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How care demands, caregiving appraisal and coping affect self-care management of informal caregivers of persons with dementia.

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HOW CARE DEMANDS, CAREGIVING APPRAISAL AND COPING AFFECT SELF-CARE MANAGEMENT OF INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA

By

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A Dissertation Approved On

April 12, 2013

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DEDICATION

This dissertation is dedicated to my husband,

Lei Zhou

And my daughter,

Sophia W. Zhou

Who have given me invaluable support and love

that carried me through this process.

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I am grateful to so many people who have helped me with this journey. First and foremost, I would like to thank Dr. Karen Robinson, my advisor and dissertation chair for consistently supporting and guiding me through this process. This Dissertation would have been impossible without the guidance from Dr. Karen Robinson. I also would like to express my appreciation to my dissertation committee members: Dr. Celeste Shawler for mentorship in qualitative analysis, Dr. John Myers for guidance in statistical analysis, Dr. Mary-Beth Coty for helping me with the theories and Dr. Wanda Lott Collins for opening the world of aging and caregiving to me. I would like to extend my sincere gratitude to Dr. Rosalie Mainous, Dr. Barbara Speck, Dr. Carla Hermann, Dr. Lee Ridner, Dr. Marianne Hutti, and all of the faculty who taught me course work and helped me get through the program of study. I am so thankful for my colleagues, Heather Hardin, Lisa Carter-Harris, Glenda Adams, Sheila Steinbrenner for their invaluable peer support.

At the last, but not least, I would like to express my deepest love to my family, my husband Lei Zhou and my daughter Sophia W. Zhou. They have given me courage and confidence to keep moving forward and never give up. With their love and support, I am able to finish this project on time.

ABSTRACT

HOW CARE DEMANDS, CAREGIVING APPRAISAL AND COPING AFFECT SELF-CARE MANAGEMENT OF INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA

XiaoRong Wang

April 12, 2013

BACKGROUND: Caring for a person with Alzheimer’s disease and related dementia (ADRD) is very stressful. Chronic stress which increases the risk for the development of disease and chronic illness is prevalent in caregivers of persons with ADRD. However, how caregiving affects self-care management of caregivers of persons with ADRD has not been well defined.

PURPOSE: The purpose of this study is to examine relationships among care demands, caregiving appraisal, coping and caregiver self-care management and to investigate whether care demands, caregiving appraisal and coping are predictors of caregiver self-care management.

METHODS: A cross-sectional study design was conducted among 45 primary informal caregivers of persons with ADRD in the southern part of the Midwest. Following an informed consent, paper-and-pencil questionnaires were administered for data collection. Quantitative data were analyzed with descriptive analysis, correlations, and multiple regressions, while responses to open-ended questions were analyzed using the principles of thematic analysis (Morse & Field, 1995).

RESULTS: Three categories of predictors (caregiver demographic variables, care demands and active coping) uniquely explained caregiver self-care management. Care-recipients ADL/IADL dependency and duration of caregiving, reflecting care demands, explained the most variance for caregiver self-care, followed by caregiver demographic variables (education, female gender and financial status) and active coping. Total explained variance in each self-care activity was considerable, ranging from 37% to 57%. Our qualitative findings indicated that caregivers' physical self-care and well-being were jeopardized given the needed care of care-recipients. In addition to self-care efforts by caregivers themselves, outside help and support as well as improved access to quality health care are essential to help caregivers improve health.

CONCLUSIONS: Findings of this study help fill the gap in the literature by demonstrating the effects of caregiving on caregiver self-care management. This result is especially significant when viewed in conjunction with the high risk of chronic diseases among caregivers. Caregivers in poor health are more likely to stop caregiving. Interventions are imperative to help caregivers manage care-recipient's needs so as to allow the needed time to the caregiver for essential medical treatment and follow-up as well as such health promotion activities as rest, sleep, relaxation, exercise, nutrition and socialization.

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CHAPTER 1 BACKGROUND AND SIGNIFICANCE

Introduction

Population Aging

The population is aging in the United States. The number of older people is gradually increasing, accounting for a proportionally larger share of the total population. The largest generation in the history of the United States- the "baby boom" generation (people born between 1946 and 1964) started turning to the age of 65 in 2011, and will all have arrived at the age of 65 or older by the year of 2030. The U.S. Census Bureau (2010) has projected that by 2050, the number of Americans aged 65 and older will be more than double, increasing to 88.5 million from approximately 40.2 million in 2010 with nearly one in every five Americans age 65 and over in 2030. The proportion of older persons is projected to increase from 13 percent of the U.S. population in 2010 to 19 percent in 2030 (U.S. Census Bureau, 2010). In addition, the oldest old (aged 85 and older) will grow the fastest, increasing from 5.8 million in 2010 to 8.7 million (2.3% of U.S. population) in 2030 and is expected to become 19 million (4.3% of the total population) in 2050 (U. S. Census Bureau, 2010).

The Challenges of Chronic Diseases and Dementia

As people age, greater risk exists for the development of chronic disease and other age-related problems such as arthritis, diabetes, cancer, cardiovascular disease, hearing impairment, poor vision and balance. Diabetes affects approximately one in four (23.1%) Americans aged 60 or over (Centers for Disease Control and Prevention, 2008). Four in five (80%) older Americans have at least one chronic condition, and one in two (50%) has two or more chronic conditions (National Center for Chronic Disease Prevention and Health Promotion, 2011). Arthritis/rheumatism, high blood pressure and back problems are the top three chronic health conditions in seniors age 65 or older. Moreover, chronic diseases are often associated with disabilities. Significant limitations in daily activities are reported by one-fourth of persons with chronic diseases (National Center for Chronic Disease Prevention and Health Promotion, 2009). Given the trend of population aging, the prevalence and impact of chronic disease is projected to intensify (Goulding, Rogers, & Smith, 2003; National Center for Chronic Disease Prevention and Health Promotion, 2011)

Advanced age is also a risk factor for Alzheimer’s disease and related dementia (ADRD), a brain disorder that leads to irreversible memory loss and progressive declines in functions of cognition, personality and daily activities. As estimated by the Alzheimer’s Association (2012), approximately 5.4 million Americans of all ages had Alzheimer’s disease in 2012. Alzheimer’s disease is the sixth-leading cause of death across all ages in the United States. Older Americans are at greatest risk for Alzheimer’s diseases. Of those with the disease, an estimated 96% are aged 65 and over (Alzheimer's Association, 2012). Prevalence of Alzheimer’s disease is evidenced by one in eight older Americans aged 65 and older (13%) having Alzheimer’s disease, and nearly one in two adults aged 85 and older (45%) being affected by the disease (Alzheimer's Association, 2012). As the population ages, the number of Americans with Alzheimer’s disease is projected to double by 2050 (Alzheimer's Association, 2012).

Current Health Care System

Chronic diseases and disabilities have posed tremendous challenges for the nation’s public health and health care delivery system. The care of persons with ADRD alone costs the nation $200 billion annually (Alzheimer's Association, 2012). However, the U.S. health care system is designed to help people with the treatment of acute illnesses or acute exacerbations of chronic diseases, but does not offer the full range of care for chronic diseases nor for long-term care (LTC) (Robinson, 2010). Traditional private insurance offers LTC programs, but they preclude applicants whose health is poor. Medicaid is the only federal program that will cover LTC, but requires beneficiaries to be poor to receive coverage (Miller, 2011). Without insurance coverage and financial support, few individuals with Alzheimer’s disease or other chronic diseases can afford to pay out-of-pocket expenses for LTC services (Alzheimer's Association, 2012). In 2009, 47 percent of people aged 65 and older had incomes less than 200 percent ($21,660) of the federal poverty level (Henry J. Kaiser Family Foundation, 2010). Even for those with higher incomes, the costs of LTC services can quickly exceed their income (Alzheimer's Association, 2012). Budget constraint impedes a substantive proportion of older adults who are at high risk of needing nursing home care from getting the service. In 2005, 84 percent of them could pay for the service for less than a year, but 75 percent could not afford to pay for even a month (Kaiser Commission on Medicaid and the Uninsured, 2005).

The Task of Family Caregiving

Family assistance in the form of Medicaid becomes the major source of LTC for older adults (Robinson & Reinhard, 2009). Unpaid care delivered by family members or other relatives accounted for 80 percent of care provided at home, and covered more than 90 percent of older adults in the home-setting (Institute of Medicine, 2008). In 2009, over 43 million Americans provided unpaid assistance with instrumental and/or daily activities of living to persons aged 50 or older (National Alliance for Caregiving and AARP, 2009). As for persons with ADRD, 80 percent care at home was provided by informal caregivers who were family members or other relatives. The estimated number of informal caregivers of persons with ADRD was 15.2 million in 2011 (Alzheimer's Association, 2012).

Caregiving Burden and Stress

Caring for older persons with chronic diseases and disabilities is very difficult, and especially so for persons with ADRD. Tasks include management of safety and problematic behaviors of care recipients, assisting with instrumental activities of daily living (e.g., shopping, preparing meals, and providing transportation), and helping with personal activities of daily living (e.g., getting in and out of bed, getting to and from the toilet, bathing, dressing, grooming, and feeding). In addition, caregivers often supervise others who provide care, arrange for medical and other care, and are responsible for household chores (Alzheimer's Association, 2011). About 43% caregivers of persons with ADRD provided the care for 1-4 years and 32% for five or more years (Alzheimer’s Association, 2011).

Given the physical and psychological demands associated with caregiving, depression, anxiety, sleep problems, poor diet and sedentary behaviors are common in caregivers of persons with ADRD (Vitaliano, Zhang, & Scanlan, 2003). Nearly two-thirds (61%) of caregivers reported high or very high levels of stress (Alzheimer's

Association, 2012), and one-third (33%) reported symptoms of depression (Taylor, Ezell, Kuchibhatla, Ostbye, & Clipp, 2008; Yaffe et al., 2002). Negative impacts were not only observed in caregivers' physical health and emotional health, but also in financial security, employment, and family relationships (Alzheimer's Association, 2011). High levels of burden and stress were among other factors that lead to nursing home placement of the impaired person (Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010; Taylor, Ezell, Kuchibhatla, Ostbye, & Clipp, 2008; Yaffe et al., 2002). Families often give up caregiving and place the impaired person in a nursing home because of being overwhelmed by care demands (Robinson & Reinhard, 2009).

Caregiver Physical Health

Prolonged caregiving stress can serve as a pathway that leads to physiological changes (Garrido, Hash-Converse, Leventhal, & Leventhal, 2011). Significant changes in physiology and biology observed in caregivers of persons with ADRD, when compared to non-caregiver controls, included escalated reactivity of cardiovascular systems and more production of circulating inflammatory markers associated with new diagnoses of hypertension, new coronary heart disease and other cardiovascular diseases (Gouin, Glaser, Malarkey, Beversdorf, & Kiecolt-Glaser, 2012; Mausbach et al., 2007; Mills et al., 2009; Vitaliano et al., 2002), and impaired immunologic functions (Bauer, Jeckel, & Luz, 2009; Gouin, Hantsoo, & Kiecolt-Glaser, 2008). In addition, chronic stress is also associated with prolonged duration and rate of wound healing (Christian, Graham, Padgett, Glaser, & Kiecolt-Glaser, 2006; Gouin & Kiecolt-Glaser, 2011; Guo & Dipietro, 2010).

Increased morbidity and mortality in caregivers of persons with ADRD has been established by studies since the 1990s. A longitudinal study among 150 spousal caregivers and 46 married controls indicated ADRD caregivers were at greater risk for serious illness when compared to their non-caregiver counterparts over a one-to-six-year period of time (Shaw et al., 1997). After a 4-year follow-up of 392 caregivers and 427 non-caregivers, Schulz and Beach (1999) found that caregivers who were under caregiving-related stress were likely to die earlier than the controls. A meta-analysis of 23 studies that compared caregiver health with demographically matched controls indicated that ADRD caregivers had poorer self-rated health, increased rate of stress hormones and antibodies, and higher numbers of chronic conditions, ill days, physician visits, and medication use, when compared to non-caregiving peers (Vitaliano et al., 2003).

Further, the likelihood of caregivers developing chronic diseases and disability were promoted by risky health behaviors that caregivers commit in response to stress (Vitaliano, Zhang, & Scanlan, 2003). Related stress reactions or problems include sleep disturbance, unhealthy eating, sedentary behavior, and substance abuse. For example, although not many caregivers smoked, Connell (1994) found that half of the smokers reported an increase in their smoking. When caregivers were questioned about coping strategies, 63.8% indicated that they ate when they were stressed by caregiving, 52.3% slept more, 34.1% used medications, and 34.1% used alcohol. Negative health behaviors were also apparent when 52 male spouse caregivers were compared with 53 demographically matched controls (Fuller-Jonap& Haley, 1995). In a study of 233 spouse caregivers, Gallant and Connell (1997) found that half of caregivers slept less than 7 hours per night. The majority of participants reported sleeping less since caregiving began and nearly 50% female caregivers and 13% male caregivers reported gaining weight after being a caregiver (Gallant & Connell, 1997). As identified by the Alzheimer's Association (2011), only three percent of caregivers used physical activities as a way to cope with stress, and two-thirds of caregivers were overweight or obese.

Most caregivers of persons with ADRD are spouses or family members, who may share similar negative life habits as the impaired person which has been identified as a risk factor for the development of ADRD, including unhealthy eating, physical inactivity, smoking and extensive alcohol consumption. The shared pattern of risk behaviors is especially true for spousal caregivers as a result of selection and mutual influence between married couples (Pinquart & Sorensen, 2003; Vitaliano et al., 2003). In addition, spousal caregivers were typically aged 65 or over, and more than half of caregivers were aged 55 or older (56%) (Alzheimer's Association, 2011) who are at risk for chronic disease, or already had it before taking on caregiving (Gallant & Connell, 1997; Vitaliano et al., 2003). Given the combined reasons (i.e., prolonged stress, physiological vulnerability, risky behavioral reactions toward stress, shared life habits, and advanced age), strong consensus has been reached in the literature that chronic diseases were prevalent in caregivers of persons with ADRD (Pinquart & Sorensen, 2003; Schulz & Martire, 2004; Vitaliano et al., 2003).

Statement of Problem

Despite overwhelming research on the prevalence of chronic disease among caregivers of persons with ADRD, few researchers have focused on caregivers' self-care needs in the context of the presence of chronic diseases. Research on self-care management by ADRD caregivers with chronic diseases is limited. A few studies have examined self-care by caregivers, but primarily in the context of the absence of illness or symptoms, referred to as health promoting self-care (Acton, 2002; McDonald, Fink, & Wykle, 1999; Sisk, 2000). Examples of healthy behaviors include resting, healthy eating and exercise (Acton, 2002), decreased alcohol consumption, exercise, sleeping, smoking cessation, and weight maintenance (Gallant & Connell, 1997). Still other healthy behaviors include spiritual growth, positive interpersonal relationships, and stress management (Acton, 2002; Sisk, 2000). Few researchers have identified caregivers' self-care needs in the context of coping with their own chronic diseases and health problems.

Self-care in response to symptoms has been investigated by Lu and colleagues (Lu & Austrom, 2005; 2007), but the actual focus of the studies was on coping of caregivers of persons with ADRD in response to physical and/or psychological discomforts, including strategies of maintaining a healthy diet, resting in bed, taking medication, asking for professional help, praying, using a home remedy, or doing nothing. Thus, little research has provided an assessment of self-care in the context of chronic-disease self-care management. Self-care management played an important role in individual health and well-being (Lorig et al., 2006). An examination of self-care management is important for all caregivers of persons with ADRD who are either managing an existing disease or preventing a future one.

Need of the Study

National reports have pointed out that caregivers of persons with ADRD often became secondary patients from the negative impact of caregiving (Alzheimer's Association, 2011). The strain of caring for persons with ADRD caused informal caregivers to use 25% more health care services than non-caregivers of the same age, and the increase was especially true for caregivers who had health problems or diseases (National Alliance for Caregiving, 2011). Insights provided by this study allow for a more holistic understanding of caregivers' health management. Based on this understanding, more effective interventions can be developed to improve caregiver health and decrease related health care costs.

Poor caregiver health was often associated with increased caregiving stress and difficulty in maintaining care (McCann, Hebert, Bienias, Morris, & Evans, 2004; Navaie-Waliser et al., 2002). In a large sample of 634 informal caregivers of persons with ADRD, perceived health and subjective burden were found to be significant predictors of nursing home replacement (Nikzad-Terhune et al., 2010). Addressing self-care management of ADRD caregivers thus will help caregivers sustain caregiving, prevent or delay nursing-home placement, and contribute to a decrease in healthcare cost of LTC. In addition, better health may allow caregivers to be more satisfied with caregiving experiences. Informal caregivers have created substantive economic value for the society. With 21.9 hours per caregiver per week on average and $12.12 per hour, informal caregivers contributed to the nation at a value of over $210 billion in 2011 (Alzheimer's Association, 2012).

Purpose

The purpose of this study was to systematically examine the impact of caring for a person with ADRD on caregiver self-care management based on the theory of Lazarus and Folkman (1984). Based on the literature and the theory, four hypotheses were proposed and tested in this study. Descriptions of the hypotheses are displayed in the Hypothesis section following the Theoretical Framework section. In addition to examining the effects of caregiving on caregiver self-care management, caregivers' demographic characteristics were also explored to identify potential relationships with caregiver self-care management.

Theoretical Framework

The Stress and Coping Theory by Lazarus and Folkman (1984), one of the most influential theoretical frameworks of stress sciences (Contrada, 2011; Smith & Kirby, 2011), was used as the theoretical framework for this study. Developed within cognitive psychology, this theoretical framework has been known as the appraisal theory, the transactional theory of stress and coping, and often has been referred to as Lazarus' stress and coping theory. Four major constructs make up the theory, including psychological stress, cognitive appraisal, coping efforts, and health-related outcomes. The impact of psychological stress on human health is a primary focus of the theory.

Psychological Stress

Lazarus and Folkman (1984) define psychological stress as "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" (p. 19). Central to the definition is the idea that stress is neither a static stressor that stimulates the stress process nor a particular reaction resulting from stress and coping processes. Stress is a relationship between the environment and individuals, and a transaction between the person and the context (Lazarus & Folkman, 1984). Lazarus' stress definition represents one of the most modern views of stress (Contrada, 2011). Others share the same views as Lazarus, referring to stress as "a process in which environmental demands tax or exceed the adaptive capacity of an organism, resulting in psychological and biological changes that may place persons at risk for disease" (Cohen, Kessler, & Gordon, 1997, p. 3).

Lazarus' stress definition also clarifies that environmental stimuli are not inherently stressful (i.e., do not necessitate stress responses), but rather are potentially stress-affiliated. External and/or internal demands function as stressors only when taxing or exceeding one's resources as appraised by the person (Lazarus & Folkman, 1984). Another key element implied by the definition is that human beings are able to manage their circumstances based on the resources that they have. Therefore, control and avoidance of stress is possible when effective coping and adaptation is used (Lazarus & Folkman, 1984).

Cognitive Appraisal

Cognitive appraisal is the evaluation of a situation about what the situation implies for the person and the potential of the situation to endanger one's well-being (Lazarus & Folkman, 1984). According to Lazarus and Folkman (1984), appraisal is a "process of categorizing an encounter, and its various facets, with respect to its significance for well-being" (p. 31). Two types of appraisal are included in the theory, including primary appraisal and secondary appraisal. Primary appraisal is primary evaluation of a situation about what the situation implies for the person. The person may ask him/herself, for example, "Am I in trouble or being benefited, now or in the future, and in what way" (Lazarus & Folkman, 1984, p. 31). Consequently, the situation may be appraised as an issue irrelevant to oneself, a benign/positive trigger to one's well-being, or, a stressful situation. As described by Lazarus and Folkman (1984), a secondary appraisal becomes relevant as the condition is appraised as stressful. Secondary appraisal concerns an evaluation of one's capability for coping with the threat, or an assessment of available options and resources for coping. In this type of appraisal, the person might ask, for example, "What if anything can be done about it" (Lazarus & Folkman, 1984, p. 31). Based on this evaluation, the event or situation can be either defined as a harm/loss in which damages have already resulted, a threat that may lead to future harm or loss, or a challenge that has potential for one's future growth or gain. Lazarus and Folkman (1984) have noted that a sense of personal control over the situation is critical to the above positive perceptions. Individuals are likely to encompass a perception of challenges as opposed to threats when a sense of personal control is developed (Lazarus & Folkman, 1984).

In addition to primary appraisal and secondary appraisal, Lazarus and Folkman (1984) further defined personal or situational factors that may influence appraisal. Individual ability and self-efficacy beliefs have been identified as important to primary appraisal. Personal goals and values that the person holds to be important have been suggested to be important antecedents of appraisal. In addition, existential beliefs, "such as faith in God, fate, or some natural order in the Universe" (Lazarus & Folkman, 1984, p. 77) have also been identified as important to one's appraisal. For example, individuals who have faith in God may have more sense of control over the situation, and thereby be more likely to appraise the situation as a challenge as opposed to a threat. In judging a situation, relevant factors include the "novelty, predictability, uncertainty, nearness, duration, and ambiguity" of the event (Smith & Kirby, 2011, p. 197). For example, a person is less likely to gain a sense of control of situations that are new and uncertain to the person as compared to situations with which he/she is familiar.

Coping

Coping efforts are made in response to stress appraisal (Lazarus & Folkman, 1984). As defined by Lazarus and Folkman (1984), coping consists of "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Lazarus and Folkman (1984) have emphasized that coping efforts in the theory should not be confounded with the outcomes of coping or lay usage of coping in which coping means a person is doing well in managing a difficult situation.

A primary focus of coping is on the management of the situation and the reduction of stress, and is referred to as problem-focused coping (Lazarus & Folkman, 1984). Problem-focused coping is "the management of the problem that is causing the distress", including acting on the situation to reduce the problem, seeking social support, or quitting (Folkman & Lazarus, 1984, p. 188). Otherwise, emotion-focused coping may be employed, which refers to "the regulation of distress" resulting from the problem (Folkman & Lazarus, 1984, p. 188). According to Lazarus and Folkman (1984), possible emotional coping includes denial, avoidance, distraction, self-blame, reinterpretation, reappraisal, wishful thinking, minimization of the problem, or magnification of the problem. The purpose of coping is to reduce or avoid stress, however, Lazarus and Folkman (1984) have noted that coping efforts used by individuals may either reduce or increase emotional distress. Effective coping includes both the management of negative feelings or emotions and the alteration of the problem, but the problems that underlie certain types of stressful encounters are not amenable to change. For coping to be effective, there must be a good match or fit between coping efforts and other agendas, including values, goals, commitments, beliefs, and preferred styles of coping (Lazarus & Folkman, 1984).

Lazarus and Folkman (1984) further described factors that influence coping. One especially key factor is the sense of personal control over the situation. As described by

Lazarus and Folkman (1984), problem-focused coping is more likely to be used in situations when the person is confident about the ability to alter the situation, whereas emotion-focused coping is more likely to be used when the person has little confidence in their ability. Thus, persons who have a sense of control over the situation are likely to perceive the situation as a challenge as well as necessitate problem-focused coping as opposed to emotion-focused coping. As for persons who lack personal control, the situation is likely to be a threat to the person, in which emotion-focused coping is likely to be used (Lazarus & Folkman, 1984). Personal ability and dispositional factors (e.g., optimism and self-efficacy) that promote one's sense of control contribute to problem-focused coping, decreasing the use of emotion-focused coping (Lazarus & Folkman, 1984).

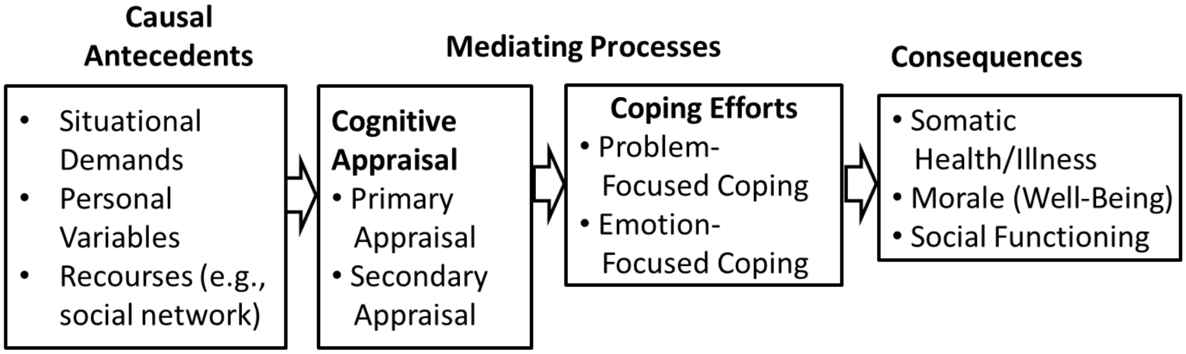
Consequences/Outcomes

A major concern of Lazarus' theory is on the impact of stress on one's health and social functioning. According to Lazarus and Folkman (1984), ineffective coping could directly cause changes in one's physiology, affect or emotion, and/or impair health by impeding adaptive health/illness-related behaviors, such as chronic-disease self-management. In addition, individuals under stress may reduce or abandon previous healthy behaviors (e.g., regular physical exercise and a well-balanced diet), or even commit risky health behaviors, such as stressful eating, smoking, alcohol and drug abuse (Lazarus & Folkman, 1984). When the stress continues over the long term, significant consequences can be expected in one's somatic health /illness, morale, well-being, and social functioning which is defined as one's fulfillment of various roles, for example, as a parent, spouse (Lazarus & Folkman, 1984).

In summary, psychological stress is an overarching concept that consists of these variables and processes, including antecedents (environmental stimuli), mediating processes (appraisal and coping), and consequences (somatic health/illness, morale, well-being, and social functioning) (Lazarus & Folkman, 1984). In the process of stress and coping, the person and the environment continue affecting each other reciprocally under the mediation of appraisal and coping. In addition, appraisal and coping continuously influence each other throughout an encounter that leads to new appraisals or reappraisals, which, in turn, engender further coping efforts (Lazarus & Folkman, 1984). See Figure 1 for Lazarus and Folkman's (1984) stress and coping theory.

Figure 1

Lazarus and Folkman's (1984) Stress and Coping theory.



Hypotheses of this Study

Based on Lazarus and Folkman's (1984) theoretical framework, the theoretical relationship of variables in this study was established and shown in Figure 2. As indicated in the figure, the following hypotheses of this study were proposed. The literature review in chapter 2 presents a detailed discussion about how these hypotheses are supported by research findings on family caregiving.

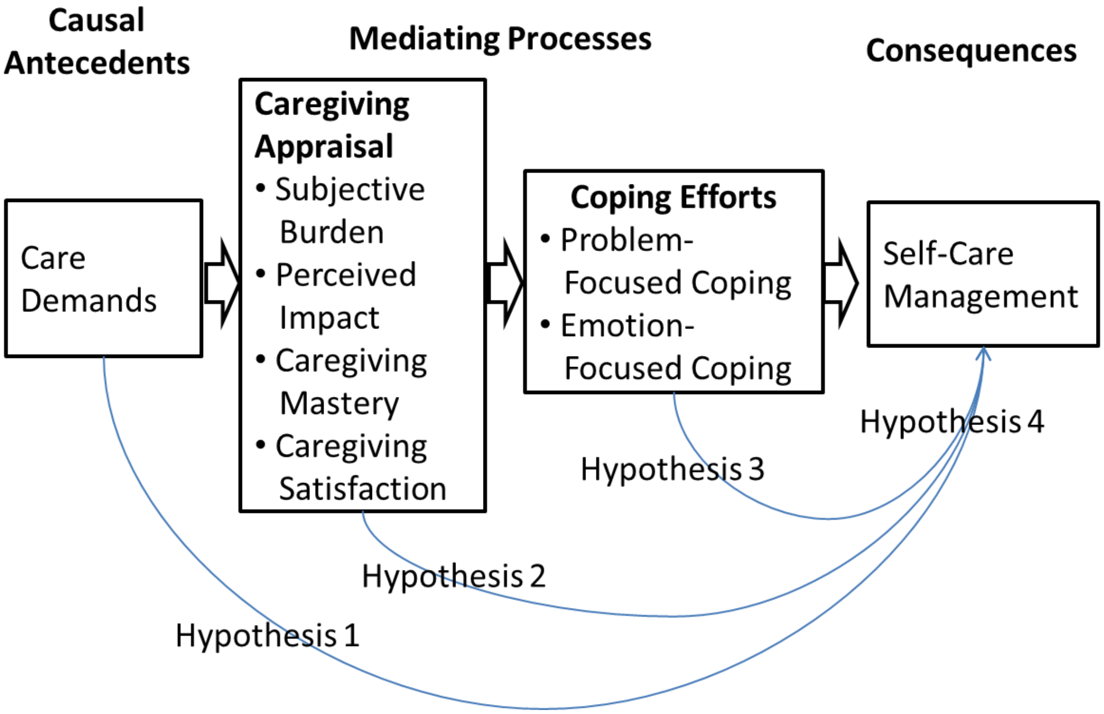
Hypothesis 1: A significant relationship will exist between care demands and caregiver self-care management, that is, care demands will be negatively related to caregiver performance of self-care management.

In previous research, negative health behavior change has been found to be significantly related to care demand, specifically, ADL tasks ($r = .72$), on-duty hours ($r = .33$), and caregiving duration($r = .18$). Caregivers who assisted with ADL activities were significantly impaired in time for rest, exercise, and rest for recovering from illness, and were more likely to miss taking medication than non-caregivers and caregivers who assisted with IADL only (Burton, Newsom, Schulz, Hirsch, & German, 1997). Taking no action was one of the most frequently used self-care strategies in caregivers of persons with ADRD (Lu & Austrom, 2005). Care demands, therefore, are expected to be negatively related to caregiver performance of self-care management.

Hypothesis 2: A significant relationship will exist between caregiving appraisal and caregiver self-care management, that is, positive caregiving appraisal (caregiving satisfaction and mastery) will be positively related to caregiver self-care management, while negative appraisal (caregiving burden and perceived environmental impact) will be negatively related to caregiver self-care management.

Figure 2

Caregiver Stress and Coping Model



In previous research, McKinney (2000) has found that self-care capability of caregivers of cancer patients was related to subjective threat appraisal (r= -. 35). Subjective burden has been found to be related to negative health behavior (r= .24) (Gallant & Connell, 1997). Studies also found positive behavioral changes in caregiver health and self-care were attributed to improved changes in caregiver self-efficacy toward caregiving (i.e., mastery) (Savundranayagam & Brintnall-Peterson, 2010). Negative apprisal (caregiver burden), therefore, is expected to be related to less self-care, while positive appraisal, specifically mastery, is related to greater performance of self-care management by caregivers.

Hypothesis 3: A significant relationship will exist between coping and self-care management, that is, problem-focused coping will be positively related to caregiver self-care management, while emotion-focused coping will be negatively related to the performance of self-care management by caregivers.

In a study, Mjelde-Mossey and colleagues (2004) found that caregivers who used self-controlling and distancing coping were more likely to abuse alcohol, and those who used confrontive coping were more likely not to have alcohol abuse. Therefore, problem-focused coping is expected to be positively related to caregiver self-care management, while emotion-focused coping is expected to be negatively related to the performance of self-care management by caregivers.

Hypothesis 4: Care demands, caregiving appraisal, and coping will significantly predict the performance of self-care management by caregivers of persons with ADRD.

In previous research, care demands, specifically, on-duty hours, caregiving duration, and ADL tasks, have been found to be the significant predictors of negative health-related behavior change in caregivers of persons with ADRD (Gallant & Connell, 1997). Care demands, therefore, are expected to be the predictor of the performance of self-care management by caregivers of persons with ADRD.

Previous studies also found that caregiving appraisal, especially, negative appraisal-caregiving burden, was a predictor of negative health-promotion self-care activities, explaining 95% of variance (Sisk, 2000). Caregiving burden was the significant predictor of negative change in five health-related behaviors (alcohol consumption, exercise, sleep, smoking and weight maintenance) among caregivers of persons with ADRD (Gallant & Connell, 1997). Caregiving appraisal, therefore, is expected to be a predictor of the performance of self-care management by caregivers of persons with ADRD.

The study of Mjelde-Mossey and colleagues (2004) found that caregivers who used self-controlling and distancing coping were more likely to abuse alcohol, and those who used positive reappraisal or confrontive coping were more likely not to have alcohol abuse. Coping, therefore, is expected to be a predictor of caregiver performance of self-care management.

Conceptual and Operational Definitions

Independent variables included in this study are care demands, caregiving appraisal, and coping. Caregiver self-care management is the single outcome variable. To provide clear semantic understanding of these concepts, the following section will present conceptual and operational definitions of each variable in this study.

Care Demands

According to Lazarus and Folkman (1984), stressors are stimuli that “produce a stressful behavioral or physiological response” (p. 15). Any life encounters, events and situations can be sources of stress according to the theory. For research purposes, however, Contrada (2011) identifies the importance of differentiating major stressful stimuli from other social-contextual factors and personal dispositions that may also serve as stressors, suggesting the most influential stressor would be the focus of research examination. Discussion about what may comprise major/primary stressors in the situation of ADRD caregiving can be found in the literature. Kinney and Sthephen (1989), for example, suggested stressors associated with ADRD caregiving are mainly the attributes of the person with ADRD, relevant familial relationships, and assistance with activities of daily living (ADL) (e.g., bathing, dressing, grooming, and laundry). Pearlin (1990) identified primary stressors of ADRD caregiving as “the needs of patients and the nature and magnitude of the care demands by these needs” (p. 587).

Over the two decades, consensus has been reached in the literature that characteristics of the person with ADRD are the most stressful demand to caregivers, consisting of functional, cognitive/memory, and behavioral status of the person with ADRD (Gaugler et al., 2003; Lai, 2010; Lawton, Moss, Hoffman, & Perkinson, 2000;

Nikzad-Terhune et al., 2010; E. Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Schulz & Martire, 2004; van den Wijngaart, Vernooij-Dassen, & Felling, 2007). For caregiver outcomes, however, actual caregiving hours could be another important indicator of care demands in addition to the measure of characteristics of care recipients (Gaugler, Kane, & Newcomer, 2007; Lawton et al., 2000; Schulz & Martire, 2004).

Conceptual definition.

In this study, care demands were defined as the situational demands put on the caregiver due to the impairment of the person with ADRD in memory, behavior, and physical function. Empirical indicators included (1) care-recipient frequency of memory and behavioral problem, (2) level of dependency in activities of daily living (ADL) and instrumental activities of daily living (IADL), and (3) time ADRD caregivers spent on caregiving.

Operationalization.

Care demands were operationalized by two standard measures: the Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992) and the Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969), along with two additional questions: (1) how many hours do you spend on caregiving during a typical week in the past month, and (2) how long (months) have you been a primary caregiver. The 24-item RMBPC was to assess care-recipient frequency of memory and behavioral problem. Caregivers were asked to indicate if any of described problems (e.g., asking the same question over and over, threats to hurt oneself) have occurred during the past week based on a 4-point Likert-scale (0 = never occurs, and 4 = occurs daily or more often). Higher scores indicate more memory and behavioral problem. The 14-item PSMS is to measure the number of activities of ADL and IADL that the care-recipient could carry on (independency), or need assistance (dependency). The ADL had six items (activities), including toilet, feeding, dressing, grooming, physical ambulation and bathing, while the IADL had eight items (activities), including using telephone, shopping, cooking, laundry, housekeeping, transportation, managing medications and finances. For each care recipient, the number of activities of ADL and ADL that need assistance was summed, indicating the person's level of dependency in ADL and IADL.

Caregiving Appraisal

According to Lazarus and Folkman (1984), primary appraisal is "an assessment of what is at stake and how much it matters". For example, to what extent there could be harm to one's physical health, safety, job goals, important relationships, financial security, or emotional well-being" (p. 315). Secondary appraisal is the person's evaluation of coping options or available resources regarding the extent to which "something can or cannot be done to alter the troubled person-environment relationship" (p. 316). Cognitive appraisal is "largely evaluative, focused on meaning or significance, and takes place continuously during waking life" (p. 31). Appraisal mediates the relationship between a stressor and the person's well-being.

Conceptual definition.

Caregiving appraisal in this study was thus defined as caregivers' cognitive evaluation (appraisal and reappraisal) of caregiving stressors/demands and an assessment of one's coping efforts related to caring for a person with ADRD (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Dimensions include subjective burden, perceived behavioral/environmental impact, caregiving mastery and caregiving satisfaction.

Caregiving burden is a major dimension of caregiving appraisal, referred to as caregivers' emotional distress regarding the impact of caregiving on their physical, psychological, and social life, including the experience of poor health, isolation, feeling of end-of-hope, loss of control on life and personal time, fatigue, and being nervous or depressed (Lawton et al., 1989). Perceived impact is caregivers' perception about how caregiving affects "one's social life, activities, work, and so on" (Lawton et al., 1989, p. 62). In later work by Lawton et al. (2000), this dimension was referred to as perceived environment impact, including the impact on personal privacy, having friends over, and relationships with other family members. Caregiving satisfaction is positive feelings evoked from caregiving, such as pleasure, affirmation, or joy in being with the person (Lawton et al., 1989). Caregiving mastery is personal self-efficacy and expectations about one's capability in handling problems and care demands, reflecting "a positive view of one's ability and ongoing behavior during the caregiving process" (Lawton et al., 1989, p. 62).

Operationalization.

The Revised Caregiving Appraisal Scale (RCAS) (Lawton et al., 2000) was used to measure caregiving appraisal by caregivers of persons with ADRD. The 24-item instrument covered areas: (1) caregiving burden (9 items), for example, "Your health has suffered because of the care you must give your loved one", and "You are isolated and alone as a result of caring for your loved one", (2) perceived environmental impact (3 items): "Caring for your loved one does not allow you as much privacy as you would like”, and “You are uncomfortable about having friends over because of your loved one”, (3) caregiving satisfaction (6 items): “You really enjoyed being with your loved one”, and “Your loved one’s pleasure over some little thing gives you pleasure”, and (4) caregiver mastery (6 items): “I feel able to handle most problems in care of my loved one”. Negative appraisal consisted of the sum of (1) caregiving burden and (2) perceived behavioral/environmental impact, with higher scores indicating more burden and negative impact. Positive appraisal consisted of the sum of (3) caregiving satisfaction and (4) caregiving mastery, with higher scores indicating more satisfaction and mastery toward caregiving.

Coping

Along with appraisal, coping mediates the relationship between the stressor and the person. Lazarus and Folkman (1984) defined coping as cognitive and behavioral efforts made to manage environmental demands that are appraised as stressful. Problem-focused coping, such as trying to come up with solutions, gathering information, making a plan, and taking actions, was focused on the management of the situation to reduce the problem. Emotion-focused coping, such as seeking emotional support, distancing, avoiding, positive thinking, and self-blame, was directed at regulating emotions that result from stressful situations. However, Lazarus and Folkman (1984) pointed out that a coping strategy may have multiple functions in practice. That is, either reducing problems, regulating emotion, or both. The actual function of certain action of coping, therefore, should be based on a careful examination of the context (Lazarus & Folkman, 1984). Researchers might keep the categories of functions (i.e., emotion-focused and problem-focused coping) in mind as a general guide, but were not advised to force coping actions to one category or the other, especially when difficulty occurs in doing so. Also, the effectiveness of a coping strategy in reducing psychological stress depends on situations and subjects (Lazarus & Folkman, 1984).

Conceptual definition.

Coping in this study referred to as caregivers' cognitive and behavioral efforts to manage care demands associated with ADRD that are appraised as stressful. Specifically, four types of coping strategies that are indicated by the literature significant to caregiving outcomes, were measured in this study, including active/problem-solving coping (Kim, Chang, Rose, & Kim, 2012; Kneebone & Martin, 2003; Pattanayak, Jena, Vibha, Khandelwal, & Tripathi, 2011), positive reframing/interpretation (Kierod, 2008), denial (Pattanayak et al., 2011) and acceptance (Kneebone & Martin, 2003).

Operationalization.

The BRIEF COPE inventory (Carver, 1997) was used as a measure of caregiver coping. Four coping factors are covered by 8 items of the instrument: (1) active/problem-solving coping, for example, "I've been concentrating my efforts on doing something about the situation I'm in", (2) positive reframing/interpretation, for example, "I've been trying to see it in a different light, to make it seem more positive", (3) denial, for example, "I've been saying to myself 'this isn't real.' ", and (4) acceptance, for example, "I've accepted the reality of the fact that it has happened". Participants were asked to indicate the frequency with which each strategy is used at a 4-point Likert scale (1= I haven't been doing this at all, 4= I've been doing this a lot). Higher scores indicated the more use of the coping strategy by caregivers.

Self-Care Management

Terms of self-care and self-management have been widely used in the field of health care, but no universal definitions for both terms exist (Barlow, 2012). The difference between both terms is unclear. Some researchers separate self-care from self-management, and define self-care as autonomous actions (Eastwood, 2002), or, preventive lifestyle changes (Clark, 2003) performed by healthy individuals for the improvement of health. Changes in nutrition, exercise, sleeping, weight control, and smoke cessation were proposed examples of self-care. Correspondingly, self-management was considered to be more disease-focused requiring interactions with health professionals (Eastwood, 2002). Self-management consisted of activities undertaken by individuals with chronic diseases and conditions, such as diabetes, hypertension, arthritis, and depression, to minimize the impact of the disease on one's health (Gallant, 2003; Redman, 2005; Lorig et al., 2006).

However, researchers also use both terms interchangeably. Hounsgaard (2011), for example, referred to self-management as general actions taken by caregivers for health promotion. Self-care was also defined as activities performed in chronic-disease management, such as "the decisions and actions taken by someone who is facing a health problem in order to cope with it and improve his or her level of health" (Health Canada, 1997, p.49). The World Health Organization (WHO) (2009) further combined the two terms, and defined self-care to include both health promotion, disease prevention, and disease control and management (WHO, 2009). Therefore, Barlow (2012) concluded that over time the boundaries between the two terms have become blurred. Given the fact

ADRD caregivers need to practice a variety of range of health-related behaviors for the improvement of health, a term of self-care management thus was employed by the study.

Conceptual definition.

Self-care management in this study was defined as activities and abilities of caregivers of persons with ADRD to “promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health-care provider” (WHO, 2009, p. 17). Related dimensions consisted of (1) caregivers’ self-care activities in health promotion (exercise, nutrition and health responsibility-an active sense of accountability for one’s own well-being, such as paying attention to health information and bodily cues of health (Walker, Sechrist, & Pender, 1987)), and (2) self-management activities toward disease control and prevention, including adhering to the use of medications, and actively using health care services and resources via appointments.

Operationalization.

Caregivers’ health-promoting behaviors in the domains of health responsibility, physical activity, and nutrition, were measured by 26 items of the Health-Promoting Lifestyle Profile II (HPLPII) (Walker et al., 1987). Examples of items included “get enough sleep”, “Eat 2-4 servings of fruit each day”, “Follow a planned exercise program”, and “Report any unusual signs or symptoms to a physician or other health professional”. Participants were asked to indicate the frequency with which each behavior is engaged at a 4-point Likert scale (1=never, 4=routinely). Higher scores indicated the use of more self-care by caregivers.

Caregivers’ adherence of medication and performance in keeping appointments with health care professionals were measured by scales adapted from the Hill-Bone

Blood Pressure Compliance Scale (HBBPC) (Kim, Hill, Bone, & Levine., 2000). Medication taking subscale focuses on measuring caregiver adherence to medications, which has six items, e.g., “How often do you forget to take your medications?” and “How often do you decide not to take your medications?”. Appointment keeping subscale has two items: (1) “How often do you miss scheduled appointments?” , and (2) “How often do you get the next appointment before you leave the clinic?” (1=never, 5=very frequently). Higher scores in both scales indicate poorer performance in self-care management by caregivers. Conceptual and operational definitions of all study variables are displayed in Table 1.

Table 1. *Conceptual Definitions and Operational Definitions of study Variables*

Variables	**Conceptual Definitions**	**Operational Definitions**
Predictor Variables: Care demands	The situational demands put on the caregiver, including (1) care-recipient frequency of memory and behavioral problem, (2) level of dependency in ADL and IADL (i.e., number of activities of ADL and IALD that need assistance), and (3) time ADRD caregivers spent on caregiving: caregiving duration and on-duty hours per week.	(1) Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992), (2) Physical Self-Maintenance Scale (PSMS) (Lawton & Brody**,** 1969), and (3) measured by two questions: (a) how many hours do you spend on caregiving during a typical week in the past month, and (b) how long (months) have you been primary caregivers.
Caregiving appraisal	Caregivers' cognitive evaluation of caregiving stressors/demands and an assessment of one's coping efforts related to caring for a person with ADRD, including (1) subjective burden, (2) perceived environmental impact, (3) caregiving mastery and (4) caregiving satisfaction (Lawton et al., 1989).	The Revised Caregiving Appraisal Scale (RCAS) (Lawton et al., 2000).
Coping	Caregivers' cognitive and behavioral efforts to manage care demands associated with ADRD that are appraised as stressful, including active coping, positive reframing, denial and acceptance.	The Brief COPE Inventory (Carver, 1997).
Outcome Variable: Self-care management	Caregivers' activities and abilities to "promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health-care provider" (WHO, 2009, p. 17), including (1) caregivers' self-care activities in health promotion (nutrition, physical activity and health responsibility) , and (2) disease control and prevention (medication taking and appointment keeping).	(1) The Health-Promoting Lifestyle Profile II (HPLPII) (Walker et al., 1987), and (2) the adapted Hill-Bone Blood Pressure Compliance Scale (aHBBPC) (Kim et al., 2000).

CHAPTER 2. LITERATURE REVIEW

In this section, an overall review of the utilization of Lazarus and Folkman's (1984) theory in family caregiving of persons with ADRD will be included first. Following that, specific review about concepts identified within the theoretical framework will be discussed, including care demands, caregiving appraisal, coping and caregiver self-care management. This review of literature will provide an understanding of selected concepts and key findings in the literature on family caregiving.

A search of literature for the last 5 years was conducted in the electronic databases of CINAHL with keywords of "care stressors/demands", "appraisal", "coping", "self-care", "self-management" and "dementia". Selection of literature was based on congruence of these studies with conceptualization by Lazarus and Folkman (1984). Earlier classic work was also included.

The Utilization of the Theory in Caregivers of Persons with ADRD

Lazarus' theory has been extensively used in the context of family caregiving (Lawton et al., 2000; R. Schulz & Martire, 2004), in which caregiver burden is defined as an external demand that has potential to be appraised as a stressor (Kinney & Stephens, 1989; Robinson, 1983). Within the framework, factors that contribute to subjective burden of caregivers of persons with ADRD have been investigated by a number of studies. Lazarus and Folkman's (1984) stress and coping process is also instrumental in investigating why women suffered more from caregiving than men. Within the framework, Yee and Schulz (2000) found that female caregivers were at higher risk for each stage of the stress process compared to men. Female caregivers tended to spend more time and provide more intensive care to care recipients, and consequently, perceived more burden and strain, yet women were reluctant to use respite care and services, but employed avoidance-coping and likely engaged in increased religious activities as a mean of coping (Navaie-Waliser, et al., 2002; Yee & Schulz, 2000).

The theory has also become the dominant theoretical model in the care of persons with ADRD for the design of family interventions (Schulz & Martire, 2004). Interventions have been designed within Lazarus' framework to improve caregiver health, such as the Coping Effectiveness Training Program (Lévesque et al., 2002), as well as combinations of group-support and individual home-visits (van den Heuvel et al., 2002). In a systematic literature review, Boschen et al. (2007) found that interventions focusing on improving the skills of problem-solving and crisis-coping were most effective in decreasing caregiver anxiety, depression, perceived stress and burden.

Based on the theory, Schulz and Martire (2004) developed the Stress and Health Model for guiding the use of interventions in ADRD caregivers. Schulz and Martire (2004) link various interventions to each stage of the stress process of Lazarus. For example, approaches of pharmacologic treatment, family counseling, and social support are recommended for minimizing the impact of potential stressors. Efforts of social support, education, and skills training are advised to help families with a positive appraisal of care demands and an improvement of adaptive capabilities. Recommended strategies for effective coping include skills training, self care, preventive health services and communication. An empirical study found that a combined effort for stress reduction was the most effective approach to improve caregiver health, and a combination of education, support, and referrals significantly decreased the level of depression among caregivers and the frequency of behavior problems in persons with ADRD (Robinson, Myers, & Buckwalter, 2013).

Care Demands

The most frequent examined relationship about care demands is the association of care demands with negative appraisal (i.e., caregiver burden, a major dimension of caregiving appraisal, and perceived environmental impact). Caregiving burden concerns caregivers' emotional distress resulting from caregiving (Lawton et al., 1989), also described as emotional strain (Fischer, 2011), "negative emotional appraisals of care demands" (Gaugler et al., 2007, p. 40), and the pressure, strain, or tension a caregiver experiences while caring for a person with ADRD (Chappell & Dujela, 2008; van den Wijngaart et al., 2007). Perceived environmental impact concerns the influence of caregiving on caregivers' social involvement and use of physical spaces in the house, referred to as activity restriction (being restricted from social and recreational activities) (Mausbach et al., 2012) and physical strain (Kim et al., 2012).

In a national study of 302 individuals randomly selected from seven states of the U.S., Kim et al. (2012) examined the multidimensional predictors of caregiver burden in caregivers of persons with ADRD. The mean age of the sample was 47.1 (SD = 15.4) years, including 57% female, 75% Caucasian, 12.6% African-American, 47% adult children caregivers, and 5.9% spouse caregivers. The mean age of persons with ADRD was 70.9 (SD = 19. 8) years, 68% were female, and they required an average number of 1.96 (SD = 2.09) in assistance with ADL and an average number of 4.33 (SD = 1.90) in assistance with IADL. Caregiver burden in the study was operationalized by three questions concerning physical strain, emotional stress and financial hardship as a function of caregiving (1 = not at all, 5 = very much), which actually represented both aspects of negative appraisal (i.e., caregiver burden and perceived behavioral/environmental impact) in Lawton et al.'s (1989) definition. Results indicated that caregiver burden (and perceived environmental impact) was positively related to caregivers age, female caregiver, spousal caregiver or co-residence with care-recipients (r = .13, .13, .23, .34, respectively), together explaining 15% of total variance together. Caregiving hours were significantly correlated to caregiving burden (and perceived behavioral/environmental impact) (r = .50), explaining 11% of variance on burden (and perceived behavioral/environmental impact) along with the number of helpers and the use of coping strategies. Caregivers experienced greater burden (and perceived more environmental impact) as the level of dependency of the person with ADRD in ADL and IADL increased (r = .27 and .46, respectively), accounting for 16% of total variance. Individually, dependency in IADL explained the most variance of caregiver burden (and perceived behavioral/environmental impact), followed by caregiving hours, co-residence, coping strategies, dependency in ADL, spousal caregiver, and female caregiver. Care-recipient level of dependency in ADL and IADL were the most significant predictors of caregiver burden (and perceived behavioral/environmental impact) followed by caregiving hours and caregiver sociodemographic factors (Kim et al., 2012).

In a nationally representative community-based study, Fisher et al. (2011) examined the impact of caregiving on caregivers of persons with ADRD (n = 120). Like the study by Kim et al. (2012), most caregivers of this study were Caucasian (66%), female (71%) and adult children of care recipients (55%) with a mean age of 60.1 (SD = 14.4) years. The mean age of the care recipients was 84.5 (SD = 3.7) years, and number of limitations in ADL was 3.3 (SD = 1.2) in IADL was 3.9 (SD = .9). Results of the study indicated that frequency of behavioral problems predicted caregiver emotional strain (i.e., caregiver burden in Lawton et al.'s (1989) definition) and hours spent in caregiving. Care-recipient cognitive/memory impairment was the predictor of caregiver depressive symptoms (Fisher et al., 2011).

Similarly, in a sample of 339 family caregivers of elderly, Lai (2010) found that care-recipient health status, dependency in ADL and IADL, and caregiver appraisal had direct predictive effects on caregiver burden. When controlled for other factors, family caregivers who provided more care in ADL and IADL and to care recipients with more illnesses experienced a significantly higher level of caregiving burden. The effect of care demands on burden was also significantly moderated by the appraisal of caregivers (Lai, 2010). In another sample of 107 ADRD caregivers, Lim et al. (2011) found that caregivers overall reported high levels of burden. Caregiver burden was positively associated with care-recipient behavioral problems and stage of dementia, both of which were significant predictors for burden, explaining 38% of total variance. Yet, unlike Kim et al., (2012), none of the caregiver characteristics (e.g., age, gender, ethnicity, relationship, marital status, education, employment, care duration, co-residency) was associated with burden in Lim et al. (2011). Differences in study settings and populations may be one possible reason.

In a study of 95 spousal ADRD caregivers, van den Wijngaart et al. (2007) examined the influence of caregiving stressors, appraisal and caregiver characteristics on burden. Results of the study indicated that caregiving burden was significantly related to dementia-related problem of care recipients, instrumental support (homecare, adult day care, or night respite care) caregivers received, as well as caregiver personal characteristics of gender, health status and self-efficacy over caregiving (van den Wijngaart et al., 2007). In particular, women and unhealthy caregivers tended to report more burden than men and healthy caregivers. Compared to others, caregivers who appraised caregiving as a threat were more likely to report increased burden.

The literature indicates that the association of care demands with caregiver burden has been well examined in the literature. There exists consensus regarding the predictive effects of care demands for burden, specifically, care-recipient behavioral problems, stage of dementia and level of dependency in ADL and IADL were the most significant predictors of burden. In addition, a number of other factors were influential, including the time caregivers spent on caregiving, co-residence status as well as such caregiver characteristics as poor health, female gender and spousal status. These findings provide support to Hypothesis 1 of this study: care demands will be negatively related to caregiver performance of self-care management.

Caregiving Appraisal

As defined before, caregiving appraisal includes negative aspects of caregiver burden and perceived environmental impact and positive aspects of caregiving mastery and satisfaction. Subjective burden and perceived negative impact as a negative outcome of caregiving has been largely examined by researchers in relationship to care demands/stressors as discussed in the previous section. Therefore, the review of literature in this section was focused on research findings about the positive aspects of appraisal, including caregiving mastery and satisfaction.

Caregiving Mastery

The mediating effect of caregiving mastery on subjective burden has been of great interest to recent researchers. With a sample of 200 spousal caregivers to people with Alzheimer's disease, Pioli (2010) investigated the mediating effects of global and caregiving mastery on the impact of care demands and subjective burden on depressive and anxious symptoms of caregivers. Closely related to self-efficacy and locus of control, global mastery was defined as sense of personal control over life and measured by a five-item scale, a shortened version of seven-item mastery scale developed by Pearlin and Schooler (1978). Caregiving mastery concerns caregivers' sense of control over the specific caregiving situation and was measured by parallel items used in the global measure, for example, "I have little control over the problems that arise in caregiving", and "There is really no way that I can solve some of my caregiving problems". Care demands, including dependency in ADL and frequency of problem behaviors, and subjective burden were all significantly and positively related to depression. The effect of global mastery was not significant, but the mediating effect of caregiving mastery was significant, suggesting that caregiving mastery functions as a moderator in the relationship between role strain and captivity (i.e., subjective burden and perceived impact) and depression and anxiety. Caregiving mastery buffered the deteriorating impact of subjective burden on depression and anxiety (Pioli, 2010).

In a sample of 126 spouse caregivers of patients with ADRD, Mausbach et al. (2012) examined how personal mastery (Pearlin & Schooler, 1978), coping self-efficacy, activity restriction (i.e., perceived behavioral/environmental impact), and avoidance coping mediated the relationship between care demands (i.e., care recipient problem behaviors), role overload (i.e. subjective burden) and depressive symptoms. Greater subjective burden was significantly related to more depressive symptoms. Lower personal mastery and coping self-efficacy as well as higher activity restriction (i.e., perceived behavioral/environmental impact) and avoidance coping also predicted greater subjective burden. These four factors mediated the relationship between subjective burden and depressive symptoms (Mausbach et al., 2012).

In a sample of 167 family caregivers of persons with ADRD, Romero-Moreno et al. (2011) examined how caregiver specific self-efficacy in managing problematic behaviors moderated the relationship between frequency of problematic behaviors and subjective burden, and how the relationship between subjective burden and caregivers' depression and anxiety was buffered by caregiver self-efficacy in controlling upset reactions toward problematic behaviors of care recipient. Perceived self-efficacy was measured using two corresponding subscales of the Revised Scale for Caregiving Self-efficacy (Steffen et al., 2002). Results indicated that the relationship between frequency of problematic behaviors and burden was not moderated by caregiver self-efficacy about their ability in managing these behaviors (Romero-Moreno et al., 2011), suggesting self-efficacy did not affect objective problematic behaviors of care recipient that was a source of subjective burden. However, high self-efficacy about one's ability in controlling upsetting reactions did moderate the link between subjective burden and depression and anxiety while caregivers' levels of burden are high. Thus, self-efficacy in controlling upset reactions decreased the level of burden and in turn reduced caregiver depression and anxiety (Romero-Moreno et al., 2011).

In conclusion, positive aspects of caregiving are relatively new in the literature. Studies predominantly focused on the functions of caregiving mastery in mediating caregiver subjective burden, depression and anxiety. Research on the effects of mastery on caregiver self-care management is limited. Existing studies overall revealed a positive effect of mastery on caregiving outcome, which is consistent with Lazarus and Folkman's (1984) theoretical directives and provides support to Hypothesis 2 of this study: caregiving mastery will be positively related to caregiver self-care management.

Caregiving Satisfaction

As defined before, caregiving satisfaction refers to positive feelings experienced from caregiving (Lawton et al., 1989). Researchers also referred to caregiving satisfaction as "rewards and benefits" (Fisher, 2011), gain (Liew et al., 2010; Lim, Griva, Goh, Chionh, & Yap, 2011) and perceived gains/values of providing care (Lai, 2010).

Very few studies have examined the impact of caregiving satisfaction on caregiving outcomes. Factors that predict caregiver rewards and gains are of great interest to researchers, though the number of studies is still limited. In a nationally representative community-based study, Fisher et al. (2011) examined factors that were related to personal rewards in caregivers of persons with ADRD (n =120). Items describing caregiving rewards or benefits were developed into five items including feelings of being useful, closer to the care recipient, good about oneself, being able to handle most problems, and that care was effective in preventing care recipients from getting worse (1 = yes, 0 = no). Results indicated that 98.3% of caregivers reported caregiving was somewhat rewarding with a mean of 4.1 (SD = 1.2). Results also indicated that assistance with ADL, such as toileting, led to lower feelings of gain, while assistance in IADL, such as help managing financial issues, was related to higher feelings of gain (Fisher et al., 2011). This suggests higher load of caregiving demands was related to lower satisfaction or gain. In another study with 95 caregivers of people with primary malignant brain tumor, Sherwood et al. (2007) found that care recipients' problem behaviors predicted caregiver mastery as measured by the adapted personal mastery of Pearlin and Schooler (1978); higher numbers of problem behaviors related to lower caregiver mastery.

In 334 caregivers (94.6% Chinese, and 71% females), Liew et al. (2010) investigated factors that were related to gain in caregiving of persons with ADRD. The proposed gain included (1) personal growth (patience, strength, self awareness, knowledge), (2) feelings of being closer to care recipient and family members), and (3) positive change in life philosophy and spiritual growth. Regression analysis indicated that three factors were significantly associated with gains including mental health of the caregiver, use of active coping (i.e., efforts to safeguard, assist, engage, stimulate and monitor care recipients), and participation in caregiver education and support group, explaining 32.3% of total variance in gain (Liew et al., 2010).

The above studies provide helpful insight into factors that are associated with rewards and gains from caregiving. These findings are instrumental in designing interventions for improving caregiver positive views over caring for the person with ADRD. Yet, how increased satisfaction further leads to other positive changes in caregivers, such as self-care management, needs to be explored further though a positive relationship seems likely.

Coping

In ADRD caregiving research, coping is often dichotomized into problem-focused coping and emotion-focused coping. In the study by Van Den Wijngaart et al. (2007), for example, coping was divided into problem-solving (problem-focused coping) and palliative reactions (emotion-focused coping), both of which were found not to be related to caregiving burden. Similarly, Riedijk et al. (2006) classified coping factors to active coping (e.g., considering several solutions and listing all the points) and passive coping (e.g., seeking distraction and trying to relax). The study investigated caregiver burden, health-related quality of life and coping in 29 frontotemporal (FTDH) dementia (the second most prevalent dementia) caregivers and 90 ADRD caregivers. Results indicated that both FTDH and ADRD caregivers made the most use of active coping strategies and least use of passive coping strategies. Passive coping was associated with increased burden (explaining 31% of variance) and decreased health-related quality of life (explaining 37% of variance of mental component of quality of life) (Riedijk et al., 2006).

How researchers define modes of coping also depends on the actual measure in use. By the Coping Orientations to Problems Experienced scale (COPE; Carver, 1969), for example, Coolidge et al. (2000) grouped coping into three styles: problem-focused coping, emotion-focused coping, and dysfunctional coping. Problem-focused coping consists of active coping (e.g., “I’ve been taking action to try to make the situation better”), planning (e.g., “I’ve been thinking hard about what steps to take”), restraint coping (e.g., “I hold off doing anything about it until the situation permits”), use of instrumental support (e.g., “I’ve been getting help and advice from other people”), and suppression of competing activities (e.g., “I put aside other activities in order to concentrate on this”). Emotion-focused coping consisted of religion, humor, acceptance, positive reinterpretation and growth, and seeking social support for emotional reasons. Variables under dysfunctional coping included behavioral disengagement (giving up/quitting), denial, self-distraction, self-blame, focus on and venting of emotions, and substance use. Using the COPE measure (Carver, 1969), Cooper et al. (2006) investigated the coping strategies and anxiety in 126 family ADRD caregivers living in the community. The results indicated that greater use of dysfunctional coping strategies significantly predicted caregiver anxiety and depression (Cooper et al., 2006).

With another measure, the Ways of Coping (WAYS) developed by Folkman & Lazarus (1985), four coping factors were identified in a cross-cultural sample of ADRD caregivers (110 from Shanghai, China, 139 from California, US) (Shaw et al., 1997). These factors were referred to as behavioral confronting (e.g., “Brought the problem on myself”), behavioral distancing (e.g., “Talk to find out more about it”), cognitive confronting (e.g., “Sometimes just bad luck”), and cognitive distancing (e.g., “Made light of the situation”).

Contrary to the above categorization, studies often examined specific coping actions without fitting them in one or the other category. Pattanayak et al. (2011), for example, examined positive coping (problem-solving) and its relationship to quality of life in 32 ADRD caregivers. The study found that positive coping positively correlated to better mental health. Caregiver characteristics, instead of the severity of dementia, determined caregiver coping styles and quality of life: the higher education of the caregiver, the more use of problem-solving and acceptance as well as the decreased use of denial (Pattanayak et al., 2011). Similar findings were also found in another study by Papastavrou et al. (2011) in 172 ADRD caregivers. Positive coping was significantly related to decreased caregiver burden and depression. Coping also mediated the effect of the care stressor on caregiver depression (Papastavrou et al., 2011).

Unlike the above findings, a negative relationship between active coping and burden was found in a prior study. With 302 individuals randomly selected from seven states of the U.S., Kim et al. (2012) examined the impact of active coping on subjective caregiver burden. Active coping in the study referred to talking to and seeking advice from friends or relatives, exercising, talking to a professional or spiritual counselor, praying, going on the Internet to find information, reading about caregiving in books or other materials and taking any kind of medications. Results of the study indicated that caregivers who used more active coping strategies had higher levels of burden ($r = .41$, $p < .01$) rather than lower burden as appeared in other studies (Pattanayak et al., 2011; Papastavrou et al., 2011). One possible reason may be the higher baseline stress level among those caregivers. Caregivers who had more stress were more likely to take coping actions compared to those with lower stress (Kim et al., 2012). This finding provides important insight into the relationship between coping and burden. As populations and settings change, studies need to include the baseline levels of burden and coping in the analysis and conclusion.

In addition to active coping, impact of acceptance on caregiving outcomes were also examined in the literature. A general tendency was noted in the literature that problem-solving and acceptance coping is beneficial to caregivers of persons with ADRD (Kneebone & Martin, 2003). Accepting the situation and emphasizing the positive were found to be associated with higher positive affect and self-rated health among 95 female caregivers of persons with ADRD (Kierod, 2008). The effects of positive reframing (or, positive reappraisal, confrontive coping) were also examined in previous studies (Mjelde-Mossey et al., 2004). Results indicated that positive reframing was important to caregivers. Compared to those who used self-controlling and distancing coping, caregivers who used positive reappraisal were less likely to be an abuser of alcohol (Mjelde-Mossey et al., 2004).

By contrast, studies indicated that the use of denial and avoidance was detrimental to caregiver health. In a longitudinal study, Power et al. (2002) followed 51 non-depressed caregivers for two years to investigate the effects of avoidance on depressive symptoms of caregivers. Avoidance coping was significantly associated with caregiver onset of depression. Similarly, another study also found that the use of avoidance led to increased depression for caregivers (Kierod, 2008). In addition, avoidance was related to lower life satisfaction and higher subjective burden (Di-Mattei et al., 2008; Sun, Kosberg, Kaufman, & Leeper, 2010). Denial was negatively related to physical and psychological quality of life (Pattanayak et al., 2011).

In summary, the literature revealed that active coping, acceptance and positive reframing overall are beneficial to caregivers, whereas denial was detrimental to caregiving situation. This result provides support to Hypothesis 3 of this study: problem-focused coping, specifically active coping, will be positively related to caregiver self-care management, while emotion-focused coping, including positive reframing, acceptance and denial, will be negatively related to the performance of self-care management by caregivers.

Self-Care Management

This section is focused on caregiver self-care management activities as a function of care demands. Given the scope and variety of definitions used for self-care and self-management, the review is divided into two sections: (1) self-care management in general without specifications, and (2) specific self-care management by caregivers, including health promoting self-care and chronic-disease self-management.

Impact of Caregiving on Caregivers’ General Self-Care Management

Qualitative findings.

A number of qualitative studies have discussed self-care by caregivers in general without the identification of specific self-care activities. Hounsgaard and colleagues (Hounsgaard et al., 2011) interviewed ten female caregivers about caregiver experiences of living with a partner with Parkinson disease and particularly their attention to personal health-“self-care management”. The study found that women caregivers knew about the importance of self-care, but set their own life aside to care for the care recipient. Those caregivers dropped hobbies, exercise, and getting together with friends in favor of the need of the care recipient (Hounsgaard et al., 2011). In ar grounded-theory study, Furlong and Wuest (2008) examined the management of self-care needs among spousal ADRD caregivers (*n* = 9). The findings indicated that ADRD spouse caregivers often did not identify the need to care for self until critical events or health declines were experienced. A concept of self-care worthiness emerged from the study, indicating caregivers started to pay attention to their own health and to restore self-care activities. Following the increased awareness of self-care, caregivers retrieved a focus on self, made plans and engaged in self-care (Furlong & Wuest, 2008).

However, another focus-group interview by Lindsay (2009) indicated that caregiving demands independently compromise caregivers' ability to cope and manage diseases no matter whether caregivers are aware of their self-care needs or not. With 53 individuals having multiple chronic diseases, the study identified that slightly more than half of participants (*n* = 28) were able to cope and adjust in the face of multiple-diseases. Those who cared for others (either dependent children or an ailing spouse), however, often encountered greater difficulty in stabilizing their illness. They discussed how their symptoms were secondary compared to meeting the needs of others within their family. Some discussed caring for a spouse who had even more disabling conditions than they did, so they did not have time to manage their own illness effectively (Lindsay, 2009).

Quantitative findings.

Difficulty in maintaining general self-care was also noted in 31 family caregivers of cancer patients (McKinney, 2000). Within Lazarus and Folkman's (1984) framework, McKinney (2000) examined relationship between care demands, caregiver preparedness, hardiness, appraisal, general self-care capability, and caregiver depression and anxiety. Appraisal and self-care capability functioned as mediators in the study. The results indicated that self-care capability was related to subjective threat appraisal (*r* = - . 35) but not correlated to objective care demands as measured by time spent in assistance with care-recipient symptoms (McKinney, 2000). The study, therefore, provides empirical evidence to Hypothesis 2 of the proposed study**:** negative appraisal is negatively related to caregiver self-care management.

Impact of Caregiving on Caregiver Specific Self-Care Management

Health promotion activities.

Only a few studies over the last 10 years examined health-promotion self-care activities in caregivers, referring to actions taken to “improve health, maintain optimal functioning, and increase general well-being” (Acton, 2002, p. 73). With a sample of 169 spouse and 156 adult children ADRD caregivers, Savundranayagam and Brintnall-Peterson (2010) examined the impact of increased self-efficacy in caregiving on the decrease in caregiver health risk behaviors and increase in self-care behaviors. A psychoeducational intervention was administered in the study, consisting of strategies of skills mastery, modeling, reinterpretation of feelings and attitudes about caregiving, and persuasion. The results indicated that after the intervention there was a significant decrease in caregiver risk behaviors (e.g., fewer missed appointments with the doctor, fewer postponed regular checkups and exams, and decreased unhealthy eating) and a significant increase in caregiving self-efficacy and self-care behaviors (e.g., exercise, stress management, and relaxation). Behavioral changes in health and self-care were attributed to improved change in caregiving self-efficacy (Savundranayagam & Brintnall-Peterson, 2010). Findings of the study add to the empirical support for Hypothesis 2 of the proposed study. Positive appraisal, specifically mastery, is related to greater performance of self-care management by caregivers.

Acton (2002) compared 46 family caregivers with 50 demographically matched non-caregivers in their frequency of engagement in activities of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. The results indicated that caregivers scored significantly lower on all measures of health promotion except on nutrition and number of medications. Health-promotion self-care was a protector for reducing the impact of caregiving stress on caregiver well-being (Acton, 2002). In a sample of 121 female caregivers of the elderly, Sisk (2000) examined the relationship between subjective caregiving burden and health-promoting behaviors, consisting of self-actualization, health responsibility, exercise, nutrition, interpersonal support, and stress management. The findings indicated that subjective burden was the only significant predictor of the mean score of health-promotion activities, accounting for 95% of the variance. Age and objective burden (i.e., changes on time, privacy, finance, and relationships with others) were significant predictors of exercise of caregivers, while age and subjective burden (e.g., worry, feeling guilty and depressed) predicted nutrition (Sisk, 2000). Subjective burden also predicted caregiver scores in self-actualization and health responsibility subscales. Gender and relationship to care recipient appear to be impacting factors as well. Male caregivers scored low on health responsibility scales and adult child caregivers were more likely to work on stress management (Sisk, 2000).

Several studies in the 1990s also provided critical insight into self-care management in caregivers of persons with ADRD. Gallant and Connell (1997) investigated five health behaviors (alcohol consumption, exercise, sleep patterns, smoking and weight maintenance) with a sample of 233 older adult spouse caregivers. The findings indicated that a majority of caregivers slept less after caregiving began, and reported weight changes. Specifically, nearly half of female caregivers and 13% of male caregivers gained weight since caregiving started. Caregivers aged 65 or younger were more likely to report weight gain than caregivers 65 years or older who either lost weight or had no weight change (Gallant & Connell, 1997). Negative health behavior change is significantly related to self-efficacy for both self- and spouse care (*r* = - .32 and - .25, respectively), duration of caregiving (*r* = .18), on-duty hours (*r* = .33), ADL tasks (*r* = .72), social support (*r* = - .18), caregiver subjective burden (r= .24), and depression (*r* = .40). Multiple regression results indicated that significant predictors of negative behavior change included on-duty hours, caregiving duration, ADL tasks, caregiving burden, health locus of control, self-efficacy for both self-care and spouse care and depression, explaining 31% of total variance (Gallant & Connell, 1997).

Burton (1997) compared preventive health behaviors between 434 spouse caregivers of community-dwelling older adults and 385 demographically matched non-caregivers. Results indicated that only caregivers who assisted with ADL activities were significantly impaired in time for rest, exercise, and rest for recovering from illness, and were more likely to miss taking medication than non-caregivers, while caregivers who assisted with IADL were not different from non-caregivers. Caregivers when compared to non-caregivers were not different in the missing of meals, doctor appointments, flu shots, and refilling of medications (Burton et al., 1997).

These studies add empirical support to Hypothesis 1: care demands are negatively related to caregiver performance of self-care management (Burton et al., 1997; Gallant & Connell, 1997; Sisk, 2000), Hypothesis 2; negative appraisal/burden is negatively related to caregiver self-care (Gallant & Connell, 1997), and Hypothesis 4: care demands significantly predict the performance of self-care management (Gallant & Connell, 1997); caregiving appraisal predicts self-care management of caregivers (Sisk, 2000)).

Chronic-disease self-management.

Very few studies have been conducted to examine the impact of caregiving on chronic-disease self-management of ADRD caregivers. Lu (2005, 2007) investigated general responses or actions taken by 99 ADRD caregivers in coping with physical and psychological symptoms, ranging from skin rash and nervousness to chest pain and depression. Self-care responses included staying in bed, changing diet, taking medication, asking for professional help, praying, using a home remedy, and doing nothing. Results indicated that the most frequently used self-care actions were using medication (37%), taking no action (34%), asking for professional help (19%), praying (13%) and using home remedies (11%) (Lu & Wykle, 2007). Family caregivers with a high level of depression reported more symptoms than those with a low level of depression but were less likely to ask for professional help (Lu & Austrom, 2005). For both groups, taking no action was one of the most frequent responses to symptoms (41% per symptom for the group with a high level of depression, 37% per symptom for the group with a low level of depression, and no significant difference between the groups) (Lu & Austrom, 2005).

Evidence in the literature is limited about the impact of ADRD caregiving on caregiver self-management of chronic diseases, but the decrease in chronic-disease management of caregivers has been identified in diabetic grandmothers. With a sample of 68 African-American diabetic women, who were either caregivers or non-caregivers, Carthron (2009) examined the impact of caregiving on caregiver’s diabetes self-management and outcomes. Compared to pre-caregiving, a significant reduction was found in caregivers’ weekly days of eating a healthy diet and number of self-managed blood glucose tests (Carthron, 2009). Those caregivers also reported poorer performance than non-caregivers in weekly self-managed blood glucose tests and annual eye exams. Comparison also indicated that caregivers had poorer diabetic health as evidenced by higher systolic and diastolic pressure and urine protein than non-caregivers (Carthron, 2009). Along with Lu & Austrom (2005), this study findings are a further support to the Hypothesis 1 (care demands is negatively related to caregiver performance of self-care management), and the Hypothesis 4 of this study (care demands predict caregiver performance of self-care management).

Summary of Literature

The literature on family caregiving was reviewed according to care demands, appraisal, coping and self-care management. The review indicated that most caregiving studies have dealt with the impact of caregiving on caregiver burden or depression, not self-care management. Research studies have also examined caregiver coping and its impact on burden, self-rated health, depression and psychological well-being. A few studies have investigated the impact of care demands and caregiving burden on caregiver health risk behaviors and health promotion self-care, but were primarily in the absence of illness and diseases on caregivers and were not based on Lazarus and Folkman’s (1984) theory. This review of literature demonstrated the need to examine the impact of care demands, appraisal and coping on caregiver’s self-care management within Lazarus and Folkman’s (1984) theoretical framework as well as in the context that most caregivers have chronic diseases and conditions.

CHAPTER 3. METHODS

Research questions and hypotheses derived from the theoretical framework were utilized using the following methodological approach. The present chapter discusses research design, sample, criteria of inclusion and exclusion, settings, procedures for data collection, instrumentation, and data analysis.

Design

A cross-sectional, descriptive, and correlational study design was used to examine the research questions of this study. Variables were described and relationships identified among care demands, appraisal, coping and caregiver self-care management. Major predictors of self-care management were investigated.

Sample

Informal caregivers of persons with ADRD who lived in a large southern Midwestern city were the population of interest. Inclusion criteria were participants who self identified as (1) being the primary caregiver for at least one year, (2) caring for a person who has received a medical diagnosis of ADRD, (3) was providing care at home, and (4) were age 21 years or over. Caregivers who were unable to communicate effectively in English were excluded.

Sample Size

Three major predictors (i.e., care demands, caregiving appraisal and coping) of self-care management were examined in the study (Hypothesis 4: care demands, caregiving appraisal, and coping will significantly predict the performance of self-care management by caregivers of persons with ADRD). Based on a common rule of thumb for sample size (five to ten participants per predictor) (Peduzzi et al., 1996), 30 caregivers of persons with ADRD were needed with 10 participants per predictor. To improve the fit of the regression model, thus, a sample of 45 caregivers of persons with ADRD was recruited for the study.

Settings

The main recruitment sites included the Geriatric clinic of the University of Louisville (UofL) Department of Geriatric and Family Medicine and the UofL Department of Neurology, as well as other clinics and other sites where care and support are given to caregivers. Home health agencies and senior centers surrounding a large midwestern city were also used.

Procedures for Data Collection

Before data collection, approval of the Health Science Center Institutional Review Board (IRB) at University of Louisville was obtained. Second, agreement by the clinic/department directors occurred with clinic doctors and nurses being asked for help with recruitment, including identifying potential participants and providing information about the study. For those who were interested in the study, the researcher verified their eligibility and arranged an interview at a place and time of convenience to the caregiver. At the beginning of the interview, a written informed consent was obtained, followed by the paper-and-pencil questionnaire for data collection.

Instrumentation

Demographic Data

Demographic information of caregivers and care-recipients was obtained, including date of diagnosis, age, gender and stage of dementia of care recipient, and caregiver personal information of age, gender, race, marital status, education, employment, relationship to the person with ADRD, general health, health compared with before the beginning of caregiving, numbers of chronic diseases and health problems, number and type of medications under use, and number and type of appointments scheduled with health care professionals during the past 12 months. Early stage of dementia was defined as memory loss only, middle stage was characterized as memory loss as well as wandering and agitation, whereas characteristics of late stage of the disease include incontinency, speech unintelligibility and bedbound.

The independent and dependent variables were assessed via the following instruments. The correspondence between instruments and variables is shown in Table 2.

Independent Variables

The Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992). The 24-item scale was to assess care-recipient frequency of memory and behavioral problem. Caregivers were asked to indicate if any of described problems (e.g., asking the same question over and over, threats to hurt oneself) had occurred during the past week based on a 4-point Likert-scale (0 = never occurs, and 4 = occurs daily or more often). Higher scores indicated more problems of care recipients in memory and behavior.

Reliability and validity: Internal consistency Cronbach's alphas were .75 for Memory-Related Problems, .82 for Depression, and .62 for Disruptive Behaviors. Factor analysis confirmed 3 first-order factors, consistent with the subscales just named, and one general factor of behavioral disturbance. Overall scale reliability was good, with alphas of .84 for care-recipient behavior. Subscale alphas ranged from .67 to .89 (Teri et al., 1992). Validity of the instrument was confirmed through comparison of RMBPC scores with well-established indexes of depression, cognitive impairment, and caregiver burden. The frequency sub-scale was correlated with the Hamilton Rating Scale for Depression (r=.44, p<.01), and Mini Mental State Examination score for the person with ADRD was correlated with the Memory Problems sub-scale (r=-.48, p<.01) (Teri et al., 1992).

The Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969). The 14-item PSMS was used to measure care-recipient level of dependency in 14 activities of ADL and IADL Each item contains one statement (activity) about the care recipient. Caregivers were asked to indicate whether the statement of each item is true (yes = the care recipient is independent in carrying out the activity, no = dependent, the care recipient needs assistance in carrying out the task). For each care recipient, the number of activities of ADL and ADL that need assistance was summed, representing the person's level of dependency in ADL and IADL. ADL activities had six items, including toileting, feeding, dressing, grooming, physical ambulation and bathing. IADL activities had eight items, including ability to use telephone, shopping, food preparation, housekeeping, laundry, transportation, taking medications, and ability to handle finances. Higher scores on both scales indicated more dependent functional status.

Reliability: Cronbach's alphas were.94 for ADL subscale and .95 for IADL subscale (Lawton & Brody, 1969).

The Revised Caregiving Appraisal Scale (RCAS) (Lawton et al., 2000). The RACS had 24 items concerning caregiving appraisal by caregivers of persons with ADRD. Areas covered included (1) caregiving burden (9 items): "Your health has suffered because of the care you must give your loved one", "You are isolated and alone as a result of caring for your loved one", (2) perceived impact (3 items): "Caring for your loved one does not allow you as much privacy as you would like", and "You are uncomfortable about having friends over because of your loved on", (3) caregiving satisfaction (6 items): "You really enjoyed being with your loved one", and "Your loved one's pleasure over some little thing gives you pleasure", and (4) caregiver mastery (6 items): "I feel able to handle most problems in care of my loved one". The caregiver was asked to specify the amount of agreement with the statement of each item with a 5-point Likert rate (1=not at all, 5=a great deal). Higher scores on these scales indicated more burden, negative impact, satisfaction, or, mastery, respectively.

Reliability and Validity: These four factors were confirmed in four large samples by Lawton and colleagues(1989; 2000), including 239 caregivers of institutionalized persons with ADRD, 632 caregivers of persons with ADRD in the community, 96 women caregivers who were providing care to a parent and 403 veteran caregivers. Cronbach's alpha for Caregiving Burden is .89, Caregiving Satisfaction .87, Caregiving Mastery .73, and Perceived Environmental Impact .78. Test-retest reliabilities range from .75 to .78 among103 caregivers of institutionalized persons with ADRD.

Validity correlations indicated that subjective burden was highly related to summary burden ratings and significantly to all of the other indicators (Lawton et al., 1989).

The BRIEF COPE (Carver, 1997). Four coping strategies (active coping, positive reframing, denial, and acceptance) were measured with corresponding subscales of the BRIEF COPE instrument, two items each and eight items in total. Participants were asked to indicate the frequency with which each strategy was used at a 4-point Likert scale (1= I haven't been doing this at all, 4= I've been doing this a lot). Higher scores indicated the use of more coping strategy by caregivers.

Reliability and Validity. Construct validity of the instrument was validated in 168 participants from a community. Factor analysis produced a similar factor structure to the full version of COPE. Cronbach's alphas of subscales all exceeded .60, except scales of Denial and Acceptance that only met the minimal acceptable level of .50 (Carver, 1997).

Dependent Variables

The Health-Promoting Lifestyle Profile II (HPLPII) (Walker et al., 1987). The HPLPII was used to measure caregivers' health promotion behaviors in the domains of health responsibility (9 items), physical activity (8 items) and nutrition (9 items). Participants were asked to indicate the frequency with which each behavior is engaged at a 4-point Likert scale (1=never, 4=routinely), with higher scores indicating more use of self-care by caregivers. Example items included "get enough sleep", "Eat 2-4 servings of fruit each day", "Follow a planned exercise program", and "Report any unusual signs or symptoms to a physician or other health professional".

Reliability and Validity: Content validity was established by literature review and review of experts. Factor analysis of data from 712 adults aged 18 to 92 years indicated construct validity of the instrument (Walker et al., 1987). A significant relationship was found between scores of the instrument and the Personal Lifestyle Questionnaire (r= .678), and a non-significant correlation with social desirability. Significant correlations were also found with measures of perceived health status and quality of life (r's = .269 to .491). The alpha coefficient of internal consistency for the total scale was .943, ranging from .793 to .872 for the subscales. Test-retest reliability was .892 for the total scale at a 3-week interval (Walker et al., 1987).

The adapted Hill-Bone Blood Pressure Compliance Scale (aHBBPC) (Kim et al., 2000). Caregivers' performance in medication-taking and appointment-keeping were measured by two subscales adapted from the HBBPC. The original 14–item HBBPC was to assess behaviors of individuals with hypertension in three behavioral domains: dietary intake of salty foods (3 items), mediation taking (8 items), and appointment keeping (2 items) (Kim et al., 2000). The adaptation from Hill-Bone Blood Pressure Compliance included (1) five of eight items from the Medication Taking subscale that were relevant to this study's purpose and were selected for use and in each selected item the word of "pills" was replaced with "medications", and (2) two of three items from the Appointment Keeping scale that were relevant to this study's purpose were chosen for use, without any change in item statement. The researcher analyzed the reliability of these items in this study. Higher scores on these items indicated poorer performance in self-care management by caregivers.

Reliability and Validity. Cronbach's alphas of the instrument ranged from .74 to .84 among 480 inner-city men and women (Stephenson, Rowe, Haynes, Macharia, & Leon, 1993). A significant relationship was found between scores of the instrument and blood pressure control (Stephenson et al., 1993). All measures of the study variables are shown in Table 2.

Open-Ended Questions. To help with understanding of quantitative findings, three open-ended questions were asked at the end of the interview: (1) "Has caregiving interfered with your health in any way, such as eating properly, exercising and resting, taking your medications, monitoring your health and going to see the doctor? If so, please tell us how caregiving has affected you managing your health?", and (2) "What do you believe is the most important in helping you manage your health needs?". (3) "I've asked you many questions about your health and self-care management, is there anything I did not ask that I should have asked and that you want to tell me?". Participants were asked to respond to both questions in written format on the provided six lines based on directives of Morse and Field (1995), "respondents tend to write in two-thirds the required space" (p. 105). The interviewer wrote the note if participants were not literate or were uncomfortable expressing themselves in writing.

Table 2

Measures and Numbers of Items of Study Variables (total items: 106)

Variables	Measures	Items
Predictor Variables: Caregiving Demands		
(1) Frequency of memory and behavioral problem	(1) Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992)	24
(2) Level of dependency in ADL and IADL	(2) Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969)	14
(3) Duration of caregiving (4) On-duty hours per week	(3) 2 single questions	2
Caregiving Appraisal	Revised Caregiving Appraisal Scale (RCAS) (Lawton et al., 2000)	
(1) Subjective Burden		9
(2) Perceived Environmental Impact		3
(3) Caregiving Mastery		6
(4) Caregiving Satisfaction		6
Coping	Brief COPE Inventory (Carver, 1997)	8
(1) Active Coping		
(2) positive Reframing		
(3) Denial		
(4) Acceptance		
Outcome Variables: Self-care management		
(1) Physical Activity	(1) Health-Promoting Lifestyle Profile II (HPLPII) (Walker et al., 1987)	26
(2) Nutrition		
(3) Health Responsibility		
(3) Medication Adherence	(2) Adapted Hill-Bone Blood Pressure Compliance Scale (aHBBPC) (Kim et al., 2000)	6
(4) Appointment Keeping		2

Data Analysis

Quantitative Analytical Procedure

Descriptive analysis (i.e., frequency, percentage, mean and standard deviation) were used to describe the sample. Correlational analysis and hierarchical multiple regressions were used to test hypotheses of this study. Cronbach's alpha for each of the standardized instruments in this study was calculated.

The hypotheses of this study were tested as followed:

Hypothesis 1: There will be a significant relationship between care demands and caregiver self-care management as operationalized by a negative relationship between independent variables of (1) frequency of memory and behavioral problems, (2) level of dependency in ADL and IADL, (3) caregiving duration and (4) caregiving hours per week, and dependent variable of caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping. Pearson-product correlations will be implemented to test this hypothesis.
A correlation matrix was constructed among these variables based on the significance of Pearson's correlation coefficients.

Hypothesis 2: There will be a significant relationship between caregiving appraisal and caregiver self-care management as operationalized by a negative relationship between negative appraisal of (1) subjective burden and (2) perceived environmental impact, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping; and a positive relationship between positive appraisal of (1) caregiving mastery and (2) satisfaction, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping.

Pearson-product correlations were implemented to test this hypothesis. A correlation matrix among these variables was obtained based on the significance of Pearson's correlation coefficients.

Hypothesis 3: There will be a significant relationship between caregiving coping and caregiver self-care management as operationalized by a negative relationship between denial and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping; and a positive relationship between coping strategies of (1) active coping, (2) positive reframing and (3) acceptance, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping.

Pearson-product correlations were implemented to test this hypothesis. A correlation matrix was constructed among these variables based on the significance of Pearson's correlation coefficients.

Hypothesis 4: Caregiving demands, caregiving appraisal and coping will be significant predictors of caregiver self-care management. Hierarchical multiple regressions were used to test this hypothesis. Specifically, variables that were significantly correlated to caregiver self-care management activities, as indicated by the results of hypothesis 1-3, were entered into the regression model for each self-care activities, respectively (i.e., physical activity, nutrition, health responsibility, medication adherence, and appointment keeping). Five regression models thus were constructed. Within each model, demographic variables that were correlated to caregiver self-care management were entered first as Block 1. After controlling these socio-demographical factors, care demands variables were entered as Block 2, followed by caregiving appraisal in Block 3 and coping strategies in Block 4, based on Lazarus and Folkman's (1984) theory. A visual explanation of each model along with possible variables is displayed as below.

1. Caregiving medication adherence = Block 1Caregiver demographics (female gender, education and financial status) + Block 2 Care demands (level of dependency in ADL and IADL, caregiving duration) + Block3 Caregiving appraisal (burden/impact) +Block4 Coping (active coping).
2. Caregiver appointment keeping = Block 1Caregiver demographics (female gender, education and financial status) + Block 2 Care demands (level of dependency in ADL and IADL, caregiving duration) + Block3 Caregiving appraisal (burden/impact) +Block4 Coping (active coping).
3. Caregiver physical activity = Block 1Caregiver demographics (female gender, education and financial status) + Block 2 Care demands (level of dependency in ADL and IADL, caregiving duration) + Block3 Caregiving appraisal (burden/impact) +Block4 Coping (active coping).
4. Caregiver nutrition = Block 1Caregiver demographics (female gender, education and financial status) + Block 2 Care demands (level of dependency in ADL and IADL, caregiving duration) + Block3 Caregiving appraisal (burden/impact) +Block4 Coping (active coping).
5. Caregiver health responsibility = Block 1Caregiver demographics (female gender, education and financial status) + Block 2 Care demands (level of dependency

in ADL and IADL, caregiving duration) + Block3 Caregiving appraisal (burden/impact) +Block4 Coping (active coping).

For each model, the overall predicting effects of the overall model with all predictors were obtained, as well as the significance of each block and each variable within the block. Amount of explained variance was also obtained for both the whole model and each individual block. Most influential predictors within each model or concerning each self-care activity were further identified by a comparison of standardized beta scores (regression coefficients) of each predictor.

Analysis of Open-Ended Questions

Responses to open-ended question, (1) “Has caregiving interfered with your health in any way, such as eating properly, exercising and resting, taking your medications, monitoring your health and going to see the doctor? If so, please tell us how caregiving has affected you managing your health?”, (2) “What do you believe is the most helpful in helping you manage your health needs?” and (3) “I’ve asked you many questions about your health and self-care management, is there anything I did not ask that I should have asked and that you want to tell me?”, were analyzed by using the method of thematic analysis of Morse and Field (1995). Data was broken down into parts verbatim for identification of specific themes; similar actions, events and objects were grouped together as categories; common themes/categories were extracted from these categories for a second level of interpretation. Peer debriefing was employed to address the issue of trustworthiness. The chair of the dissertation committee and one committee member who is a doctorally prepared qualitative expert reviewed the data analysis process and how themes were developed.

CHAPTER 4. RESULTS

This chapter describes data analysis and results of this study, including both (1) statistical analysis and findings for quantitative data, and (2) qualitative analysis and findings from open-ended questions. Analysis of quantitative data is presented first, including (a) data preparation, (b) statistical analysis, and (c) study findings. Discussion for the open-ended questions is presented last, including (a) methods used for analysis and (b) results.

Analysis of Quantitative Data

Data Preparation

Before data entry, cases were checked for missing values. All cases satisfied a standard of less than 5% missing values and therefore were all entered into SPSS version 17.0 computer program for analysis. Reversed items on standardized questionnaires were all recoded according to scoring instructions. Mean scores substituted for missing values. Sum of each scale was calculated.

To prepare for further data analysis, extreme scores or outliers of each measure were screened by using the method of box plots based on advocated methods outline in Tukey (1977), i.e., values that are more than three interquartile ranges (IQRs, the range of the values extending from the 25th percentile to the 75th percentile) are defined as extreme outliers, and values between 1.5 and 3 IQRs from the upper and lower edges of the box are minor outliers. No extreme outlying values were identified in this study, although five minor outliers on the variables of care duration, medication adherence and exercise were identified. To preserve potentially important information, univariate minor outliers were retained in the data set, but were substituted with a score one unit smaller (or larger) than the next most extreme score in the distribution to retain their place in the distribution as advocated and outlined in Tabachnick and Fidell (2001).

Statistical Analysis

Descriptive statistical analysis was initially calculated to describe characteristics of the sample as well as major variables of the study (predictors and outcomes). Internal consistency reliabilities (Cronbach's alpha) of standardized instruments were analyzed. Pearson's correlation coefficients were then calculated to test Hypotheses 1-3. Prior to the correlational analysis, all continuous variables were checked for normality. To reduce skewness, variables whose ratio of mean to SD less than 4.0 was transformed (Hair et al., 1998). Specifically, the years of caregiving (care duration) and the scores of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) were transformed using a square root function; the weekly hours of caregiving and the scores of exercise were transformed using a log function. Significant improvement in normal distribution was noticed with the presence of greater ratios of mean to SD compared to pre-transformation as well as the skewness and kurtosis value closer to 0 (Munro, 2005). All analysis was performed at two-tailed sides with an alpha level of 0.05.

Hierarchical multiple regression techniques were used to test Hypothesis 4 of the study. Before developing the model, assumptions of normality and linearity were checked by examining normal probability plots of residual and scatter plots of residuals versus predicted residuals; no violations were detected. Homoscedasticity of residuals was also supported, i.e., for every value of the independent variable, the distribution of the dependent variable has approximately equal variability. To reduce collinerarity, variables that were strongly interrelated were combined. In addition, influential datapoints were detected and deleted based on a recommendation of the value of studentized residuals over 2 and the value of Cook's D greater than .50 (Munro, 2005).

Quantitative Findings

This section presents quantitative findings of this study. Discussion is organized according to (a) description of sample, (b) descriptions of major variables, (c) relationships among variables, and (d) results of hypothesis testing. Cronbach's alphas for standardized instruments in this study are also described and presented following the sample description and each major variable.

Sample Description

Demographic information of the sample is presented in the Table 3. The sample consisted of 45 caregivers of persons with ADRD who were recruited from a University of Geriatric clinic *(n* = 19) and local communities (*n* = 26), including Alzheimer's support groups, churches, internet newsletters and word of mouth.

Demographics of caregivers. Participant caregivers ranged in age from 43 years to 92 years with a mean age of 66.8 ± 10.5 years old. Caregiver relationships to care recipients were 17 (37.8%) adult daughters, 14 (31.1%) wives, 7 (15.6%) husbands, 5 (11.1%) sons and 2 (4.4%) other relationships. The majority of caregivers were married (82.2%), female (68.9%), Caucasian (86.7%), were spouses (46.7%) or a child of the care recipient (48.9%) (Table 3.1). Caregivers were primarily unemployed or retired (64.4%) and had no financial strain caused by caregiving (62.2%). Caregiver average years of education were 14.7 ± 2.4, ranging from 7 years to 20 years. Over three-fourths (75.5%)

of caregivers reported good or excellent general health and about two-thirds (60.0%) indicated that their health was about the same compared to pre-caregiving.

As many as 91.1% of caregivers reported routinely taking medications for health problems or taking vitamins as diet supplement (Table 3.2). The mean number of medications caregivers routinely took was 4.8 ± 2.9. A mean number of 6.0 ± 5.1 medical appointments were reported as in the past 12 months, and 88.9% of caregivers had appointments with health care providers during the same period of time. These appointments were for diagnosing health problems (66.7%) or for routine wellness, physical check-up or health screening (68.9%), as well as for dental (48.9%) or eye appointments (37.8%). In addition, about 91.1% of caregivers reported having chronic diseases, and the mean number of chronic diseases was 2.7 ± 1.9.

Demographics of care recipients. Care recipients were aged 81.4 ± 7.9 years, ranging from 64 to 95 years old and were primarily female (63.6%) (Table 3.3). Approximately 54.5% of care recipients were in the early stage of dementia, 35.6% in the middle stage and 11.1% were in the late stage of dementia.

Table 3. Description of Caregivers and Care Recipients (*n* = 45)

1. Demographics of caregivers

Variables	*n* (%)
Gender	
Female	31 (68.9)
Male	14 (34.1)
Race	
Caucasian	39 (86.7)
African American	6 (13.3)
Marital Status	
Married	37 (82.2)
Others	8 (17.8)
Employment (no)	29 (64.4)
Financial strain (no)	28 (62.2)
Coresidence	32 (71.1)
Relationship	
Spouse	21 (46.7)
Wives	14 (31.1)
Husbands	7 (15.6)
Child	22 (48.9)
Others	2 (4.4)
General Health	
Poor	1 (2.2)
Fair	10 (22.2)
Good	28 (62.2)
Excellent	6 (13.3)
Health Compared to Before	
Worse	12 (26.7)
About the same	27 (60.0)
Better	1 (2.2)
Do not know	5 (11.1)
	Mean ± SD
Age (years)	66.8 ±10.5 *range 43-92*
Education (years)	14.7 ±2.4 *range 7-20*

2. Caregiver medications, appointments and chronic diseases

Variables	Mean ± SD	*n* (%)[a]
Medications	4.8 ± 2.9	41 (91.1)
for health problems	4.0 ± 2.5	41 (91.1)
for diet supply	1.1 ± 1.3	26 (57.8)
Appointments	6.0 ± 5.1	40 (88.9)
for health problems	3.4 ± 4.5	30 (66.7)
for check-ups	1.2 ± 1.1	31 (68.9)
for dental	1.0 ± 1.3	22 (48.9)
for eye	0.5 ± .8	17 (37.8)
Chronic Disease	2.7 ± 1.9	41 (91.1)

a. the number (percentages) of caregivers who routinely took medications or had medical appointments during the past 12 months.

3. Demographic of care recipients

Variables	*n* (%)
Gender	
Female	29 (64.4)
Male	16 (35.6)
Stage of Dementia	
Early	24 (53.3)
Middle	16 (35.6)
Late	5 (11.1)
	Mean ± SD
Age (years)	81.3 ± 7.9
	range 64-95

Descriptions of Major Variables of the Study

Major variables of this study consisted of predictor variables and outcome variables. Predictor variables included care demands, caregiving appraisal and coping. The outcome variable was caregiver self-care management.

Care demands.

Care demands in the study consisted of care duration, weekly caregiving hours, care–recipient ADL dependency (number of ADL activities needing assistance), IADL dependency (number of IADL activities needing assistance) and frequency of problem behaviors. Descriptions of these major variables of the study are presented in Table 4. Caregiver average years of caregiving were 4.4 ± 2.6, ranging from .5 to 12 years. Average caregiving hours per week were 74.1 ± 60.4, ranging from 10 to 168 hours. The mean frequency of problem behaviors was 36.6 ± 16.1, ranging from 10 to 78 (possible range 0-96). The average number of ADL activities that needed assistance was 3.4 ± 2.2, ranging from 0 to 6 (possible range 0-6), while the average number of IADL activities that needed help was 6.2 ± 1.8, ranging from 2 to 8 (possible range 0-8).

*Reliabilities. R*eliabilities of care demands measures have been supported in this study. Cronbach's alpha for the measures of ADL and IADL were .86 and .76, respectively. As for the measures of care-recipient problem behaviors, the reliabilities ranged from .76 to .89 (Table 5).

Table 4. Description of Care Demands

Variables	Mean ±SD
Care duration (years of caregiving)	4.4 ±2.6 *range .5-12*
Weekly caregiving hours	74.1 ±60.4 *range 10-168*
ADL dependency (number of ADL needing assistance)	3.4 ±2.2 *possible range 0-6* *observed range 0-6*
IADL dependency （number of IADL needing assistance）	6.2 ±1.8 *possible range 0-8* *observed range 2-8*
Frequency of care-recipient problem behaviors	36.6 ±16.1 *possible range 0-96* *observed range 10-78*

Table 5. Reliabilities for Standardized Instruments

Scales	Cronbach's alpha in this study	Cronbach's alpha previously reported	# of items
Care-recipient dependency			
ADL	.86	.94	6
IADL	.76	.95	8
Care-recipient problem behaviors			
Memory	.87	.75	7
Depression	.89	.82	9
Disruption	.76	.62	8
Caregiving appraisal			
Burden	.89	.89	9
Impact	.70	.78	3
Mastery	.32	.73	6
Satisfaction	.87	.87	6
Coping			
Active coping	.85	.68	2
Positive reframing	.74	.64	2
Denial	.70	.54	2
Acceptance	.83	.57	2
Self-Care management			
Exercise	.89	.81	8
Nutrition	.74	.76	9
Health Responsibility	.82	.81	9
Medication Adherence	.88	.84	6
Appointment keeping	.13	.74	2

Caregiving appraisal.

Caregiving appraisal in this study included four dimensions: subjective burden, perceived environmental impact, caregiving mastery and satisfaction, measured by 5-point Likert type scales with various numbers of items on each subscale. To retain the 5-point meaningful metric, responses to these measures were summed and then divided by the total number of items as advocated by the developers of the respective instruments.

For example, there were 3 items on the scale of perceived environmental impact, participants were requested to respond to each statement with 1 = not at all, 2 = a little, 3 = moderately, 4 = quite a bit, 5 = a great deal. If one participant responded to these items with 3, 2, 1, respectively, then, (3 + 2 + 1) / 3 = 2 was this person's mean response to this scale. According to the 5-point meaningful metric, the perceived environmental impact by this caregiver was interpreted as "a little". In this way, all participants' mean response to the scale was calculated. Thereafter, the mean (*SD*) response for the whole sample to the measure can be obtained and depicted using the 5-point metric. A mean of 2.2 ±1.0, for example, indicated that the mean level of perceived impact for this sample was "a little". In this way, frequencies (percentages) of participants that rated at "a little" in the sample could be obtained as well as proportions on all five levels. To save space and maintain consistent across measures, responses on 5-point scales were adjusted by combining 4 (= quite a bit) and 5 (= a great deal) together as 4-5 (= a lot).

As shown in Table 6, the majority caregivers reported their level of burden and perceived environmental impact to be "a little" (48.9% and 40.0%, respectively). Over two-thirds (68.9%) had gained a "medium" amount of mastery over caregiving. "A lot" of satisfaction was reported by more than half (53.3%) of caregivers. The mean level of burden for the sample was 2.5 ±.9, which was between "a little" to "medium". The mean level of perceived impact for the whole sample was “a little” (2.2 ± 1.0), and the mean levels of the sample on both caregiving mastery and satisfaction were “medium” (3.0 ± .5 and 3.5 ± 1.0, respectively).

*Reliabilities. R*eliabilities of most measures of caregiving appraisal have been supported in this study, ranging from .70 to .89 (Table 5). One exception was the caregiving mastery scale (Cronbach’s α = .32). A low reliability indicated the caregiving mastery scale was not reliable in measuring the concept in this caregiver population, which was not a surprise since the previous instrumentation study also indicated that the scale was problematic, whose factor structure failed to be confirmed through factor analysis (Lawton et. al., 1989). Continuing instrument development is needed.

Coping.

Coping strategies measured in this study included active coping, positive reframing, denial and acceptance. Given these variables being measured using 4-point Likert scales with two items per scale, mean responses of each caregiver to these measures were calculated using the same methods as described in previous section for caregiving appraisal to retain the 4-point meaningful metric. In this way, the mean (SD) response for the whole sample to these measures was obtained using the 4-point metric. Proportions of participants on all four levels were calculated.

As shown in Table 7, nearly half of caregivers reported using “a lot” active coping (46.7%), one-third used “a lot” of positive reframing, and over half (55.6%) used “a little” amount of denial. The number of caregivers who reported using “a lot” of acceptance was as high as 71.1%. The average use of active coping and acceptance in the

Table 6. Description of Caregiving Appraisal

Variables	Mean ± SD	*n* (%)			
	Range 1-5	*1 No*	*2 A little*	*3 Medium*	*4-5 A lot*
Subjective Burden	2.5 ± .9	3 (6.7)	22 (48.9)	13 (28.8)	7 (15.6)
Perceived Impact	2.2 ± 1.0	14 (31.1)	18 (40.0)	7 (15.6)	6 (13.3)
Mastery	3.0 ± .5	0 (0)	4 (8.9)	31 (68.9)	10 (31.1)
Satisfaction	3.5 ± 1.0	1 (2.2)	7 (15.6)	13 (28.8)	24 (53.3)

Table 7. Description of Coping

Variables	Mean ± SD	*n* (%)			
	Rang 1-4	*1 No*	*2 A little*	*3 Often*	*4 A lot*
Active Coping	3.1 ± .9	0 (0)	12 (26.7)	12 (26.7)	21 (46.7)
Positive Reframing	2.6 ± 1.1	7 (15.6)	11 (24.4)	12 (26.7)	15 (33.3)
Denial	1.5 ± .8	25 (55.6)	15 (33.3)	2 (4.4)	3 (6.7)
Acceptance	3.5 ± .8	2 (4.4)	1 (2.2)	10 (6.7)	32 (71.1)

sample were “often” (3.1 ±.9 and 3.5 ±.8, respectively). The average use of denial in the sample was 1.5 ±.8, between “no” and “a little”. The average use of positive reframing in the sample was 2.6 ±1.1, between “a little” and “often”.

*Reliabilities. R*eliabilities of all coping measures have been supported in this study. Cronbach’s alphas ranged from .70 to .85 (Table 5).

Caregiver self-care management.

Caregiver self-care management was the sole proposed outcome variable in this study, consisting of exercise, nutrition, health responsibility, medication adherence and appointment keeping. Given these variables being measured using 5-point Likert scales with various numbers of items, mean responses of each caregiver to these measures were calculated using the same methods as described in previous sections for caregiving appraisal and coping to retain the 5-point meaningful metric. To save space, responses of 4 (= quite a bit) and 5 (= a great deal) were combined together as 4-5 (= a lot).

As shown in Table 8, as many as 24.4% of caregivers reported “no” physical activities at all, and 53.3% reported only “a little” amount of physical activities. In comparison, concerning caregiver’s performance on nutrition, 51.2% of caregivers reported often paying attention to diet and eating healthy, while another 40.0% reported healthy eating sometimes (i.e., “a little”). As is similar in the health responsibility, half (50.0%) of caregivers reported often taking actions in improving health or obtaining health information and an additional 38.7% responded with “a little”. As for medication adherence, the majority (90.2%) of caregivers responded that they took medications routinely with good compliance, and less than 3% indicated that sometimes they forgot to take their medication as prescribed. For appointment keeping, 87.5% reported they did well (i.e., “often”) in keeping appointments with health care providers, and less than 3% indicated that sometimes they did not keep the appointment.

Overall, caregivers performed better in medication adherence and appointment keeping than exercise, nutrition and health responsibility. A mean score of greater than 4 (= quite a bit) was reported on the former measures (4.4 ± .7 and 4.2 ± .7, respectively). By contrast, mean scores on nutrition and health responsibility were much lower, 2.6 ± .6, 2.5 ± .6, respectively, indicating the performance on both activities was less than “often”. Caregivers report in exercise, however, was the lowest. The related mean score for the whole sample was 1.9 ± .8, indicating physical activities were performed less than “a little”.

*Reliabilities. R*eliabilities of most self-care measures have been supported in this study, ranging from .74 to .89 (Table 5). The only exception was Appointment Keeping (Cronbach’s alpha = .13). This measure only had two items, which somehow contributed to the low reliabilities of the scale. Adapted from the Hill-Bone Compliance to High Blood Pressure Therapy Scale, the scale was primarily used among clients with hypertension. More items that pertain to the caregiving situation are needed to add richness as well as improve the representativeness of the scale in reflecting unique situations caregivers have in appointment keeping.

Table 8. Description of Caregiver self-care management

Variables	Mean ± SD	*n* (%)			
	Range 1-5	*1 Never*	*2 A little*	*3 Often*	*4-5 A lot*
Exercise	1.9 ± .8	11 (24.4)	24 (53.3)	8 (17.6)	2 (4.4)
Nutrition	2.6 ± .6	2 (4.4)	18 (40.0)	23 (51.2)	2 (4.4)
Health Resp	2.5 ± .6	3 (6.8)	17 (38.7)	22 (50.0)	2 (4.5)
Medication	4.4 ± .7	0 (0)	1 (2.2)	3 (7.4)	41 (90.2)
Appointment	4.2 ± .7	0 (0)	1 (2.2)	4 (10.0)	35 (87.5)

Health Resp = health responsibility, Medication = medication adherence, Appointment = appointment keeping.

Correlations among Variables

This section presents Pearson-product-moment correlations among study variables. Discussion is organized according to (a) correlations among demographic variables, (b) correlations between demographic variables and predictor variables, (c) correlations between demographic variables and outcome variables, (d) correlations among predictor variables and (e) correlations among outcome variables. The strength of correlation in this study was described based on the definition of Cohen (1988): a small effect of a correlation coefficient as .10, a moderate correlation effect as .30, and a large effect to be .50.

Correlations among demographic variables.

Significant intercorrelations were found among demographic variables (Table 9). Caregivers with high financial status were potentially less likely to report that health became worse compared to pre-caregiving (r = - .29, p = .05). Caregiver education was potentially associated with good general health (r = .29, p = .05). Spousal status was strongly associated to caregiver age (r = .71, p < .01) and moderately linked to a status of coresidence (r = .42, p < .01). Coresidence was also moderately related to weekly caregiving hours (r = .36, p = .02). Caregiver’s general health was negatively related to worse health, indicating caregivers with poor health were more likely to report that health became worse compared to pre-caregiving (r = - .33, p < .03).

Table 9. Correlations among Caregiver Demographic Variables

Variables	1	2	3	4	5	6	7	8
1 Age	1							
2 Female gender	-.24	1						
3 Education	.05	.06	1					
4 Financial status	.24	-.11	.06	1				
5 Spouse status	.71**	-.13	.06	.26	1			
6 Coresidence	.23	-.12	.03	-.07	.42**	1		
7 General health	.15	-.02	.29	.28	.02	.23	1	
8 Worse health	-.09	.20	.06	-.29	-.07	-.16	-.33*	1

Worse health=health was worse compared to pre-caregiving. * $p < .05$, ** $p < .01$.

Correlations between demographic and predictor variables.

Demographic variables had significant correlations with care demands, caregiving appraisal and coping (Table 10). Female gender was positively related to caregiving satisfaction (r = .30, p = .04) and negatively related to care-recipient IADL dependency (r = - .30, p = .04). Caregiver financial status was moderately and negatively related to burden and perceived impact (r = - .37 and - .38, p = .01 and .01). Spousal status was negatively related to caregiving mastery (r = - . 30, p = .04). Coresidence was positively related to perceived impact (r= .35, p = .02), and was negatively associated with positive reframing (r = - .37, p = .01). Education was negatively associated with the use of denial as a way of coping (r = - .33, p = .02). Caregiver's general health was negatively related to burden (r = - .41, p < .01), whereas positively related to caregiving mastery (r = .35, p = .02). Care-recipient's frequency of problem behaviors was positively related to a report of worse health compared to pre-caregiving (r = .34, p = .02). Worse health was also positively related to burden (r = .43, p < .01), potentially related to less mastery (r = - .29, p = .05), and negatively related to the use of denial in coping (r = -. 33, p = .03).

Table 10. Correlations between Demographic and Predictor Variables

Variables	Age	FG	Ed	FS	SS	CR	General health	Worse health
Problem behaviors	.07	-.22	.17	-.22	.05	-.02	-.07	.34**
ADL dependency	.24	-.14	.15	-.04	.12	.13	-.02	.15
IADL dependency	.24	-.30*	.13	.01	.15	.17	-.15	.20
Care duration	-.01	.10	.13	-.13	.05	-.01	-.09	.21
Weekly hours	.05	-.04	-.20	-.16	.13	.36**	.15	.02
Burden	.03	-.21	-.28	-.37*	.01	.08	-.41*	.43**
Impact	-.26	-.22	.02	-.38*	-.28	.35**	-.28	.28
Mastery	-.20	.07	.15	.02	-.30*	-.07	.35**	-.29
Satisfaction	-.22	.30*	.12	.14	-.19	-.27	-.02	- .07
Active coping	.10	-.02	.23	.13	.11	.01	.10	.02
Positive reframing	-.19	.09	.26	-.19	-.20	-.37*	-.20	.23
Acceptance	-.16	.15	.14	-.21	.23	-.02	.21	.06
Denial	.10	.02	-.33*	.18	.01	.10	.02	-.33*

FG = female gender, Ed = education, FS = financial status, SS = spouse status, CR = coresidence, Worse health = health was worse compared to pre-caregiving. * $p < .05$, ** $p < .01$.

Correlations between demographic and outcome variables.

Significant correlations existed between caregiver demographic variables and self-care management activities (Table 11). Education was positively related to medication adherence (*r* = .32, *p* = .04). Female gender was positively related to nutrition (*r* = .37, *p* = .01). Caregiver's general health was positively related to exercise (*r* = .48, *p* < .01).

Table 11. Pearson's Correlations between Demographic and Outcome Variables

Variables	Age	FG	Ed	FS	SS	CR	General health	Worse health
Exercise	.16	-.04	.25	.24	.23	.13	.48**	-.05
Nutrition	.17	.37**	.23	.29	.28	.05	.13	.10
Health responsibility	.10	.20	.21	.21	.26	.01	.16	.02
Medication adherence	.24	-.20	.32**	.26	.23	.05	.25	-.19
Appointment keeping	.08	-.05	-.15	.11	.25	- .12	- .05	-.25

FG = female gender, Ed = education, FS = financial status, SS = spouse status, CR = coresidence, Worse health = health was worse compared to pre-caregiving. * *p* < .05, ** *p* < .01.

Correlations among predictor variables.

Intercorrelations were found among predictor variables (Table 12). Predictors under examination included care demands, caregiving appraisal and coping. Each predictor has several dimensions or variables. The discussion therefore is organized according to (a) pairwise correlations inside the predictor, and (b) correlations of the predictor outside with other predictors.

Care demands. Within care demands, the study found that care-recipient ADL dependency was strongly related to IADL dependency ($r = .77$, $p < .01$), and moderately associated with care duration ($r = .34$, $p = .02$) and weekly care hours ($r = .33$, $p = .03$). IADL dependency was significantly related to care duration ($r = .33$, $p = .03$) and weekly caregiving hours ($r = .45$, $p < .01$). In addition, care-recipient problem behaviors were moderately related to caregiver burden ($r = .33$, $p = .03$) and satisfaction ($r = - .34$, $p = .02$). Care-recipient dependency in ADL was moderately related to caregiving burden ($r = .39$, $p < .01$) and the use of active coping($r = .33$, $p = .03$). Care-recipient dependency in IADL was related to burden ($r = .44$, $p < .01$) and perceived impact ($r = .30$, $p = .04$). Weekly caregiving hours were also related to burden ($r = .47$, $p < .01$) and perceived impact ($r = .32$, $p = .04$).

Caregiving appraisal. Inside the appraisal total variable, subjective burden was significantly related to perceived environmental impact ($r = .56$, $p < .01$). Caregiving satisfaction was associated with less impact ($r = - .38$, $p = .01$), more mastery ($r = .31$, $p = .03$).

Coping. Within coping variables, positive reframing was significantly related to active coping (*r* = .31, *p* = .03) and acceptance (*r* = .38, *p* = .01). Denial was negatively related to acceptance (*r* = - .36, *p* = .02).

Correlations among outcome variables.

Caregiver self-care management was the sole outcome variable in this study and included five dimensions: nutrition, exercise, health responsibility, medication adherence and appointment keeping. Correlations among these self-care activities are presented in Table 13. Exercise was significantly related to nutrition (*r* = .47, *p* < .01), health responsibility (*r* = .57, *p* < .01) and medication adherence (*r* = .35, *p* = .03). Health responsibility was strongly correlated to nutrition (*r* = .60, *p* < .01). Medication adherence was positively associated with appointment keeping (*r* = .36, *p* = .03).

Table 12. Correlations among Predictor Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13
1 Problem behaviors	1												
2 ADL dependency	.09	1											
3 IADL dependency	.24	.77**	1										
4 Care duration	.21	.34*	.33*	1									
5 Caregiving hours	.01	.33*	.45*	.16	1								
6 Burden	.33*	.39**	.44**	.22	.47*	1							
7 Impact	.25	.26	.30*	.15	.32*	.56**	1						
8 Mastery	-.06	-.06	-.12	.19	-.14	-.15	-.02	1					
9 Satisfaction	-.34*	.01	-.06	.24	-.14	-.28*	-.38*	.31*	1				
10 Active coping	-.16	.33*	.25	-.03	-.08	-.06	-.09	-.12	.25	1			
11 Positive reframing	.18	-.05	.03	.20	-.11	-.02	.08	.01	.16	.31*	1		
12 Acceptance	.01	.05	.07	0.2	.09	-.05	.17	.21	-.04	.03	.38*	1	
13 Denial	.01	-.15	-.25	-0.3	.02	.05	.06	-.06	-.07	-.10	-.04	-.36*	1

* *p* < .05, ** *p* < .01.

Table 13. Correlations among Outcome Variables.

Variables	1	2	3	4	5
1 Exercise	1				
2 Nutrition	.47**	1			
3 Health responsibility	.57**	.60**	1		
4 Medication adherence	.35*	.27	.24	1	
5 Appointment keeping	.02	-.01	.13	.36*	1

* $p < .05$, ** $p < .01$.

Results of Hypothesis Testing

This section presents results of hypothesis testing. Results of each hypothesis are presented followed by the corresponding tables.

Hypothesis 1. There will be a significant relationship between care demands and caregiver self-care management as operationalized by a negative relationship between independent variables of (1) frequency of memory and behavioral problems, (2) level of dependency in ADL and IADL, (3) caregiving duration and (4) caregiving hours per week, and dependent variable of caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping.

To test Hypothesis 1, Pearson's correlation coefficients between care demand and self-care activities were examined. The results are displayed in the Table 14. Based on the significance of correlation coefficients, care-recipient problem behaviors, caregiver's care duration and weekly caregiving hours were found not to be related to any caregiver self-care management activities ($p > .05$). Care-recipient dependency in ADL as well as in IADL were both strongly correlated to caregiver appointment keeping (r = -. 54, - .54, respectively, $p < .01$), and was moderately related to caregiver medication adherence (r = -. 27 and - .32, respectively, p = .04 and .03). Caregiving duration was strongly and negatively correlated with caregiver medication (r = -. 46, $p < .01$). Thus, the results supported this hypothesis, but not strongly.

Table 14. Correlations between Care Demands and Self-Care Variables

Variables	PB	ADL	IADL	CD	CH
Exercise	-.10	-.05	-.09	-.10	-.08
Nutrition	-.18	.01	-.07	-.23	-.06
Health responsibility	-.14	-.16	-.19	-.06	-.15
Medication adherence	-.06	-.27*	-.32*	-.46*	-.24
Appointment keeping	-.14	-.54*	-.54*	-.18	-.12

PB = Problem behaviors, ADL = ADL dependency, IADL = IADL dependency, CD = Care duration, CH = Weekly caregiving hours. * $p < .05$, ** $p < .01$.

Hypothesis 2. There will be a significant relationship between caregiving appraisal and caregiver self-care management as operationalized by a negative relationship between negative appraisal of (1) subjective burden and (2) perceived environmental impact, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping; and a positive relationship between positive appraisal of (1) caregiving mastery and (2) satisfaction, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping.

Pearson-product correlations were implemented to test Hypothesis 2. As shown in Table 15, caregiving burden was found to be negatively related to caregiver exercise (r = - .36, p = .02) and medication adherence (r = - .32, p = .04). No significant relationships were found between mastery and satisfaction with self-care activities. Therefore, similar to above, the results supported this hypothesis, but not strongly.

Table 15. Correlations between Caregiving Appraisal and Self-Care Variables

Variables	Burden	Impact	Mastery	Satisfaction
Exercise	-.36*	-.18	.09	.20
Nutrition	-.27	-.22	-.24	.10
Health responsibility	-.25	-.25	-.03	.22
Medication adherence	-.32*	-.26	-.19	-.06
Appointment keeping	- .13	-.09	-.08	-.13

* $p < .05$, ** $p < .01$.

Hypothesis 3. **There will be a significant relationship between caregiving coping and caregiver self-care management as operationalized by a negative relationship between denial and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping; and a positive relationship between coping strategies of (1) active coping, (2) positive reframing and (3) acceptance, and caregiver performance in (1) physical activity, (2) nutrition, (3) health responsibility, (4) medication adherence, and (5) appointment keeping.**

Pearson-product correlations were implemented to test this hypothesis. Related results are shown in the Table 16. The results indicated that active coping was significantly related to caregiver performance on nutrition ($r = .49$, $p < .01$) and health responsibility ($r = .42$, $p < .01$). Positive reframing was related to health responsibility ($r = .30$, $p < .05$). Acceptance and denial was not significantly associated with any self-care activities. Therefore, the results supported this hypothesis, but not strongly.

Table 16. Correlations between Coping and Self-Care Variables

Variables	Active coping	Positive reframing	Acceptance	Denial
Exercise	.21	.13	.05	.14
Nutrition	.49**	.15	-.03	-.09
Health responsibility	.42**	.30*	.07	.23
Medication adherence	.09	-.10	-.13	.05
Appointment keeping	-.19	- .02	-.12	.17

* $p < .05$, ** $p < .01$.

Hypothesis 4. **Caregiving demands, caregiving appraisal and coping will be significant predictors of caregiver self-care management. Hierarchical multiple regressions were used to test this hypothesis.**

Five regression models were constructed to test this hypothesis. Ten variables that were significantly correlated to caregiver self-care management activities in hypotheses testing 1-3 were identified as predictors. First variables were caregiver demographic variables of education, female gender and financial status; next were care demand variables of ADL and IADL dependency and caregiving duration; then caregiving appraisal variables of caregiving burden and perceived environmental impact, and finally coping approaches of active coping and positive reframing.

As stated earlier, assumptions of normality, linearity, or homoscedasticity of residuals were checked before regression. No violations were found. Influential datapoints were deleted based on a recommendation of the value of studentized residuals over 2 and the value of Cook's D greater than .05 (Munro, 2005). To reduce collinerarity, ADL dependency and IADL dependency, two strongly interrelated variables ($r = .77$, $p < .01$), were combined to be one predictor defined as "living dependency", whereas the perceived caregiving impact was integrated into caregiving burden ($r = .56$, $p < .01$). Therefore the final number of predictors were eight, including three caregiver demographic variables (i.e., education, female gender and financial status), two care demand variables (i.e., living dependency and caregiving duration), one caregiving appraisal (i.e., caregiving burden) and two coping variables (i.e., active coping and positive reframing).

Based on Lazarus and Folkman's (1984) theory, caregiver demographics were entered into regression model first (Block 1). After controlling these socio-demographical factors, care demands were entered into Block 2, followed by caregiving appraisal in Block 3 and coping strategies in Block 4.

Caregiver medication adherence. The results of regressing on caregiver medication adherence are displayed in the Table 17. The overall model was statistically significant, with the eight predictors explaining 53% of total variance in caregiver medication adherence (R^2 (coefficient of determination) = .53, adjusted R^2 = .40, F (8, 31) = 4.31, $p < .01$). Specifically, for Block 1, female gender of caregivers, education and financial status together explained 22% of variance in caregiver medication adherence (R^2 change = .22, F (3, 36) = 3.30, $p = .03$); Block 2, care-recipient living dependency and caregiving duration, explained 29% of variance in caregiver medication adherence, after controlling for caregiver demographics in Block 1 (R^2 change = .29, F (2, 34) = 9.92, $p < .01$). After controlling for demographics (Block 1) and care demands (Block 2), caregiving appraisal (Block 3) and coping (Block 4), however, were not significant for explaining more variance in caregiver medication adherence. Therefore, only the first two blocks of variables (caregiver demographics and care demands) of variables significantly contributed to the variance of caregiver medication adherence.

Through the examination of individual regression coefficients, three variables were identified as significant individual predictors for caregiver medication adherence: caregiver education, caregiving duration and care-recipient living dependency. Standardized regression coefficients (β) were .54 ($p < .01$) for caregiver education, - .37 ($p = .02$) for caregiving duration, and - .42 ($p = .04$) for care-recipient living dependency.

That indicated, when controlling for all the other predictors, one point increase in caregiver education would lead to .54 point increase in caregiver medication adherence. While one point increase in caregiving duration would lead to .37 decrease in medication adherence, and one point increase in care-recipient living dependency would cause .42 point decrease in caregiver medication adherence. Caregiver education thus was the most influential individual predictor for caregiver medication adherence, followed by care-recipient living dependency and caregiving duration.

Table 17. Hierarchical Multiple Regression Analysis on Medication Adherence

Predictors	R^2 Change	*F* ratio for R^2 change	*B*	SE	*β*
Demographics	.22*	3.30			
Female Gender			-2.14	1.13	1.26
Education			.91**	.25	.54
Financial Status			.88	1.08	.13
Care Demands	.29**	9.92			
Living Dependency			-1.57*	.75	-.42
Caregiving Duration			-2.40*	1	-.37
Caregiving Appraisal	< .01	.53			
Burden			.18	.09	.15
Coping	.01	.50			
Positive Reframing			-.26	.32	-.14
Active Coping			.32	.37	.15
R^2(adjusted R^2)	.53 (.40)**	4.31			

* $p < .05$. ** $p < .01$

Caregiver appointment keeping. The results of regression on caregiver appointment keeping are displayed in the Table 18. The overall model was statistically significant with eight predictors together explaining 37% of the total variance in caregiver appointment keeping ($R^2 = .37$, adjusted $R^2 = .21$, $F\ (8, 31) = 2.30$, $p = .04$). Block 1-female gender of caregivers, education and financial status did not significantly contribute to variance in caregiver appointment keeping (R^2 change = .04, $F\ (3, 36) = .43$, $p > .05$). Yet, Block 2, care-recipient living dependency and caregiving duration, significantly explained 32% of the variance in caregiver appointment keeping (R^2 change = .32, $F\ (2, 34) = 8.36$, $p < .01$), after controlling for caregiver demographics in Block 1. Block 3 and 4 (caregiving appraisal and coping) did not significant contribute to the variance in caregiver appointment keeping beyond Block 1 (demographics) and Block 2 (care demands). Therefore, only the second block (care demands) of variables significantly contributed to the variance of caregiver appointment keeping.

Care-recipient living dependency was the only significant individual predictor for caregiver appointment keeping. Yet, the effect of this predictor on appointment keeping was very influential. Standardized regression coefficients (β) of care-recipient living dependency was - .73 ($p < .01$), indicating, when controlling for all the other predictors, one point increase in care-recipient living dependency leads to .73 decrease in caregiver appointment keeping.

Table 18. Hierarchical Multiple Regression Analysis on Appointment Keeping

Predictors	R^2 Change	*F* ratio for R^2 change	*B*	SE	*β*
Demographics	.03	.43			
Female Gender			-.43	.49	-.13
Education			.02	.11	.03
Financial Status			.16	.49	.06
Care Demands	.32**	8.36			
Living Dependency			-1.05**	.31	-.73
Caregiving Duration			.25	.45	.10
Caregiving Appraisal	.02	.94			
Burden			.04	.04	.20
Coping	< .01	.05			
Positive Reframing			-.03	.14	-.05
Active Coping			.05	.16	.05
R^2 (adjusted R^2)	.37 (.21) *	2.30			

* $p <$ .05. ** $p <$ .01

Caregiver physical activity. The results of regressing on caregiver physical activity are displayed in the Table 19. The overall model was not statistically significant (R^2= .22, adjusted R^2 = .04, F (8, 35) = 1.22, p >.05). None of the blocks, Block 1 (demographics), Block 2 (care demands), Block 3(caregiving appraisal) and Block 4 (coping) contributed significantly to the variance in caregiver physical activity. Neither was any significant individual predictors identified for caregiver physical activity. Therefore, the regression model on caregiver physical activity needs further exploration in the future.

Table 19. Hierarchical Multiple Regression Analysis on Physical Activity

Predictors	R^2 Change	*F* ratio for R^2 change	*B*	SE	*β*
Demographics	.14	2.11			
Female Gender			-.03	.05	-.10
Education			.01	.01	.14
Financial Status			.05	.04	.18
Care Demands	.02	.48			
Living Dependency			-.01	.03	-.05
Caregiving Duration			-.01	.04	-.03
Caregiving Appraisal	.03	1.53			
Burden			-.01	.01	-.24
Coping	.03	.61			
Positive Reframing			.01	.01	.10
Active Coping			.01	.02	.12
R^2 (adjusted R^2)	.22 (.04)	1.22			

* $p < .05$. ** $p < .01$

Caregiver nutrition. The results of regression on caregiver nutrition are displayed in Table 20. The overall model was statistically significant with eight predictors together explaining 57% of the total variance in caregiver appointment keeping (R^2= .57, adjusted R^2 = .48, F (8, 36) = 5.98, p < .01). Block 1-female gender of caregivers, education and financial status was significant, explaining 36% of variance in caregiver nutrition (R^2 change = .36, F (3, 41) = 7.69, p < .01). Block 2 (care demands) and Block 3 (caregiving appraisal) were not significant in explaining variance in caregiver nutrition, after controlling for caregiver demographics in Block 1. Block 4 (caregiving coping) significantly explained 17% of variance in caregiver nutrition beyond Block 1 (demographics), Block 2 (care demands) and Block 3 (caregiving appraisal) (R^2 change = .17, F (2, 36) = 7.01, p < .01). Therefore, two blocks of variables (caregiver demographics and coping) significantly contributed to the variance of caregiver nutrition.

Three significant individual predictors were identified for caregiver nutrition, including female gender, financial status, and active coping. Standardized regression coefficients (β) of female gender was .48 (p < .01), for financial status was .28 (p = .03), and for active coping was .44 (p < .01). That indicated, when controlling for all the other predictors, female gender of caregivers leads to .48 decreases in performance of nutrition. One-point increase in financial status leads to .28 point increase in caregiver performance of nutrition, and a one-point increase in active coping leads to .44 point increase in the performance of nutrition. Female gender was the most influential predictor for nutrition, followed by caregiver active coping and financial status.

Table 20. Hierarchical Multiple Regression Analysis on Nutrition

Predictors	R^2 Change	*F* ratio for R^2 change	*B*	SE	*β*
Demographics	.36**	7.69			
Female Gender			4.82**	1.21	.48
Education			.28	.28	.13
Financial Status			2.27*	1.02	.28
Care Demands	.04	1.40			
Living Dependency			-.32	.69	-.07
Caregiving Duration			-1.45	.98	-.18
Caregiving Appraisal	.01	.01			
Burden			.04	.09	.07
Coping	.17**	7.01			
Positive Reframing			.08	.30	.03
Active Coping			1.19**	.35	.44
R^2 (adjusted R^2)	.57 (.48)**	5.98			

* $p < .05$. ** $p < .01$

Caregiver health responsibility. The results of regression on caregiver health responsibility are displayed in the Table 21. The overall model was statistically significant with eight predictors together explaining 44% of the variance in caregiver health responsibility (R^2= .44, adjusted R^2 = .32, F (8, 36) = 5.98, p < .01). The Block 1-female gender of caregivers, education and financial status was significant, explaining 18% of variance in caregiver health responsibility (R^2 change = .18, F (3, 41) = 2.99, p = .04). The Block 2 (care demands) and Block 3 (caregiving appraisal) were not significant in explaining variance in caregiver nutrition, after controlling for caregiver demographics in Block 1. Block 4 (caregiving coping) significantly explained 22% of variance in caregiver nutrition beyond Block 1 (demographics), Block 2 (care demands) and Block 3 (caregiving appraisal) (R^2 change = .22, F (2, 36) = 7.23, p < .01). Therefore, two blocks of variables (caregiver demographics and coping) significantly contributed to caregiver health responsibility.

Two significant individual predictors were identified for predicting caregiver health responsibility, including care-recipient living dependency and caregiver active coping. Standardized regression coefficients (β) of care-recipient living dependency was -.40 (p = .03), and for active coping was .45 (p < .01). That indicated, when controlling for all other predictors, a one-point increase in care-recipient living dependency leads to .40 points decrease in caregiver performance of health responsibility, and one-point increase in active coping leads to .45 point increase in the performance of health responsibility. Active coping was the most influential predicator for health responsibility, care-recipient living dependency was the next.

Table 21. Hierarchical Multiple Regression Analysis on Health Responsibility

Predictors	R^2 Change	*F* ratio for R^2 change	*B*	SE	*β*
Demographics	.18*	2.99			
Female Gender			2.05	1.63	.17
Education			.36	.37	.14
Financial Status			2.34	1.37	.24
Care Demands	.03	.85			
Living Dependency			-2.14*	.93	- .40
Caregiving Duration			.54	1.32	.06
Caregiving Appraisal	.01	.07			
Burden			.09	.13	.12
Coping	.22**	7.23			
Positive Reframing			.41	.41	.14
Active Coping			1.44**	.48	.45
R^2 (adjusted R^2)	.44 (.32)**	3.54			

* $p <$ .05. ** $p <$ .01

Qualitative Analysis of Open-Ended Questions

Analysis Procedures

Responses to open-ended question, (1) “Has caregiving interfered with your health in any way, such as eating properly, exercising and resting, taking your medications, monitoring your health and going to see the doctor? If so, please tell us how caregiving has affected you managing your health?”, (2) “What do you believe is most important in helping you manage your health needs?” and (3) “I’ve asked you many questions about your health and self-care management, is there anything I did not ask that I should have asked and that you want to tell me?”, were analyzed by using the method of thematic analysis of Morse and Field (1995).

Open-ended questions were transcribed verbatim. The data were systematically reviewed to establish data segments and initial themes. Similar actions, events and objects were grouped together as categories, from which common themes/categories were extracted for a second level of interpretation. To establish trustworthiness, a member of the dissertation committee who is an expert in qualitative methods reviewed the data analysis process and how themes were developed. The chair of the dissertation committee confirmed that the findings from the open-ended questions substantially adds to the understanding from the perspective of caregiver as they attempt to balance self care and care of a person with ADRD. The data analysis process and findings are described below in a narrative format and illustrated with diagrams and tables.

Qualitative Findings

Question 1.

Forty participants responded to the question 1, “Has caregiving interfered with your health management in any way? If so, please tell us how caregiving has affected your health needs?” Of these respondents, 14 indicated that caregiving has not interfered with their health management by a simple reply of “no” or “not at all”. Whereas the remaining 26 identified that their health management had been affected in several ways. To detect whether there are differences between the groups, demographic characteristics of both groups were examined. Of the former group who indicated “no” interference, seven (50%) of 14 caregivers were caring for persons with early stage of dementia, four (28.6%) caring for persons with middle stage of the disease and 3 (21.4%) caring for persons with late stage of dementia; half (50%, *n* = 7) of the group were male, consisting of 4 husbands and 3 sons, while the remaining half (*n* = 7) were females, consisting of 4 wives, 2 adult daughters and 1 daughter-in-laws; overall, spouses accounted for 57.1% (*n* = 8) of the group, as for adult children the percentage was 42.9% (*n* = 6). As for the latter group who indicated that their health management was affected, 16 (57.1%) were caring for persons with early stage of dementia, 11 (39.3%) caring for persons with middle stage of the disease and 1 (3.6%) caring for persons with late stage of dementia; 21.4% (*n* = 6) of the group were male, consisting of 3 husbands and 3 sons, while the remaining 78.6% (*n* = 22) were females, consisting of 7 wives, 13 adult daughters and 1 other relation; overall, spouses accounted for 39.3% (*n* = 11) of the group, while adult children were 57.1% (*n* = 16) and other were 3.6% (*n* = 1). No significant differences in demographic variables were observed between the two groups.

Following the initial analysis, seven categories were identified from the responses of the latter group, including (1) lack of healthy eating, (2) seldom exercising, (3) severe lack of sleep or rest, (4) inability to schedule or keep own doctor appointments, (5) deferred medication compliance, (6) mental health stress, and (7) complicated planning for social involvement. Of these categories, (1) lack of healthy eating, (2) seldom exercising and (3) severe lack of sleep or rest were brought up most by caregivers. For example, a 64-year-old daughter who cared for a 95-year-old Mom at the middle stage of dementia described that:

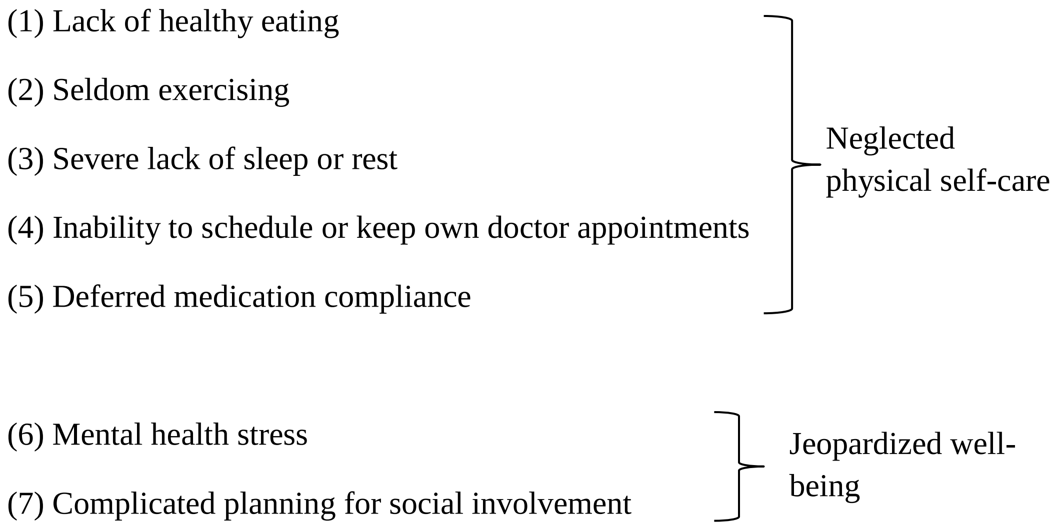
> "I've eaten too much, consumed more wine than usual, and exercised too little. Also sleep deprived. Not a pretty picture which has had a detrimental effect on my self esteem. I'm working on it! I'm clearly a better advocate and caregiver for others than I am for myself. That's changing."(participant # 14)

Another 56-year-old daughter who cared for a 77-year-old Mom at the middle stage of dementia narrated that: "It's hard to even take a shower because my mom regular 24/7 monitoring. She [the patient] is still ambulatory so worrying about wandering is an issue." (participant # 45)

The second category that was cited often is (4) inability to schedule or keep own doctor appointments. For example, a 74-year-old husband who cared for a 75-year-old wife at the early stage of the disease described that: "I have deferred personal health care because of concerns for continuity of care for my wife. My current concerns are exercise, weight management, BPH [benign prostatic hyperplasia] evaluation and probable surgical intervention." (participant # 32)

The second phase of extraction involved synthesizing so that themes were combined into a small number of themes that were broader and more encompassing. To do so, the researcher and the doctorally prepared qualitative expert discussed the seven categories and grouped them into two final themes based on a mutual agreement of similarities existing among these categories. Specifically, five categories emerged in the first extraction: (1) lack of healthy eating, (2) seldom exercising, (3) severe lack of sleep or rest, (4) inability to schedule or keep own doctor appointments and (5) deferred medication compliance, were combined into one final theme defined as neglected physical self-care, given their association with caregivers' physical health. While the last two categories of (6) mental health stress and (7) complicated planning for social involvement were combined into a final theme as jeopardized well-being, given their relationship to caregivers' mental, social health and well-being. Therefore, a total of two themes were generated from the final analysis. The second extraction made the categories broader and more reflective of the overall data analysis. A visual exhibition of the second level of extraction is displayed in Diagram 1. Exemplar excerpts for categories and final themes are presented in Table 22.

Diagram 1. A second level of extraction for Question 1



(1) Lack of healthy eating

(2) Seldom exercising

(3) Severe lack of sleep or rest

(4) Inability to schedule or keep own doctor appointments

(5) Deferred medication compliance

Neglected physical self-care

(6) Mental health stress

(7) Complicated planning for social involvement

Jeopardized well-being

Table 22. Results and Excerpts for the Open- Ended Question 1

Data Excerpts	**First Theme**	**Second Theme**
• **Defer eating**...always eat fast foods, which is not good (participant #2) • I **don't get** time for **breakfast or lunch** (participant # 41) • We **do not eat as well**...has affected how that I **prepare food and plan**, also the continued stress has affected my stomach (participant #10) • I **lived on chocolate and meat** for therapy and energy (participant # 33) • I've **eaten too much**, consumed more wine than usual (participant # 14)	(1) Lack of healthy eating	Neglected Physical Self-Care
• **Defer...exercising**...**only** could **walk once a week** in the weekends (participant # 2) • **Does not get in fitness walking** like I was used to (participant # 12) • I **don't have time for exercise** and **seldom do** (participant # 41) • I do **not have time for exercise**. I need sleep before exercise (participant # 43) • Gained 20 pounds last year due to **lack of exercise**… (participant # 8)	(2) Seldom exercising	
• **Not getting enough sleep** (participant # 24) • I do **not get enough down time** for myself (participant # 17) • **Woke several nights** per week 2-4am, due to stress and worries (participant # 8) • Husband has Parkinson with dementia and Lewy Bodies and sun downs, **wakes me every night** with house wandering and noise (participant # 22)	(3) Severe lack of sleep or rest	
• I have **put off making routine appointments** – checkups (participant # 43) • **Put off for a year getting myself a doctor** (participant # 12) • Have to prepare for someone to come … [so I could go] for my own **doctor appointments** (participant # 6) • Just **forgot my own appointments** - try to make it, sometimes forgot (participant # 27) • I have **cancelled my doctors' appointments** (participant # 29)	(4) Inability to schedule or keep own doctor appointments	
• **Defer...taking medications** (participant # 2)	(5) Deferred medicine compliance	

Table 22. (continued)

Data Excerpts	**First Theme**	**Second Theme**
- **Mental stress**-when he gets irritated and agitation with me. It upsets me. Sometimes I can **feel sad** about the whole situation (participant # 16)	Mental health stress	Jeopardized Well-Being
- Can't do things on the spur of the moment. **Everything must be scheduled**, tennis, bike rides, gym, dinners with friends etc. (participant # 36)	Complicated planning for social involvement	

Question 2.

Forty-one participants responded to the question 2, ‘What do you believe is the most helpful in helping manage your own health needs?” Seven broad categories of beneficial approaches were identified in the analysis. One category that was brought up most by caregivers was (1) self-care. Four subcategories were included: (a) information, knowledge and resources, (b) awareness, and (c) self-care activities. Specified self-care activities consisted of the following areas: eating healthy, maintaining routine, resting, relaxation, exercising, taking medication, regular physical check-ups and talking to health care professionals. For example, a 70-year-old wife who cared for a 79-year-old husband at the middle stage of dementia described the importance of health information and knowledge:

> “Prior knowledge about what is important in keeping and staying healthy [is the most helpful in helping manage my own health]. When I do not know about something, I use resources that are available (computer, friends, family, text)[to obtain information and knowledge].” (participant # 17).

Another 70-year-old wife who cared for a 77-year-old husband at the early stage of dementia narrated the importance of exercise, eating healthy, taking medications and relaxation:

> “Exercise (walking) when I can; trying to eat healthy foods and avoid sweets and controlling my weight, recently research my weight goal @ weight watcher; taking medication as prescribed; spending time away from patient, with friends on doing activities everyday (shopping and eating lunch).” (participant # 11).

The second category caregivers believed to be the most helpful was (2) help and support, including both (a) informal support from family, friends, neighbor, and (b) formal help from health professionals, Alzheimer's caregivers support groups and home health care aids. For example, a 64-year-old daughter who cared for a 92-year-old father at the middle stage of dementia shared the nice spousal support she had: "I have had good support from my spouse. I also have got respite 2-3 times per week for my father over the last 4 years." (participant # 18). Another 65-year-old daughter who cared for an 85-year-old Mom at the early stage of dementia spoke for the need of caretakers: "Having caretakers so I can feel comfortable leaving mom. Having a schedule helps me to complete tasks and get to exercise activities. Having friends who hold me accountable. " (participant # 36)

Other identified categories were (3) time availability for respite and rest, (4) socialization, (5) stay motivated, active and positive, (6) availability and access to good health care, and (7) trust in higher power-God. Similar to the analysis of Question 1, a second phase of extraction was conducted to combine these categories into a small number of themes that are broader and more encompassing based on a mutual agreement of the researcher and the doctorally prepared qualitative expert. Specifically, four categories emerged in the first extraction: (1) self-care, (4) socialization, (5) stay motivated, active and positive, and (7) trust in higher power-God, were combined into one final theme defined as intrinsic efforts given they all reflect the caregiver looking inward to identify causes and actions that can be done from personal side to improve self-care and stay healthy. Three categories of (2) help and support, (3) time availability for respite and rest and (6) availability and access to good health care were combined as extrinsic influence, as they were all outside factors that influence caregivers' health management. This final analysis therefore resulted in two final themes that were more reflective of the overall data analysis. A visual exhibition of the second level of extraction is displayed in Diagram 2. Exemplar excerpts for categories and final themes are presented in Table 23.

Diagram 2. A second level of extraction for Question 2

(1) Self-care
    (a) Information, knowledge and resources
    (b) Awareness
    (c) Activities
(4) Socialization
(5) Stay motivated, active and positive
(7) Trust in higher power-God

Intrinsic efforts

(2) Help and support
    (a) Informal support
    (b) Formal support
(3) Time availability for respite and rest
(6) Availability and access to good health care

Extrinsic influence

Table 23. Results and Excerpts for the Open-Ended Question 2

Data Excerpts	**First Theme**	**Second Theme**
• **Knowledge** about what is important in keeping and staying… using **resources** that available (computer, friends, family, text) (participant # 17) • **Being educated** in your…health problems (participant # 3) • **Education** (participant # 27)	(1) Self-care (a) Information, knowledge and resources	Intrinsic efforts
• **Making** my **well-being a priority** (participant #14) • Keeping **aware of them** [my own health needs](participant #12)	(b) Awareness	
• **Exercise** (walking)...trying to **eat healthy** foods and avoid sweets…**taking medications** (participant # 11) • **Maintain my long-standing routine** as much as possible (participant # 13) • **Adhere to a regimen** of self-managed **pharmacology**, common sense **diet** and informed **health care initiatives** gained from reading (participant # 32) • **Regularly doctor visits** (participant # 12)	(c) Activities	
• Have to have some **social contact** to...release my stress (participant # 7) • **Socializing** (participant # 16)	(4) Socialization	
• **Stay busy and active**, try **not to worry** too much (participant # 28) • **Eliminate ANTs** (automatic negative thoughts) (participant # 14) • **Focus on the positive** and try to take just one day at a time so don't get overwhelmed (participant # 42)	(5) Stay motivated, active and positive	
• Relationship with **the highest God** (participant # 27)	(7) Trust in God	

Table 23. (continued)

Data Excerpts	**First Theme**	**Second Theme**
• **Support of my family**. Going to lunch or a movie as a school activity with daughters (participant # 22) • Having **a spouse that helps** me understand and work together (participant # 3) • Reaching out to **those who know more or who have been there** (participant # 14)	(2) Help and support (a) Informal support	Extrinsic influence
• Attended **Alzheimer's support groups** (participant # 28) • Get some **aids** to watch Mom in the evening 1-2 hours per day, so I could go for walk (participant # 2) • To have **someone** to stay with patient while I go to appointments (participant # 35) • Having **caretakers** so I can feel comfortable leaving mom…. get to exercise activities (participant # 36)	(b) Formal Support	
• Taking **time** for myself (participant # 20) • **Time** to exercise, read and relax (participant # 40) • **Time** - another caregiver (participant # 39)	(3) Time availability for rest/respite	
• **A competent physician** who helps me with my health problems (participant # 29) • **More doctors** trained in Geriatrics (participant # 15) • Having a **good long-term care insurance** (participant # 1) • [Affordable] **health insurance** (participant # 30) • **Assistant living** community (participant # 15)	(6) Availability and access to good health care	

Question 3.

Twenty-one caregivers responded to question 3 by emphasizing issues of concern that were not addressed enough in the survey. Following the first and second extractions, two final comprehensive themes emerged in the analysis. The first theme is (1) the massive stress and emotional toll associated with caregiving. A number of emotions and feelings that were brought up in the question were governed under this theme, including anger & frustrations, anxiety, overwhelmed, stress & distress, grief and uncertainty. Of them, a feeling of stress and distress was cited most by caregivers. For example, a 59-year-old wife caregiver narrated that, "[Caregiving] It's the hardest thing I've ever done" (participant # 16). While a 57-year-old daughter eloquently put her distress in the following way:

> "Health concerns and the physical requirements are really only one part of the equation and not even the hardest part. The most difficult thing to deal with is the mental and emotional toll it takes from a person to watch a loved one slowly slipping into infirmity and pain and not being able to do anything about it. I was prepared for the physical demands when my mom came to live with us but I had no clue about how emotionally draining it would turn out to be." (participant # 42)

The second comprehensive theme that was extracted is (2) enormous individual differences in caregiving. A number of differences that were noted from caregiver responses were put under this category. The first difference is having helpers with caring for one person vs. no helpers but caring for multiple persons. Three caregivers indicated that their caregiving duty were nicely shared by spouse, other family members and friends, whereas two others indicated that they not only did not have helpers but also took care of another or multiple family members besides the person with dementia. Here is a vivid example from a 56-year-old daughter who cared for multiple persons beside the patient:

> "…besides the geriatric patient, I have custody of three grandchildren, monitor my 83 years old father who is in a nursing facilitate, and have a 57 years old mentally retarded brother in a care facility who I must also mention." (participant # 45)

A second difference is between female and male caregiver. Differences in relaxations were brought up as an example by a 74-year-old husband caregiver who cared for her wife at middle stage of dementia:

> "There is a difference between men as caregiver and women caregivers…My example: Four days in a canoe on a Class II or III river while fishing would provide respite for me. Conventional advice recommends that I put my wife in adult day care for 6 hours, go to a movie and get a haircut." (participant # 32)

Third, differences in care demands and caregiving needs were also noted by the researcher as one 59-year-old daughter who cared for a 87-year-old mother asked, "How to receive more service for incontinency?" (participant # 37). Finally, large differences in caregiver personal health were documented in the description of three caregivers about their health problems and disabilities. A visual exhibition of the second level of extraction of this question is displayed in Diagram 3. Exemplar excerpts for categories and final themes are presented in Table 24.

Diagram 3. A second level of extraction for Question 3

(1) Anger & frustrations
(2) Anxiety
(3) Overwhelmed
(4) Stress & distress
(5) Grief
(6) Uncertainty

(1) Massive stress & emotional toll associated with caregiving

(7) Family and friend support to share caregiving
(8) Lone caregiver for multiple persons
(9) Gender difference
(10) Incongruence between caregiving demands & needs
(11) Serious health problems of caregivers

(2) Enormous differences in individual caregiving situation

Table 24. Results and Excerpts for the Open-Ended Question 3

Data Excerpts	**First Theme**	**Second Theme**
• Questionnaires do not address caregivers' **feelings of anger**... with patient's repetitions, lack of task completion, lack of motivation to do anything. Because patient is still able to do something. These are my **frustrations**. (participant # 11)	Anger & frustrations	(1) Massive stress & emotional toll associated with caregiving situation
• I have had a lot of **mental anxiety**. (participant # 31)	Anxiety	
• We did not talk about how **overwhelmed** I get. (participant # 12),	Overwhelmed	
• "It's **the hardest thing** I've ever done" (participant # 16). • **The most difficult thing** to deal with is **the mental and emotional toll** it takes from a person to watch a loved one slowly slipping into infirmity and pain and not being able to do anything about it. (participant # 42). • …to watch a loved one slowly slipping into infirmity and pain and **not being able to do anything about it**. (participant # 42). • **How can I get more energy to do all the things I need to do?** (participant #06)	Stress & distress	
• One of most difficult things about Alzheimer's disease to accept is the reality that your affected loved one may look about the same, but **the person you know who lived in that body no longer lives there** and that you are not neglecting her when you don't see her every day. Guilt takes its toll. (participant # 28). • **My wife is no longer part of my daily life**-leaving avoid. (Participant #13)	Grief	
• My husband is early stage Alzheimer's. **I don't know** how fast his needs will progress or how our home will have to be attended. (participant # 29) • **I do not know** when my mental health will drop. (participant # 05) • Financing caregivers is a **concern**. **I worry about** that - being at home, on her on schedule had been fantastic and just what she needs - I just want to make sure I can continue. (participant # 36)	Uncertainty	

Table 24. (Continued)

Data Excerpts	**First Theme**	**Second Theme**
• I have **a great group of friends who provide fabulous support** for me and my mother... (participant # 36) • **My wife shares in many of the caregiver responsibilities** but was not addressed in the survey. (participant #20) • You did not ask **family member support**. (participant #22) having family support	Family and friend support to share caregiving	(2) Enormous individual differences in caregiving
• **Caring for two "Moms**" need to include in overview of my personal situation 14. • **… besides the geriatric patient**. **I have custody of three grandchildren, monitor my 83 years old father** who is in a nursing facilitate, and **have a 57 years old mentally retarded brother in a care facility** who I must also mention. (participant #45).	Lone caregiver for multiple persons	
• There is a **difference between men as caregiver and women** caregivers. (participant #37).	Gender difference	
• **How to receive more service for incontinency** (participant # 32).	Incongruence between caregiving demands & needs	
• **Mental physical problems or disability**….I have lost hearing in left ear. I have trouble telling where sounds originate. (participant # 31). • I have **had prostate cancer removed, double knee replacement, ankle repair, back surgery twice**. (participant # 10) • [**Disabled** since a serious spinal cord injury in 1978] use cane or walker for short distances, use power chair for long distance. (participant # 25)	Serious health problems of caregivers	

Summary of Qualitative Findings

To summarize, the results of our analysis indicate that caregiving has comprehensively interfered with caregivers' physical self-care, jeopardized their mental, social health and well-being. Caregiver health management is influenced by both intrinsic factors that are within caregivers' ability of control and extrinsic factors that were out of caregiver's control. Both categories of factors are perceived by caregivers as important to their health management. In addition, our findings also provide insight into how massive stress and emotional toll caregivers might have as a result of caregiving and how there are vast differences between caregivers. For example, some caregivers had received help and support from family or friends, while others had no support but needed to handle double or multiple caregiving duties. Besides that, massive difference also existed in genders, caregiver personal health, and actual care demands and caregiving needs.

Summary of Study Findings

This section has presented all findings of the study, including descriptive statistics for the sample (caregivers and persons with ADRD) and description of other predictors (caregiving appraisal and coping) and outcome variables (caregiver self-care management: physical activity, nutrition, health responsibility, medication adherence and appointment keeping). Following the description, pairwise correlations between caregiver demographics, care demands, appraisal, coping and self-care management were widely examined and presented. The results provided important insight into associations between these variables, specifically, for the testing of the Hypotheses 1-3 that were all somewhat supported as indicated in previous sections.

Based on the results of Hypotheses 1-3, the hypothesis 4 was tested using eight variables that were significantly correlated to caregiver self-care management as predictors. Five regression models, one for each self-care management activity, were constructed. Four models were statistically significant except for caregiver physical activity. No significance was found in the overall regression model as well as individual predictors for caregiver physical activity. In conclusion, over and above the effects of demographic variables, the hypothesized variables accounted for 29% of the total explained variance in medication adherence, 32% of the total explained variance in appointment keeping, 17% in nutrition, and 22% in health responsibility.

Two themes were identified from analysis of each open-ended question. These categories further support our statistical results as well as provide in-depth understanding of both significant and non-significant findings of this study. A detailed discussion about the study findings are presented in the following section

CHAPTER 5. DISCUSSION

This chapter presents a brief summary and major findings of this study. The study summary includes (a) theoretical framework, (b) major variables, and (c) subjects. Following the summary, major findings of this study are presented. Discussion is organized according to (a) an overview of major findings of this study, (b) findings on caregiver demographic variables, (c) significant predictors of self-care, and (e) nonsignificant variables. Related findings in the literature are also discussed. Finally, conclusions, recommendations as well as limitations of the study and future directions are presented.

Summary of the Study

This study investigated the effects of caregiving on self-care management of informal caregivers of persons with ADRD. Lazarus and Folkman's (1984) theory was used as the theoretical framework. Based on the theory, care demands are proposed to be a potential stressor that stimulates psychological stress so as to affect caregiver functions in self-care management. Two processes, appraisal and coping, mediate the stress process and correspondingly affect its outcome. Derived from the theory, four hypotheses were proposed in this study, that is, self-care management would be correlated with care demands, caregiving appraisal and coping, and be explained by these three factors.

Major Variables of this Study

Care demands.

Care demands in the study were defined as situational demands that were put on the caregiver due to the impairment of the person with ADRD in memory, behavior and physical function. Empirical indicators included care-recipient frequency of problem behaviors, ADL and IADL dependency, caregiving duration and weekly caregiving hours. Care-recipient frequency of problem behaviors was measured by the Revised Memory and Behavior Problem Checklist (RMBPC) (Teri et al., 1992). Care-recipient ADL and IADL dependency were operationalized as number of ADL and IADL activities that need assistance by using the Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969).

Reliability and Validity. All scales demonstrated acceptable reliabilities in the study with a Cronbach's alpha greater than .70. Validities of the measures were confirmed in this study through correlations. For example, the scores of RMPBC were correlated with the RCAS score for caregiver subjective burden ($r = .33$, $p < .05$) and satisfaction ($r = -.34$, $p < .05$). The scores of PSMS for ADL dependency were correlated with caregiving duration($r = .34$, $p < .05$), weekly caregiving hours ($r = .33$, $p < .05$), IADL dependency ($r = .77$, $p < .01$), and caregiving burden ($r = .39$, $p < .01$). The scores of PSMS for IADL dependency were correlated with weekly caregiving hours ($r = .45$, $p < .05$), care duration ($r = .33$, $p < .05$), caregiving burden ($r = .44$, $p < .01$) and perceived environmental/behavioral impact ($r = .30$, $p < .05$). All correlation coefficients ranged from .30 to .77 and were significant at least at the .05 level, providing support for the validity of the scales in this study.

Caregiving appraisal.

Caregiving appraisal was defined as caregiver's cognitive evaluation of care demands or caregiving situation as well as an assessment of one's coping efforts related to caring for the person with ADRD. Caregiving appraisal in this study consisted of four dimensions (subjective burden, perceived environmental/behavioral impact, caregiving mastery and satisfaction) and was operationalized using the Revised Caregiving Appraisal Scale (RCAS) (Lawton et al., 2000).

Reliability and Validity. The RCAS scale demonstrated acceptable reliabilities in the study with Cronbach's alphas of all scales being greater than .70 except the measure of caregiving mastery (Cronbach's $\alpha = .32$). The low reliability indicated the caregiving mastery scale was not reliable in measuring the concept in this caregiver population. This is not a surprise though since previous studies also indicated that the scale was problematic, whose factor structure failed to be confirmed through factor analysis (Lawton et. al., 1989).

Validities of these measures were confirmed in this study through correlations. The RCAS score for subjective burden were strongly correlated with perceived impact ($r = .56$, $p < .01$), moderately related to caregiving satisfaction ($r = -.34$, $p < .05$), care-recipient frequency of problem behaviors ($r = .33$, $p < .05$), ADL dependency ($r = .39$, $p < .01$) and IADL dependency ($r = .44$, $p < .01$). The scores of RCAS for perceived impact were positively correlated with weekly caregiving hours ($r = .32$, $p < .05$) and negatively related to RCAS scores for caregiving satisfaction ($r = -.38$, $p < .05$). The scores of RCAS for mastery were positively related to scores for satisfaction ($r = .31$, $p < .05$).

Coping.

Coping was referred to as caregivers' cognitive and behavioral efforts to manage care demands associated with ADRD. Four coping strategies (active/problem-solving coping, positive reframing/interpretation, acceptance and denial) that the literature indicated to be correlated to caregiver self-care management were measured in this study using Brief COPE Inventory (Carver, 1997).

Reliability and Validity. All coping scales demonstrated acceptable reliabilities in the study with Cronbach's alphas greater than .70. As evidence of validity, positive correlations were observed among the scores of Brief COPE, including positive framing and active coping ($r = .31$, $p < .05$) plus positive framing and acceptance ($r = .38$, $p < .05$). Negative correlations were observed between denial and acceptance ($r = - .36$, $p < .05$).

Self-care management.

Self-care management in this study was defined as caregivers' activities and abilities to "promote health and to cope with illness and disability with or without the support of a health-care provider" (WHO, 2009, p. 17). Empirical indicators include caregivers self-care activities in (1) disease control and prevention (medication adherence and appointment keeping) and (2) health promotion (exercise, nutrition and health responsibility (an active sense of accountability for one's own well-being)). The total number of activities under examination was five. Caregiver medication adherence and appointment keeping were measured by items adapted from the Hill-Bone Blood Pressure Compliance Scale (HBBPC) (Kim et al., 2000). Caregivers' performance in exercise, nutrition and health responsibility was measured with the Health-Promoting Lifestyle Profile II (HPLPII) (Walker et al., 1987).

Reliability and Validity. All self-care management scales demonstrated acceptable reliabilities in the study with Cronbach's alphas greater than .74, except appointment keeping (Cronbach's α = .13). Two reasons might contribute to the low reliability for the measure of appointment keeping: (1) the measure had only two items, and (2) the measure was specifically designed and used for individuals with hypertension.

Validities of the scales were supported by correlations. The scores of HPLPII for exercise were correlated to the HBBPC scores for medication adherence (r = .35, p < .05), and were strongly related to the scores of HPLPII for nutrition (r = .47, p < .01) and health responsibility (r = .57, p < .01). In addition, the scores of HPLPII for nutrition were strongly related to health responsibility (r = .60, p < .01). The score of HBBPC for medication adherence were positively correlated to appointment keeping (r = .36, p < .05).

Subjects of this Study

Subjects of this study consisted of 45 caregivers of persons with ADRD from a large metropolitan area in a southern part of Midwestern state. Subjects were recruited from local Alzheimer's support groups, churches, a University of Geriatric clinic, internet newsletters and word of mouth. Participants ranged in age from 43 years to 92 years with a mean age of 66.8 ± 10.5 years old. Seventeen were adult daughters, 14 were wife, 7 were husband, 5 were son and 3 were other relationships. The average length of time caregivers had been in caregiving role was 4 years and 5 months and each gave an average of 74.1 hours of care per week. For data collection, participants met with the researchers at locations of their choice to complete the questionnaire. Ongoing feedbacks indicated that caregivers had no difficulty in comprehending the questions on the questionnaire. Therefore, an amendment to the IRB protocol was made. Participants who were enrolled in this study thereafter completed the questionnaire on their own time and returned it back by mail.

Major Findings

This section discusses major findings of this study in light of the literature. Discussion is organized according to (a) an overview of major findings of this study, (b) caregiver demographic variables, (c) significant predictors of self-care and (d) nonsignificant variables.

An Overview of Major Findings

Findings based on the correlational analysis of the demographic variables of caregivers and caregiving situation indicated that education, female gender and financial status were significantly related to both independent and dependent variables of this study. Education had a negative relationship with denial, as well as a positive relationship with caregiver medication adherence. Female gender was negatively associated with denial and positively related to caregiver self-care performance on nutrition. Caregiver financial status had a significant and negative relationship with caregiving burden and impact. Financial status was also positively related to caregiver self-care performance on nutrition.

Relationships between independent and dependent variables as proposed by the theoretical framework were tested. The results indicated that care-recipient ADL/IADL dependency and caregiving duration were the only dimensions that were significantly related to caregiver self-care outcome variables. A strong negative relationship was found between ADL/IADL dependency and caregiver appointment keeping, indicating the increase of care-recipient ADL/IADL dependency leads to the decrease in caregiver appointment keeping. In addition, ADL/IADL dependency was moderately and negatively associated with medication adherence. A strong negative relationship was observed between caregiving duration and caregiver medication adherence, suggesting the increase in caregiving duration is related to the decrease in medication adherence.

Burden was the only dimension of caregiving appraisal that was significantly and modestly related to caregiver self-care outcome variables. Caregivers with more burden were less likely to be physical active and adhere to medication regimen. Two of four coping approaches, active coping and positive reframing, were found to be significantly associated with self-care outcome variables. Active coping had a strong, positive effect on caregiver nutrition and health responsibility (an active sense of accountability for one's own well-being). A modest positive relationship was observed between positive reframing and caregiver health responsibility. Caregivers who used more positive reframing had better outcome in health responsibility.

The best predictors of medication adherence were education (22% of variance) as well as ADL/IADL dependency and caregiving duration (29% of variance); together, two predictors accounted for 51% of total variance in medication adherence. The best predictors of appointment keeping were ADL/IADL dependency, which accounted for 32 % of total variance in appointment keeping. The best predictors for nutrition included caregiver demographic variables (female gender and financial status, 36% of variance) and active coping (17% of variance); together, all the predictors accounted for 53% of total variance in nutrition. The best predictors for health responsibility were female gender (18% of variance), ADL/IADL dependency (3% of variance) and active coping (22% of variance); together, 43% of total variance in health responsibility was explained by all the predictors. No variables were identified as significant predictors for physical activity.

Overall, ADL/IADL dependency explained the most variance for caregiver self-care management, including medication adherence and appointment keeping (explained 29% and 32% of total variance, respectively, after controlling for caregiver demographic variables). Caregiver demographics (education, female gender and financial status) also explained considerable variance for self-care management, including medication adherence (22%), nutrition (36%) and health responsibility (18%). Coping was significant in predicting health responsibility and explained 22% of variance when controlling for all other variables. The anticipated relationship between caregiving and caregiver physical activity was not supported in this study.

Caregiver Demographic Variables

The following characteristics of caregivers are discussed in this section: (a) age, (b) female gender, (c) spouse status, (d) education, and (e) financial status. These variables were believed to be associated with self-care management for caregivers.

Age.

With a mean age of 66.8 ± 10.5 (ranging from 43 to 92), the age distribution of our sample was congruent with that of a nationally representative sample (Fisher et al., 2011). To examine whether caregiver age was associated with self-care, the relationships of age with self-care were checked. Results indicated that age was not related to any self-care management. Very few studies exist in the literature about the effects of caregiving on caregiver self-care management. Unfortunately, findings of the only two known studies appear to be inconsistent. One study by Sisk (2000) found that the increase in caregiver age was associated with a decrease in exercise, while another study by Robinowitz et al., (2007) indicated that increased age was associated with better practice of health behaviors including exercise. One possible reason for this inconsistency in findings may be that advanced age combined with another latent factor such as poor general health are barriers to caregiver exercise. Poor health was projected to contribute to increased burden (Schulz & Martire, 2004; Vitaliano, Zhang, & Scanlan, 2003). Both Sisk (2000) and Robinowitz's (2007) studies, however, did not examine caregiver health status. Therefore, it is unknown whether general health was a factor that contributed to differences in the findings of both studies.

In this study, good and excellent health was reported by over 75% of participants; the increase in age was not associated with decreased general health or increased burden. The findings indicate that poor health is not an issue for the present sample including caregivers with advanced age whose health was not significantly different from their younger counterparts. Congruent with our findings, another large sample, longitudinal study observed that older caregivers generally had better physical health compared to non-caregivers (McCann, Hebert, Bienias, Morris, & Evans, 2004). Better physical health was a prerequisite for seniors taking on the role of caregiving in the first place, supporting our finding that age is not associated with general health. As discussed earlier, increased age combined with poor health may be significant barriers to self-care. Thus, good health of senior caregivers of the present sample explains lack of relationship between age and self-care, such as exercise, in this study.

Female gender.

Caregiving is traditionally viewed as a role of women. Females accounted for over two-thirds of this study sample, consisting of wife caregivers (45%) and adult daughters (55%). Female gender in this study was associated with greater caregiving satisfaction and better performance in nutrition. These findings are not unexpected since female caregivers compared to male caregivers were more likely to commit to a caregiver role and view caregiving as part of their familial duties (Navaie-Waliser, Spriggs, & Feldman, 2002; Yee & Schulz, 2000). By contrast, male caregivers often experience conflicts in their gender role due to traditional beliefs of masculinity (Baker, Robertson, & Connelly, 2010), and therefore, understandably, are less likely to identify meaning or satisfaction from caregiving than women. Similarly, planning and preparing foods were the traditional familial role of women. Given the cumulative experience in food preparation, it is conceivable that women were more knowledgeable in food selection and consumption for the sake of continued family health and well-being.

Different from findings in previous studies, female gender was not related to increased burden in this study. Previous studies indicated that female caregivers experienced greater burden and poorer emotional well-being than male caregivers (Kim, Chang, Rose, & Kim, 2012; Navaie-Waliser et al., 2002; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Yee & Schulz, 2000). However, it was not the case in our study. One possible reason for this finding may be the characteristics of the present sample. Over half of care-recipients were in the early stage of the disease and therefore the effects of caregiving were not in as much evidence. As a result, very low burden was found in this sample and over half of participants reported “a little” burden or “no burden at all”.

Spouse status.

Nearly half of participants in our study were spouses, two-thirds of whom were wives and one-third were husbands. Spouse status in this study was significantly associated with coresidence and less caregiving mastery. No significant relationships were found between spouse status and self-care, consistent with previous studies (Rabinowitz & Gallagher-Thompson, 2007; Sisk, 2000). Spouse status was also not associated with burden in this study, further indicating that poor health may play an important role in other studies that observed greater burden in spouse caregivers (Kim et al., 2012). In other words, being a spouse as well as having poor health together may explain the escalated burden in spouse caregivers.

Education.

Educational attainment in this study was 14.7 ± 2.4 years, equal to approximately 3 years post high school, indicting a relatively high educational attainment of this sample. Education has been a well-known indicator of health and life expectancy in the general population. A general belief about education is that knowledge, skills and better life circumstances transferred through education contributed to better health (Feinglass et al., 2007). Further, caregiving literature pointed out that education was also instrumental in helping caregivers better cope with stress of caregiving (Sampson & Laub, 2010). Studies found that older caregivers with higher education attainment reported better life satisfaction and physical health (Lee, Brennan, & Daly, 2001; Rose-Rego, Strauss, &

Smyth, 1998). Consistent with these findings, this study indicates that education was significantly associated with better general health, less denial and more medication adherence for caregivers.

Financial status.

Similar to educational attainment, socioeconomic status was well-known to be associated with better life circumstances and access to medical care (Feinglass et al., 2007). Seniors with higher household income were found generally having better health and life expectancy than others whose socioeconomic status was low (Batty & Deary, 2004; Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2005; Shishehbor, Litaker, Pothier, & Lauer, 2006). Studies revealed that the disparity of socioeconomic status in health was also evident among caregivers, because health care accessibility mediated the adverse effects of caregiving on caregiver health (Schulz & Sherwood, 2008). Our study confirms these findings. About two-thirds of our study subjects reported no financial strain, three-fourths had good or excellent health; financial status was positively associated with better caregiver health. In addition, financial status in this study was positively associated with less burden and impact, decreased report that health worsened since beginning caregiving and better performance in nutrition.

Predictors of Caregiver Self-Care Management

The following variables were found to be the best predictors of caregiver self-care management: (a) care-recipient ADL and IADL dependency, (b) care duration, and (c) active coping, when controlling for caregiver demographic variables. These variables explained the largest amount of variance in caregiver self-care management.

Care-recipient ADL and IADL dependency.

Care recipients ADL/IADL dependency was the best predictor for medication adherence and appointment keeping. After controlling for all other variables, ADL/IADL dependency uniquely explained 32% of total variance in appointment keeping. The predictor also explained 29% of total variance in medication adherence along with caregiving duration. This result indicates that the more dependent care-recipients were in ADL/IADL, the less likely caregivers adhere to prescribed medication and keep own doctor appointments. Consistent with our findings, in a sample of caregivers of community-dwelling older adults the study, Burton (1997) found that caregivers who assisted older adults with ADL activities were more likely to miss taking medication, compared to noncaregivers at the same age and gender. Yet, the effect of IADL dependency on medication taking was not significant in Burton (1997). Different characteristics of care-recipients may be the reason. Care recipients of our study all had ADRD, whose dependency in IADL was considerable: 91.1% needed assistance for at least four IADL activities, and the mean number of IADL dependency was 6.2 ± 1.8. By contrast, IADL dependency in Burton (1997) was minor: care recipients were from a general population of older adults, the majority (86%) had less than three IADL activities that needed assistance. Thus, assisting with IADL activities may not affect medication-taking as significantly in Burton (1997) as was found in our study.

As expected, burden and impact were also significantly associated with ADL and IADL dependency in this study. This result confirmed findings of Kim et al. (2012). With a sample of 302 caregivers randomly selected from seven states of the U.S., the study found that ADL/IADL dependency was significantly associated with caregiver burden, and were the most significant predictors of burden (Kim et al., 2012). Both findings of this study and Kim et al. (2012) suggest that care-recipient ADL and IADL dependency are important indicators of care demands and caregiving burden.

Care duration.

Caregiving duration was one of the best predictors of medication adherence, explaining 29% of variance along with ADL/IADL dependency. Therefore, the longer duration of caregiving, the greater negative effects on medication adherence. This result confirms the major doctrine of the chronic stress theory of caregiving. This theory proposes that caregiving created prolonged stress over extended periods of time, whose detrimental effects were largely attributed to its chronic nature (Mittelman, Roth, Clay, & Haley, 2007; Schulz & Martire, 2004; Schulz & Sherwood, 2008). Similar findings also included that caregivers who were in the early stage of caregiving were not as much affected as those who had been caregivers for many years (Hirst, 2005; Kramer, 1997).

Active coping.

As discussed in previous sections, active coping was strongly and positively correlated with nutrition and health responsibility. Active coping is the best predictor for nutrition and health responsibility, explaining 17% and 22% of total variance, respectively, after controlling for all other variables. These results indicated that caregivers who concentrated efforts or took action to make the situation better were also more attentive to diet and health. Our study is the first known study that examines the effects of caregiving on caregiver self-care management by taking into account the effects of coping based on the Lazarus and Folkman’s (1984) theory. Two known studies that shared the same interest in caregiver self-care did not consider coping (Rabinowitz &

Gallagher-Thompson, 2007; Sisk, 2000). Nonetheless, our findings were supported by our clinical observation and results of our qualitative analysis. Per clinical observation, consulting professionals and/or using resources (computers, family, friends and books) to obtain information about health and ADRD is one common approach used by caregivers to cope with the disease. Eating healthy was believed by caregivers as one of the most important approaches in helping them manage health according to results of our qualitative analysis. These findings support the relationship between active coping with improved nutrition and increased health responsibility.

Nonsignificant Variables

In addition to the above factors, the following variables were not predictive of caregiver self-care management even though significant relationships were expected in the theoretical framework. Possible reasons for the lack of relationship are discussed in this section. Since research on caregiver self-care is limited in the literature, reasons are primarily explored in conjunction with our qualitative findings and clinical observations.

Frequency of problem behaviors.

Care-recipient frequency of problem behaviors was not associated with any caregiver self-care management activities in this study. One possible reason for this finding may be that as the disease progresses to the late stage, care-recipient dependency in ADL/IADL increases but problem behaviors often decrease. In the interview, caregivers often commented that the person with ADRD was in the late stage of the disease, slept a lot during the day, seldom talked and there really were not that many problem behaviors. One care-recipient even wholly lost speech ability and was bedbound due to comorbidity of stroke. In such a situation, caregivers devoted considerable time to meet the person's needs whereas had no time for self-care. Self-care thus decreased but appeared not to be associated with problem behaviors which were reported low given the stage of care recipients. Next, symptoms of ADRD are well-known to vary by individuals so that some care-recipients in the early and middle stages of dementia also exhibited less problem behaviors than others though the needed care in ADL and IADL activities might be the same. In this case, self-care decreased because of the increase in care-recipient ADL/IADL dependency but the decrease in self-care appeared not to be associated with increased problem behaviors given those scores were low. Additionally, after getting treatment, care-recipient problem behaviors were often controlled by medications, thus became less important in reflecting the actual caregiving situation. Here is an example, "Since my husband was put on a low dose of meds [medications], his levels or frequency of agitation had improved, it has also helped him to sleep better and be more rested (before the meds, he was very agitated)…. [but this is not the real case, how could I] get other people to know that the patient 'Really' does have a problem (even when no signs are apparent in front of them)" .

Given the above reasons, using frequency of problem behavior as indicator for care demands is problematic. Future studies need to check the consistency and correlations of problem behaviors with other variables before using it as an indicator of care demands. In our study, frequency of problem behavior was not correlated with other care demands variables (ADL and IADL dependency, care duration, weekly duration hours), further indicating it is not a valid care-demand indicator in this study. Thus, it is not surprising that the measure (i.e., care-recipient frequency of problem behaviors) was not associated with any caregiver self-care management activities in this study.

Weekly caregiving hours.

Weekly caregiving hours were not associated with any caregiver self-care management activities in our study. Lack of specifications in the item of the measure may be a reason. The item used was, “How many hours do you spend on taking care of the person during a typical week in the past month?”. In response to this question, participants often reported the time they stayed with the person with ADRD. Consequently, a report of 24/7 (24 hours per day for seven days a week) was often seen among caregivers who lived together with the care recipient. Common comments from these caregivers included, “24/7, because I lived with her [the person with ADRD]”, “24/7 except the three hours a day when I was out”, “24/7 except the 20 hours when I was in work”, and “24/7 except the time when I slept”. Thus, the reported hours were largely subject to caregivers’ self perception and comprehension of the item, which were only moderately correlated with care-recipient dependency in ADL and IADL (r = .33 and .45). To better measure caregiving hours, future studies might consider adding such specifications in the questionnaire, “time spent on care-recipient’s personal care, on household tasks and arranging for help”, in addition, need to double check consistency of the results of the measure with other care-demand variables in the analysis.

Burden and Impact.

Caregiving burden was correlated with medication adherence, health responsibility, exercise and nutrition, however, the relationship was not found to be a strong one in prediction, after controlling demographics and care-demand variables. One possible reason for this finding may be the strong interrelationship between burden/impact with ADL and IADL dependency as appeared in our study and being indicated by a previous study (Kim et al., 2012). In the study, Kim and colleagues found that care-recipient ADL and IADL dependency was the most influential predictor of caregiving burden, accounting for 16% of the total variance in burden. Due to the collinerarity, burden and impact may become nonsignificant when controlling for the effect of ADL and IADL dependency on self-care.

Caregiving satisfaction.

An overwhelming majority of our study participants (82.1%) reported a "medium" amount or "a lot" satisfaction over caregiving; yet, caregiving satisfaction was not correlated with any caregiver self-care activities in this study. One possible reason for this finding may be that even for caregivers who were emotionally satisfied with caregiving, the objective demands of care (i.e., required energy and time) still remain the same. In the literature, effects of caregiving satisfaction on subjective outcomes, such as burden, depression, anxiety and self-rated health, has been examined intensively (Mausbach et al., 2012; Quinn, Clare, & Woods, 2012; Romero-Moreno et al., 2011). But little is known about how these good experiences decrease objective burden, i.e., the needed care time and attention. According to clinical observations of the researcher, obtaining a sense of satisfaction is unlikely to decrease care demands. As evidence, no correlations were found between satisfaction and care-demand variables in our study. How to get time for rest and self-care is still an issue among caregivers who identified satisfaction from helping the person with ADRD. Accordingly, "no time" was cited often as a major barrier to self-care in our open-ended questions: "I do not have time for exercise and seldom do", "I do not get enough down time for myself", "I do not have time for exercise. I need sleep before exercise", "I drive home [from work] at lunch [to make sure the person with ADRD is doing fine] so some days I don’t get time for breakfast or lunch”, “I have to prepare for someone to come and stay with my husband for my own appointments”. Time availability is one critical extrinsic issue that influences caregiver self-care performance yet is out of their ability to control.

Caregiving mastery.

An overwhelming majority of our study participants (91.1%) reported a “medium” amount or “a lot” mastery over caregiving. Yet, like satisfaction, caregiving mastery was not significantly related to any care-demand indicators and self-care in this study. Measurement problem, i.e., the low internal consistency of the Mastery scale, may be a reason for this nonsignificant finding. The lack of relationship between mastery and self-care, however, may also reflect the reality - caregiving mastery neither decreased care demands nor significantly improved self-care. Defined according to Lawton et al. (1989), mastery in this study reflects caregiver’s view of one’s capability in handling most problems during the caregiving process. Caregivers with high mastery therefore might be able to work on intrinsic factors which are under their own ability to control. Yet, again, as indicated by our qualitative analysis, their own self-care is subject to the influence of extrinsic factors that are out of individual control, such as whether helpers are available to help watch the person with ADRD so that the caregiver can take time for sleep, rest, exercise and go to their own doctor’s appointments. The need for help and support was frequently expressed by our study participants as being critical in helping them do their self-care. Exemplar responses included, “Get some aids to watch Mom in the evening 1-2 hours per day, so I could go for walk”, “To have someone to stay with patient while I go to appointments", and "Have caretakers so I can feel comfortable leaving mom…go to exercise".

Expanding mastery over some intrinsic and extrinsic factors together, a prior study found that self-efficacy in controlling upsetting thoughts (one intrinsic effort) and obtaining respite (an extrinsic control) was associated with decreased risky behaviors of smoking, alcohol consumption, weight gain and missing meals (Rabinowitz & Gallagher-Thompson, 2007). Both variables explained 5% of the total variance in these behaviors. The analysis was conducted among 256 caregivers from the REACH project (the National Institutes of Health's Resources for Enhancing Alzheimer's Caregiver Health). However, unlike our study the associations of risky health behaviors with care-recipient cognitive status and ADL and IADL dependency were not significant in this REACH project, implying potential differences in outcome measures of both studies. Risky health behaviors were the focus of the REACH study, whereas self-care is the particular interest of our study. Both outcomes are fairly different since caregivers who neglected self-care may not necessarily engage in risky behaviors such as smoking and extensive alcohol drinking.

Similar to the findings of the REACH project, a recent interventional study indicated that improving caregiver confidence in managing inside emotions and obtaining outside help decreased frequencies of missing appointments, postponing routine checkups and unhealthy eating (Savundranayagam & Brintnall-Peterson, 2010). Six-session psychoeducational training was given out in the study for 325 family caregivers of persons with ADRD; variables were measured immediately pre- and post-training for assessing outcomes of the training. Results of the study indicated that increased confidence was the only significant predictor of the decrease in these health behaviors, explaining 10% of the total variance (Savundranayagam & Brintnall-Peterson, 2010). These findings indicate that further investigation with valid and reliable measures is essential to further ascertain how caregiving mastery in intrinsic and extrinsic aspects of caregiving is associated with better self-care for caregivers.

Positive reframing, denial and acceptance.

Three emotion-focused coping were measured in this study, including positive reframing, denial and acceptance. Previous studies indicated that denial led to more burden, depressive symptoms and abuse in use of alcohol, while acceptance and positive reframing were beneficial for the decrease in burden and depression (Kierod, 2008; Kneebone & Martin, 2003; Mjelde-Mossey, Barak, & Knight, 2004; Pattanayak, Jena, Vibha, Khandelwal, & Tripathi, 2011). Different from these findings, neither denial and acceptance, nor positive reframing was correlated with burden in this study. Further examination of this sample revealed the reason. The majority of caregivers reported low denial but high positive reframing and acceptance, indicating intensively using emotional coping and therefore resulting in emotional dysfunction, such as more distress and burden, was not an issue for this group of caregivers who had a relatively high educational attainment (Pattanayak et al., 2011).

Regarding the lack of relationship between emotional coping and self-care, the reason may be that although caregivers were well regulated in their emotions and reported less burden, care-recipient demands in daily living possibly remained the same without receiving any help assisting with the duty. Of this group of caregivers, having own life and self-care may not be possible until the end of care according to the sharing of two caregivers in our interview who had recently placed the person with ADRD to nursing home. The two caregivers cited that they were substantially overwhelmed by caring for the person with dementia, started to see a clear picture of their own life until placing the patient to the nursing home. For example, one caregiver commented, “six weeks ago I placed my husband permanently. Since then, I feel more rested, enthusiastic, and able to cope with my ADLs and also spend time with him daily. This return to health (lack of stress) didn't begin until after 4 weeks. For the years prior to the Nursing Home I felt exhausted, overwhelmed, not able to keep up. Prior to the Nursing Home I lived on chocolate and meat for therapy and energy!... Now, that my husband is in a home, the ability to function without trying to anticipate the behavior and needs of another person has greatly decreased my stress! Now, I can focus, plan, participate, sleep, eat and actually feel peace and joy returning to my being.” Therefore, staying motivated, active and positive was essential for caregivers in improving health and well-being, whereas the influence of extrinsic factors, such as recieving no help and support, cannot be neglected.

Limitations of this Study

Several limitations are noted in this study. First, a cross-sectional study design was used in this study, which only reflected the effects of caregiving on caregiver self-care management at a single point in time. Given this limitation, changes in the results are expected over time and the course of caregiving. Due to the same reason, our findings are also subject to the influence of situational factors of the survey time, such as caregiver mood, personal comfort, recent life events, physical environments of the survey location as well as the comfort of care recipients, e.g., whether the care recipient was taken care of by others while the caregiver participated in this study.

Second, our sample size meets the minimum requirement of 5 cases per predictor (the actual ratio of cases to predictors is 5.6), however, the size is still relatively small compared to other studies. As a result, the power of this study in detecting significant results is somewhat weak. Specifically, only correlation efficient of .30 or greater were identified to be significant at the alpha of .05 level with two-side tests and the R^2 changes of 17% or greater were significant in the regression analysis. Small effect size might be the reason that the relationship between independent variables and caregiver physical activity was not supported in this study. For example, caregiver demographics explained as many as14% of physical activity in this study yet the *p* value is not significant at .05 level. Given the relationship is clinically significant, further exploration with a larger sample size thus is needed.

Small sample size might also cause the lack of diversity of the present sample in education, appraisal and coping, and in turn contributed to the nonsignificant findings of appraisal and coping on self-care activities. Within the theoretical framework, care appraisal and coping were proposed to be mediators between care demands and caregiver self-care. However, relationships between all caregiving appraisal variables (burden, impact, satisfaction and mastery) and most coping variables (denial, acceptance and positive reframing) were not supported in our regression analysis. Further investigation with larger and a more diverse sample is needed to further ascertain the proposed relationships under the theory.

A third limitation of this study is the low internal reliability of two measures (mastery and appointment keeping) in this study. Decreased internal consistency might lead to lack of relationship between mastery and self-care, and as for appointment keeping, a substantial amount of variance may remain underdetermined. Measure issue also concerned results for caregiving hours. Given the ambiguity in its item of measure, the variable was not associated with any self-care in our study as suggested by another study (Sisk, 2000). Therefore, future work with valid and reliable measures is needed to further explore these relationships.

Future Research

This study has obtained salient findings about the effects of caregiving on caregiver self-care management, yet, the effects should be explored further with large, diverse sample and valid, reliable measures, as there may be aspects that did not come to light due to the limitations existed in the study sample and measures. Specifically, relationships that have clinical significance but not statistical significance, such as caregiving and caregiver physical activity, need be examined further with a larger sample size. Valid and reliable measures are needed to study how caregiver mastery in both intrinsic (e.g., managing emotions) and extrinsic factors (e.g., obtaining outside help and aids) contribute to better self-care management; and how large the effect size of caregiving on appointment keeping can be. The two items for appointment keeping was adapted from the Hill-Bone Scale and was primarily used among clients with hypertension. More items that are pertain to caregiving situation are needed to add richness as well as improve the representativeness of the scale for caregiving situation. Exemplar items can be “How often do you forget your own doctor’s appointments?”, “How often do you put off your own doctor’s appointments because of the needed care of the person with ADRD”, “How often do you cancel your appointments because of the needed care of the person with ADRD”.

Results of this study support replications of this study in other settings and populations to ascertain whether the relationships between caregiving factors and self-care variables subject to the influence of environmental and social factors, or, remain the same as in the setting of this study. To better ascertain the relationships between caregiving and self-care, longitudinal studies are needed to investigate the changes that occur in caregiver self-care management as caregiving progresses. Prospective research designs that measure caregiver self-care management prior to the initiation of the caregiving event are also instrumental in investigating how transition to caregiver role affects caregiver self-care management by controlling for prior levels of self-care management in the analysis.

Emotions and support play an important role in caregiving situations according to our qualitative findings. More research thus is needed on how emotions cause changes in caregiver self-care management; how social and family support contributes to improved self-care; and how the adverse effects of caregiving on self-care intensify among lone caregivers who have multiple caregiving duties. Valid and reliable instruments for emotions and social support are critical for studying the function of the two variables in caregiver self-care management.

Conclusions

This study examined the predictive ability of multidimensional factors for assessing self-care management in caregivers of persons with ADRD, using a convenient sample of 45 caregivers from a local community in the southern part of Midwest of U.S. Results indicated that three categories of predictors-caregiver demographic variables, care demands and active coping – uniquely explained caregiver self-care. Care-recipients

ADL/IADL dependency and caregiver caregiving duration, reflecting care demands, explained the most variance for caregiver self-care, followed by caregiver demographic variables (education, female gender and financial status) and active coping. Total explained variance in each self-care activity was considerable, ranging from 21% to 48%.

Specifically, the best predictors for medication adherence were higher education, lower ADL/IADL dependency and shorter caregiving duration. The best predictors for appointment keeping were lower ADL/IADL dependency. The best predictors for better nutrition included female gender, higher financial status and active coping. The best predictors for health responsibility were active coping, lower ADL/IADL dependency and female gender. Overall, the dependency of care-recipient in ADL and IADL is the most influential factor for caregiver self-care, whose effects are especially strong on medication adherence and appointment keeping.

This study is the first known study that examines the impact of caregiving on caregiver self-care by comprehensively taking into account all dimensions proposed in the theory of Lazarus and Folkman (1984). Findings of this study filled a gap in the literature by demonstrating the effects of caregiving on caregiver self-care management using empirical evidence. In particular, care-recipient dependency in ADL and IADL is the most influential factor for caregiver medication adherence and appointment keeping; the more impaired care-recipients were in ADL and IADL, the less likely caregivers were to take medications and keep appointments with the doctor. This result becomes more significant when viewed in conjunction with the high prevalence of chronic illnesses among caregivers: a large portion of caregivers had chronic illnesses, need to routinely take their medications and regularly follow-up with their health provider but cannot do so because of the care needed by the person with ADRD. As for the whole caregiver group who are at risk for chronic illnesses, self-care is determinant to their health promotion and disease prevention. Yet, of this group of population, a common self-care profile is that of no routine wellness or physical check-ups, seldom exercising, little time for socialization and healthy eating, and severe lack of sleep and rest. This study expands understandings of the caregiver literature about the adverse effects of caregiving on caregiver health.

Recommendations and Clinical Implications

This study has the following implications for clinical practice. Findings of this study suggest that the most pressing priority in improving caregiver self-care is to help caregivers find relief from caregiving duty. Applicable interventions as noted in the literature can be (a) providing referral resources such as local chapters of Alzheimer's Association, Area Agency on Aging and Case Management Services, (b) recruiting other family members to help provide care, and (c) using religious groups and social and friendship groups for special activities such as playing card games, quilting, working on puzzles with the person with ADRD (Robinson, Buckwalter & Reed, in press). These interventions will allow caregivers with chronic disease needed time for essential medical treatment and follow-up, as well as assisting healthy caregivers in preventing health declines because more personal time will be granted for health promotion activities such as rest, sleep, relaxation, exercise, improve nutrition and socialization.

In addition to ensuring time availability for caregiver self-care, interventions are also needed to motivate and train caregivers for working on improving self-care, according to our qualitative findings. Particularly, nurses can take initiative to be self-care advocates and educators for caregivers through (a) providing health information, education and resources, (b) raising self-care awareness, as well as (c) providing emotional support to help cope with stress and emotions resulted from caregiving. In addition to these general approaches for helping caregivers overall, differences in individual caregiving situations must be considered. Such supplemental training can be implemented as providing nutritional guidance for male caregivers and incontinency care training for caregivers in particular need to address individual difference.

Besides the efforts to motivate caregiver improve self-care, external factors that influence caregiver self-care also should be addressed, according to our qualitative findings. Example of efforts can be (a) providing in-home health assessment, (b) improving availability and caregiver access to quality health care and (c) offering affordable long-term insurance and home health care on a sliding scale basis. In-home health assessment will be especially important for caregivers who are unable to get out of the house for routine wellness and physical check-ups because of the care needed by the person with ADRD. Availability and access to quality health care are critical to those who had serious health problems and disabilities. Health policy and legislation are needed for supporting caregivers long-term insurance and home health care on a sliding scale basis. This approach can be an effective help for lone caregivers who care for multiple persons of different generations.

Studies have clearly identified that caregivers with poor health are more likely to stop caregiving. Administering interventions thus is a fruitful way of improving health and well-being of both caregivers and persons with ADRD. Alzheimer’s disease has become an important public health issue of the U.S. According to the latest report of Alzheimer’s Association (2013), Alzheimer's disease is the sixth leading cause of death in the United States; more than 5 million Americans are living with the disease; 1 in 3 seniors dies with Alzheimer's or related dementia. Health care of the disease is costly, in a single year of 2013, the cost is projected to be $203 billion. As an invaluable health resource, in 2012, a total of 15.4 million caregivers provided more than 17.5 billion hours of unpaid care valued at $216 billion (Alzheimer’s Association, 2013). By helping caregivers, thus, a large saving in health care dollars is expected because caregivers will be able to keep the person with ADRD at home longer compared to when no help is received.

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Appendix A. Study Questionnaires

Patient Demographic Information

1. Date of diagnosis (Month/Year) ___________
2. Patient Age: ________years old
3. Patient Gender: 1 Male 2 Female
4. Stage of dementia:
    1. Early (memory loss)
    2. Middle (wandering, agitation)
    3. Late (incontinent, speech unintelligible, bedbound)

Caregiver Demographic Information

5. Caregiver Age ________years old
6. Caregiver Gender: 1. Male 2. Female
7. Caregiver Ethnic group
    1. White
    2. African American
    3. Native American/Alaska Native
    4. Asian
    5. Native Hawaiian or Other Pacific Islander
8. How many years of formal education do you have? _______ (e.g., high school/GED=12 years, college=16 years).
9. Marital status
    1. Married
    2. Divorced
    3. Widowed
    4. Single
10. Are you employed? 1. Yes, ( ) hours a week 2. No
11. Relationship to impaired person, please specify_________
    1. Spouse
    2. Child
    3. Sibling
    4. Friend
    5. Others
12. How long have you been primary caregiver? _____years______ months
13. How would you describe your financial situation?
    1. Difficulty paying monthly bills.
    2. Able to pay bills, very little or none leftover.
    3. Able to pay bills, regularly have some leftover.
14. Are you living with the impaired person: 1.Yes 2. No
15. How many hours do you spend on taking care of the person during a typical week in the past month? _________hours per week on average.

Appendix A. Continued

Revised Memory and Behavior Problems Checklist

The following is a list of problems a person with dementia sometimes have. Please indicate how often your relative has exhibited the following problems during the past week.	
0 = never occurred 1 = not in past week 2 = 1-2 times in past week	3 = 3-6 times in past week 4 = daily or more often 9 = don't know

1. Asking the same question over and over.	0	1	2	3	4	9
2. Trouble remembering recent events (e.g., items in the newspaper or on TV).	0	1	2	3	4	9
3. Trouble remembering significant past events	0	1	2	3	4	9
4. Losing or misplacing things.	0	1	2	3	4	9
5. Forgetting what day it is.	0	1	2	3	4	9
6. Starting, but not finishing.	0	1	2	3	4	9
7. Difficulty concentrating on a task.	0	1	2	3	4	9
8. Destroying property.	0	1	2	3	4	9
9. Doing things that embarrass you.	0	1	2	3	4	9
10. Waking you or other family members up at night.	0	1	2	3	4	9
11. Talking loudly and rapidly.	0	1	2	3	4	9
12. Appears anxious or worried.	0	1	2	3	4	9
13. Engaging in behavior that is potentially dangerous to self or other.	0	1	2	3	4	9
14. Threats to hurt self.	0	1	2	3	4	9
15. Threats to hurt others.	0	1	2	3	4	9
16. Aggressive to others verbally.	0	1	2	3	4	9
17. Appears sad or depressed.	0	1	2	3	4	9
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens"; "Life isn't worth living"; "I'd be better off dead").	0	1	2	3	4	9
19. Crying and tearfulness.	0	1	2	3	4	9
20. Commenting about death of self or others (e.g., "Life isn't worth living"; "I'd be better off dead").	0	1	2	3	4	9
21. Talking about feeling lonely.	0	1	2	3	4	9
22. Comments about feeling worthless or being a burden to others.	0	1	2	3	4	9
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life.	0	1	2	3	4	9
24. Arguing, irritability, and/or complaining.	0	1	2	3	4	9

Appendix A. Continued

Physical Self-Maintenance Scale

Please indicate the level of activities of daily living of the person with dementia.
Could the person

	1	0
1. Care for self at toilet completely (i.e., no incontinence, no accidents, no need to be reminded or help in cleaning)?	YES	NO
2. Eat and clean up after meals without any assistance?	YES	NO
3. Dress, undress, and select clothes from own wardrobe without any assistance?	YES	NO
4. Always neatly dressed, well-groomed (neatness, hair, nails, hands, face, clothing) without any assistance?	YES	NO
5. Go about grounds or city?	YES	NO
6. Bath self (tub, shower, sponge bath), and get in and out of tub without help?	YES	NO

	1	0
7. Use some telephone?	YES	No, does not use telephone at all.
8. Take care of all shopping needs independently?	YES	NO
9. Plan, prepare, and serve adequate meals independently?	YES	NO
10. Participates in some housekeeping tasks?	YES	No, does not participate at all.
11. Do personal laundry completely?	YES	NO
12. Travel independently on public transportation, taxi, or drives own car?	YES	NO
13. Take medication independently in correct dosages at correct time.	YES	NO
14. Manage financial matter independently, or, only needs minor assistance with banking and major purchases.	YES	NO

Appendix A. Continued

Caregiving Appraisal

The next group of questions is about how you feel about the caregiving situation. Please indicate your amount of agreement with each statement.

1=not at all 2=a little 3=moderately

4=quite a bit 5=a great deal

1. Your health has suffered because of the care you must give your family member.	1 2 3 4 5
2. You are isolated and alone as a result of caring for your family member.	1 2 3 4 5
3. You will be unable to care for your family member much longer.	1 2 3 4 5
4. You have lost control of your life since your family member's illness.	1 2 3 4 5
5. You are very tired as a result of caring for your family member.	1 2 3 4 5
6. Taking care of your family member gives you a trapped feeling.	1 2 3 4 5
7. Your social life has suffered because you care for your family member.	1 2 3 4 5
8. Because of the time you spend with your family member, you don't have enough time for yourself.	1 2 3 4 5
9. You can fit in most of the things you need to do in spite of the time taken by caring for your family member.	1 2 3 4 5
10.You really enjoy being with your family member.	1 2 3 4 5
11.Your family member's pleasure over some little thing gives you pleasure.	1 2 3 4 5
12. Helping your family member has made you feel closer to him/her.	1 2 3 4 5
13. Taking responsibility for your family member gives your self-esteem a boost.	1 2 3 4 5
14. Caring for your family member doesn't allow you as much privacy as you would like.	1 2 3 4 5
15. You are uncomfortable about having friends over because of your family member.	1 2 3 4 5
16. Caring for your family member has interfered with your use of space in your home.	1 2 3 4 5
17. You get a sense of satisfaction from helping your family member.	1 2 3 4 5
18. Caring for your family member gives more meaning to your life.	1 2 3 4 5
19. You feel able to handle most problems in care of my family member.	1 2 3 4 5
20. You are pretty good at figuring out what to do about your family member.	1 2 3 4 5
21. You feel reassured knowing about what to do about your family member.	1 2 3 4 5
22. You feel uncertain about what to do about your family member.	1 2 3 4 5
23. You feel that you should be doing more.	1 2 3 4 5
25. You feel that you could do a better job in caring for your family member.	1 2 3 4 5

Appendix A. Continued

Caregiver Self-Care Management

Has caregiving interfered with your health management in any way, such as eating properly, exercising and resting, taking your medications, monitoring your health and going to see the doctor? If so, please tell us how caregiving has affected your health needs?

1. Would you say your health in general is
    1. Poor
    2. Fair
    3. Good
    4. Excellent

2. Compared with before the start of your caregiving, would you say your health is now
    1. Worse
    2. about the same
    3. better
    4. Don’t know

3. Do you have any chronic diseases and health problems [i.e., long-lasting conditions that are rarely cured] ?
    1. No
    2. Yes, please specify

Appendix A. Continued

4. Are you currently taking any medications (including insulin, oral contraceptives, over-the-counter medications, vitamins, diet supplements, herbal preparations, etc.).

1. No, **<u>please turn to next page</u>**
2. Yes, please specify

the number of medications under use (<u>not the number of pills</u>), and the purposes (for example, 2 medications taken for diabetes, 3 for hypertension, 2 vitamins for bone).

The number of medications Taken for

(Adapted Hill-Bone Blood Pressure Compliance Scale – Medication Adherence)

Please thinking over the past 2 weeks and considering all your medications, respond to the following items
(1=never, 2= rarely, 3=sometimes, 4=often, 5=all the time).

5. How often do you forget to take your medications?	1	2	3	4	5
6. How often do you decide not to take your medications?	1	2	3	4	5
7. How often do you run out of the supply?	1	2	3	4	5
8. How often do you miss taking them when you feel sick?	1	2	3	4	5
9. How often do you miss taking them when you feel better?	1	2	3	4	5
10. How often do you miss taking them when you are careless?	1	2	3	4	5

Appendix A. Continued

11. During the past 12 months, have you scheduled any appointments with a doctor or other health care provider?

1. No, **please turn to next page**
2. Yes, please specify

the number of appointment you have scheduled, and the purposes (for example, 1 appointment for diagnosis of new health problems, 2 for follow-up hypertension and diabetes, 1 for checking blood pressure, cholesterol and sugar, 1 for colon screening, 1 for dental exam, 1 for eye, and 1 for prostate or mammography exam).

The number of appointments	Scheduled for

(Adapted Hill-Bone Blood Pressure Compliance Scale – Appointment Keeping)

Please considering all these appointments, respond to the following items (1=never, 2= rarely, 3=sometimes, 4=often, 5=all the time).

12. How often do you miss scheduled appointments?	1	2	3	4	5
13. How often do you get the next appointment before you leave the clinic?	1	2	3	4	5

Appendix A. Continued

Caregiver COPE Inventory

Different people deal with things in different ways, we are interested in how you've tried to deal with problems associated with taking care of your relative. Think over the time when you confront difficult or stressful events associated with taking care of your relative, tell us how much or how frequently you've been using the following ways of coping.

[Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.]

1 = I have not been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. concentrating your efforts on doing something about the situation you are in.	1	2	3	4
2. saying to yourself, "this isn't real."	1	2	3	4
3. taking action to try to make the situation better.	1	2	3	4
4. refusing to believe that it has happened.	1	2	3	4
5. trying to see it in a different light, to make it seem more positive.	1	2	3	4
6. looking for something good in what is happening.	1	2	3	4
7. accepted the reality of the fact that it has happened.	1	2	3	4
8. learned to live with it.	1	2	3	4

Appendix A. Continued

Caregiver Lifestyle Profile II

This questionnaire contains statements about your present way of life or personal habits. Please respond to each item as accurately as possible, and try not to skip any item.

1=never 2=sometimes 3=often 4=routinely

1. Choose a diet low in fat and cholesterol.	1	2	3	4
2. Report any unusual signs or symptoms to a physician or other health professional.	1	2	3	4
3. Follow a planned exercise program.	1	2	3	4
4. Limit use of sugars and food containing sugar (sweets).	1	2	3	4
5. Read or watch TV programs about improving health.	1	2	3	4
6. Exercise vigorously for 20 or more minutes at least three times a week, such as brisk walking, bicycling, aerobic dancing, using a stair climber.	1	2	3	4
7. Eat 6-11 servings of bread, cereal, rice and pasta each day.	1	2	3	4
8. Question health professionals in order to understand their instructions.	1	2	3	4
9. Take part in light to moderate physical activity, such as sustained walking 30-40 minutes 5 or more times a week.	1	2	3	4
10. Eat 2-4 servings of fruit each day.	1	2	3	
11. Get a second opinion when I question my health care provider's advice.	1	2	3	4
12. Take part in leisure-time (recreational) physical activities, such as swimming, dancing, bicycling.	1	2	3	4
13. Eat 3-5 servings of vegetables each day.	1	2	3	4
14. Discuss my health concerns with health professionals.	1	2	3	4
15. Do stretching exercises at least 3 times per week.	1	2	3	4
16. Eat at least 2-3 servings of milk, yogurt or cheese each day.	1	2	3	4
17. Inspect my body at least monthly for physical changes/danger signs.	1	2	3	4
18. Get exercise during usual daily activities, such as walking during lunch, using stairs instead of elevators, parking car away from destination and walking.	1	2	3	4
19. Eat no more than 2-3 servings of meat, poultry, fish, dried beans, eggs, and nuts group each day.	1	2	3	4
20. Ask for information from health professionals about how to take good care of myself.	1	2	3	4
21. Check my pulse rate when exercising.	1	2	3	4
22. Read labels to identify nutrients, fats, and sodium content in packaged food.	1	2	3	4
23. Attend educational programs on personal health care.	1	2	3	4
24. Reach my target heart rate when exercising.	1	2	3	4
25. Eat breakfast.	1	2	3	4
26. Seek guidance or counseling when necessary.	1	2	3	4

Appendix A. Continued

What do you believe is the most helpful in helping manage your own health needs?

I've asked you many questions about your health and self-care management, is there anything I did not ask that I should have asked and that you want to tell me?

Thank you for your participation!

Appendix B. Recruitment Flier

Caregivers Self-Care Study - Information Sheet

You are invited to participate in a research study conducted by Karen M Robinson, PhD, PMHCNS-BC, Professor and Xiaorong(Sharon) Wang, BSN, PhD Candidate, University of Louisville School of Nursing.

What: To examine how unpaid family caregivers feel about caregiving, how they cope, and how caregiving affects their ability to manage their own health concerns.

Who: Primary/main unpaid family caregiver who is:
  (1) over 21 years of age,
  (2) providing care for more than 1 year,
  (3) to a person who has received a medical diagnosis of Alzheimer's Disease or Related Disorder and is still living at home.

When and Where: a time and place of convenience to you.

How: Meet for approximately 45 minutes with an interviewer to complete a set of questionnaires, or, complete the questionnaires by own at your own time.

Benefits and Risks: no foreseeable risks. This study may not benefit you directly, but will help future caregivers.

Contact Information

Karen M Robinson, PhD, PMHCNS-BC, FAAN, Professor
Xiaorong (Sharon) Wang, BSN, PhD Student
Maureen McDermott RN, MSSW, Research Assistant

School of Nursing 555 S. Floyd St.
4th Floor K Building University of Louisville
Louisville, KY 40202

Phone: (502) 852-4293
FAX: (502) 852-8783
Email: x0wang23@louisville.edu

APPROVED
Oct 31, 2012
UNIVERSITY OF LOUISVILLE
INSTITUTIONAL REVIEW BOARD

Appendix C. Participant Mail-In Sheet

1

Caregiver Self-Care Study Mail-In Sheet

I am interested in participating in the Caregiver Self-Care Study being conducted by Karen Robinson, PhD, PMHCNS-BC, FAAN, Professor and Xiaorong (Sharon) Wang, BSN, PhD Candidate, University of Louisville School of Nursing.

My name (in print):

Address:

Phone Number:

Best way to contact, or, Best time to call:

Other notes for the researchers:

Please email your above information to x0wang23@louisville.edu, or, mail back this form to the following address:

555 S. Floyd St. School of Nursing
4th Floor K Building, University of Louisville
Louisville, KY 40202
Attn: Xiaorong (Sharon) Wang

APPROVED
Oct 31, 2012
UNIVERSITY OF LOUISVILLE
INSTITUTIONAL REVIEW BOARD

Appendix D. Subject Informed Consent

IRB #: 12.0376

Subject Informed Consent Document

How Caregiving Demands, Caregiver Appraisal, and Coping Affect Self-Care

Management of Informal Caregivers of Persons with Dementia

Investigator(s) name & address: Karen M Robinson and Xiaorong Wang, School of Nursing, University of Louisville (U of L), K Building, 555 S. Floyd St. Louisville, KY 40202
Site(s) where study is to be conducted: U of L Geriatric Clinic and Department of Neurology
Phone number for subjects to call for questions: (502) 852-2273, 852-8512, 852-2972

Introduction and Background Information

You are invited to participate in a research study. The study is being conducted by Karen M Robinson, PhD, PMHCNS-BC, FAAN (Principal Investigator) and Xiaorong Wang, BSN, PhD Candidate. The study is sponsored by the University of Louisville School of Nursing. The study will take place at U of L Geriatric Clinic and Department of Neurology. Approximately 50 subjects will be invited to participate.

Purpose

The purpose of this study is to examine how your caregiving situation, how you feel about your caregiving situation, and what you do to cope with caregiving affect your ability to manage your own health problems.

Procedures

In this study, you will be asked questions about yourself, your feelings about your caregiving situation, the efforts you make in coping with caregiving, and your activities in managing your own health problems. Your participation in this study is voluntary and will last for approximately 30 minutes to 1 hour. You may decline to answer any questions that may make you uncomfortable.

Potential Risks

There are no foreseeable risks, although talking about your caregiving situation could cause you to feel some distress.

Benefits

Possible benefits you might receive from this study include being able to talk with someone about your caregiving experience and how it affects your health. The information collected may not benefit you directly, but the information gained in this study may be helpful to others.

Compensation

You will not be compensated for your time, inconvenience, or expenses while you are in this study.

Confidentiality

Total privacy cannot be guaranteed. Your privacy will be protected to the extent permitted by law. If the results from this study are published, your name will not be made public. While unlikely, the following offices may look at the study records:

> The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, and Privacy Office
>
> Office for Human Research Protections (OHRP),
>
> Office of Civil Rights
>
> The data collected in this research study will be secured by being locked in a file cabinet and kept in a secured area.

HIPAA Research Authorization

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides federal safeguards for protected health information (PHI). Examples of PHI are your name, address, and birth date. PHI may also include your medical history, results of health exams and lab tests, drugs taken and results of this study. Your PHI cannot be used or shared without your agreement, unless it meets one of the HIPAA exceptions. You will be asked to sign a "Research Authorization" form. This allows the use and sharing of your PHI by those listed in the “Research Authorization.”

Voluntary Participation

Taking part in this study is voluntary. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify. You will be told about any changes that may affect your decision to continue in the study.

Research Subject's Rights, Questions, Concerns, and Complaints

If you have any concerns or complaints about the study or the study staff, you have three options.

You may contact the principal investigator Dr. Karen Robinson at 502-852-8512.

If you have any questions about your rights as a study subject, questions, concerns or complaints, you may call the Human Subjects Protection Program Office (HSPPO) (502) 852-5188. You may discuss any questions about your rights as a subject, in secret, with a member of the Institutional Review Board (IRB) or the HSPPO staff. The IRB is an independent committee composed of members of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. The IRB has reviewed this study.

If you want to speak to a person outside the University, you may call 1-877-852-1167. You will be given the chance to talk about any questions, concerns or complaints in secret. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

This paper tells you what will happen during the study if you choose to take part. Your signature means that this study has been discussed with you, that your questions have been answered, and that you will take part in the study. This informed consent document is not a contract. You are not giving up any legal rights by signing this informed consent document. You will be given a signed copy of this paper to keep for your records.

Appendix D. Continued

Signature of Subject/Legal Representative Date Signed

Signature of Person Explaining the Consent Form Date Signed
(if other than the Investigator)

Signature of Investigator Date Signed

Karen M Robinson	502-852-8512
Xiaorong (Sharon) Wang	502-852-2972

Appendix E. HIPAA Research Authorization

AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR HEALTH INFORMATION FOR RESEARCH

IRB#:	**Study Title**
12.0376	How Caregiving Demands, Caregiver Appraisal, and Coping Affect Self-Care Management of Informal Caregivers of Persons with Dementia.

PRINCIPAL INVESTIGATOR/PROJECT DIRECTOR (PI/PD)

Name (Last Name, First Name, MI) Robinson, Karen M.	**Email Address** kmrobi01@louisville.edu
Mailing Address – Include University Department (if applicable) School of Nursing, University of Louisville (U of L), K Building, 555 S. Floyd St. Louisville, KY 40202	**Telephone Number** 502-852-8512
	Pager/Cell Phone Number 502*******
	Fax Number **502-852-8783**

Please read this form before you sign it.

In our research, we will look at and may share information about you and your health. Federal law requires that health providers and researchers protect this information and keep it private (confidential). "We" or "us" in this document refers to the following places (institutions, facilities, and practices) that are checked (✓).

Affiliated Sites			**Non-Affiliated Sites**
[✓]	University of Louisville (Do not remove this check.)	[ ]	Louisville Metro Public Health & Wellness
[ ]	Jewish Hospital & St. Mary's Healthcare	[ ]	KY Cabinet for Health & Family Services
[ ]	Norton Healthcare, Inc., including Kosair Children's Hospital	[ ]	Seven Counties Services
[ ]	University of Louisville Hospital/J. Graham Brown Cancer Center	[ ]	Other(s):

University of Louisville Research Foundation (ULRF) Clinical Sites

[ ]	Children & Youth Clinic	[ ]	UL Pathology Flow Cytometry Lab (BCC)
[ ]	Dentistry Clinics (Undergraduate DMD; Graduate, Perio, Endo and Ortho; Oral Surgery and GPR at ACB; Faculty Practice, Graduate Pedodontic Clinic)	[ ]	UL Pathology Special Procedures Lab
[✓]	Family Medicine – (Newburg and Central Station; also Geriatrics and Sports Medicine at Central Station)	[ ]	University Health Services (HSC and Belknap)
[ ]	Harambee Nursing Center	[ ]	Weisskopf Child Evaluation Center
[ ]	Kidney Disease Program (Dialysis Unit and UL Renal Transport Lab)	[ ]	WHAS Crusade For Children Audiology & Spee Pathology Center
[ ]	Neonatal Follow Up Program	[ ]	WINGS Clinic – (ACB)

Faculty Practice Group Sites

[ ]	University Anesthesiology Associates, PSC	[ ]	University Pediatrics Foundation, Inc. d/b/a University Child Health Specialists, Inc. (UCHS)
[ ]	University Radiological Associates, PSC	[ ]	University Children's Sleep Specialists, LLC
[ ]	University Physicians Associates (UPA)/ UPG – Radiology, PSC	[ ]	University Children's Infectious Disease Specialists, LLC
[ ]	University Emergency Medicine Associates, PSC	[ ]	University Children's Kidney Specialists, LLC
[ ]	University Family Practice Associates, PSC	[ ]	University Children's Sedation Service, LLC
[ ]	University Physicians Associates (UPA), PSC	[ ]	University Pediatric Endocrinology, LLC
[ ]	University Medical Associates, (UMA), PSC	[ ]	Bone Marrow Transplant, LLC
[ ]	Associates in Dermatology, PLLC	[ ]	Neonatal Associates, PSC

Appendix E. Continued

☐	University Neurologists, PSC	☐	Pediatric & Perinatal Pathology Associates, PSC
☐	Neurosurgical Institute of Kentucky, PSC	☐	Pediatric Cardiology Associates, PSC
☐	University GYN/OB Foundation, Inc.	☐	Pediatric Hematology/Oncology Specialists, PSC
☐	University OB/GYN Associates, PSC	☐	Pediatric Pulmonary Medicine, PSC
☐	Ophthalmological Services, Inc. – Primary Eye Clinic	☐	University Psychiatric Foundation, Inc.
☐	Eye Specialists of Louisville, PSC	☐	University Psychiatric Services, PSC
☐	Kentucky Vision Center, Inc.	☐	University Radiotherapy Associates, PSC
☐	Shea, Tillett, Malkani, Caborn , PSC	☐	University Surgical Associates, PSC
☐	Spine Institute, PSC	☐	University Pediatric Surgery Associates, PSC
☐	Orthopedic Trauma Associates, PSC	☐	University Cardiothoracic Surgical Associates, PSC
☐	University Pathologists, PSC	☐	University Urology, PLLC
☐	Louisville Pathology Laboratory Associates, Inc.	☐	Other:

The law allows us to look at and share your health information for research, if you agree to let us do this and if we protect it as required.

This form explains how we will look at and share your health information, as well as, who may see it and use your information. If you sign this form, it means you are letting us look at and share information for research.

1. Health information about you from the items checked below may be looked at or given out to others.

☐ Consultation reports
☑ Diaries and questionnaires
☐ Discharge summaries
☐ Healthcare provider orders
☐ History and physical exams
☐ Laboratory, x-ray, and other tests

☐ Records of your operation(s)
☐ Medical progress notes
☐ Photos, videotapes, or digital or other images
☐ Records about the study device
☐ Records about the study drug and other drugs you may be taking
☑ Other: personal interview

☑ WE WILL NOT BE LOOKING AT ANY OF THE ITEMS LISTED BELOW FOR THIS STUDY.

OR

☐ THE INFORMATION WE MAY LOOK AT OR GATHER FOR THIS RESEARCH MAY INCLUDE:

☐ HIV / AIDS status
☐ Hepatitis infection
☐ Sexually transmitted diseases
☐ The diagnosis and treatment of a mental health condition
☐ Other reportable infectious diseases

2. The following people or groups may share, receive and/or look at yo information:

- The people and organizations listed on this form to conduct, analyze, and understand this study;
- You or your personal representative;
- Others as allowed or required by law;
- Government entities that have the responsibility to oversee this research;
- The offices and departments responsible for oversight of research at the University of Louisville;
- Health care providers and others where you receive care during your participation in this study;
- Health care providers and others, as appropriate, for compliance oversight; and
- People responsible for sending and receiving payments related to your participation in the study.
- **In addition, the groups checked below may share, receive and/or look at your information:**

[✓] The sponsor of the study and the people that the sponsor may contract with for the study. The name of the sponsor is: University of Louisville School of Interdisciplinary and Graduate Studies.
[✓] Investigators and research staff at other places that are participating in the study;
[✓]An outside institution al review board (human subjects review board)
[✓] The Data Safety Monitoring Board
[✓] Other:
If you have questions about who these people or organizations are, you may ask us.

3. **While we are required to protect your health information, once any information leaves our institutions, we cannot promise that others will keep it private (confidential).**

4. **The information we look at or give to others as part of the research will be analyzed and further studied to answer the research questions and to make sure that the research was done correctly.**

5. **You have the following rights:**
You do not have to sign this form. However, if you do not sign this form you will not be able to take part in this research. This will not change the health care or health care benefits you would otherwise receive.

You may cancel the permission you have given in this form at any time. This means you can tell us to stop using and sharing your information. If you cancel your permission:

- We will stop collecting information about you.
- You may not withdraw information that we had before you told us to stop.
    - We may already have used it or shared it.
    - We may need it to complete the research.
- Staff may follow-up with you if there is a medical reason to do so.

To cancel your permission, you should complete a written "Revocation of Research Authorization" form. Please send completed form to:

Institutional Review Board
MedCenter One, Suite 200
501 E. Broadway
Louisville, KY 40202

A revocation form may be obtained from your study doctor, designated personnel or from the Human Subjects Protections Program Office website (http://louisville.edu/research/humansubjects/subject-information). If you have any questions, call the Human Subjects Protections Program Office at (502) 852-5188.

6. **The time period when information can be used or shared ends when all activities related to this study are completed.**

7. **Your access to your health information** [ ] **will** [✓] **will not be limited during this study.**

If you do not know what something means, you may ask us. Before you sign this, you may talk it over with someone you trust. You will be given a copy of this form after you have signed it.

FOR ADULTS (OR MINORS) CAPABLE OF GIVING AUTHORIZATION:

Subject's Signature	Date Signed	Printed Name

FOR CHILDREN OR ADULTS NOT CAPABLE OF GIVING AUTHORIZATION:

Signature of Parent/Surrogate/ Guardian/Health Care Agent for Subject	Date Signed	Printed Name

Relationship of representative (Surrogate) to Subject:
____

NOTE: **THE PRINCIPAL INVESTIGATOR MUST:**

- PROVIDE A COPY OF THE SIGNED AUTHORIZATION TO THE SUBJECT
- RETAIN THE ORIGINAL SIGNED AUTHORIZATION IN THE RESEARCH RECORD
- PLACE A COPY OF THE SIGNED AUTHORIZATION IN THE SUBJECT'S MEDICAL RECORD

Appendix E. Continued

REVOCATION OF AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR HEALTH INFORMATION FOR RESEARCH

Return To:

PI Address:____School of Nursing, University of Louisville (U of L), K Building, 555 S. Floyd St.
Louisville, KY 40202

PI Phone: 502-852-8512

Institutional Review Board

MedCenter One, Suite 200

501 E. Broadway

Title of Study: How Caregiving Demands, Caregiver Appraisal, and Coping Affect Self-Care Management of Informal Caregivers of Persons with Dementia.

IRB #: _12.0376_________

To Whom It May Concern:

I would like to discontinue my participation in the research study noted above. I understand that health information already collected will continue to be used as discussed in the Authorization I signed when joining the study.

Your options are (***choose one***):

☐ **Withdraw from Study & Discontinue Authorization:**

Discontinue my authorization for the future use and disclosure of protected health information. In some instances, the research team may need to use your information even after you discontinue your authorization, for example, to notify you or government agencies of any health or safety concerns that were identified as part of your study participation.

☐ **Withdraw from Study, but Continue Authorization:**

Allow the research team to continue collecting information from my personal health information. This would be done only as needed to support the goals of the study and would not be used for purposes other than those already described in the research authorization.

I understand that I will receive confirmation of this notice.

Appendix E. Continued

______________________ ______________________

Signature of Subject Date Signed

______________________ ______________________

Signature of Subject Representative (if subject unable to sign) Date Signed

______________________ ______________________

Printed Name of Subject OR Subject Representative Birthdate

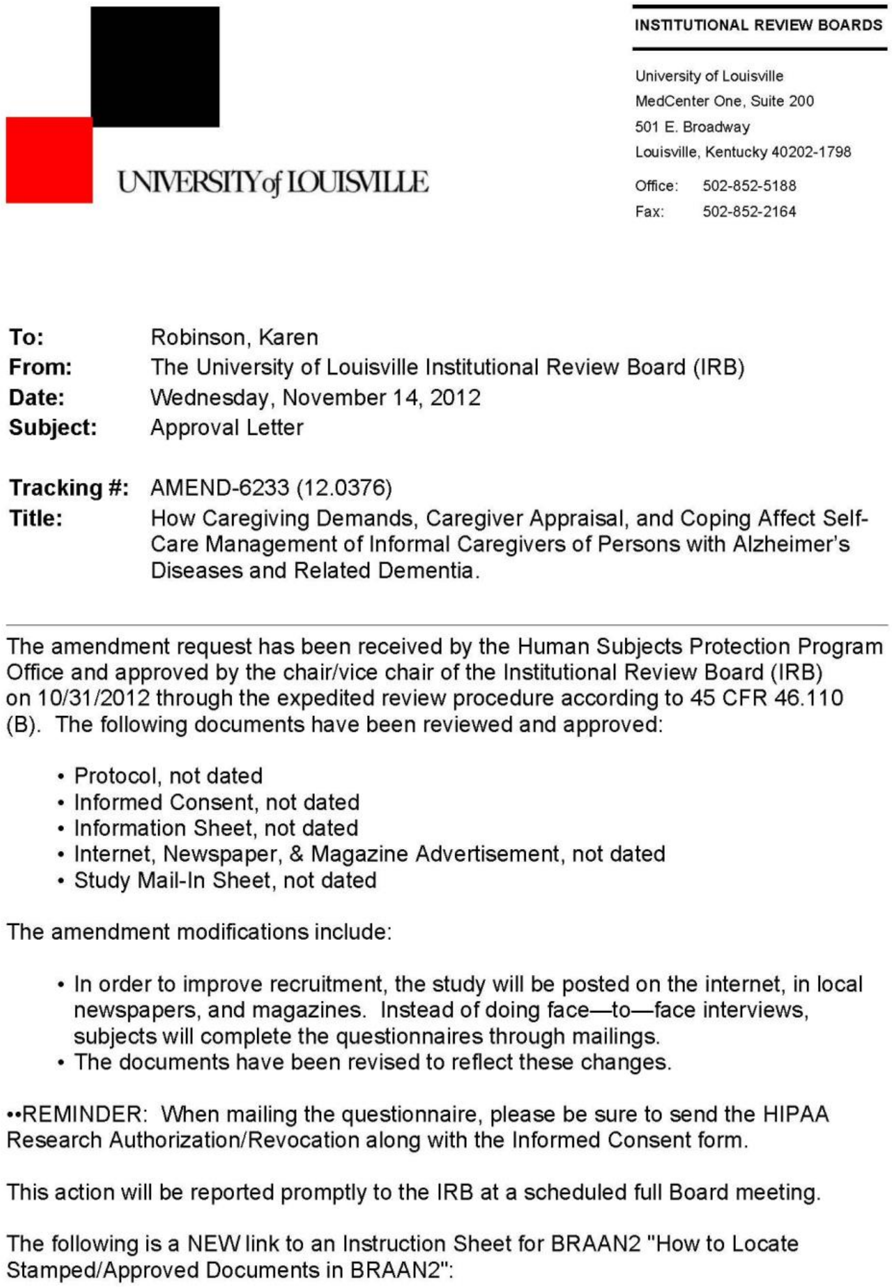
______________________ ______________________

Address Phone Number

Optional:

I am ending my participation in this study because:

Appendix F. Institutional Review Board Approvals



UNIVERSITY of LOUISVILLE

INSTITUTIONAL REVIEW BOARDS

University of Louisville
MedCenter One, Suite 200
501 E. Broadway
Louisville, Kentucky 40202-1798

Office: 502-852-5188
Fax: 502-852-2164

To: Robinson, Karen
From: The University of Louisville Institutional Review Board (IRB)
Date: Wednesday, November 14, 2012
Subject: Approval Letter

Tracking #: AMEND-6233 (12.0376)
Title: How Caregiving Demands, Caregiver Appraisal, and Coping Affect Self-Care Management of Informal Caregivers of Persons with Alzheimer's Diseases and Related Dementia.

The amendment request has been received by the Human Subjects Protection Program Office and approved by the chair/vice chair of the Institutional Review Board (IRB) on 10/31/2012 through the expedited review procedure according to 45 CFR 46.110 (B). The following documents have been reviewed and approved:

- Protocol, not dated
- Informed Consent, not dated
- Information Sheet, not dated
- Internet, Newspaper, & Magazine Advertisement, not dated
- Study Mail-In Sheet, not dated

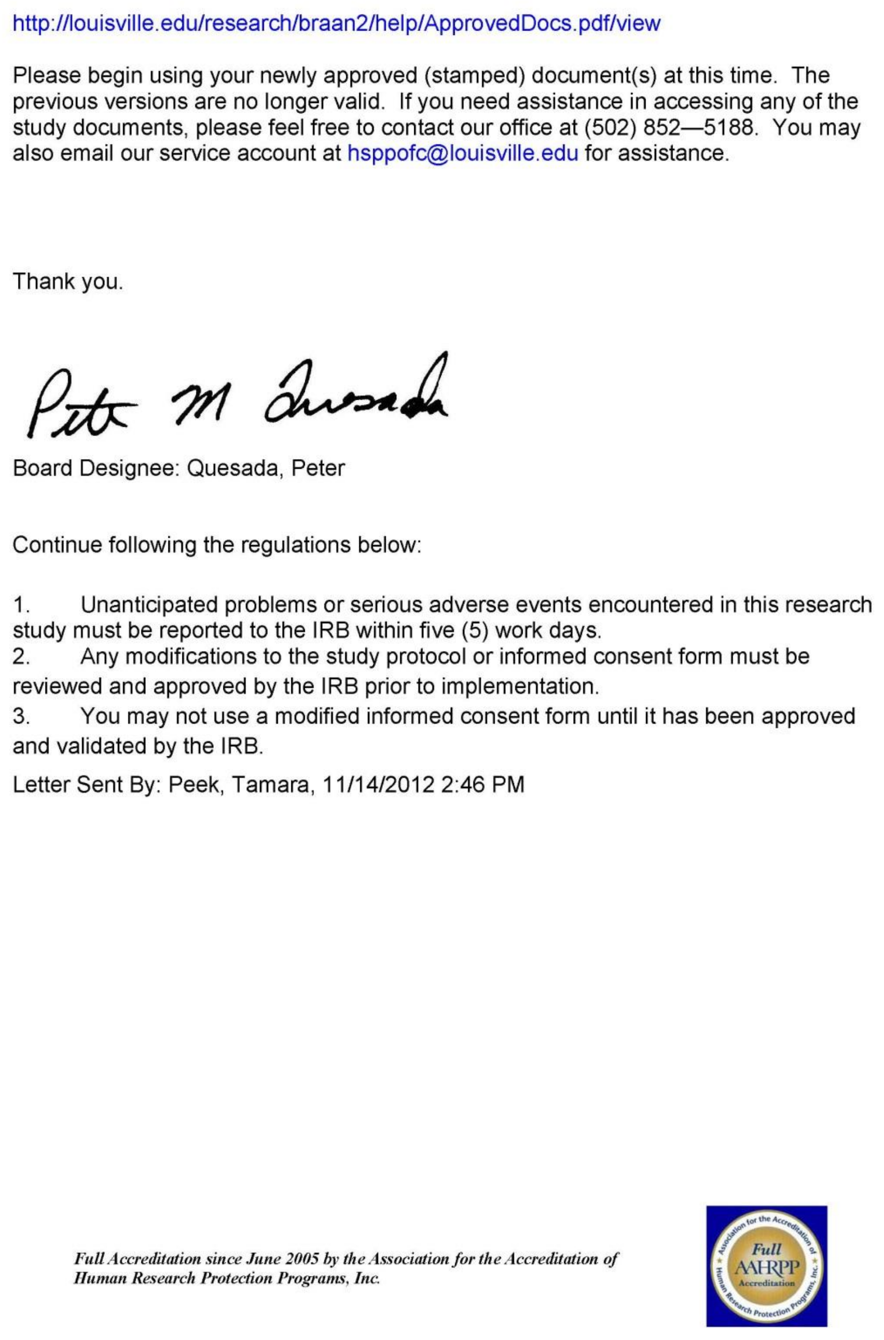
The amendment modifications include:

- In order to improve recruitment, the study will be posted on the internet, in local newspapers, and magazines. Instead of doing face—to—face interviews, subjects will complete the questionnaires through mailings.
- The documents have been revised to reflect these changes.

••REMINDER: When mailing the questionnaire, please be sure to send the HIPAA Research Authorization/Revocation along with the Informed Consent form.

This action will be reported promptly to the IRB at a scheduled full Board meeting.

The following is a NEW link to an Instruction Sheet for BRAAN2 "How to Locate Stamped/Approved Documents in BRAAN2":



http://louisville.edu/research/braan2/help/ApprovedDocs.pdf/view

Please begin using your newly approved (stamped) document(s) at this time. The previous versions are no longer valid. If you need assistance in accessing any of the study documents, please feel free to contact our office at (502) 852—5188. You may also email our service account at hsppofc@louisville.edu for assistance.

Thank you.

Peter M Quesada

Board Designee: Quesada, Peter

Continue following the regulations below:

1. Unanticipated problems or serious adverse events encountered in this research study must be reported to the IRB within five (5) work days.
2. Any modifications to the study protocol or informed consent form must be reviewed and approved by the IRB prior to implementation.
3. You may not use a modified informed consent form until it has been approved and validated by the IRB.

Letter Sent By: Peek, Tamara, 11/14/2012 2:46 PM

Full Accreditation since June 2005 by the Association for the Accreditation of Human Research Protection Programs, Inc.

CURRICULUM VITA

XiaoRong Wang, BSN
555 S. Floyd St.
School of Nursing
University of Louisville
Louisville, KY 40202
x0wang23@gmail.com (email)

A. Education

2008-Present	**Doctoral Student (anticipated date of graduation May 2013).** University of Louisville, Louisville, Kentucky Major: Nursing Minor: Gerontology, Chronic Disease Self-Management, Dementia Caregiving
2006-2008	Graduate Student Shandong University, Jinan, Shandong Province, China Major: Nursing
1998-2003	Bachelor of Science in Nursing Shandong University, Jinan, Shandong Province, China Major: Nursing

B. Employment

2012-2013	Graduate Research Assistant Caregivers Research Project of Dr. Karen Robinson School of Nursing, University of Louisville, Louisville, Kentucky
2011- 2012	Graduate Teaching Assistant Undergraduate Program School of Nursing, University of Louisville, Louisville, Kentucky

2010-2011	Graduate Research Assistant Longitudinal Study: "Older Mothers and Adult Daughters: High Blood Pressure Self-Management Behaviors". National Institutes of Health: National Institute of Nursing Research, 1K01NR010239-01A1 (Primary Investigator: Dr. Celeste Shawler) School of Nursing, University of Louisville, Louisville, Kentucky
2008-2009	Graduate Research Assistant Research Office School of Nursing, University of Louisville, Louisville, Kentucky
2003-2008	Instructor, Lecturer Jinan Nursing School Jinan, Shandong Province, China

C. Honors and Awards

2013 April	Graduate Dean's Citation Award School of Interdisciplinary and Graduate Studies University of Louisville, Louisville, Kentucky
2012-2013	Dissertation Completion Award School of Interdisciplinary and Graduate Studies University of Louisville, Louisville, Kentucky
2012; 2013	Ruth B. Craddock Award School of Nursing University of Louisville, Louisville, Kentucky
2012 July	Community Engagement Award Office of Health Disparities and Community Engagement School of Nursing University of Louisville, Louisville, Kentucky
2011-2012	Paul Ambrose Scholar Association of Prevention, Teaching, and Research Washington, DC
2009-2010	University Graduate Fellow School of Interdisciplinary and Graduate Studies University of Louisville, Louisville, Kentucky
2006-2007	Student Research Innovation Award Shandong University, Jinan, Shandong, China

2004	Essay Contest, Third Winner Jinan Board of Health Jinan, Shandong, China
2002	Student Leadership Excellence Award Shandong University Jinan, Shandong, China
2001	Student Leadership Excellence Award & Academic Excellence Award Shandong University Jinan, Shandong, China
2000	Community Service Award & Academic Excellence Award Shandong University Jinan, Shandong, China

D. Community Services

2011-present	Facilitator, Chronic-Disease Self-Management Program, Department of Geriatric & Family Medicine, University of Louisville, Louisville, KY
2008-Present	Health Advocate for Immigrants who speak Mandarin, Louisville Metro area, Louisville, KY
1998-2000	Reporter of the *Shandong University Newspaper*, Jinan, Shandong, China

E. Grant Funding

2012-2013	Exploring the Impact of Caregiving on Self-Care Management of Family Caregivers of Persons with Alzheimer's Disease and Related Dementia (PI). School of Interdisciplinary and Graduate Studies, University of Louisville, Louisville, KY. $1000, funded.
2011-2012	Implementing the Living Well Workshops in Immigrants Who Speak Chinese Mandarin (PI). Association of Prevention, Teaching and Research, the Office of Disease Prevention and Health Promotion, Washington, DC. U.S. $200, funded.
2006-2007	Exploring effective teaching methods in the course of Nursing Foundation based on the Theory of Problem-Based Learning (PI). Shandong University Student Innovative Research Grant, Shandong, China, ￥2,000, funded.

F. Publications and Conference Abstracts

a. Conference Abstracts

Wang, X. R., Robinson, K. How Caregiving Affects Medication Adherence and Appointment Keeping of Caregivers of Persons with Dementia. 2013 Annual Conference of Midwest Nursing Research Society. March 7-10, 2013, Chicago, IL.

Robinson, K., **Wang, X. R.**, McCarthy, V.. Does Church Involvement Influence Social Support, Burden, and Depression in Alzheimer's Disease Caregivers? Sigma Theta Tau International European Regional Conference, *Diversity across Europe: Implications for Nursing*, July12-14, 2012, Cardiff, Wales, UK.

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