study with the criteria for the caregiver and the person with AD. At the initial visit, the caregiver and investigator discussed the consent form. If the caregiver signed the consent form, this indicated agreement to participate in the study. One copy of the consent form was kept by the caregiver and the other copy was kept by the principal investigator.

The caregiver was then asked to complete the Demographic Questionnaire. If the caregiver and care recipient agreed, the principal investigator administered the MMSE to the care recipient.

The study instruments were assembled into a packet in the specified order as noted above to control for testing/instrumentation effects and to help the subject understand and answer the material easily. Self-care behavior questions were placed in the first part of the packet and more sensitive questions, such as demographic data, was placed in the last part of the packet. The principal investigator collected the completed questionnaires and answered any questions for the caregiver at the end of the initial visit.

Next, the principal investigator discussed the Actiwatch-L® with the caregiver. The Actiwatch-L® was worn on the non-dominant wrist as recommended by manufacturer. This is a wristwatch-sized device that continually records activity and light for a 7-day period with a 30-second epoch. The caregiver was only to remove the Actiwatch-L®, when it could be soaked with water such as bathing and washing the dishes.

After discussing the Actiwatch-L® with the caregiver, the principal investigator discussed the sleep diary. The sleep diary was completed for each day of actigraphic data collection, which

provided subjective estimates of various sleep-wake parameters, including sleep onset latency, number of awakenings during the night, first wake time after sleep onset, time spent awake after initial sleep onset until last awakening, total sleep time, and sleep efficiency (K. L. Lichstein et al., 2003).

Following the explanation of the sleep diary, the principal investigator discussed the saliva collection procedure. The participant was provided a salivary cortisol kit and was instructed to engage in the collection procedure on Days 3 and 4. The collection kit consisted of (a) 8 polypropylene 50 mL tubes pre-labeled with the date and time of each scheduled collection, (b) a permanent marker, (c) a specimen transport bag with a biohazard symbol, and (d) a brochure detailing instructions for collecting the salivary cortisol specimens. Specifically, the participant was asked to provide 4 saliva samples on Days 3 and 4. The participant was instructed to collect samples upon awakening, 30 minutes after awakening, 1100, and 1700 hours on each day. The subject was asked to abstain from eating, smoking, or drinking for 30 minutes prior to obtaining the specimen.

At the appropriate time, the participant swallowed to dry the mouth and then took one polypropylene tube from the collection kit; and provided a nonstimulated saliva sample. Participants were instructed to refrigerate all samples they collected.

On Day 7, the samples were collected from participants and were transferred to the USF College of Public Health Biobehavioral Nursing Laboratory. Once transferred, samples were pipetted into microcentrifuge tubes (Fisher Scientific) and then centrifuged at 3000 R.P.M. for 15 minutes. They were then pipetted into Fisherbrand siliconized/low retention microcentrifuge tubes (Fisher Scientific), and stored in the -80° C freezer in the College of Public Health Biobehavioral Nursing Laboratory until assayed.

Saliva was assayed under the supervision of Dr. Maureen Groer using a High Sensitivity Salivary Cortisol Enzyme Immunoassay Kit from Salimetrics, Inc. (State College, PA) according to kit instructions (Salimetrics Inc 96-Well Kit). The intra-assay coefficient of variation was calculated and it was 8% which is within range. A reasonable target for the percentage of coefficient variation is less than 10% (Murray, Peter, & Teclaw, 1993; Reed, Lynn, & Meade, 2002; Seronie-Vivien et al., 2005). The intra-assay coefficient of variation is calculated within the samples on the same plate. The inter-assay coefficient of variation was not calculated due to cost of the ELISA assay kits. The inter-assay correlation of variation is calculated between duplicate samples that are run on different days. Cortisol values were examined for outliers and any raw data that fell outside the physiological range (0.01-2.54 μ g/dl) was excluded from analyses.

For the salivary IgA, the principal investigator used the High Sensitivity Salivary Secretory IgA Indirect Enzyme Immunoassay Kit from Salimetrics, Inc. (State College, PA) according to kit instructions (Salimetrics Inc., 96-well kit). Intra-assay coefficients of variation, inter-assay values, and assay sensitivity were calculated. IgA values were examined for outliers and any raw data that fell outside the physiological range was excluded from analyses.

On Day 7, the investigator visited the subject, had the subject complete the series of instruments, and collected the Actiwatch-L®, sleep diary and saliva specimens which were transported in a temperature controlled container back to the lab and then stored as mentioned above. If the principal investigator was unable to administer the MMSE to the care recipient on the initial visit, it was then administered on Day 7.

Finally, maintaining high quality data (e.g., the extent of item non-response and missing scale scores) is an important issue in any health science research because it reflects the

respondents' understanding and acceptance of the survey (McHorney, Ware, Lu, & Sherbourne, 1994). Data quality is defined as the completeness of data and score reliability. The investigator inspected each survey questionnaire to see whether it was completely filled out. The principal investigator telephoned those subjects who did not answer the questions completely the first time in order to obtain more complete questionnaires.

Data Confidentiality and Integrity

All data was identified by a subject identification number only. The key between the subject name and the identification number was kept in a password protected Access database which is housed at the USF College of Nursing in a protected mainframe space. Data collected electronically was collected on a computer that required password access and was collected into a password protected file. Actiwatch-L® data was stored in the mainframe computer (this computer is backed up to tape on a 24-hour basis). Sleep diaries were identified only by number and these were stored in a locked file cabinet in the investigator's office at the USF College of Nursing.

Protection of Human Rights

The study was approved by both the USF HSC Institutional Review Board and the UF Institutional Review Board. The principal investigator recruited subjects in Tampa, Florida. Assurances of confidentiality and freedom to discontinue participation at any time were explained to each subject. The nature of the study and his/her involvement was explained to each potential subject and written consent was obtained.

The subjects were told that if they had any concerns or questions before, during, or after completion of the study, the principal investigator was available to answer those questions. The subjects could terminate at any time if they became uncomfortable while answering the questions

or collecting the saliva samples. Subjects were notified that their name(s) would not appear on the questionnaires, and they could leave blank any questions that made them feel uncomfortable.

The principal investigator assigned an identification number to each subject, and these numbers were written on the questionnaires and saliva samples, data coding sheets, and computer files. All completed questionnaires, data coding sheets, and computer files were kept in a locked file cabinet in the principal investigator's office. The data was only accessible to the principal investigator and her consultants. The results of the study were analyzed and reported only as a group, and no individual was identified. The forms of data storage devices included disk and paper/raw data, and these data were stored in the principal investigator's office and will be stored for at least 5 years.



- Weight 16 grams
- Size: 28X27
- Non-Volatile Memory: 64 Kbytes
- Lux Range: 0.1 to 150,000
- Battery Life: 180 days

Figure 3-1. Mini Mitter ActiWatch-L (From ActiWatch-L Actograph, 2005)

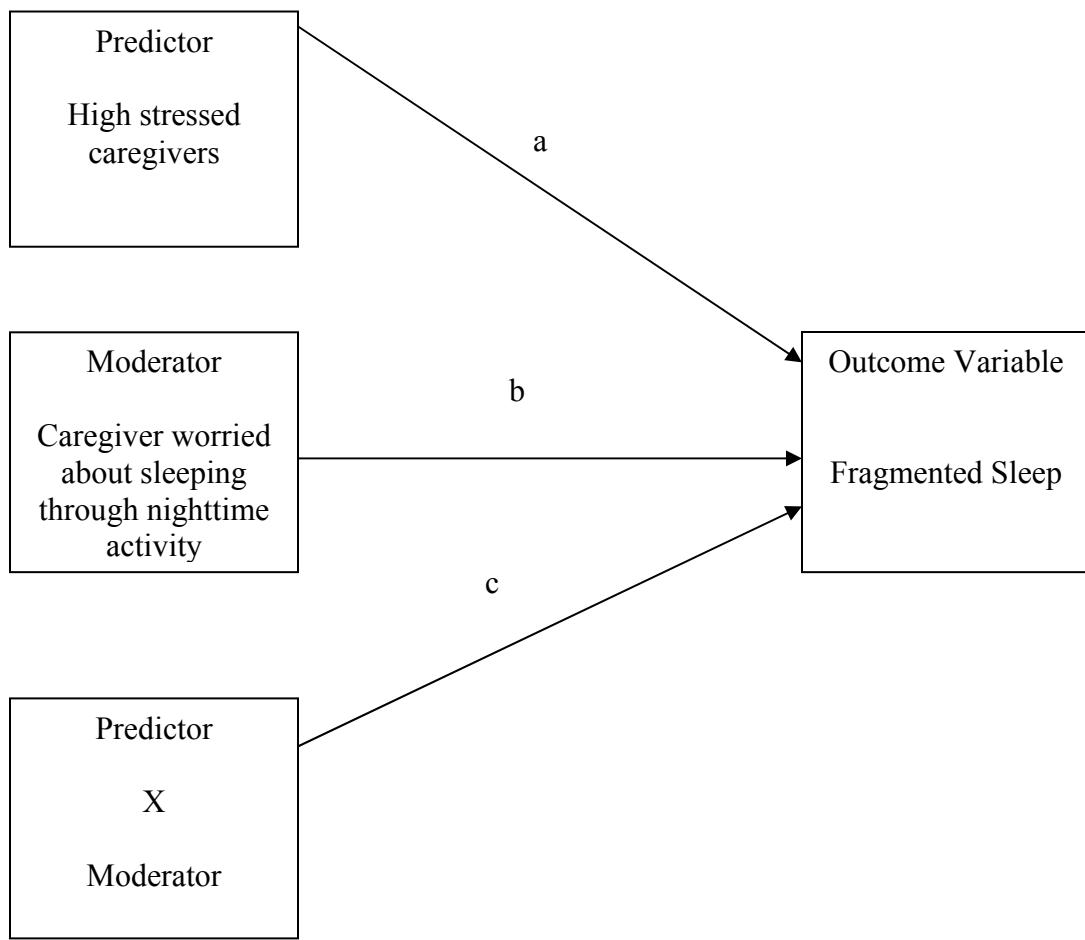


Figure 3-2. Moderator model (adapted from Berry and Kenny, 1986)

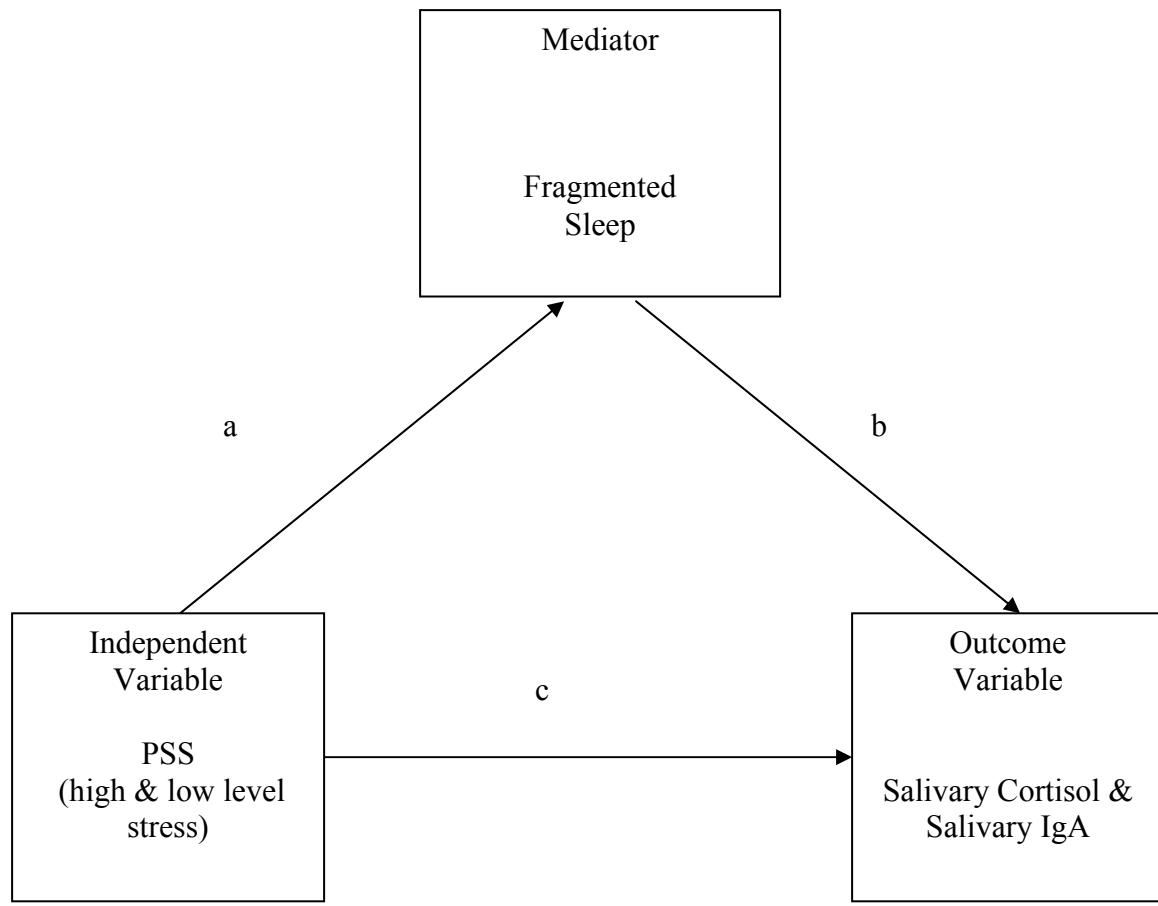


Figure 3-3. Mediator model (adapted from Berry and Kenny, 1986)

Table 3-1. Measures

Measures	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Demographic questionnaire	X						
ESS						X	
PSQI						X	
Caregiver nighttime worry scale						X	
ACS						X	
NPI-Q						X	
PSS						X	
CES-D						X	
Sleep diary	X	X	X	X	X	X	X
MMSE						X	
Salivary cortisol		X	X				X
Salivary IgA		X	X				X

Table 3-2. Data analysis

Research aim/hypothesis	IV & DV	Statistical Test
Hypothesis 1: Caregivers with higher levels of stress will have more sleep fragmentation (lower sleep efficiency and higher number of awakenings) and more daytime sleepiness.	IV: High & low stress (PSS) DV: Actigraphic variables & Caregiver sleep log variables (SEa & SEs)	Correlation
Hypothesis 2a: Caregivers with higher levels of stress will have more abnormal daytime salivary cortisol levels.	IV: Caregivers with higher levels of stress (PSS) DV: Salivary cortisol measures	Correlation
Hypothesis 3a: Caregivers with higher levels of stress will have decreased salivary IgA levels.	IV: Caregivers with higher levels of stress (PSS) DV: Salivary IgA measures	Correlation
Hypothesis 4a: The relationship between high stressed caregivers and fragmented sleep will be moderated by worrying about sleeping through nighttime activity.	IV: Caregivers with higher levels of stress (PSS), Moderator: Caregiver nighttime worry scale DV: SEa & SEs	
Hypothesis 4b: Fragmented sleep will mediate the relationship between level of caregiver stress and daytime salivary cortisol levels.	IV: High & low stress (PSS) Mediator: Fragmented sleep (SEa & SEs) DV: Salivary cortisol measures	Multiple Regression using Berry & Kenny Method
Hypothesis 4c: Fragmented sleep will mediate the relationship between level of caregiver stress and salivary IgA levels.	IV: High & low stress (PSS) Mediator: Fragmented sleep (SEa & SEs) DV: Salivary IgA measures	

CHAPTER 4 RESULTS

The purpose of the proposed study was to explore sleep patterns in high and low stressed caregivers of cognitively impaired community-dwelling individuals who worry about nighttime activity and to explore the proposed link between stress of caregiving role and the physiologic/psychologic changes that occur in caregivers with high and low levels of stress that worry about nighttime activity. In this chapter, descriptive statistics regarding the caregivers' characteristics, care recipients characteristics, and the major study variables are presented, along with study's results and a discussion of the findings.

Description of the Sample (Caregivers)

The sample consisted of caregivers of cognitively impaired community-dwelling individuals. The sample for the study was obtained from the USF Memory Disorders Clinic in Tampa, Florida. The diagnosis of probable dementia was made by a psychiatrist at the clinic. The investigator met weekly at the clinic during their staffing meeting. At the staffing meeting, the psychiatrist, social worker, and radiologist discussed their findings of a probable diagnosis of dementia. At the staffing meeting, either the psychiatrist or social worker, recommended caregivers who met the criteria for the study. The social worker would contact the caregiver and explain the study. If the caregiver was interested in the study, the investigator contacted the potential subject.

There were a total of 38 who met all criteria for inclusion in the study. Out of 38, a total of 31 agreed to participate in the study (93%) with 7 caregivers refusing to participate (7%). The 7 caregivers who refused to participate gave reasons for refusal such as they did not have the time, they had too many other problems to deal with, or it was not the right time for the person with the diagnosis of dementia.

Of the 31 who were visited, 30 completed the entire process, which included wearing the actigraphy watch, completing the sleep diary, collecting 2 days of saliva, and completing the packet of instruments. Only one caregiver was dropped from the study. The daughter of the caregiver contacted the investigator and asked that her mother be dropped from the study. The daughter felt her mother was not physically capable of completing the study. The investigator traveled an average of 20 miles to interview each caregiver and then another 20 miles to obtain the Actiwatch-L® and saliva specimens. It was a range of approximately 10 miles up to 120 miles with the majority of the subjects living in an urban/suburban setting. There were only two subjects who lived in a rural setting.

During the home visit, the caregiver was asked if he/she wanted the investigator to telephone during the 7 days of keeping the sleep diary and the 2 days of saliva collection. Only 2 caregivers asked to be telephoned on the first day of saliva collection. The others who did not want to be telephoned were encouraged to call the investigator if there were any questions and/or concerns. There were no major problems indicated by the caregivers when the investigator telephoned. The caregivers were concerned about the saliva collection and wanted to ensure that the collection was valid.

Twenty-nine caregivers completed the sleep diary, wore the Actiwatch-L®, collected saliva, and completed the packet of instruments. One caregiver was unable to locate the saliva that he stored in the refrigerator and his folder that contained the sleep diaries. The caregiver stated, “(my wife) has a habit of moving my items and misplacing them. I collected the saliva on Days 3 and 4, but two days later I noticed they were no longer in the refrigerator.” The folder containing the sleep diaries and the saliva specimens were misplaced by the care recipient.

The characteristics of the 30 caregivers are summarized in Table 4-1. The age of the caregivers ranged from 26 to 85, with a mean of 65.7 (median=70.5, SD=15.7) years of age. Of this sample, 22 were female and 8 were male. As expected, the sample contained significantly more female caregivers than male caregivers. The majority of the caregivers were white (n=30, 86.7%), with four being Latino. As for education, 70% of the caregivers had at least some college education.

Eighty-three (83.3%) subjects were married, and 66.7% were spouses. Sixty-three (63.3%) caregivers were retired and 23.4% reported full-time paid work. These characteristics are consistent with other studies', which show that the majority of caregivers are spousal caregivers (Kiecolt-Glaser et al., 2003; McKibbin et al., 2005; Sherwood et al., 2005). The caregivers reported from 0 to 200 minutes of time spent awake per night caregiving. In addition, there were 3 subjects who used sleep medication (Ambien CRTM and RozeremTM) on 2 nights out of the 7-day study.

Description of the Care Recipients

The majority of the care recipients were female (53.3%), white (90%), and married (83%). The age of care recipients ranged from 60 to 93 years. The majority of care recipients were diagnosed with probable AD (70%) and nine care recipients (30%) were diagnosed with vascular dementia. Table 4-2 shows the breakdown of characteristics of care recipient by sex, race, marital status, and dementia diagnosis.

The MMSE was also administered to the care recipient. It is a brief cognitive screening measure which is divided into two sections, verbal responses and ability to name and follow verbal and written commands. The range of test scores is between 0 and 30. Lower scores are indicative of higher the cognitive impairment (Folstein et al., 1975). The mean of the MMSE was 15.5 (SD=6.97). Eight care recipients (26.5%) scored between 21 and 30, twelve (39.9%)

between 11 and 20 and six (23.1%) between 0 and 10. The care recipients in this study displayed mild to severe cognitive impairment. Table 4-2 displays the breakdown of the MMSE.

Description of Study Variables

There were nine instruments used for measuring the variables of interest which included the following: Perceived Stress Scale (PSS), Caregiver Nighttime Worry Scale, General Health Question, Epworth Sleep Scale (ESS), sleep diary, actigraphy, salivary cortisol, salivary IgA, and MMSE (Table 4-3). There was some missing data. There were 3 subjects who were missing 1 of the 7-day of the sleep diary, 2 subjects who were missing 2 days of sleep diary, and one subject missing all 7-day of the sleep diary. The subject missing all 7 days of the sleep diary was excluded from the analyses when the sleep diary was required. A mean of the available days was created for the subjects who were missing 1 or 2 days of the 7-day of the sleep diary and was utilized for the analyses when the sleep diary was required.

There were a total of 8 saliva specimens for each subject. The salivary cortisol and salivary IgA results were analyzed from these 8 saliva specimens. The saliva specimens were collected at four time points: upon awakening, 30 minutes after awakening, 11:00 a.m. and 5:00 p.m. on Days 3 and 4 out of the 7-day study period. There were 11 subjects who had all eight saliva specimens. One subject was missing all 8 specimens and was excluded from the analyses when the salivary cortisol and IgA specimens were required. There were three subjects missing 7 specimens, three subjects missing 6, one subject missing 4 specimens, three subjects missing 2, one subject missing 3, and 6 subjects missing one. For the area under curve mean salivary cortisol in respect to ground analyses the subject was required to have 3 out of the 4 salivary cortisol specimens on Days 3 and 4. The subject was also required to have upon awakening salivary cortisol specimen. If the subject was missing the upon awakening specimen or less than 3 out of the 4 specimens, this subject was excluded from the area under curve mean salivary

cortisol analyses. For the mean total IgA analyses, the subject was required to have at least one salivary IgA specimen.

Salivary Cortisol and IgA Calculation

Daily total cortisol concentration was estimated by calculating the area under the curve (AUC) formed by the 4 measured salivary cortisol levels on Days 3 and 4 of the 7-day period using the trapezoid formula (Schmidt-Reinwald et al., 1999). The computation of the AUC is a frequently used method in endocrinological research and the neurosciences to comprise information that is contained in repeated measurements over time (Pruessner, Kirschbaum, Meinlschmid, & Hellhammer, 2003). The AUC in endocrinological studies is used to estimate ultradian and circadian changes of hormones and to assess the overall secretion over a specific time period. The computation of the AUC allows the researcher to simplify the statistical analysis and increase the power of the testing without sacrificing the information contained in multiple measurements (Pruessner et al., 2003). This approach also reduces the number of statistical comparisons between groups, which minimizes the need for adjustment of the significance level. With AUC, the number of statistical comparisons only depends on the number of groups to be compared, as opposed to the original repeated data. In addition, when the time interval between repeated measurements is not identical, the use of AUC provides an alternative because repeated measures analysis of variance, using the original data, has no proven method to adjust for these differences (Pruessner et al., 2003). AUC was chosen because this study has a time interval between the repeated measurements that are not identical (Upon awakening, 30 minutes after awakening, 1100 am, and 500 pm).

AUC measure establishes a link between cortisol levels and psychological functioning (Pruessner et al., 2003). The AUC is derived from the trapezoid formula. Two pieces of information are needed in order to calculate the AUC: (a) the measurements themselves and

(b) the time distance between the measurements (Davis et al., 2004; Pruessner et al., 2003). The AUC formula takes into account the difference between each single measurements (i.e., change over time) and the distance of these measures from the ground, or zero (i.e., the level at which the changes over time occur). Since it calculates the area under the curve with respect to ground, it has been named AUC_G . AUC_G is the total area under the curve of all measurements. It takes into account both sensitivity (the difference between the single measurements from each other) and intensity (the distance of these measures from ground). With endocrinological data, AUC_G is assumed to be a measure more related to total hormonal output (Fekedulegn et al., 2007). This formula is independent of the total number of measurements and can be used with any number of repetitions. The AUC_G formula is illustrated below:

$$AUC_G = \sum_{i=1}^{n-1} \frac{(m_{(i+1)} + m_i) \cdot t_i}{2}$$

After the AUC_G mean cortisol was calculated, a log transformation was then completed. The log transformation was performed in order for the data to be distributed normally.

Daily total salivary IgA concentration was estimated by calculating the sum for Day 3 and for Day 4. The sum was calculated by adding the values of the salivary IgA specimens for each day; a mean value of the 2 days total IgA was used in the analysis.

Salivary Cortisol and IgA

Area under the curve in respect to ground mean cortisol was calculated for 22 caregivers, because 8 of the caregivers were unable to provide specimens. Area under the curve in respect to ground mean cortisol was calculated from the remaining 22 caregivers. The area under the curve in respect to ground mean cortisol average was 273.05 (range 86.23-781.11). Next, mean total IgA will be discussed. The mean total IgA was calculated for 27 caregivers, because 3 of the caregivers were unable to provide specimens. Mean total IgA was calculated from the remaining

27 caregivers. The mean total IgA average was 3504.07 (range 1138.24-4808.00). In addition, the drawn sample and the analyzed sample were not significantly different from each other in age, gender, or salivary cortisol and IgA levels (Table 4-7).

PSS and CES-D

Perceived mental health measures included the CES-D and the PSS. The mean score of CES-D was 13. 6 ($SD=10.6$) and the mean score of PSS was 24.9 ($SD=4.79$). Almost 40% of the subjects (n=12, 39.8%) scored 16 or above on the CES-D, which means that those subjects showed signs of probable clinical depression. With regard to stress, six subjects reported scores from 20 to 28 with most subjects (n=24, 79.9%) scoring higher than 29. The PSS is designed to measure the degree to which situations in one's life are appraised as stressful (Cohen et al., 1983). The higher the degree and longer the duration of self-perceived stress, indicated by a higher score, is considered a risk factor for a clinical psychiatric disorder. The Cronbach's alpha for the CES-D was 0.82 and for the PSS it was 0.88, indicating adequate reliability for both instruments.

In this study, perception of health was measured by a single self-reported health question. The mean score of the general health questionnaire was 1.73 ($SD=1.11$). Only 5 caregivers (16.7%) reported their health as excellent and 8 caregivers reported their health as very good (26.7%). Seven caregivers (23.3%) reported their health as good and ten caregivers (33.3%) reported their health as fair. There were no caregivers (0%) who reported their health as poor. The majority of the caregivers in this study reported their health as either good or fair.

There was one instrument in this study that measured daytime sleepiness, the ESS. The ESS is a brief self-administered retrospective questionnaire of the behavioral aspects of sleepiness to evaluate self-reports of sleep tendency (Johns, 1991). A score of 10 or more is considered sleepy. ESS scores of 16 or higher are indicative of a high level of daytime

sleepiness. The mean score of the ESS was 14.7 (SD=4.7). In this study, 14 caregivers (63.3%) scored from 5 to 15 which indicated a low level of daytime sleepiness. Eleven (36.5%) of the caregivers scored 16 or higher which indicated a high level of daytime sleepiness. The Cronbach's alpha was .75

Sleep Efficiency

The sleep diary sleep efficiency was calculated from 29 caregivers, because one of the caregivers could not locate his sleep diaries. The sleep diary sleep efficiency was calculated from the remaining 29 caregivers. The sleep diary average sleep efficiency was 82% (range 41.1-98.4). Seventeen caregivers of the 29 (59%) had a sleep efficiency < 85%. Next, actigraphy sleep efficiency will be discussed. One of the actigraphs did not produce results, because the caregiver refused to wear the watch continuously. Actigraphical values were calculated from the remaining 29 caregivers. The actigraphy average sleep efficiency was 82% (range 53.7-92.7). Sixteen caregivers of the 29 (55%) actigraphically measured subjects who had sleep efficiency < 85%. The missing data for the sleep diaries and actigraphy are reported in Table 4-7.

Total Wake Time

The sleep diary total wake time was also calculated from 29 caregivers, because one of the caregivers could not locate his sleep diaries. Sleep diary total wake time was calculated from the remaining 29 caregivers. The sleep diary average total wake time was 92 minutes (range 10-304). Next, actigraphy total wake time will be discussed. One of the actigraphs did not produce results, because the caregiver refused to wear the watch continuously. Actigraphical values were calculated from the remaining 29 caregivers. The actigraphy average total wake time was 54 minutes (range 20.2-136.9).

Caregiver Worry Scale

This tool measures the caregiver's worry about nighttime activity. The Caregiver Worry Scale was calculated from 30 caregivers. The mean score of the Caregiver Worry Scale was 16.2 (SD=13.2). The range was 0-40 and the Cronbach's alpha was .942. There were 9 caregivers who scored >20 which indicates a high degree of worry about nighttime activity.

Results of Research Questions

- **Specific aim 1:** To describe differences in sleep patterns between caregivers with high and low levels of stress.

- **Hypothesis 1a:** Caregivers with higher levels of stress will have more sleep fragmentation (lower SEo & SEs) and more daytime sleepiness.

The first step was to examine the relationship between caregivers with high and low levels of stress and sleep fragmentation. There was no significant relationship between caregiving stress as measured by Perceived Stress Scale and sleep fragmentation as measured by sleep diary ($r = -.073$, $p= .354$) and actigraphy sleep efficiency ($r = -.127$, $p= .256$) (Table 4-4).

- **Specific aim 2:** To describe daytime salivary cortisol levels among caregivers with high and low levels of stress.

- **Hypothesis 2a:** Caregivers with higher levels of stress will have more abnormal daytime salivary cortisol levels.

There was no significant relationship between caregiving stress and daytime salivary cortisol levels (Table 4-4). Hypothesis 2a was not supported, in that caregiving stress (Perceived Stress Scale) was not significantly correlated with daytime salivary cortisol levels specifically area under curve mean cortisol in respect to ground ($r = -.094$, $p=.339$). Results indicated that stressed caregivers did not have more abnormal daytime cortisol.

- **Specific aim 3:** To describe IgA levels among caregivers with high and low levels of stress.
 - **Hypothesis 3a:** Caregivers with higher levels of stress will have decreased salivary IgA levels.

There was no significant relationship between caregiving stress (Perceived Stress Scale) and daytime salivary IgA levels (Mean Total Salivary IgA) (Table 4-4). Hypothesis 3a was not supported, in that caregiving stress (Perceived Stress Scale) was not significantly correlated with daytime salivary IgA levels specifically total mean IgA ($r = .090$, $p=.328$). Results indicated that caregiving stress was not associated with salivary IgA.

Finally, the Caregiver and Ineffective Sleep model was tested to see if it predicted the relationship between caregivers with high and low levels of stress, fragmented sleep, and caregiver well-being.

Testing Assumptions for Multiple Regression

In this study, linear regressions were used to test hypotheses 4a, 4b, and 4c (Figure 2-1). In order to appropriately estimate the population parameters and test the study hypotheses for statistical significance, an overall analysis for the assumptions of multiple regression was performed (Berry & Feldman, 1985) and is discussed in this section. The regressions are forms of the general linear model must meet the following assumptions: independence of the error term, normal distribution of the error term, homoscedasticity, and linear relationships.

Independent Samples

In this study, the sample was independent because the data were all collected at one time point and there was no repeated measure of the same subject. Therefore, the assumption of an independent sample was not violated.

Normal Distribution

The assumption of normality of the distribution is determined by examining the frequency of distribution and histograms of the residuals of the regression model. According to the central limit theorem, when estimation is based on a large sample, the sample distribution of regression coefficient estimators is a normally distributed regression. As the sample size increases, there is decreasing concern for whether the normality assumption is met (Polit, 1996; Tabachnick & Fidell, 1996). A sample size greater than 30 is considered sufficient to overcome this violation (Polit, 1996; Tabachnick & Fidell, 1996). In this study, the sample size was small ($n=30$); therefore, violation of the normality assumption is of concern. This assumption was tested using the residuals of the regression.

Linearity

Bivariate scatterplots for each IV-DV relationship were screened. There was no evidence of curvilinear relationships.

Residual Analysis for Assumption of Regression

In the regression model, six assumptions related to the residual term were examined to test each hypothesis. These six assumptions are: the residual mean is zero, the residual variance is equal at all points of the predicted dependent variable, the residuals are normally distributed, the residuals indicating the independent variable has a fixed distribution, the residuals show no evidence of departure from linearity, and the residuals are independent (Polit, 1996; Tabachnick & Fidell, 1996). The residual by predicted value plots were to evaluate whether the assumption of the regression model for this study were met (Polit, 1996; Tabachnick & Fidell, 1996). In this study, the assumptions for hypothesis 4a, 4b, and 4c (Figure 2-1) were addressed through a single regression equation containing all variables. In general, the residual analyses of

hypotheses 4a, 4b, and 4c revealed no violations in the statistical assumptions. The results of the residual analysis for hypotheses 4a, 4b, and 4c are summarized in the following section.

First, the assumption of the residual means was zero which was supported since residual statistics for each regression showed that all residuals had a mean of zero. Second, the residual variance is equal at all points of the predicted dependent variable. The standardized residuals were plotted against the predicted dependent values on a scatter plots. All the points in the scatter plots appeared to be random. Therefore, residual variance was equally distributed across all levels of the DV.

Third, the normality of the residuals was examined by using histograms of residuals and normal probability plots. The histogram of the residuals revealed a fairly normal, but slightly skewed distribution, while the p-plot indicated an approximately normal distribution of residuals. The Shapiro-Wilk test was used to test for the normal assumption. It checks the normal assumption by constructing W statistic, which is the ratio of the best estimator of the variance (based on the square of a linear combination of the order statistics) to the usual corrected sum of squares estimator of the variance (Shapiro & Wilk, 1965). To perform the test, the W statistic is constructed by considering the regression ordered sample values on corresponding expected normal order statistics, which is linear for a sample from a normally distributed population (Royston, 1992). W is positive and less than or equal to one. Small values of W lead to the rejection of normality, while being close to 1 indicates normality of the data. However, the distribution of W is highly skewed. The large values of W ($W=0.9$) may be considered small and lead to the rejection of normality (Royston, 1992). The assumption of normality was met for hypotheses 4a, 4b, and 4c (Figure 2-1).

The fourth assumption is the assumption of independence. The procedure for assessing independence is to examine residual plots. The independence assumption was satisfied and the residuals did fall into a random display of points (Polit, 1996). The assumption was not violated because the residuals did not fall into a cyclical pattern. Also the Durbin-Watson statistic was less than 2.6.

The fifth assumption is that the residual shows no evidence of departure from linearity. There was no evidence of nonlinearity in the null plots.

The issue of outliers, influential cases, and multicollinearity needed to be evaluated before conducting the actual regression equation for hypotheses 4a, 4b, and 4c. First, studentized residuals should be calculated to identify outliers. Observations with studentized residuals greater than 2 in absolute value are usually worth further investigation. Three cases had a studentized residuals value of greater than 2, indicating possible outliers (Polit, 1996; Tabachnick & Fidell, 1996). Then the df-betas were calculated to identify whether the outliers had a large influence on the regression line. Df-betas are valuable diagnostic statistics for assessing regression models because they directly measure how much each observation affects the realization rate. Observations which affect the realization rate by more than a one may be worth investigating. There was no df -betas greater than one, in turn, the investigator kept these cases in the data set for further statistical analyses.

Finally, multicollinearity among the study's independent variables was examined. Each independent variable was treated individually as a dependent variable, and all other independent variables were entered simultaneously. In this data set, the condition index was less than 30 and the values for VIF were less than 10 which provided support for no multicollinearity (Polit, 1996).

- **Specific aim 4:** To test whether the Caregiver and Ineffective Sleep model predicts the relationship between caregivers with high and low levels of stress, fragmented sleep, and caregiver well-being.

- **Hypothesis 4a:** The relationship between high stressed caregivers and fragmented sleep will be moderated by worrying about sleeping through nighttime activity.

In order to test this hypothesis an interaction term was created from a centered stress variable and a centered worry variable. In the model with each predictor and the interaction term, there was no significant relationships between the predictors or the interaction term on sleep diary sleep efficiency ($F=.171$, $p=.915$). In sum, the results showed that the relationship between caregiving stress and fragmented sleep was not moderated by worrying about sleeping through nighttime activity. There was also no significant relationship when actigraphy sleep efficiency was tested with the two predictors and one interaction term ($F=.598$, $p=.623$).

- **Hypothesis #4b:** Fragmented sleep will mediate the relationship between level of caregiver stress and daytime salivary cortisol levels.

This multiple regression was not performed because the bivariate correlation between caregiver stress and daytime salivary cortisol levels, area under curve mean cortisol, was not significant ($r = -.094$, $p=.339$).

- **Hypothesis #4c:** Fragmented sleep will mediate the relationship between level of caregiver stress and salivary IgA levels.

This multiple regression was not performed because the bivariate correlation between caregiver stress and salivary IgA levels, total mean IgA, was not significant ($r = .090$, $p=.328$) (Table 4-4).

Secondary Analysis

Past studies have revealed strong evidence that there are relationships between sleep and salivary cortisol and IgA measures (Dadoun et al., 2007; Michaud et al., 2006), but that was not found in the present study. One rationale for the different findings in the current study is that the

researcher chose to test the hypothesized relationships using different measurement intervals for the sleep and salivary measures. The weekly sleep means did not correlate with the 2-day salivary cortisol and IgA measures. Additionally, during the development of this dissertation, Rowe and colleagues (2007) identified unique findings concerning caregiver sleep. In this study of older adults, the researchers demonstrated that there was significant night-to-night variability across 6 consecutive nights of actigraphic data (Rowe, Campbell, McCrae, & PeBenito, 2007). Intra-individual night-to-night variability is becoming a more widely recognized variable of importance in sleep research (Knutson, Rathouz, Yan, Liu, & Lauderdale, 2007; Rowe et al., 2007; Sforza & Haba-Rubio, 2005). Next, the intra-individual night-to-night variability in caregiver sleep will be discussed.

Past research has provided data that PWD have abnormal, irregular patterns of nighttime awakening (McCurry et al., 2007; McKibbin et al., 2005). Because of these abnormal, irregular patterns of nighttime behavior in the PWD, the caregivers experience significant night-to-night variability in their sleep (Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Rowe et al., 2007). Caregivers frequently awaken to assess the care recipient's safety and provide needed care during the night. These frequent awakenings may change from night-to-night depending on the needs of the care recipient or the overall fatigue of the caregiver. The importance of studying intra-individual variability in the caregiving and dementia setting has also been demonstrated; researchers found that behavioral problems of dementia and stress levels of caregivers were not stable over a 3-month period (Fauth et al., 2006). In addition, another study of adults between the ages of 38 and 50 examined night-to-night variability. This was an ancillary study to the Coronary Artery Risk Development in Young Adults (CARDIA) study, an ongoing cohort study of cardiovascular risk. The researchers found that for each of the 4 sleep characteristics (time in

bed, sleep duration, sleep latency, and sleep efficiency), nightly variability was much greater than yearly variability, meaning sleep behavior changes little in one year, despite large daily fluctuations (Knutson et al., 2007). Next, the effects of sleep deprivation on cortisol will be examined.

Researchers have found that sleep deprivation results in a significant increase in cortisol the next day. Voderholzer and colleagues (2004) demonstrated that 1 night of therapeutic sleep deprivation slightly but significantly increases nocturnal cortisol secretion. The study also demonstrated that the persons who were sleep deprived exhibited a significant rise of cortisol during the first half of the next day (Voderholzer et al., 2004). In addition, Chapotot and colleagues found that prolonged wakefulness increased plasma cortisol levels at night and on the following daytime phase. They also found that the sleep deprivation-related changes in cortisol release were significantly associated with the changes in frontal waking EEG gamma activity (Chapotot, Buguet, Gronfier, & Brandenberger, 2001). Another study also concluded that sleep deprivation results in a significant reduction of cortisol secretion the next day and this reduction appears to be, to large extent, driven by increase of slow wave sleep during the recovery night (Vgontzas et al., 1999). Sleep disturbance has a stimulatory effect on the HPA axis and a suppressive effect on the GH axis. Their findings support previous hypotheses about the restitution and immunoenhancement role of slow wave (deep) sleep (Vgontzas et al., 1999).

It was mentioned earlier that an important parameter of immune status is salivary secretory immunoglobulin A (IgA). Secretory IgA is the main immunological defense of mucosal surfaces and levels measured in saliva are thought to be representative of functional status of the entire mucosal immune system (Mestecky, 1993). Studies have explored the relationship between salivary IgA and chronic exposure to psychological stress or individuals

particularly prone to stress. Such studies consistently revealed stress-related down regulation (Evans et al., 1995; Lucas et al., 2007). Another study found that sleep deprivation causes changes in parameters of serum humoral immunity (IgG, IgA, IgM, C3 and C4) (Hui, Hua, Diandong, & Hong, 2007). The purpose of this study was to investigate the effects of 24 hour sleep deprivation on parameters of humoral immunity.

Because the more recent data suggests caregiver sleep is more variable from night-to-night and sleep deprivation results in a significant increase in cortisol the next day, secondary analyses were conducted using the sleep data on nights 2 and 3 and the cortisol and IgA data on Days 3 and 4. On Day 3 (Table 4-5), the caregivers had increased actigraphy total wake time and decreased actigraphy sleep efficiency ($r = -.407$, $p=.014$). The caregivers also had increased actigraphy total wake time and decreased sleep diary sleep efficiency ($r = -.387$, $p=.021$). On Day 4 (Table 4-6), the caregivers again had increased actigraphy total wake time and decreased actigraphy sleep efficiency ($r = -.407$, $p=.014$). Once more, the caregivers had increased actigraphy total wake time and decreased sleep diary sleep efficiency on Day 4 ($r = -.360$, $p = .033$). These findings support the sleep research on the importance of night-to-night variability. In the current study, the caregivers also had abnormal daytime salivary levels. The caregivers had increased cortisol after awakening and decreased actigraphy sleep efficiency ($r = -.590$, $p=.002$) on Day 3.

Table 4-1. Description of the caregiver sample (N=30)

Variable	N	%	Mean, (SD)	Skewness
Age (years)	30		65.7, (15.7)	-.702
Gender				1.112
Female	22	73.3		
Male	8	26.7		
Race				2.273
Caucasian	26	86.7		
Hispanic	4	13.3		
Education				.298
Some HS	1	3.3		
HS graduate	8	26.7		
Some college	11	36.7		
College graduate	4	13.3		
Graduate school	6	20.0		
Marital Status				1.884
Married	25	83.3		
Previously married	5	16.7		
Employment status				-1.580
Unemployed	24	80.0		
Employed	6	20.0		
Relationship to care recipient				1.609
Spouse	20	66.7		
Son	1	3.3		
Daughter	6	20.0		
Granddaughter	1	3.3		
Friend	2	6.7		
Nights/Week Caregiving				-.266
0 nights	5	16.7		
1-2 nights	6	20.0		
3-4 nights	4	13.3		
5-6 nights	3	10.0		
Every night	12	40.0		
Times/night caregiving				-.257
0 times	6	20.0		
1-2 times	10	33.3		
3-4 times	13	43.3		
> 4 times	1	3.3		
# Minutes/night awake caregiving			54.78 (52.688)	1.235
0-20	10	33.3		
21-40	5	16.7		
41-80	10	33.3		
81-120	4	16.6		
121-200	2	6.6		

Table 4-2. Description of care recipient (n=30)

Variables	N	%	Mean, SD	Skewness
Age (years)	30		78.5, (7.6)	-.702
Gender				.141
Female	16	53.3		
Male	14	46.7		
Race				2.809
Caucasian	27	90.0		
Hispanic	3	10.0		
Marital status				1.884
Married	25	83.3		
Previously married	5	16.7		
Dementia diagnosis				.920
Dementia	21	70.0		
Vascular	9	9.0		
MMSE			15.2, (6.97)	-.686
0-10	6	23.3		
11-20	12	39.9		
21-30	8	26.5		

Table 4-3. Descriptive statistics for major study variables (N=30)

Variables	n	%	Mean, SD	Possible Range	Actual Range	Skewness	r*
PSS							
20-30	9	30.0	32.3, (4.8)	0-56	20-45	.298	.88
31-40	19	63.3					
41-50	2	6.6					
CESD			13.6, (1.6)	0-60	0-39	.447	.90
0	4	13.3					
1-15	14	46.6					
16-20	3	10.0					
>21	8	29.8					
Caregiver worry scale			36.4, (28.9)	0-90	0-90	.247	.94
0							
1-15	5	16.7					
16-30	10	33.2					
31-45	3	9.9					
46-51	4	13.2					
52-65	4	13.2					
66-90	3	9.9					
	6	20.0					
General health question			1.73, (1.11)	0-4	0-3	-.235	
0	5	16.7					
1	8	26.7					
2	7	23.3					
3	10	33.3					
4	0	0					
ESS			14.7, (4.7)	1-48	8-28	.876	.75
5-10	5	16.7					
11-15	14	46.7					
16-20	9	29.9					
21-30	2	6.6					

Table 4-4. Correlation matrix of major study variables

Variable	PSS	WS	SEs	SEo	AUC _{GMC}	TMIgA
PSS	1.000	.561**	-.073	-.127	-.094	.090
WS	.561**	1.000	.054	-.049	-.239	-.151
SEs	-.073	.054	1.00	.249	-.104	-.097
SEo	-.127	-.049	.249	1.000	.033	-.376*
AUC _{GMC}	-.094	-.239	-.104	-.033	1.000	.235
TMIgA	.090	-.151	-.097	-.376*	.235	1.000

Note: PSS=perceived stress scale, WS=worry scale, SEs=sleep efficiency sleep diary, SEo=sleep efficiency actigraphy, AUC_{GMC}=area under curve mean cortisol in respect to ground, TMIgA=Total mean IgA. **Correlation is significant at 0.01 level. *Correlation is significant at 0.05 level.

Table 4-5. Correlation matrix of secondary analysis Day 3

Variable	PSS	WS	SEs	SEo	TWTs	TWTo	CWK	AUC _{GC}
PSS	1.000	.561**	.015	-.180	-.068	.055	-.308	-.010
WS	.561**	1.000	.085	-.091	-.094	-.108	-.457**	-.188
SEs	.015	.085	1.000	.288	-.979**	-.387*	.167	-.383*
SEo	-.180	-.091	.288	1.000	-.191	-.407*	-.590**	.054
TWTs	-.068	-.094	-.979**	-.191	1.000	.376*	.124	.132
TWTo	.055	-.108	-.387*	-.407*	.376*	1.000	-.160	.347
CWK	-.308	-.457**	.167	-.590**	-.160	.124	1.000	-.248
AUC _{GC}	-.010	-.188	-.383*	.054	.347	.132	-.248	1.000

Note: PSS=perceived stress scale, WS=worry scale, SEs=sleep efficiency sleep diary, SEo=sleep efficiency actigraphy, TWTs=total wake time sleep diary, TWTo=total wake time actigraphy, CWK=cortisol upon awakening, AUC_{GC}=area under curve cortisol in respect to ground.

**Correlation is significant at 0.01 level. *Correlation is significant at 0.05 level.

Table 4-6. Correlation matrix of secondary analysis Day 4

Variable	PSS	WS	SEs	SEo	TWTs	TWTo	CWK	AUC _{GC}
PSS	1.000	.561**	.004	.077	-.021	.014	-.254	-.154
WS	.561**	1.000	-.066	.158	.018	-.116	-.124	-.459*
SEs	.004	-.066	1.000	.200	-.988**	-.360*	-.221	-.213
SEo	.077	.158	.200	1.000	-.234	-.821**	-.251	.070
TWTs	-.021	.018	-.988**	-.234	1.000	.397*	.210	.182
TWTo	.014	-.116	-.360*	-.821**	.397*	1.000	.092	.291
CWK	-.254	-.124	-.221	-.251	.210	.092	1.000	.039
AUC _{GC}	-.154	-.459*	-.213	.070	.182	.291	.039	1.000

Note: PSS=perceived stress scale, WS=worry scale, SEs=sleep efficiency sleep diary, SEo=sleep efficiency actigraphy, TWTs=total wake time sleep diary, TWTo=total wake time actigraphy, CWK=cortisol upon awakening, AUC_{GC}=area under curve cortisol in respect to ground.

**Correlation is significant at 0.01 level. *Correlation is significant at 0.05 level.

Table 4-7. Study variables and missing data

Instrument	Total number of items	Missing items
PSS	14	0
Caregiver nighttime worry scale	5	0
MMSE	11	4 caregivers missing all 11 items
General health question	1	0
ESS	18	1 caregiver missing 1 item
CESD	20	1 caregiver missing 1 item
Sleep Diary	19 items -7 days of sleep diary	1 caregiver missing days 1 & 2 1 caregiver missing all 7 days
Actigraphy	30 actigraphs	1 caregiver was not analyzed
Salivary cortisol	8 specimens -4 specimens on Day 3 -4 specimens on Day 4	2 caregivers missing all 8 specimens 2 caregivers missing 7 specimens 1 caregiver missing 5 specimens 2 caregivers missing 6 specimens 1 caregiver missing 4 specimens
Salivary IgA	8 specimens -4 specimens on Day 3 -4 specimens on Day 4	2 caregivers missing all 8 specimens 2 caregivers missing 7 specimens 2 caregivers missing 6 specimens 1 caregiver missing 5 specimens 1 caregiver missing 4 specimens

CHAPTER 5

DISCUSSION AND FUTURE RESEARCH

This study was a nonexperimental prospective cross-sectional design that explored the sleep patterns in high and low stressed caregivers and explored the link between stress of the caregiving role and the physiologic/psychologic changes that occur in these high and low stressed caregivers. The discussion first addresses the primary analyses and then addresses the secondary analyses with consideration of related research in the literature. Lastly, the discussion addresses issues pertaining to the research design of the study and directions for future research.

Discussion

The present study investigated the relationships among stress, sleep, salivary cortisol, and salivary IgA among community-dwelling caregivers. The profile of these community-dwelling caregivers indicates individuals at significant risk. Almost 40% of the caregivers had elevated levels of depressive symptoms as measured by the CES-D. This rate of depression is slightly higher than that documented in other family dementia caregiving studies, where elevated CES-D scores (≥ 16) have been reported in 25.9% to 38.8% of family caregivers (Baumgarten et al., 1992; Gallant & Connell, 1997; Moritz, Kasl, & Berkman, 1989; Pruchno & Potashnik, 1989; Shanks-McElroy & Strobino, 2001; Williamson & Schulz, 1993). With regard to stress, 79.9% of the caregivers scored higher than 29 on the PSS. Due to this high score, these caregivers were also at risk for a clinical psychiatric disorder. This finding on the PSS is consistent with other studies of caregivers who care for persons with dementia (Gallagher-Thompson, Shurgot et al., 2006; Kiecolt-Glaser et al., 2003; von Kanel et al., 2006).

In addition, the study also collected data on the perception of health. It was measured by a single self-reported health question. There were 16.7% who reported their health as excellent, 26.7% as very good, 23.3% as good, and 33.3% reported their health as fair. This finding is

significantly higher than the finding reported by Creese and colleagues. In their study, most of the caregivers reported good health; 77% rated their physical health as good or excellent, while 23% rated their health as fair or poor (Creese et al., 2008).

Furthermore, the mean objective and subjective sleep efficiency in this study was 81%, which is below the 85% average sleep efficiency for persons between 45 and 69 years old (Bliwise, 2005). Another aspect of sleep which is extremely important in the older adult is the number of awakenings. The number of awakenings through the night increases in the older adult as sleep becomes lighter and rarely enters the deepest stages. Lighter sleep with more awakenings is normal in older adults and has no damaging effects on daytime functioning (Bliwise, 2005). In this study however, the reported mean wake time by the caregivers was 92 minutes.

The primary analysis tested the hypothesized relationships using weekly sleep means and there was no significant relationship among perceived stress and sleep. There was also no significant relationship between perceived stress and daytime salivary cortisol and IgA levels using weekly sleep means. The secondary analysis was then completed because more recent data suggests caregiver sleep is more variable from night-to-night likely indicating that poor nights of sleep are mixed with good nights of sleep. The secondary analysis found significant results by examining the sleep variables on a nightly basis. On Day 3, the caregivers had increased actigraphy total wake time and decreased actigraphy sleep efficiency. The caregivers also had increased actigraphy total wake time and decreased sleep diary sleep efficiency. On Day 4, the caregivers again had increased actigraphy total wake time and decreased actigraphy sleep efficiency. Once more, the caregivers had increased actigraphy total wake time and decreased sleep diary sleep efficiency.

Several aspects of the study may have led to nonsignificant findings. First was the choice of measurements for each of the variables. The pattern of findings related to stress and sleep fragmentation prompts questions regarding why perceived stress was not associated with more aspects of sleep fragmentation. It is possible that the PSS did not fully capture the life stress “distress” that participants were experiencing. Although the PSS has been widely used in studies involving caregivers of persons with dementia (Lampley-Dallas, Mold, & Flori, 2005; Li et al., 2007; Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993; Thommessen et al., 2002), the use of this instrument may have limited findings, given that the PSS measures a rather narrow conceptualization of stress. The PSS is designed to measure the degree to which situations in one’s life are appraised as stressful during the past month (Cohen et al., 1983). It is important in this population to choose a more comprehensive measure of stress, in that it assesses caregivers’ emotional reactions to specific, relevant life stressors that may have been experienced. It is possible that both reactions to acute and chronic specific life stressors should be assessed instead of appraisals of acute, global stress. Therefore, future research should include measures of life event stress in addition to measures of perceived stress.

Also the nonsignificant relationship between perceived stress and cortisol is perplexing. As mentioned before, it is probable that caregivers did not appraise their situation as demanding. It is also possible that the relationship between stress and cortisol may have been confounded by other variables. For example, it is possible that mood, caregiver burden, and depression may affect stress and cortisol.

Another variable that may have lead to nonsignificant findings was IgA. In this study, IgA was calculated as mean total IgA for Days 3 and 4 out of the 7-day study. The latest research involving stress and salivary IgA suggest calculating IgA as a flow rate (Farran et al.,

2001; Kiecolt-Glaser et al., 1984; Lawrence et al., 2005; Yang & Glaser, 2002). According to the research, the unstimulated whole saliva should be collected over a 2- to 5-minute period and placed into a polypropylene tube. The saliva volume is then estimated by weighing the polypropylene tube immediately after collection to the nearest mg and saliva density is assumed to be 1.00 g/ml. From this, the saliva flow rate is determined by dividing the volume of saliva by the collection time. In future research, the salivary IgA should be calculated as a flow rate.

The current study is also limited by a small sample size and the resulting lack of power to identify relationships between the variables of interest. The small sample size is not surprising, given that caregivers are stressed and have significant burden. Our sample size was also further limited by the inclusion and exclusion criteria. Such stringent criteria are necessary to ensure internal validity in studies examining the relations between psychological and physiologic variables. These criteria resulted in a smaller sample of caregivers who met eligibility criteria for recruitment.

Finally, the researcher chose to use weekly means to investigate the sleep and daytime salivary cortisol and IgA variables. As mentioned above caregiver sleep is more variable from night-to-night likely indicating that poor nights of sleep are mixed with good nights of sleep. A set of secondary analyses found significant findings in sleep fragmentation, salivary cortisol and IgA.

Implications for Future Research

The data from this pilot study provided a new perspective on the phenomena of caregiving stress, sleep fragmentation, and salivary cortisol and IgA levels. Based on the results of this study, recommendations for future nursing research include the following:

- Investigate the nature of the relationships among caregiving stress, depression, anxiety, sleep fragmentation, and salivary cortisol and IgA levels in caregivers who care for persons with AD by employing different statistical analyses, such as structural equation

modeling to tease out the strength of the effects of the relationship among study variables.

- Test Lazarus and Folkman's model by using large, diverse samples of caregivers and noncaregiver comparisons to examine further the relationship between caregiving stress, depression, anxiety, sleep fragmentation, and salivary cortisol and IgA levels in caregivers who care for persons with AD.
- Conduct a longitudinal study to focus on changes in key predictor variables (caregiving stress, depression, anxiety, sleep fragmentation) and their relationship to salivary cortisol and IgA levels over time.
- Conduct a longitudinal study comparing caregivers who were provided education on improving sleep and a control group to explore the relationships between key predictor variables (caregiving stress, depression, anxiety, and sleep fragmentation) and their relationship to salivary cortisol and IgA levels.
- Develop a precise measurement tool that accurately captures the reason for the caregiver getting up at night. This measurement tool will distinguish between the caregiver getting up at night to assist the care recipient and the caregiver getting up at night for other reasons.
- Obtain IRB approval to collect and compare MMSE data on the care recipient during the physician's visit and at the home.

The current pilot study explored the relationships among stress, sleep, and cortisol and IgA levels among caregivers of persons with dementia. Contrary to hypothesis, perceived stress was not related to cortisol, IgA, and sleep when using weekly sleep variables. The findings from the secondary analysis suggest significant relationships between perceived stress, cortisol, IgA, and sleep when using nightly sleep variables. This study provides preliminary data to support future research examining the relationship between psychosocial factors, sleep, and cortisol and IgA levels among caregivers of persons with dementia. Future research is needed to further examine the predictors of cortisol, IgA, and sleep as well as to examine the relationships between cortisol, IgA, and sleep among caregivers of persons with dementia.

APPENDIX A
APPRAISAL OF CAREGIVING SCALE

Subject _____ Date _____

This group of questions represents feelings, beliefs, or attitudes that someone like you might have about providing care.

Please think about your own situation in providing care for _____ *in the future*. Circle the number that indicates how much you agree or disagree with each of the statements listed below. There are no right or wrong answers.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1. This situation will make me feel more appreciated by others.	1	2	3	4	5
2. This situation will be stressful for me in the future.	1	2	3	4	5
3. I feel things are going to get worse for me.	1	2	3	4	5
4. I will not be doing very well with this situation in the future.	1	2	3	4	5
5. This situation will affect my independence.	1	2	3	4	5
6. I worry that I will not be able to meet all my responsibilities.	1	2	3	4	5
7. I worry that I'll have to give up a lot of things in the future.	1	2	3	4	5
8. My relationships with friends and family will be affected by this situation.	1	2	3	4	5
9. This situation will affect how I feel about myself.	1	2	3	4	5
10. I am afraid that in the future I will not have the energy and endurance I have now.	1	2	3	4	5
11. I will grow a lot as this situation continues.	1	2	3	4	5
12. There is nothing I can do that will make a difference in how the feels.	1	2	3	4	5
13. My responsibilities will continue to be what they have always been.	1	2	3	4	5
14. This situation will affect my lifestyle.	1	2	3	4	5
15. This situation will threaten to overwhelm me.	1	2	3	4	5
16. My relationships with others will become closer as this situation continues.	1	2	3	4	5
17. I am afraid my own physical health will begin to suffer.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
18. This situation will affect my relationship with .	1	2	3	4	5
19. I believe good things will come my way because of how I am handling this situation.	1	2	3	4	5
20. I worry that I will not be able to help in the future.	1	2	3	4	5
21. I worry that my emotional health will begin to suffer.	1	2	3	4	5
22. Each day will become more meaningful as this situation continues.	1	2	3	4	5
23. I am concerned that this situation will cause financial hardship for me in the future.	1	2	3	4	5
24. I will discover resources I never knew I had.	1	2	3	4	5
25. I am not sure I can handle this situation in the future.	1	2	3	4	5

APPENDIX B
CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

Subject _____ Date _____

Instructions:

For the following 20 items, please select the choice that best describes how you have felt *over the past week.*

R: Rarely or none of the time (< 1 day)

S: Some or a little of the time (1-2 days)

O: Occasionally or a moderate amount of the time (3-4 days)

M: Most of the time (5-7 days)

1. I was bothered by things that usually don't bother me.	R	S	O	M
2. I did not feel like eating; my appetite was poor.	R	S	O	M
3. I felt that I could not shake off the blues even with the help from my family and friends.	R	S	O	M
4. I felt that I was not as good as other people.	R	S	O	M
5. I had trouble keeping my mind on what I was doing.	R	S	O	M
6. I felt depressed.	R	S	O	M
7. I felt that everything I did was an effort.	R	S	O	M
8. I felt hopeless about the future.	R	S	O	M
9. I thought my life had been a failure.	R	S	O	M
10. I felt fearful.	R	S	O	M
11. My sleep was restless.	R	S	O	M
12. I was unhappy.	R	S	O	M
13. I talked less than usual.	R	S	O	M
14. I felt lonely	R	S	O	M
15. People were unfriendly.	R	S	O	M
16. I did not enjoy life.	R	S	O	M
17. I had crying spells.	R	S	O	M
18. I felt sad.	R	S	O	M
19. I felt that people disliked me.	R	S	O	M
20. I could not get "going".	R	S	O	M

APPENDIX C
EPWORTH SLEEP SCALE

Subject # _____

Date Completed _____

How likely are you to doze off or fall asleep in the following situations, in contrast to feeling just tired? This refers to your usual way of life *during the past 2 weeks*. Even if you have not done some of these things recently, imagine how they would have affected you. Use the following scale to choose the *most appropriate number* for each situation:

1 = would *never* doze

2 = *slight* chance of dozing

3 = *moderate* chance of dozing

4 = *high* chance of dozing

1.	Sitting and reading.....	_____
2.	Watching TV.....	_____
3.	Sitting, inactive in a public place (such as a theater or a meeting).....	_____
4.	As a passenger in a car for an hour without a break.....	_____
5.	Lying down to rest in the afternoon when circumstances permit.....	_____
6.	Sitting and talking to someone.....	_____
7.	Sitting quietly after lunch without alcohol.....	_____
8.	In a car, while stopped for a few minutes in the traffic.....	_____

APPENDIX D
MINI MENTAL STATUS EXAM

Subject # _____

Researcher _____ Date _____ Time _____

Instructions: Check items answered correctly. Write incorrect or unusual answers in space provided. If necessary, urge patient to complete task. Introduction to patient: "I would like to ask you a few questions. Some you will find very easy and others may be very hard. Just do your best."

Task	Instructions	Scoring	Max Score	Obtained Score
Date Orientation	"Tell me the date?" Ask for omitted items.	One point each for: year season date day of week month	5	
Place Orientation	"Where are you?" Ask for omitted items.	One point each for: state county town building floor or room	5	
Register 3 Objects <i>clock, automobile, telephone</i>	Name three objects slowly and clearly. Ask the patient to repeat them.	One point for each item correctly repeated.	3	
Serial Sevens	Ask the patient to count backwards from 100 by 7. Stop after five answers. (Or ask them to spell "world" backwards.)	One point for each correct answer (or letter) 93-86-79-72-65-58 <i>D-L-R-O-W</i>	5	
Recall 3 Objects	Ask the patient to recall the objects mentioned above.	One point for each item correctly remembered <i>clock, automobile, telephone</i>	3	
Naming	Point to your watch and ask the patient "what is this?" Repeat with a pencil.	One point for each correct answer <i>watch pencil</i>	2	
Repeating a Phrase	Ask the patient to say "no ifs, ands, or buts."	One point if successful on first try	1	
Verbal Commands	Give the patient a plain piece of paper and say "Take this paper in your right hand, fold it in half, and put it on the floor."	One point for each correct <i>paper in right hand, fold it in half, put it on the floor</i>	3	
Written Commands	Show the patient a piece of paper with "CLOSE YOUR EYES" printed on it.	One point if the patient's eyes close	1	

Task	Instructions	Scoring	Max Score	Obtained Score
Writing	Ask the patient to write a sentence. One point if sentence has a subject, a verb, and makes sense		1	
Drawing	Ask the patient to copy a pair of intersecting pentagons onto a piece of paper.	One point if the figure has ten corners and two intersecting lines	1	
		TOTAL		

(Adapted from Folstein et al., 1975)

APPENDIX E
NEUROPSYCHIATRIC INVENTORY QUESTIONNAIRE

Neuropsychiatric Inventory Questionnaire

Subject _____

Date _____

Please answer the following questions based on *changes* that have occurred since the patient first began to experience memory problems.

Circle "yes" only if the symptom has been present in the *PAST MONTH*. Otherwise, circle "no".

For each item marked "yes", rate the severity and distress using the provided scale.

Please answer each question honestly and carefully. Ask for assistance if you are not sure how to answer any question.

Delusions	Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			
Hallucinations	Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			
Agitation or aggression	Is the patient stubborn and resistive to help from others?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			
Depression or dysphoria	Does the patient act as if he or she is sad or in low spirits? Does he or she cry?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			
Anxiety	Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			
Elation or euphoria	Does the patient appear to feel too good or act excessively happy?						
Yes	No	Severity: 1 2 3		Distress: 0 1 2 3 4 5			

Apathy or indifference		Does the patient seem less interested in his or her usual activities and in the activities and plans of others?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		
Disinhibition		Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		
Irritability or lability		Is the patient impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		
Motor disturbance		Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		
Nighttime behaviors		Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		
Appetite and eating		Has the patient lost or gained weight, or had a change in the food he or she likes?			
Yes	No	Severity: 1 2 3	Distress: 0 1 2 3 4 5		

Neuropsychiatric Inventory Questionnaire. Adapted with permission from Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci* 2000;12:233-9. Copyright© J.L. Cummings, 1994.

APPENDIX F
PITTSBURGH SLEEP QUALITY INDEX

Subject_____

Date _____

INSTRUCTIONS:

The following questions relate to your usual sleep habits during the past month *ONLY*. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer *all* questions.

1. During the past month, when have you usually gone to bed at night?

USUAL BED TIME _____

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

NUMBER OF MINUTES _____

3. During the past month, when have you usually gotten up in the morning?

USUAL GETTING UP TIME _____

4. During the past month, how many hours of *actual sleep* did you get at night? (This may be different than the number of hours you spend in bed.)

HOURS OF SLEEP PER NIGHT _____

Instructions:

For each of the remaining questions, check the one best response. Please answer *all* questions.

5. During the past month, how often have you had trouble sleeping because you.....	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
a. Cannot get to sleep within 30 minutes				
b. Wake up in the middle of the night or early morning				
c. Have to get up to use the bathroom				
d. Cannot breathe comfortably				
e. Cough or snore loudly				
f. Feel too cold				
g. Feel too hot				
h. Had bad dreams				
i. Have pain				
j. Other reason(s), please describe				

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
• How often during the past month have you had trouble sleeping because of this?				
6. During the past month, how often have you taken medicine (Prescribed or over the counter) to help you sleep?				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
Very good	Fairly good	Fairly bad	Very bad	
8. During the past month, how would you rate your sleep quality overall?				
	No problem at all	Only a very slight problem	Somewhat of a problem	A very big problem
9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?				
	No bed partner or do not share a room	Partner/flat mate in other room	Partner in same room, but not same bed	Partner in same bed
10. Do you have a bed partner or share a room?				

APPENDIX G

SLEEP DIARY

Subject # _____

Day of Diary _____

Please answer the following questionnaire WHEN YOU AWAKEN IN THE MORNING.
 Definitions explaining each line of the questionnaire are provided on the front cover of the folder
 COMPLETE _____ MORNING

	EXAMPLE	
1. NAP (yesterday)	<i>70 minutes</i>	
2. BEDTIME (last night)	<i>10:55 pm</i>	
3. TIME TO FALL ASLEEP	<i>65 minutes</i>	
4. # of AWAKENINGS during night	<i>4</i>	
5. MINUTES AWAKE during night	<i>110 minutes</i>	
6. FINAL WAKE-UP	<i>6:05 am</i>	
7. OUT OF BED	<i>7:10 am</i>	
8. QUALITY RATING	<i>2</i>	1 = very poor, 2 = poor, 3 = fair, 4 = good, 5 = excellent
9. MEDICATIONS FOR SLEEP (include amount & time)	<i>Halcion 0.25 mg 10:40 pm</i>	

PANA Scale

Please indicate the extent to which you have experienced the following emotions by checking the appropriate box:

EMOTION	Not at all	A little	Moderately	Quite a bit	Very much
Distressed					
Excited					
Strong					
Scared					
Irritable					
Alert					
Nervous					
Determined					
Jittery					
Active					

APPENDIX H
CAREGIVER WORRY SCALE

Subject # _____ Date _____
Answer each question by placing a vertical mark across the answer line at a point which BEST REFLECTS YOUR OPINION.

Example: How worried are you about it raining today?

not at all _____ | _____ my greatest
worried

1. These questions are about your worry of _____ LEAVING THE HOME AT NIGHT
 - a. How often do you worry about this?
not at all _____ constantly worry
 - b. How much does worrying about this affect your life (distress you)?
not at all _____ very distressed
2. These questions are about your worry of _____ BEING UP DURING THE NIGHT WITHOUT YOU KNOWING
 - a. How often do you worry about this?
not at all _____ constantly worry
 - b. How much does worrying about this affect your life (distress you)?
not at all _____ very distressed
3. These questions are about how worried you are that _____ will be INJURED AT NIGHT
 - a. How often do you worry about this?
not at all _____ constantly worry
 - b. How much does worrying about this affect your life (distress you)?
not at all _____ very distressed
4. These questions are about your worry of _____ possibly GETTING UP LATE AT NIGHT
 - a. How often do you worry about this?
not at all _____ constantly worry
 - b. How much does worrying about this affect your life (distress you)?
not at all _____ very distressed
5. How much does _____'s ACTUAL GETTING UP AT NIGHT disrupt your sleep?
not at all _____ a great deal

APPENDIX I
PERCEIVED STRESS SCALE

Subject_____

Date_____

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, you will be asked to indicate your response by placing an "X" over the circle representing HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

	Never	Almost never	Sometimes	Fairly often	Very often
1. In the last month, how often have you been upset because of something that happened unexpectedly?					
2. In the last month, how often have you felt that you were unable to control the important things in your life?					
3. In the last month, how often have you felt nervous and "stressed"?					
4. In the last month, how often have you dealt successfully with day to day problems and annoyances?					
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?					
6. In the last month, how often have you felt confident about your ability to handle your personal problems?					
7. In the last month, how often have you felt that things were going your way?					
8. In the last month, how often have you found that you could not cope with all the things that you had to do?					
9. In the last month, how often have you been able to control irritations in your life?					
10. In the last month, how often have you felt that you were on top of things?					

	Never	Almost never	Sometimes	Fairly often	Very often
11. In the last month, how often have you been angered because of things that happened that were outside of your control?					
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?					
13. In the last month, how often have you been able to control the way you spend your time?					
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?					

APPENDIX J
DEMOGRAPHIC QUESTIONNAIRE

Subject # _____

Date Completed _____

Caregiver Information

Age _____ Gender _____ Race _____ Relationship to Care receiver _____

Occupation _____ Currently working Y/N

Education: What is the highest level you went in school?

- | | |
|---|------------------------------------|
| 1. less than 7 years | 2. junior high school (grades 7-9) |
| 3. some high school (grades 10-11) | 4. high school graduate |
| 5. some college or technical school | 6. college graduate |
| 7. graduate school (masters degree or beyond) | |

Marital status – currently married _____ never married _____ previously married _____

Estimate of # of times per night you generally awaken to provide care:

- | | | | |
|----------|--------------------|--------------------|-------------------|
| 0. never | 1. 1-2 x per night | 2. 3-4 x per night | 3. >4 x per night |
|----------|--------------------|--------------------|-------------------|

Estimate of # of nights per week you generally awaken to provide care

- | | | |
|------------------------|-----------------------|------------------------|
| 0. never | 1. 1-2 night per week | 2. 3-4 nights per week |
| 3. 5-6 nights per week | 4. every night | |

How many minutes per night are you awake _____

What is the hardest thing to manage in the care of your relative

- | | |
|------------------------------------|--|
| 1. manage nighttime problems _____ | |
| 2. other _____ | |

Others living in the home: 1. child 2. adult child 3. caregiver spouse
4. care receiver spouse 5. other relative 6. paid caregivers
7. friends 8. other

Others providing care: 1. adult child 2. caregiver spouse
3. care receiver spouse 4. other relative 5. paid caregivers 6. friends
7. other

Other measures used to manage nighttime activity:

- | | |
|-------------------|-----------------------------------|
| 1. change locks | 2. changed where caregiver sleeps |
| 3. other monitors | 4. respite care 5. other |

Caregiver meds:

1. _____
 2. _____
 3. _____
 4. _____
 5. _____

In the last year how would you rate your general health?

Excellent very good good fair poor

Dementia Age _____ dementia Gender _____ dementia Race _____

Dementia Diagnosis: 1. dat 2. Lewybody 3. vascular 4. parkinson's
 5. mixed 6. not specified 7. other

Person with dementia meds:

1. _____
 2. _____
 3. _____
 4. _____
 5. _____

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BIOGRAPHICAL SKETCH

Brandy Lee Lehman was born on March 27, 1974 in Steubenville, Ohio. She graduated from Wintersville High School in Wintersville, Ohio in 1992. She earned her B.S. in nursing from Thiel College (1996) and her M.S. in nursing from University of Wisconsin-Milwaukee (2000).

Upon graduating in 1996 with her B.S. in nursing, she served in the United States Navy as a commissioned officer in the Nursing Service Corps as a Lieutenant J.G. until September 2000. As a Naval Officer, Brandy's past experience ranged from psychiatry, medical-surgical, critical care and operating room nursing.

After graduating with her M.S. in nursing, Brandy worked at University Community Hospital in Tampa, Florida as an Operating Room Clinical Nurse Specialist. Brandy educated staff, physicians, and patients in the field of operating room nursing. In 2002, Brandy had a burning passion to teach undergraduate nursing students. Brandy has been teaching since 2002 at the University of South Florida College of Nursing. In the past 6 years she has taught medical-surgical nursing, nursing pharmacology, and fundamentals of nursing. She has also taught several medical-surgical and fundamentals of nursing clinical rotations.

Upon completion of her Ph.D. program, Brandy will continue to work as an Assistant Professor at the USF College of Nursing. She plans to work with Maureen Groer in the College of Nursing Biobehavioral Laboratory. Brandy has been married to Lorne Lehman for 8 years and they have four children: Nicholas, age 5; Jessica, age 7; Michael, age 9; and Benjamin, age 9.